Implementing cognitive rehabilitation for people with Multiple Sclerosis: Translating research into clinical practice

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Abstract

People with multiple sclerosis frequently report cognitive problems, which can affect function and quality of life. Although the effectiveness of cognitive rehabilitation to address these problems is evaluated in research studies, inadequate reporting of the content of the interventions may hamper clinical implementation. This research aimed to explore avenues to increase the clinical impact of trials of cognitive rehabilitation through the development of a clinician-informed, evidence-based checklist to guide researchers to better report cognitive rehabilitation studies in MS. The overarching design was exploratory mixed-methods, involving three separate intertwining studies.

Study one: A systematic review of descriptions of the content of cognitive interventions to document salient details and omissions in reporting. Ten electronic databases were searched, and 54 studies involving various types of MS and techniques to improve difficulties with memory, attention and executive function were included in the review. The results showed that important features of cognitive rehabilitation were not reported well. This was particularly in relation to the content of interventions (reported completely in 48% of the articles), how the interventions were delivered (reported completely in 44% of the articles) and the mechanism of action of the interventions (reported completely in 39% of the articles).

Study two: A video-based observational study, using time-sampling and content analysis to examine the content of treatment sessions delivered within the Cognitive Rehabilitation of Attention and Memory in MS (CRAMMS) trial. A total of 252 completely recorded treatment session videos were observed and coded. Content analysis indicated that all components of the CRAMMS manual were delivered as planned (intervention fidelity). The most frequently discussed topic for both therapists

and the people with MS related to memory and attention coping strategies (17% and 16% of observations, respectively). Findings from studies one and two were integrated and informed the initial questionnaire for study three.

Study three: A modified Delphi consensus study of three rounds, with clinicians and researchers who deliver cognitive rehabilitation to people with MS. This was conducted to ascertain the key aspects of cognitive rehabilitation that research studies should report to enable implementation in clinical practice. 'Experts' were asked to rate the importance of a number of reporting statements for inclusion in a reporting checklist (from low importance to high importance). Fourteen experts completed all three rounds. Based on the pre-specified criteria, consensus was achieved for 29 reporting statements. These statements were subsequently grouped based on how the expert panel rated their importance, forming a Priority 1 and 2 list of reporting statements. The checklist with the reporting statements should be used by researchers to describe cognitive rehabilitation programmes in the published literature.

The evidence-based, clinician-informed checklist developed in this research is important because it will enable researchers to report important aspects of complex cognitive rehabilitation interventions. This should be regarded as the first step towards the implementation of such research in clinical practice.

List of publications and presentations

The findings of this research were disseminated throughout the PhD process and the outputs include the following:

Peer Reviewed Publications

1. Mhizha-Murira, J. R., Drummond, A., Klein, O. A. and das Nair, R. (2017) Reporting interventions in trials evaluating cognitive rehabilitation in people with multiple sclerosis: a systematic review. *Clinical Rehabilitation* [Online], 32(2). pp.243-254. doi: https://doi.org/10.1177/0269215517722583.
2. Klein, O. A., Drummond, A., Mhizha-Murira, J. R., Mansford, L., & das Nair, R. (2017). Effectiveness of cognitive rehabilitation for people with multiple sclerosis: a meta-synthesis of patient perspectives. *Neuropsychological Rehabilitation*, pp. 1-22. doi: https://doi.org/10.1080/09602011.2017.1309323.

Oral Presentations

1. Mhizha-Murira, J. R., das Nair, R., & Drummond, A. Implementing cognitive rehabilitation for people with MS: Translating research into clinical practice. MS Society UK Nottingham visit December 2018.
2. Mhizha-Murira, J. R., das Nair, R., & Drummond, A. Implementing cognitive rehabilitation for people with MS: Translating research into clinical practice. Faculty of Medicine and Health Sciences Research Showcase June 2016.

Peer Reviewed Conference presentations

1. Mhizha-Murira, J. R., Drummond, A., Klein, O. A. and das Nair, R. (2017) Quality of reporting of cognitive rehabilitation for people with multiple sclerosis: A systematic review of research studies. UK MS Society MS Frontiers Edinburgh, June 2017.

2. Mhizha-Murira, J. R., das Nair, R. & Drummond, A. (2017, October) Implementing cognitive rehabilitation for people with MS: translating research into clinical practice. *Multiple Sclerosis Journal*, 23: pp. 962-963. MS European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) Paris October 2017.
3. Mhizha-Murira, J. R., das Nair, R., & Drummond, A. (2018, May) Implementing cognitive rehabilitation for people with multiple sclerosis: bridging the gap between research and clinical practice. *Multiple Sclerosis Journal*, 24(6): pp. 857-857. The 23rd Annual Conference of Rehabilitation in Multiple Sclerosis (RIMS) 'MS Rehabilitation Across the Lifespan,' Amsterdam, 31 May-2 June 2018. ***Best poster prize award.***
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Manuscripts in preparation

1. Mhizha-Murira, J. R., das Nair, R. and Drummond, A. (in preparation) A consensus on cognitive rehabilitation in multiple sclerosis, a modified Delphi study.
2. Mhizha-Murira, J. R., Drummond, A. and das Nair, R. (in preparation) Time-sampling and content analysis of the Cognitive Rehabilitation of Attention and Memory in people with multiple sclerosis (CRAMMS) trial.

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“Put first things first. Keep the main thing the main thing.”

Stephen Covey

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Abbreviations

AAN	American Academy of Neurology
ADL	Activities of Daily Living
AP	Assistant Psychologist
CENTRAL	Cochrane Central Register of Controlled Clinical Trials
CFIF	Consolidated Framework for Implementation Fidelity
CFIR	Consolidated Framework for Implementation Research
CNS	Central nervous system
CONSORT	Consolidated Standards of Reporting Trials
CRAMMS	Cognitive Rehabilitation for Attention and Memory in people with MS
DoH	Department of Health
EQUATOR	Enhancing the Quality and Transparency of Health Research
fMRI	Functional Magnetic Resonance Imaging
HRA	Health Research Authority
HTA	Health Technology Assessment
JARS	Journal Article Reporting Standards
JLA	James Lind Alliance
MRC	Medical Research Council
MRI	Magnetic Resonance Imaging
MS	Multiple Sclerosis
NICE	National Institute for Clinical Excellence
NIHR	National Institute for Health Research
PPI	Public and Patient Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT	Randomised controlled trial
RTT	Rehabilitation Treatment Taxonomy
TIDieR	Template for Intervention Description and Replication

Chapter 1 Background

1.1 Introduction to the Thesis

Cognitive rehabilitation is a structured set of therapeutic activities designed to address cognitive problems (such as memory, attention and executive dysfunction) by using a variety of approaches to improve individuals' everyday functional abilities and promote independence. Although the effectiveness of such rehabilitation programmes is evaluated in trials, oftentimes, researchers do not provide the details of their interventions which would allow clinicians to replicate the rehabilitation as tested; this influences whether or not people with MS benefit more widely from these programmes. The overall purpose of this research is to increase the clinical impact of trials of cognitive rehabilitation. Thus, this thesis describes the systematic development of a reporting checklist for cognitive rehabilitation in MS.

1.2 Chapter Overview and Introduction

This chapter presents the background literature to this research. It describes the neurodegenerative condition MS, the cognitive problems that are common in MS and the impact these have on the daily lives of people with MS. Cognitive rehabilitation activities that aim to reduce cognitive issues in MS and improve the daily lives of people with MS are then presented. As this research was embedded within a large randomised controlled cognitive rehabilitation trial for memory and attention problems in people with MS, the focus of the overall research and this chapter is on these specific cognitive domains. Cognitive rehabilitation will then be discussed within the context of complex interventions, and the associated challenges of implementation and translating research evidence into clinical practice of these interventions, with a focus on the quality of reporting of interventions in published literature. The research gaps, which form the basis of the research conducted in this thesis, are identified. The chapter concludes with the presentation of the research aims and the research methodology. The philosophical position of the research is also presented.

1.3 Background literature review

1.3.1 Multiple Sclerosis

MS is a demyelinating neurological condition resulting from chronic focal inflammation of the central nervous system (CNS), causing damage to both white and grey matter (Malik et al., 2014, Modica et al., 2016). Globally, MS affects approximately 2.3 million people, with the prevalence ranging from less than five cases per 100, 000 people (e.g., in countries located closer to the equator such as Kenya and Colombia) to over 200 cases per 100, 000 further away from the equator (e.g., in Denmark and Canada) (Browne et al., 2014, Thompson et al., 2018b). Although MS is present in all regions of the world, its prevalence is commonly associated with latitude (Malik et al., 2014): MS prevalence is highest in Europe and North American (up to 140 cases per 100 000 people) and lowest in Sub-Saharan African and East Asia (up to 2.2 cases per 100 000) (Browne et al., 2014). There are also regional differences in the prevalence of MS, with Sweden having the highest incidence of MS in Europe (189 per 100 000) compared with Estonia at 82 per 100 000 (European Multiple Sclerosis Platform, 2015). It is estimated that over 100 000 people live with MS in the UK (Mackenzie et al., 2014).

Although the exact cause of MS is unknown, it is associated with environmental and genetic factors (Love, 2006, Thompson et al., 2018b). Environmental factors include latitude and migration, low levels of dietary vitamin D, and smoking (Cameron et al., 2013, Thompson et al., 2018b). Genetic factors associated with MS are the increased risk of MS for people with a family member diagnosed with MS (Malik et al., 2014). MS is more common in women than in men (3:1 ratio) (Malik et al., 2014). There are also differences in the prevalence and progression of MS based on ethnicity (Ventura et al., 2017). Sociodemographic factors associated with MS include the age of onset,

and the average age of onset of MS in the UK is 32 years (European Multiple Sclerosis Platform, 2015). Globally, the onset of MS is most common between the ages of 20 and 40 (Cameron et al., 2013, Thompson et al., 2018b). Furthermore, the onset of MS in women typically occurs five years earlier than in men (Cameron et al., 2013).

A diagnosis of MS requires an integration of clinical expertise, laboratory and imaging findings (Filippi et al., 2016, Thompson et al., 2018a), and typically ensues when there is objective clinical evidence of lesions (occurring at different times and different regions of the brain) (Malik et al., 2014). Due to variations in the duration and site of inflammation in the CNS, MS is characterised by variability in its clinical symptoms and course (Cameron et al., 2013, Malik et al., 2014). The subtypes and patterns of MS that guide prognosis and treatment decisions are: relapsing-remitting disease (accounts for 65-70% of people with MS [Malik et al., 2014]) and progressive disease (primary progressive and secondary progressive) (Lublin et al., 2014).. Periods of relapse and remission are common in people with MS, particularly in the early stages of the disease. Relapsing-remitting disease can either be active or not active, determined by clinical relapses and magnetic resonance imaging (MRI) activity indicating an increase in the number or size of lesions (Lublin et al., 2014). A progressive course ensues either from the onset (primary progressive) or after initial relapses and remissions (secondary progressive), and is determined through an annual clinical evaluation (Lublin et al., 2014, Thompson et al., 2018b). Progressive disease is categorised as: (1) active and with progression, (2) active and without progression, (3) not active and with progression, (4) not active and without progression (Lublin et al., 2014). Disease progression occurs typically within one to two decades of disease onset (Love, 2006, Lublin et al., 2014, Thompson et al., 2018b). The clinical course of MS is illustrated in Figure 1.

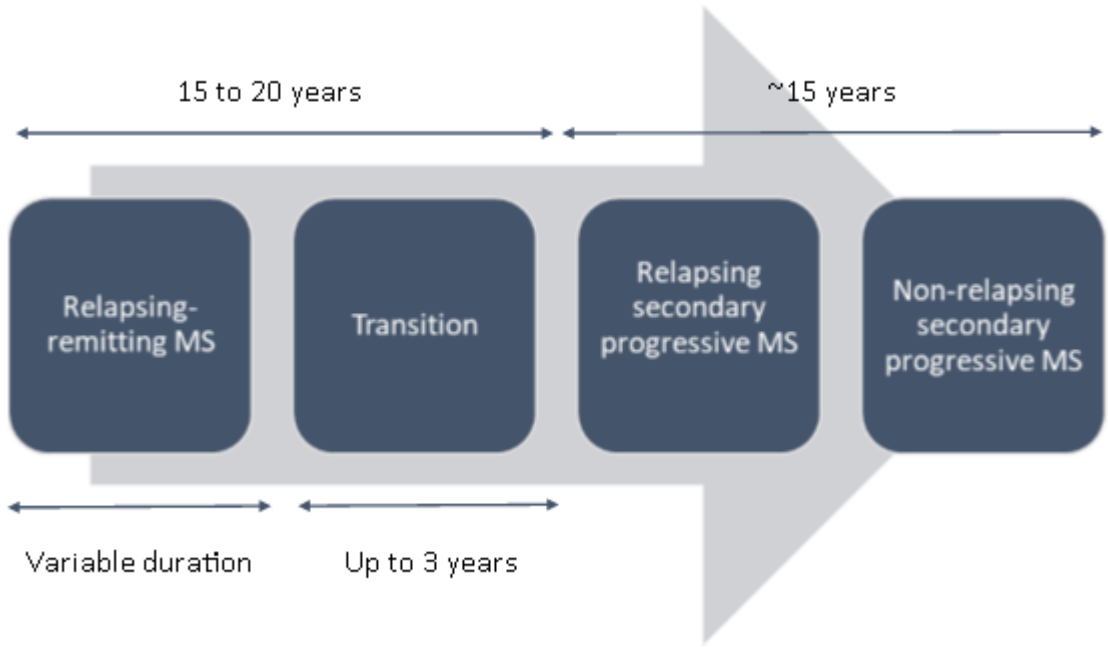


Figure 1 Clinical Course of MS.
Modified from Katz Sand et al. (2014), Lublin et al. (2014), Rovaris et al. (2006)

There is great variation in the presentation of MS, dependent on the location of the white matter lesions and damage to the myelin sheath in the brain and spinal cord tissue (Evangelou et al., 2018, Malik et al., 2014). The most common clinical symptoms in MS include fatigue, mobility issues, pain, numbness, speech problems, depression, and cognitive difficulties (Love, 2006, Malik et al., 2014, Thompson et al., 2018b). These “visible and invisible” symptoms of MS have an economic and social impact (Lorefice et al., 2018), with costs over £30,000 per year per patient for health and societal costs in the UK (Kobelt et al., 2017). The symptoms of MS have an impact on informal care, prescription costs and employment (i.e., early retirement or reduced occupational activity) (Berg et al., 2016, Campbell et al., 2017, Fantoni-Quinton et al., 2016, Hawton and Green, 2016, Salter et al., 2017). As there is no cure for MS, interventions are focused on disease and symptom management to reduce suffering and maintain functional performance in activities of daily living (ADL) (World Health Organisation (WHO), 2001).

1.3.2 Cognitive problems in MS

Between 40% and 65% of people with MS experience cognitive difficulties (Langdon, 2010, Matias-Guiu et al., 2017, Messinis et al., 2018, ÖZakbaŞ, 2015). Cognitive issues experienced by people with MS are estimated to be mild to moderate in up to 50% of people with MS who experience these issues, with up to 20% experiencing severe cognitive problems (Hämäläinen and Rosti-Otajärvi, 2016, Leavitt et al., 2018, Planche et al., 2016). Similar to other symptoms of MS, cognitive deficits vary depending on the changes to the white and grey matter of the CNS (Amato et al., 2010, Damasceno et al., 2014, Stellmann et al., 2016). The occurrence and severity of cognitive problems in MS are heterogeneous, affecting a number of cognitive domains differentially according to the type of MS (Matias-Guiu et al., 2017). Cognitive impairment has been shown to be more severe in people with a diagnosis of primary and secondary progressive MS (60-70%) compared to those with relapsing-remitting MS (40%) (Huijbregts et al., 2004, Johnen et al., 2017, Ruet et al., 2013). Cognitive issues may also occur during relapses (Benedict et al., 2014, Morrow et al., 2011).

Several cognitive domains are affected in MS, with the most common deficits in memory (episodic), information processing speed, attention (selective and divided attention), executive function (e.g., verbal fluency) and visual perception (Benedict et al., 2006, Chiaravalloti and DeLuca, 2008, Guimarães and Sá, 2012, Leavitt et al., 2018, Nabavi and Sangelaji, 2015, Planche et al., 2016, Sumowski et al., 2018). Evidence suggests most cognitive issues experienced by people with MS are due to a failure in the acquisition of new knowledge as opposed to problems with retrieval of stored information from long-term storage (Chiaravalloti and DeLuca, 2008).

The cognitive problems in MS can be debilitating and can severely affect the quality of life for both the individual and family (Jongen et al., 2012, Sgaramella et al., 2015,

van Capelle et al., 2016). The impact of cognitive issues varies according to the type of MS (Salter et al., 2017). Cognitive difficulties in MS are often associated with less involvement in treatment decisions (Malik et al., 2014), poorer disease management (Forwell and Ross, 2013), and financial implications such as unemployment (Campbell et al., 2017, Johnson and Fraser, 2013, Krause et al., 2013) and reduced financial decision-making skills (Tracy et al., 2017). For example, in a systematic review investigating the association between cognitive performance and unemployment in MS conducted by Clemens and Langdon (2018), people with MS who were unemployed performed less well on neuropsychological tests than those who were employed or compared to healthy controls. Deficits in cognitive domains of information processing speed, immediate and delayed recall, and executive function are attributed to poorer employment prospects in MS (Clemens and Langdon, 2018, Strober et al., 2014).

Kalb et al. (2018) summarised the impact of domain-specific cognitive issues on daily function and quality of life. For example, slower information processing speed and impaired visual-spatial memory impaired driving ability (Kalb et al., 2018). These cognitive issues could have an impact on the outcome of physical rehabilitation and contribute to caregiver strain (Kalb et al., 2018, Pakenham and Finlayson, 2013, Rosti-Otajärvi and Hämäläinen, 2014).

1.3.3 Cognitive rehabilitation

When people with MS report cognitive issues, often they are describing an observed change in function (Sumowski et al., 2018). For example, observing that they lose track of what they are doing or find it difficult to multi-task (issue with attention, concentration and processing speed), or failing to recall recent events (decline in episodic memory). The International Classification of Functioning, Disability and

Health (ICF) (World Health Organisation (WHO), 2001) core sets for measuring health and disability describe three levels of functioning: body functions, participation and activities. Contextualising cognitive rehabilitation in multiple sclerosis within the ICF core sets (Anderson et al., 2012, Beer et al., 2012, Conrad et al., 2014):

- Impairment in MS refers to neuropsychological functions such as memory issues
- Activity limitations relate to the impact of, for example, memory problems on an individual's ability to conduct daily activities such as preparing a meal
- Participation is associated with changes in an individual's engagement in employment, for example, due to memory problems.

Cognitive rehabilitation (also referred to as neuropsychological rehabilitation) refers to a structured set of therapeutic cognitive activities designed to address cognitive deficits, to improve individuals' everyday functional abilities and promote independence (Beer et al., 2012, Coltheart et al., 2005, Sohlberg and Mateer, 2001). Therefore the overall aim of cognitive rehabilitation is to improve activity and participation of people with MS who experience cognitive problems (e.g., increase engagement in employment, recreational activities, problem solving, carrying out daily routine activities) (Conrad et al., 2014, Holper et al., 2010). Improvements in activity and participation for people with MS is achieved through a range of approaches to retrain or compensate for these cognitive problems.

It is important to note that rehabilitation does not equate to 'recovery', but refers to a two-way interaction between people with MS as they work with healthcare professionals, family and the wider community to achieve psychological, social and physical wellbeing (Wilson, 2017). This aligns with the biopsychosocial model of health (Engel, 1977), whereby rehabilitation is a multidisciplinary approach aiming to address the biological, psychological (e.g., cognitive, emotional) and social (e.g.,

employment, family) aspects of MS (Beer et al., 2012, Palmer and Wegener, 2003, Wilson, 2008). Underpinning cognitive rehabilitation are models and theories from several disciplines, such as clinical psychology, health psychology and neuropsychology (das Nair, 2015). The different perspectives of illness and the assumptions underpinning cognitive rehabilitation (e.g., from neuroscience, cognitive development (Katz et al., 2006)) are discussed in the following sections.

1.3.3.1 Theories underpinning cognitive rehabilitation

The cognitive, emotional and psychosocial issues that people with MS experience are intertwined (Anderson et al., 2012). Although the cognitive aspects are the primary focus of cognitive rehabilitation, a holistic approach is often undertaken to address all these issues (Wilson, 2017, Wilson, 2008). An overview of the models and theories underpinning cognitive rehabilitation is now presented.

Behavioural models enabled the understanding of the management of illness, and most importantly, behaviour change (Wilson, 2008). Learning theory is a fundamental component of behaviour theory and behaviour modification. In cognitive rehabilitation, behavioural modification approaches were used to help better understand the learning of new techniques to compensate for or reduce the cognitive deficit (Wilson, 2017). Behavioural psychology facilitates the use of behaviour change techniques such as positive reinforcement, modelling and shaping in cognitive rehabilitation (Wilson, 2017).

Beck and Weishaar (1989) cognitive therapy model, based on an information-processing model, was incorporated into cognitive rehabilitation to address emotional factors such as social isolation, anxiety and depression often experienced by people with MS (Feinstein, 2011). The cognitive therapy model posited that individuals'

perceptions of their experiences (or illness) had emotional, behavioural and physiological consequences (Beck, 1991).

Social identity theory (Tajfel et al., 1979) suggested that an individual's sense of self (including self-esteem) was dependent on their membership of a social group. This has particular relevance to the changes that occur due to MS (e.g., loss of employment and changes in the social network) (Wilson, 2017).

Cognitive rehabilitation, therefore, incorporates approaches geared to equip people with MS with appropriate coping skills to manage cognitive issues and their emotional aspects (Wilson, 2017).

1.3.3.2 Aims and approaches to cognitive rehabilitation

The theoretical models applied to cognitive rehabilitation vary along several dimensions. Cognitive rehabilitation may focus on improving a particular cognitive domain (i.e., process specific) such as memory, attention or executive function. It may be skills-based with the aim to enhance an individual's functional ability in a particular activity such as driving (Katz et al., 2006).

The broad approaches to cognitive rehabilitation are cognitive training, compensatory strategies, including environmental modifications, and holistic approaches (Cicerone et al., 2000, Mateer, 2005). The following section provides a brief overview of each approach.

Cognitive training

A cognitive training approach aims to restore function through the reinforcement, strengthening and re-establishment of pre-existing neural plasticity (Cicerone et al., 2000). Repeated practice of cognitive exercises is designed to strengthen elementary

cognitive skills upon, which are grounded upon more complex cognitive processes (Anderson et al., 2012).

Compensatory approaches

Compensatory approaches aim to provide ways in which to circumvent the neural damage and resulting cognitive issues while maintaining or reducing the effects of task performance (Cicerone et al., 2000). Internal compensatory approaches rely on the individual making an effort to apply new ways to support learning and memory processes (Anderson et al., 2012). External compensatory approaches help the individual establish new patterns of behaviour, to increase the utilisation of objects in their environment to support learning and memory (Anderson et al., 2012, Cicerone et al., 2000).

Holistic approaches

Holistic approaches to cognitive rehabilitation aim to enable individuals to adapt to and cope with cognitive issues (Cicerone et al., 2000, Wilson, 2008).

Multidimenstional appraches

A multidimentional approach to cognitive rehabilaition aims to consider the biopsychosocial aspects of cognitive issues in indviduals. These approaches include aspects of cognitive training, and compensatory and holistic approaches in their rehabilitation programmes. The objectives of these interventions are: (1) to restore or reduce cognitive impairment; (2) to minimize the negative impact of cognitive impairment; (3) to increase awareness of the prevalence and impact of cognitive issues on MS, and to increase self-efficacy of people with MS in their management of cognitive deficits (Hämäläinen and Rosti-Otajärvi, 2016, Tsaousides and Gordon, 2009).

The following section will discuss the principles and approaches of cognitive rehabilitation as they relate to the cognitive domains of memory, attention and executive dysfunction. These cognitive domains were the focus of the systematic review (Chapter 2) and the CRAMMS intervention (Chapter 3).

1.3.3.3 Cognitive rehabilitation of memory, attention and executive dysfunction

Memory

Memory is “the ability to take in, store and retrieve information” (Wilson, 2009, p. 1) and adjusting behaviour, based on the stored information (Lajiness-O'Neill et al., 2013). Biologically, the creation of memory results in structural changes in the neurocircuitry of an individual’s brain as a consequence of experience (Lajiness-O'Neill et al., 2013). From a functional perspective, memory represents the brain's propensity to recreate awareness of experience in the absence of external stimuli (Lajiness-O'Neill et al., 2013). It involves a complex combination of processes, namely attention, encoding, consolidation, storage and retrieval (Baddeley, 2004). These stages are linked closely and interact (Sohlberg and Mateer, 2001). Issues with recall arise when there is a disruption in any one of these stages. There are different types of memory: those that are time-dependent and those that are context dependent (Sohlberg and Mateer, 2001). Time dependent memory relates to short-term (working memory) and long-term memory. Between five and nine pieces of information can be stored for between 15 and 30 seconds in working memory. There is no memory decay for an unlimited period of time once the information is in long-term memory (Sohlberg and Mateer, 2001).

Memory impairment in MS is most commonly associated with deficits with retrospective memory (recollection of previously acquired information) and prospective memory (difficulty learning new information or forgetting to carryout future

tasks) (Parker et al., 2017). Memory theory has implications for managing problems associated with creating, storing and retrieving information. These techniques are divided into those that aim to restore memory ability or compensate for the loss in neural plasticity (Anderson et al., 2012, Halligan and Wade, 2005).

Attention and executive dysfunction

Attention is often defined by the behaviours or task demands it is commonly associated with (Styles, 2005). In this vein, attention is a process which allocates resources based on information-processing demands (Fish, 2017). A clinical model of attention includes focused, sustained (vigilance and working memory), selective, alternating and divided attention (Sohlberg and Mateer, 2001, Styles, 2005). As the capacity of attention is understood to be limited (Fish, 2017), this hierarchical model emphasises the importance of assessment to identify specific attention impairments. Therefore, prioritising or directing what is attended to (Fish, 2017). The management of impairments with attention focuses on attention process training, which involves repetitive drills or exercises to provide opportunities to practice with increasing task difficulty as the individual progresses (Sohlberg and Mateer, 2001). Attention is not only associated with memory processes, but also with executive function. The term ‘executive function’ broadly refers to goal-related functions that enable planning, purposive action, and self-regulation (Cicerone et al., 2006, Gonçalves et al., 2014). Symptoms of executive dysfunction include poor decision-making (e.g., poor anticipation of the consequences of behaviour), poor initiation of behaviour and difficulties paying attention (Burgess and Simons, 2005). These issues are argued to be the result of working memory impairments (i.e., in the central executive)

1.3.4 Cognitive rehabilitation for people with MS

In the earlier stages of MS (i.e., relapsing-remitting), when the cognitive deficits are milder and more focused (e.g., affecting a specific cognitive domain or aspect of a

domain such as episodic memory and selective attention), cognitive training is often employed. This is usually delivered through computerised training programs such as RehaCom software package (e.g., (Bonavita et al., 2015, Cerasa et al., 2013, Sastre-Garriga et al., 2011), or one-to-one interventions such as the modified Story Technique (Leavitt et al., 2014) and the Sclerosi Multipla Intensive Cognitive Training (Mattioli et al., 2014). For example, Cerasa et al. (2013) conducted a randomised controlled trial (RCT) to assess the effectiveness of a computer-based intensive attention and information-processing training program in people with relapsing-remitting MS. The degree of task difficulty increased as participants' performance improved. Participants in the intervention group had significantly higher scores on the Stroop colour and word test (Bench et al., 1993), an objective measure of attention and executive function ability, compared to the control group.

Although the cognitive aspects are the primary focus of cognitive rehabilitation, a holistic or multidimensional approach is often undertaken (Wilson, 2017, Wilson, 2008).

A summary of the different approaches to the cognitive rehabilitation of memory, attention and executive function is presented in Table 1.

Table 1 Summary of different approaches to the cognitive rehabilitation of memory and attention and executive dysfunction

Approaches	Description
Internal compensatory strategies	Functionally relevant tasks to provide a structure for the information stored in memory or to reduce the quantity. These recall strategies include the PQRST, cueing, chunking, visual imagery and mnemonics. Metacognitive strategy training based on personalised and functional activities. This involves self-monitoring of thinking and the ability to adapt to changes in the environment or to task demands.
External compensatory strategies	To aid performance on tasks that are functionally relevant. For example, using a diary to reduce the burden on working memory
Cognitive training/ Restitution strategies	Drill and practice memory training (e.g., computer-based training) to restore damaged neural circuitry or establish novel neural pathways. For example, learning lists; letter or number cancelation. repetitive practice of attention tasks to improve sustained attention (e.g., Attention Process Training by Sohlberg and Mateer (2001)).
Environmental modifications	Managing external distractions by reducing noise; managing internal distractions such as mood or fatigue. Use of labels and routines.

Summarised from Fish (2017), Fish and Manly (2017), Kelly and O'Sullivan (2015), Parker et al. (2017), Ponsford et al. (2014)

1.3.4.1 Evidence for cognitive rehabilitation

There is mixed evidence for the effectiveness of cognitive rehabilitation for people with MS. Most of this evidence comes from case studies and non-randomised group comparisons (Mitolo et al., 2015, O'Brien et al., 2008), with some randomised controlled trials (RCTs) demonstrating the effectiveness of cognitive rehabilitation in people with MS (Carr et al., 2014, Hildebrandt et al., 2007, Solari et al., 2004, Stuifbergen et al., 2012). A Cochrane review on the effectiveness of memory rehabilitation for people with MS by das Nair et al. (2016) demonstrated a positive impact of memory rehabilitation on objective measures of immediate (small effect size, Cohen's d=0.23) and long-term memory (small effect size, Cohen's d=0.26), and

improvements in quality of life, but not on other outcomes. Another Cochrane review assessing the effectiveness of cognitive rehabilitation (more generally) on health-related factors in people with MS found that cognitive training alone, or when combined with other neuropsychological methods, improved aspects of memory (e.g., memory span, immediate verbal memory; medium effect size of 0.54 and small effect size of 0.31, respectively) and attention (small effect size of 0.15) (Rosti-Otajärvi and Hämäläinen, 2014).

Narrative reviews of cognitive rehabilitation for people with MS (Mitolo et al., 2015, O'Brien et al., 2008) and individual studies with people with MS (Brissart et al., 2013, Mattioli et al., 2010, Solari et al., 2004) provide some support for cognitive rehabilitation. For example, evidence suggests that attention retraining may be helpful for people with MS with attention problems (Cerasa et al., 2013), even at nine-months follow-up (Rosti-Otajärvi et al., 2013b). Supporting evidence also comes from qualitative studies of perceived benefits of cognitive rehabilitation for people with MS (Chouliara and Lincoln, 2016, das Nair and Lincoln, 2013), including meta-syntheses (das Nair et al., 2015b, Klein et al., 2017).

Although there is emerging evidence for the positive effects of cognitive rehabilitation for people with MS, most reviews on both attention and memory concluded that there was a paucity of high quality trials (Mitolo et al., 2015, Rosti-Otajärvi and Hämäläinen, 2014). For example, in their review that examined published studies of cognitive rehabilitation interventions with people with MS, Mitolo et al. (2015) found that none of the 33 included studies were classified as Level 1 (evidence is obtained from a well-designed RCT). Arguably, the equivocal findings for the effectiveness of cognitive rehabilitation for people with MS were due to the quality of the evidence and the heterogeneity of the participants in the studies (i.e., cognitive deficits and the type of MS) (Mitolo et al., 2015, O'Brien et al., 2008).

The cognitive rehabilitation used in this thesis was the Cognitive Rehabilitation for Attention and Memory in people with MS (CRAMMS) trial [ISRCTN 09697576]. Study two (Chapter 3) of this research was embedded within the CRAMMS trial. The overall trial is described in detail in the following section, and specific information about the content of CRAMMS relating to the research is described in Chapter 3.

1.3.4.2 The CRAMMS trial

CRAMMS was a two-group, pragmatic, multi-centre RCT comparing cognitive rehabilitation for memory and attention plus usual care (intervention) with usual care alone (control) in people with MS (Lincoln et al., 2015). Pragmatic trials are used in implementation research to assess the effectiveness of interventions with study participants that could benefit from the intervention. Additionally, they are often conducted in the setting where the intervention is likely to be delivered in routine practice (Peters et al., 2013). Participants in the CRAMMS trial were recruited from charities such as the UK MS Society, NHS hospitals (e.g., neurology clinics), and rehabilitation centres across five sites in England. Participants were identified on the basis of a self-reported screening measure, the Multiple Sclerosis Neuropsychological Screening Questionnaire (2003). Those meeting the inclusion criteria (e.g., with cognitive deficits) were then assessed on the Brief Repeatable Battery (Rao, 1990), a comprehensive test of cognitive function. Participants completed a number of baselines assessments and were randomised (ratio 6:5) to intervention or control, stratified by recruitment site. The primary outcome was the psychological impact of MS on everyday life, measured using the Psychological Subscale of the Multiple Sclerosis Impact Scale (MSIS-Psy) (Hobart et al., 2001) at 12 months post-randomisation.

The cognitive rehabilitation programme was delivered in a group format by assistant psychologists, under the supervision of clinical psychologists. The focus of the intervention was on helping participants to identify strategies and techniques that would best help them overcome the memory and attention problems they had, adapting them to suit their needs and improve daily function (Lincoln et al., 2015). CRAMMS was a manualised programme, with content tailored to the participants' cognitive status and to any deficits that had been identified during baseline assessments. Participants also set goals, and these were incorporated into the group sessions. Participants received 10 group cognitive rehabilitation sessions (i.e., one a week for 10 weeks), each lasting approximately 90 minutes.

The intervention used restitution and compensatory approaches to cognitive rehabilitation. The restitution strategies taught were to retrain memory and attention, incorporating strategies to enhance memory processes such as encoding and retrieval. Compensatory strategies such as internal memory strategies and the use of external memory aids were also taught. The CRAMMS intervention was developed following previous studies conducted by the researchers (das Nair et al., 2017, das Nair et al., 2015a). The rationale for introducing participants to both restitution and compensatory strategies in one programme was based on the argument that people with MS experiencing cognitive problems could benefit from both approaches, when in previous studies cognitive rehabilitation incorporated only one of these approaches. Cicerone et al. (2005) supported this rationale, arguing that a combination of restitution training with compensatory strategy training increased the effectiveness of cognitive rehabilitation programmes. Moreover, in a study by das Nair and Lincoln (2012) participants in the restitution versus compensation only groups had similar outcomes.

Evaluating the effectiveness of cognitive rehabilitation interventions, and CRAMMS in particular, is not purely dependent on cognitive outcomes. It is essential to understand other factors that should be considered when evaluating cognitive rehabilitation in MS. This is discussed in the following section.

1.3.5 Cognitive rehabilitation is a complex intervention

According to Craig et al. (2008), an intervention is considered 'complex' if it consists of:

- Several interacting components
- A number of different behaviours are required to deliver and receive the intervention
- Various groups in receipt of the intervention
- Different outcomes
- A degree of adaptability permitted to meet the context in which it is.

Cognitive rehabilitation interventions for people with MS are considered 'complex interventions' as often these interventions consist of multiple components (e.g., different aims and approaches), can be delivered by a number of individuals from various healthcare professions (e.g., occupational therapists, assistant psychologists) and are often tailored to meet the individual needs of the people with MS experiencing cognitive issues.

The UK Medical Research Council (MRC) guidance outlined iterative phases involved in the development and evaluation of randomised controlled trials of complex interventions (Campbell et al., 2000, Craig et al., 2008, Craig et al., 2013, Moore et al., 2015). These are illustrated in Figure 2. The relevance of the MRC guidance to

the development of cognitive rehabilitation interventions for people with MS is discussed in the following sections.

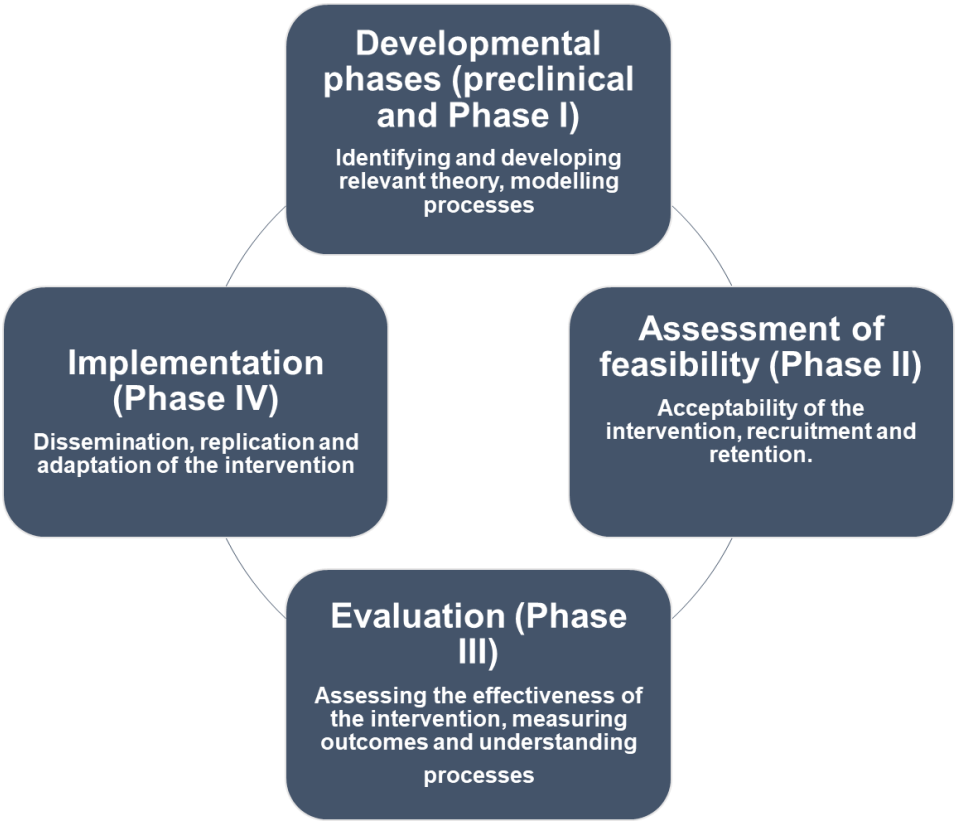


Figure 2 Phases involved in the development and evaluation of complex interventions Modified from Campbell et al. (2000), Craig et al. (2013)

1.3.6 Developmental phases: Theory and modelling of cognitive rehabilitation

The MRC framework emphasises the importance of developing theory and using this to model how components of the interventions influence intended outcomes. The theories underlying cognitive rehabilitation approaches in MS were discussed in section 1.3.3.1. Efforts to identify the intervention components that influence outcomes, and the mechanisms underpinning them (i.e., the modelling phase of the MRC framework) have included the Rehabilitation Treatment Taxonomy (RTT) proposed by Hart et al. (2014b) and Hart and Ehde (2015). Within this tripartite

framework of treatment theory, rehabilitation interventions are defined by the theories that underpin them. According to Hart et al. (2014b), interventions are classified by:

- The targets (or measurable aspects of function that are intended to affect).
- The 'active ingredients', which can be the measurable therapist and patient behaviours and decisions that are key to effecting changes in cognitive function (i.e., the content of the intervention, including strategies).
- The mechanisms (mechanisms of action such as knowledge or skill acquisition, motivation and self-efficacy) by which these ingredients influence outcomes (Hart et al., 2014b).

Using the RTT model, the different cognitive rehabilitation approaches (i.e., ingredients) and their goals (i.e., targets) are identified and measurable. That is, restorative interventions that aim to boost the underlying neurophysiological basis of memory, and compensatory approaches that aim to improve memory through strategies (e.g., mnemonics) or aids (e.g., diaries).

1.3.7 Evaluation of cognitive rehabilitation in MS

Effective and reliable evaluations of cognitive rehabilitation interventions for people with MS are not solely dependent on the robustness of the study design (e.g., RCT) and outcomes, but also on the *processes* involved during the study (Saunders et al., 2005). This constitites Phase III in the development and evaluation of complex interventions (Figure 2) (Campbell et al., 2000, Craig et al., 2013). Consequently, it is necessary to consider the extent to which any study outcomes are due to the components of the intervention as opposed to-non-intervention factors (Poltawski et al., 2014, Resnick et al., 2011). To enable conclusions of the clinical effectiveness of interventions to be credible, it is vital to consider the extent to which they are implemented as intended (Moore et al., 2015). The relevance of processes and

implementation to cognitive rehabilitation interventions is discussed in the following section.

1.3.7.1 Process evaluations

Process evaluations look inside the 'black-box' of what occurs in the intervention delivery stages of trials (Saunders et al., 2005). By conducting process evaluations, the ways in which cognitive rehabilitation interventions in MS are implemented can be explored, thus providing insight into why an intervention was found to be effective or not (Craig et al., 2008). Process evaluations nested within cognitive rehabilitation trials are used to assess the quality of implementation (e.g., intervention fidelity), and identify context-specific factors and mechanisms that influence outcomes (Craig et al., 2013, Moore et al., 2015). For example, Masterson-Algar et al. (2016) conducted a systematic review to examine how process evaluations in neurological rehabilitation were designed and conducted. Out of the 124 studies included in the review, two studies (Shatil et al., 2010, Shevil and Finlayson, 2009) specifically focused on cognitive rehabilitation in people with MS. Shevil and Finlayson (2009) nested a process evaluation within a pilot before and after study (Shevil and Finlayson, 2010) that evaluated the effectiveness of a group-based cognitive rehabilitation intervention (internal and external compensatory strategies) for memory, attention, information processing and executive dysfunction. Participants' perceptions of the intervention and their attendance at sessions were measured, and the outcomes of the study were linked to the findings of the process evaluation (Shevil and Finlayson, 2009). Therefore, processes pertain to what aspects of the intervention were delivered and how these were delivered (Moore et al., 2015). This is also referred to as intervention or implementation fidelity – i.e., the degree to which interventions are implemented as intended (Carroll et al., 2007, Moore et al., 2015).

Process evaluations could also be used to ascertain the different 'active ingredients' (i.e., the content of the intervention) within a multi-component intervention. This enables an investigation of how the various components interact with each other to generate (or constrain) outcomes across different clinical settings and when adapted to meet individual patient needs (Masterson-Algar et al., 2014). Different components may be associated with varying challenges of implementation, which is particularly relevant to fidelity (Masterson-Algar et al., 2014). When assessing intervention fidelity, it is also beneficial to understand the extent to which adaptation of the intervention was permitted (e.g., to meet individual needs) or if complete standardisation was the aim (Craig et al., 2013). Craig et al. (2008) argued that to facilitate replication of the intervention, it was important for any variability in the implementation of intervention components to be reported fully, with complete and clear descriptions of the intervention provided. Therefore, when evaluating cognitive interventions such as CRAMMS, it is vital to examine the implementation of intervention components and to report the processes completely. This is discussed in more detail in the following sections.

1.3.7.2 Intervention fidelity

As previously discussed, evaluating intervention fidelity is an integral part of the process and therefore the evaluation of complex interventions. In their systematic approach for developing process evaluation plans, Saunders et al. (2005) proposed that the outcomes of intervention fidelity (or quality) assessment would be used: (1) to describe or quantify how the intervention had been implemented, and (2) to monitor and adjust the implementation of the intervention as necessary. This would maintain the quality of intervention delivery and ensure that the intervention delivered was consistent with its theoretical underpinnings (Saunders et al., 2005). Therefore, an examination of intervention fidelity has several benefits for complex cognitive

rehabilitation interventions. These include the early detection of errors (i.e., protocol deviations), increasing participant retention and ensuring that the same intervention is delivered across multiple sites. If interventions were delivered as planned, they would facilitate the examination of the 'mechanism of change'; that is, how the intervention variables were considered to mediate outcomes (Hart and Ehde, 2015).

At the time of writing this research, there was a lack of a standardised approach to defining the key components of intervention fidelity, and its assessment, within the literature. Some conceptualisations of fidelity included the trial design and delivery (e.g., study design, how the intervention was delivered, and how participants responded to this delivery). For example, the National Institutes of Health Behaviour Change Consortium (BCC) (Bellg et al. (2004) suggested a five-component model of fidelity for psychologically-focussed interventions, to assist researchers in incorporating treatment fidelity practices into their work more consistently. These components were study design, facilitator training, treatment delivery, receipt of treatment and treatment enactment skills (Bellg et al., 2004). As Borrelli (2011) summarised, treatment delivery was concerned with whether the desired treatment and not another treatment was delivered (treatment differentiation); whether or not the treatment provider maintained the necessary skills to deliver the intervention (treatment competency); and whether the treatment components were delivered as planned (treatment adherence).

Carroll et al.'s (2007) consolidated framework for implementation fidelity (CFIF) conceptualised fidelity that focused on the measurement of adherence (i.e., intervention content, frequency, duration of delivery and coverage) and its potential moderators (e.g., participant responsiveness to the intervention and the strategies undertaken to facilitate implementation). Within this framework, adherence was defined as the extent to which the delivery of the intervention was consistent with the

study methods (as per the protocol). The content of the intervention referred to the 'active ingredients' or the key intervention components (e.g., skill acquisition or knowledge) that the intervention was designed to deliver to recipients. The frequency, duration and coverage of the intervention constitute the 'dose' of the intervention. All components of Carroll et al.'s (2007) CFIF are therefore quantifiable, as *actual* adherence could be compared to what was initially planned. In this vein, an evaluation of the degree of implementation fidelity achieved for an intervention was based on the degree to which the intervention content or frequency was implemented (Carroll et al., 2007). Therefore, intervention fidelity would be assessed as 'high' or 'low'. The CFIF was modified by Hasson and colleagues to include additional moderating factors such as context and recruitment (Hasson, 2010).

Gearing et al. (2011) identified the need for a standardised conceptualisation of fidelity and the negative impact that the plethora of definitions and conceptualisations had on the assessment of fidelity. In their systematic review, the authors identified four components of intervention fidelity, that is, design, training, monitoring intervention delivery and receipt of the intervention. Furthermore, the authors classified intervention delivery, and the monitoring of it, as the fundamental element of fidelity. Aspects of this component and its assessment included whether core intervention elements (as opposed to prohibited components or other interventions) and the 'dose' of the intervention were delivered (Gearing et al., 2011). This was a view supported by Masterson-Algar et al. (2014). Their study, which aimed to increase the independence of stroke survivors living in UK care homes, highlighted the challenges associated with investigating fidelity of the implementation of a complex rehabilitation intervention. Masterson-Algar et al.'s (2014) findings not only highlighted aspects of fidelity that were neglected by current frameworks for fidelity assessment but also emphasized the need for a conceptual model of fidelity that appropriately represents the concepts, context and language of fidelity in rehabilitation research.

Upon examination of the central conceptualisations of intervention fidelity identified in the literature and presented here, it was apparent that 'intervention delivery' constituted a significant feature of intervention fidelity. The terms 'adherence' (Carroll et al., 2007, Hasson, 2010), 'treatment delivery' (Bellg et al., 2004, Borrelli, 2011) and 'intervention delivery' (Gearing et al., 2011) all referred to aspects of the intervention as defined in the protocol. That is, the key or essential components of the intervention that differentiated it from another intervention, which were grounded in theory, and were hypothesised to be the mechanism of change (e.g., behaviour change) of the intervention. These were, therefore, aspects of the 'content' of the intervention.

1.3.7.3 CRAMMS cognitive rehabilitation intervention

CRAMMS was a complex intervention (Campbell et al., 2000), as it comprised several interacting components, including multiple sites and different group compositions (Campbell et al., 2000), and the manual allowed for a degree of adaptability to meet the individual needs of participants in the groups. Trained Assistant Psychologists, under the supervision of Clinical Psychologists, delivered the CRAMMS intervention. When evaluating the effectiveness of the CRAMMS, it was important to consider the effects of the content of the intervention (i.e., the cognitive rehabilitation) in light of interacting factors such as therapist skill in delivering the intervention. It was essential to determine whether the CRAMMS intervention was delivered in accordance to the manual (intervention fidelity), and to assess what *actually* happened spontaneously in the interaction between group members and the therapists during the intervention (i.e., content/description of intervention). Fidelity was, therefore, a vital methodological requirement when testing the effectiveness of the CRAMMS intervention. This held importance for both validity (internal and external validity) and trial replication (Bellg et al., 2004, Carroll et al., 2007). These concepts are closely

associated with the dissemination and implementation of cognitive rehabilitation interventions and are discussed in the following section.

1.3.8 The dissemination and implementation of cognitive rehabilitation

1.3.8.1 Dissemination, translation and implementation research

Dissemination and implementation constitute Phase IV of the MRC framework discussed in section 1.3.5 (and illustrated in Figure 2). Dissemination refers to the active and strategic communication of research evidence that is tailored to the intended audience (Lomas, 1993, MacLean, 1996), to increase effective use and uptake of this research (Dearing et al., 2018). Translational research is concerned with: (1) transforming research from basic science into novel treatments and (2) ensuring research knowledge of the effectiveness or potential benefit of treatments is translated into routine clinical practice, with health as the primary outcome for patient populations (Rubio et al., 2010, Woolf, 2008). Whereas the former focuses on the more lab-based, experimental and preliminary stages of research (similar to the initial, Phase I stages of the design of interventions: Campbell et al. (2000)), the latter is concerned with the effectiveness, dissemination and translation of research in real-world settings (Rabin and Brownson, 2018, Woolf, 2008).

'Implementation science' refers to the scientific examination and evaluation of methods to promote the efficient uptake of research evidence (e.g., clinical treatments) into routine practice to improve health outcomes (BMC Implementation Science, Eccles and Mittman, 2006). Both dissemination and implementation science are ultimately concerned with factors that influence behaviour change (i.e., on a patient-, clinician- and organizational-level (Curtis et al., 2017)), taking into consideration the influence of organisational, societal and political factors that

moderate the uptake of research evidence into healthcare practice (Bauer et al., 2015). Of importance are the barriers and facilitators that affect decision-making when considering whether or not to adopt an intervention in practice in the first instance, and the changes in behaviour required to implement intervention (Dearing et al., 2018). Behaviour change theories facilitate understanding of the processes involved in changing individual behaviours (such as improving the reporting of cognitive rehabilitation interventions in MS or increasing the uptake of these interventions in practice).

Knowledge translation, which is the process of generating, dissemination and adoption into routine practice (Curtis et al., 2017, Nilsen, 2015) is not solely dependent on research evidence but on factors associated with implementation science (Curtis et al., 2017, Kristensen et al., 2016). Implementation science focuses on evidence-based practice that is under-utilised in clinical practice and identifies potential reasons for the gap at the healthcare provider and healthcare system level (Bauer et al., 2015). Therefore, the translation of evidence-based practices into clinical practice requires an understanding of these factors.

Nilsen (2015) and Tabak et al. (2018) presented the various theories, models and frameworks that sought to provide insight into the factors that contributed to the gap between research evidence and practice, as well as to provide frameworks to guide and evaluate implementation processes. These are summarised in Table 2.

Table 2 Summary of dissemination and implementation theories, models and frameworks relevant to healthcare research

Aim	Model	Description	Examples
To describe or guide the steps involved in the translation of research evidence into practice	Process models	Provide practical guidance on how to plan and execute implementation strategies	Knowledge-to-Action Model (Graham et al., 2006)
To understand and explain moderators of implementation outcomes	Classic theories	Describe the behaviour change mechanisms involved in implementation. Includes psychological behaviour change theories	The Social Cognitive Theory Bandura (Bandura, 1986); The Theory of Planned Behaviour (TPB) (Ajzen, 1985) and the Theory of Reasoned Action (TRA) (Ajzen and Fishbein, 2000); The Trans-theoretical or Stages of Change Model (Prochaska and DiClemente, 1982)
	Implementation theories	Facilitate the understanding of the characteristics of implementation	Normalisation Process Theory (May and Finch, 2009)
	Determinant frameworks	Describe the determinants of implementation outcomes such as behaviour change or adherence to clinical guidelines	Consolidated Framework for Implementation Research (CFIR) (Damschroder et al., 2009)
To evaluate implementation strategies	Evaluation frameworks	Guide the evaluation of implementation research.	The RE-AIM model (Glasgow et al., 1999)

Determinant frameworks such as the Consolidated Framework for Implementation Research (CFIR) (Damschroder et al., 2009) suggested five domains that could influence the outcomes of implementation research. The domains include the implementation process, characteristics of the individuals involved in the implementation of research, and the outer and inner characteristics of the setting. Of

relevance to the current research was the 'intervention characteristics' domain of the CFIR. Damschroder et al. (2009) highlighted the importance of the following factors:

- The quality of the evidence for research
- The adaptability of the intervention (i.e., to meet the needs of the healthcare setting and/or patient population)
- Whether the intervention could be tested on a small scale
- The complexity of the intervention
- How the intervention was presented
- The associated costs of the intervention

These characteristics of the intervention identified by Damschroder et al. (2009) are similar to the five perceived moderators of dissemination and implementation of research as suggested by Rogers (2003). Intervention characteristics that influence the extent and speed of adoption in practice include the compatibility and appropriateness of the intervention for the setting and patient group, the effectiveness of the intervention relative to an alternative (i.e., the relative advantage) and the complexity of the intervention (Rogers, 2003).

1.3.8.2 The gap between cognitive rehabilitation research evidence and clinical practice in MS

The ability of researchers to disseminate the results of studies and the ability of clinicians to assess this evidence for adoption in their own clinical setting relies significantly on the evidence-base (Davidson et al., 2003). Evidence-based practice in the cognitive rehabilitation of MS is not only influenced by outcomes. The research evidence, the clinicians' expertise in delivering the intervention and the preferences and goals of the people with MS are potential barriers and facilitators to evidence-based practice in the cognitive rehabilitation of MS (Lilienfeld et al., 2013).

Evidence-based practice, as it relates to cognitive rehabilitation in MS, is an approach that integrates current best evidence on the effectiveness and efficacy of these interventions with the individual clinical needs of the people with MS (Bauer et al., 2015, Davidson et al., 2003). Whilst efficacy is concerned with the outcome of interventions under ideal conditions (i.e., explanatory trials), effectiveness describes the outcome of interventions in 'usual' healthcare practice circumstances (i.e., pragmatic trials) (Kim, 2013). Since the 1980s, evidence-based medicine has contributed to the development of clinical guidelines to improve the healthcare of patients (Davidson et al., 2003).

It is estimated to take up to 17 years for research evidence to be transformed into evidence-based practice (Morris et al., 2011). Despite the evaluation of the effectiveness of cognitive rehabilitation programmes in previous research studies, with some promising findings (as discussed in 1.3.4.1), few people with MS routinely receive any formal cognitive rehabilitation in the UK. This is despite recommendations from professional and national bodies for the provision of cognitive rehabilitation for people with MS (e.g., European Handbook of Neurological Management (Cappa et al., 2010), National Service Framework for Long term Conditions Department of Health (2005) and the National Institute for Clinical Excellence (NICE) (2014) guidelines for Multiple Sclerosis: management of multiple sclerosis in primary and secondary care)). NICE (2014) guidelines, for instance, recommended that people with MS experiencing memory or other cognitive problems should be considered for referral to occupational therapists or neuropsychologists to assess and manage these issues. There were various potential reasons for this lack of implementation and delivery of cognitive rehabilitation for people with MS.

First, there is an issue with the provision of neurorehabilitation services in the United Kingdom (UK). Croft et al. (2016) conducted the 'MS Forward View consensus

project,' funded by the MS Trust (UK). The aims of this project included mapping MS services and understanding the needs of people with MS. Mapping of services involved surveys with healthcare professionals, including MS specialist nurses, neurologists and rehabilitation medicine consultants. The outcome was statements highlighting the propriety areas necessary to improve the effectiveness, equity, and efficiency of MS services in the UK. Although neurorehabilitation was identified as a key component to ensuring people with MS had quality of life and participated in society, MS services in the UK were skewed towards meeting the needs of people with MS who were taking disease-modifying drugs than managing symptoms of MS, including cognitive issues, through neurorehabilitation.

Furthermore, there was a short supply of neurorehabilitation specialists. Specifically, psychological services that are mainly involved in the assessment and management of cognitive problems in MS (Mynors et al., 2016, Roberts et al., 2016). Although some people with MS did receive cognitive assessments, most were directed to other sources of information or organisations outside of the NHS (Klein et al., 2018). Most advice in the UK was gained through information booklets and web content provided by organisations such as the MS Society and the Rehabilitation in Multiple Sclerosis (RIMS) Psychology and Neuropsychology Clinical Care Committee (2014).

Second, while there are costs associated with providing cognitive rehabilitation, studies demonstrating the cost-effectiveness of cognitive rehabilitation in MS is lacking. Therefore, commissioners may be reluctant to offer such services.

Finally, a pertinent problem that many clinicians face is how to deliver an intervention that has been found to be effective in research studies, due to the poor quality of reporting of the content of the intervention. The quality of reporting and its effect on

the implementation of cognitive rehabilitation interventions for people with MS is discussed in the following section.

1.3.9 Quality of reporting of interventions and reporting checklists

1.3.9.1 Quality of reporting

Precise and complete descriptions of interventions are needed in rehabilitation research to enable replication of the evaluated interventions by other researchers and implementation into clinical practice (Dijkers, 2015). Arguably, to enable healthcare providers to assess the suitability of cognitive rehabilitation for their setting and patient group, utilising the characteristics identified by Damschroder et al. (2009) in section 1.3.8.1, this information needs to be communicated to them more effectively (e.g., in research papers). The quality of reporting of cognitive rehabilitation is an important initial step to dissemination, translation and implementation research.

Michie et al. (2009) stressed the need for greater transparency in reporting complex interventions, with the salient effective components of the intervention, or the 'active ingredients,' needing to be described clearly in research studies. 'Active ingredients' of a complex intervention are the components of the intervention that are "essential to achieving good outcomes for those targeted by the intervention" (Michie et al., 2009, p. 40). Through their intervention taxonomy, Davidson et al. (2003) and Schulz et al. (2010) identified intervention delivery and content factors (e.g., delivery mode, the duration and intensity of the intervention, the mechanism of action, who delivered the intervention and intervention strategies) that were important to know to aid replication and implementation. The poor quality of reporting has wider implications for the synthesis of research findings in systematic reviews and clinical guidelines (Dijkers, 2015), such as those produced by NICE. There are also economic (resource

wastages) and ethical (participant involvement, avoiding interventions that have been shown to be harmful and poor uptake of interventions that have been shown to be effective in clinical practice) implications of inadequate reporting of rehabilitation interventions in MS (Dijkers, 2015, Michie et al., 2009). Therefore. it is important to know the functional relationship between components of the intervention and outcomes as this informs the training of intervention facilitators and how to adapt interventions to suit individual and organisational needs for example, which are key features of implementation (Michie et al., 2009) as previously discussed

As previously discussed, the 'what' and 'how' of interventions was of particular significance to cognitive rehabilitation programmes, as these programmes are complex and therefore are influenced by various interactive factors. Research evidence suggests that between 50% and 70% of non-pharmacological interventions are poorly reported (Glasziou et al., 2008, Hoffmann et al., 2013, Samaan et al., 2013). Glasziou et al. (2008) examined 80 articles from the journal *Evidence-based Medicine*, including systematic reviews and individual trial reports (drug and non-drug treatments). Descriptions of the interventions were reported fully in drug trials versus non-drug trials (e.g., psychological interventions). Moreover, descriptions of the intervention procedures or intervention materials were found to be the most poorly reported aspects of the interventions. The completeness of intervention description increased after authors were contacted to provide further information (increased from 49% to 76%). The authors concluded that where information was reported comprehensively in research papers, without the need to seek further clarification from authors, this would facilitate greater implementation in clinical practice. However, this is an assertion that would need to be empirically tested.

1.3.9.2 Reporting checklists

Davidson et al. (2003) reviewed the status of evidence-based medicine and concluded that the adequate and standardized reporting of RCTs, in particular, was an important knowledge-source that could guide evidence-based practice. There is evidence that checklists can improve the quality of reporting of interventions (Kane et al., 2007, Plint et al., 2006, Smith et al., 2008). For example, Kane et al. (2007) compared the reporting of RCTs in two medical journals; one which stipulated that research authors use the Consolidated Standards of Reporting Trials (CONSORT) reporting guidelines and one which did not. The quality of reporting of the RCTs was found to have significantly improved in the journal that sanctioned the CONSORT reporting guidelines. However, in a scoping review of systematic reviews of adherence to reporting guidelines by Samaan et al. (2013), 43 (86%) of included reviews reported poor levels of adherence of studies to reporting guidelines. The authors provided recommendations to improve adherence, including the use of *appropriate* reporting guidelines. The Enhancing the Quality and Transparency of Health Research (EQUATOR) website is an initiative that aims to promote transparency and accurate reporting in published health research. This database contains reporting guidelines for different research designs and interventions. However, none of the available reporting checklists are specific to complex interventions such as cognitive rehabilitation in MS.

It was important, therefore, to gain a better understanding of what details clinicians delivering cognitive rehabilitation to people with MS need to know about an intervention to facilitate the translation of positive research findings into clinical practice. This was a viewpoint supported by Cicerone (2005), who argued that imprecise descriptions might lead to disagreements when interpreting the research evidence.

Consistent with this, van Heugten et al. (2012) evaluated the reporting of interventions across 95 RCTs of cognitive rehabilitation. The review presented the content of included trials across a variety of cognitive domains, such as language skills, memory and executive function. The authors concluded that reporting of complex interventions is poor, particularly for descriptions of *actual* treatment dose (reported in 22% of the included studies), delivery format (i.e., group, individual or blended: this was unknown in 33% of the studies), and information about the staff who delivered the intervention (unknown in all 95 studies). The authors suggested developing a checklist for reporting interventions in a standardised way. Subsequently, Hoffmann et al. (2014) developed the Template for Intervention Description and Replication (TIDieR) checklist. However, as TIDieR is a general tool for pharmacological and non-pharmacological studies, specific aspects of cognitive rehabilitation (e.g., intervention strategies, delivery mode, and take-home activities) could be overlooked.

Martin et al. (2015) investigated the specific attributes of the reporting of group-based cognitive rehabilitation interventions for neurological conditions, focusing only on RCTs. Of the 14 studies included in their review, information relating to session-specific content was not reported in 71% of the included studies, and the duration of the programme was not reported in 43% of the included studies. Based on their findings, they developed a checklist to be used as an adjunct to the TIDieR checklist for researchers (Hoffmann et al., 2014) to describe group-based cognitive rehabilitation in publications. A limitation of their review is that, by only including RCTs, the findings do not provide a comprehensive overview of research in this field. Furthermore, of the 14 studies reviewed, only three included people with MS. Therefore, based on Mitolo et al.'s (2015) findings, there were potentially more studies that could inform the development of a checklist.

In light of the evidence presented, a disease- and domain-specific reporting checklist (i.e., that is *appropriate*) may facilitate better reporting of the content of cognitive rehabilitation for people with MS.

1.4 Rationale for this research

Although the effectiveness of cognitive rehabilitation programmes for people with MS has been evaluated in trials, researchers often did not provide sufficient details of the interventions, to enable clinicians to replicate the rehabilitation tested. Consequently, the potential benefit of these programmes for people with MS is limited. There is evidence that checklists could improve the quality of reporting of interventions (Cobo et al., 2011, Smith et al., 2008). Based on their scoping review of systematic reviews of adherence to reporting guidelines, Samaan et al. (2013) provided recommendations to improve adherence, including the use of *appropriate* reporting guidelines. Due to limitations within existing systematic reviews, a more exhaustive examination of what was reported about cognitive interventions for people with MS is needed. This would strengthen the validity of the reporting checklist.

A large RCT evaluating the clinical and cost-effectiveness of Cognitive Rehabilitation for Attention and Memory in people with MS (CRAMMS) (Lincoln et al., 2015) provided a unique opportunity to examine the actual content of the cognitive rehabilitation being delivered. However, note that the research undertaken and reported in this thesis was unique and independent to the CRAMMS trial. The component nested within the CRAMMS trial had the aim to increase the clinical impact of cognitive rehabilitation trials. It was also important to gain a better understanding of what intervention details clinicians delivering cognitive rehabilitation to people with MS needed to know to facilitate the translation of positive research findings into clinical practice.

The research reported in this thesis was aligned with the MRC framework for the design and evaluation of complex interventions. Specifically, these are: Phase I (theory and modelling), Phase III (understanding processes) and Phase IV (dissemination and implementation). Furthermore, this research was consistent with the priorities set by the MS Society Research Strategy 2013-2017 and James Lind Alliance (JLA), who identified finding effective treatments for cognitive problems as a 'top 10' research priority.

1.5 Aim of the research

The overall aim of this research was to explore avenues to increase the clinical impact of trials of cognitive rehabilitation, ultimately through the development of a consensus checklist for the reporting of the content of cognitive interventions for people with MS. It was anticipated this checklist would be used by researchers, to facilitate complete reporting of the intervention, which would enable replication of the intervention in other studies. Moreover, by highlighting the salient parts of the intervention, this would facilitate the adoption of these interventions by clinicians in routine practice. In order to do this, there were three specific aims.

1.6 Specific aims of the research

The aims corresponded to the three research studies. These were:

- Study one: To produce a 'state of the science' systematic review of how cognitive rehabilitation for people with MS was reported in scientific journals. This would build upon systematic reviews conducted in this area already (Martin et al., 2015, van Heugten et al., 2012), but was specific to people with MS and interventions targeting memory, attention, and executive function.

- Study two: To complete a detailed analysis of the actual content of a large-scale RCT of cognitive rehabilitation in MS (CRAMMS), to examine what the CRAMMS therapists delivered and what therapists and participants discussed during the treatment sessions. This would facilitate the understanding of how the content of cognitive rehabilitation compared to what was planned.
- Study three: To reach clinician- and researcher-consensus on the content of cognitive rehabilitation interventions for people with MS that should be reported in the research literature. This was unique and had not been undertaken for cognitive rehabilitation before. Developing a checklist to aid improvement of the reporting of these interventions will potentially facilitate increased implementation of interventions in practice by clinicians.

1.7 Overall Methodology and Study Configuration

This section details the rationale for the methodology for this research. This was a mixed- methods study whereby quantitative and qualitative approaches were combined in a single study to provide a better understanding of a research area (Creswell and Clark, 2007). The use of mixed-methods research is justified when there are a number of research questions in a study requiring different approaches (Clark and Badiee, 2010).

The overall approach to this study followed an exploratory mixed-methods design (Creswell and Clark, 2011), which begins with qualitative data collection and analysis. The findings then inform a quantitative phase. This design is used for instrument development, as it facilitates the identification of important variables that are unknown. Phenomena are explored in the qualitative phases, with the results used to identify and develop an instrument in the quantitative phase (Creswell and Clark, 2007). The qualitative codes and themes generated in study one (Chapter 2) and

study two (Chapter 3) were converged (Fetters et al., 2013, Guetterman et al., 2015) to produce reporting statements for the initial round in study three (i.e., quantitative outcomes; Chapter 4). This process is illustrated in

Figure 3.

The three studies mapped onto Moher et al.'s (2010) recommendations for developing guidelines for reporting health research. A reporting guideline was defined as "a checklist, flow diagram, or explicit text to guide authors in reporting a specific type of research, developed using explicit methodology" (Moher et al., 2010, p. 1). The authors identified five overarching themes to developing reporting guidelines, involving 18 steps. These included:

- Identifying the need for a guideline and review the literature to assess the quality of reporting in published research papers (Study one).
- Identifying key information that needs to be included and could be related to the potential sources of bias in the assessment of reporting quality of relevant studies (Study one and Study two).

The outcome of these two steps would be the generation of a list of items for consideration in the guideline.

- The third step involved seeking consensus, through a Delphi exercise, to determine which items to include in the guideline (Study three).

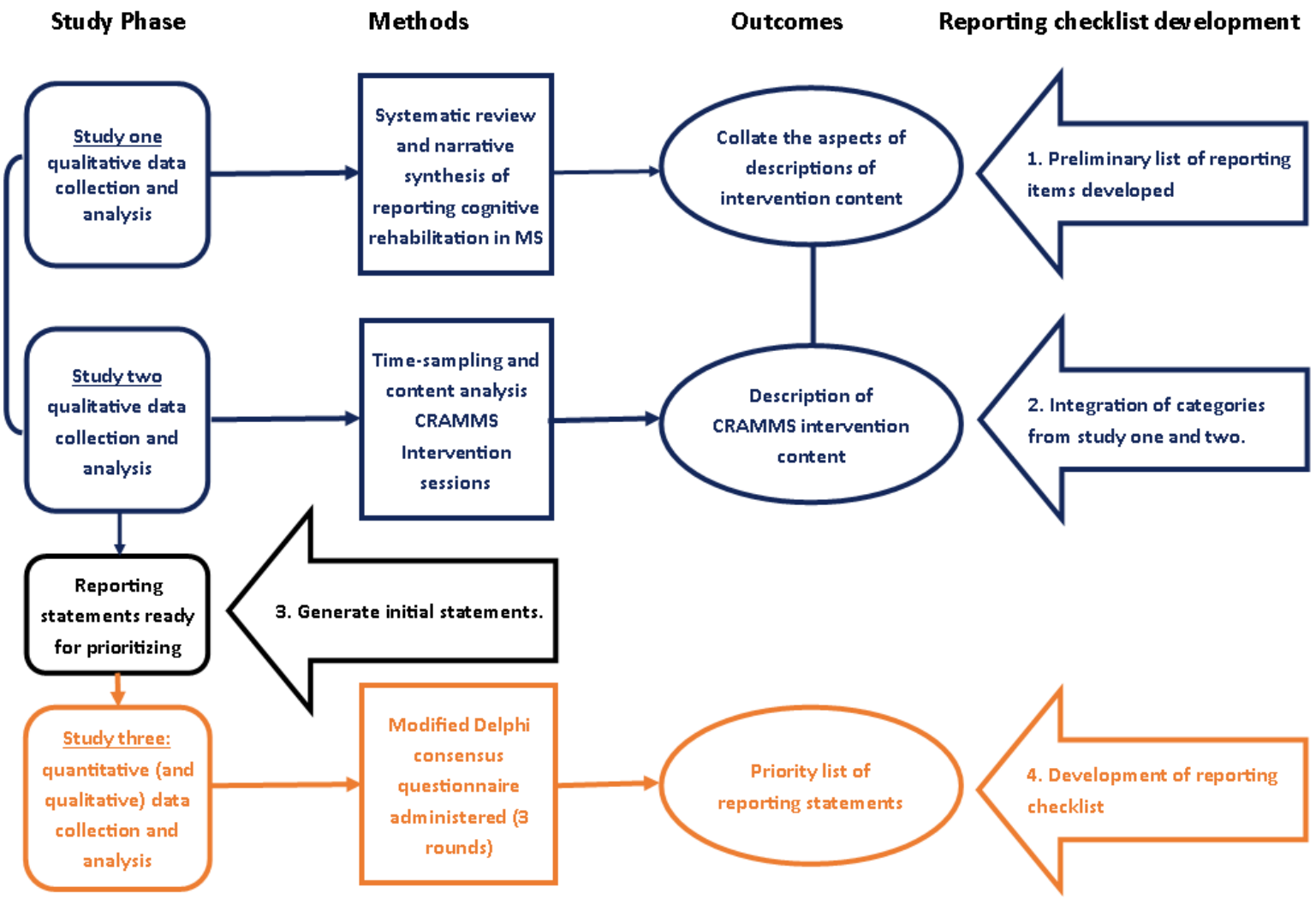


Figure 3 The exploratory mixed-methods research process

This figure illustrates the configuration of the three studies of the research, methods undertaken, the outcomes and how these contributed to the development of the reporting checklist.

1.8 Philosophical underpinnings of the research

The framework for any research relies on ontological and epistemological positions (Denzin and Lincoln, 2011). Ontology refers to the nature of reality and epistemology refers to the science or theory of knowledge, that is, how knowledge is generated and justified and its relationship with the researcher (Carter and Little, 2007, Creswell and Clark, 2011). Epistemological assumptions are based on ontological positions, and they modify the methodology and methods within research. Methodology justifies the methods used within research, which in turn produces ways of data collection and analysis, from which knowledge is subsequently created (Carter and Little, 2007).

As highlighted earlier, the studies of the research were designed based upon the recommendations of Moher et al. (2010) for the development of reporting guidelines. These recommendations advocate a sequential process that combined qualitative and quantitative methodologies (i.e., a mixed methods approach), as presented in the previous section. The use of mixed methods approaches has seen an increase in health research (Creswell and Clark, 2011). Mixed-methods approaches are consistent with a critical realist epistemology, which advocates methodological pluralism as opposed to individualism (Benton and Craib, 2011, Mesel, 2013), and views methodological choices as dependent on the research question and objectives (Edwards et al., 2014). The research had clear aims and objectives, which informed the particular methods used in each study and their suitability to answer the research questions.

A critical realist epistemology views the world as operating in an ‘open system’, and focused on tendencies that represent underlying mechanisms and not laws (i.e., to aid prediction) (Benton and Craib, 2011). This is consistent with each phase of the

planned research programme which starts with an initial question guided by theory, and aimed to contribute to (i.e., generate knowledge) a revealing of the underlying mechanisms and structures that may account for the poor implementation of cognitive rehabilitation for people with MS in clinical practice.

1.9 Overall thesis structure

Chapter 1 provides the background literature, justification for the research and overall methodology. Chapters 2, 3 and 4 report the methods and results of each of the three studies. Chapter 5 provides the overall synthesis of findings and discussion of the studies as they relate to the research aims and objectives. Also discussed were the implications of the findings in the broader research as well as the implementation of cognitive rehabilitation for people with MS in practice. The thesis concludes by discussing the implications of the findings with respect to future research and clinical practice.

Chapter 2 Examining the quality of reporting of cognitive rehabilitation, a systematic review - Study One

2.1 Chapter overview

This chapter presents a systematic review of the quality of reporting of cognitive rehabilitation for people with MS, the first stage of the process Moher et al. (2010, p. 2) recommended for developing health research reporting guidelines. This has been published (Mhizha-Murira et al., 2017).

2.2 Introduction

The limitations of previous systematic reviews that assessed the quality of reporting of content cognitive rehabilitation were previously discussed in Chapter 1. Due to weaknesses (e.g., a focus on RCT studies only), a more exhaustive examination of what was reported about cognitive interventions for people with MS was needed. This would strengthen the comprehensiveness of the cognitive rehabilitation reporting checklists developed in this research.

The systematic reviews conducted by van Heugten et al. (2012) and Martin et al. (2015) examined the content of cognitive rehabilitation interventions for a range of neurological conditions, including MS. These two reviews considered several cognitive domains (e.g., memory, attention, executive function, language, awareness and visuospatial functioning) and found the overall quality of reporting was poor. The outcome of both these reviews included the drafting of a checklist for specific and non-specific cognitive interventions, with the conclusion that more research was necessary to enhance the reporting of cognitive interventions further. The current study built on the findings of these reviews, but focused solely on cognitive rehabilitation for with people with MS. The systematic review presented in this chapter was unique also because of its focus on the cognitive rehabilitation of memory, attention and executive dysfunction for people with MS. These cognitive processes had often been considered separately in systematic reviews (das Nair et al., 2016,

Martin et al., 2015). However, as argued by Sohlberg and Mateer (2001), it is advantageous and of scientific merit to integrate all three in this review. Memory, attention and executive function are commonly the targets of rehabilitation for people with MS. For example, in their review looking at cognitive rehabilitation in MS, Mitolo et al. (2015) found that out of the 33 published studies included, 23 (70%) targeted the cognitive domains of memory, attention and executive function. A second reason for integration provided by Sohlberg and Mateer (2001) was based on the argued interdependency of these processes, underpinned by overlapping neurocircuitry that serves these processes (Bekken and LeSueur, 2013). The third argument, presented in the background Chapter 1, is that as these processes are overlapping and therefore interactive, it would be difficult to separate the domains in any discussions.

Taking into consideration the different types of reviews and their associated methodologies (summarised by Grant and Booth (2009)), a systematic literature search and review was undertaken. The purpose of this was to:

- Enable an exhaustive and comprehensive search of the research evidence (i.e., cognitive rehabilitation interventions for people with MS), that covered a variety of research evidence of varying research designs
- Allow for a range of data synthesis methods in order to to provide a summary of the current state of reporting content of cognitive interventions
- Identify gaps in the literature.

A systematic review method was consistent with the aim and objectives of the review, which were not focused on the assessment of knowledge on policy or practice issues (e.g., rapid review) per se or to identify gaps in primary or secondary research (e.g., mapping review) (Grant and Booth, 2009).

2.3 Aim

The aim was to produce a 'state of the science' systematic review of the aspects of cognitive rehabilitation for people with MS reported in scientific journals. This was specific to people with MS and interventions targeting memory, attention, and executive dysfunction. This review also included a wider range of study designs than previous systematic reviews (presented in section 1.3.9.2).

2.4 Objectives

The primary objective was to collate and summarise, through a systematic review method, details of how cognitive rehabilitation for people with MS was reported in scientific journals.

The secondary objectives were:

- To evaluate the quality of reporting of interventions,
- To suggest ways of improving the reporting of cognitive interventions

2.5 Systematic review methods

A search strategy was developed based on the following criteria:

2.5.1 Types of studies

Studies evaluating the effectiveness of cognitive rehabilitation interventions for people with MS were considered for review. As one of the objectives of this review was to conduct a systematic and *comprehensive* search of research evidence for the content group-based cognitive interventions for people with MS, the researcher did not adopt the strict study design inclusion criteria that are commonly undertaken (e.g., by the Cochrane Collaboration). Debates on the equivocal findings on the effectiveness of cognitive rehabilitation (Cicerone et al., 2005, Cicerone et al., 2011, Mitolo et al.,

2015) that may be due to an over-reliance on the evidence from RCTs (Cicerone et al., 2009) and issues involved in utilisation of control groups in rehabilitation research (Hart and Bagiella, 2012, Hart et al., 2008) were also taken into consideration. As both van Heugten et al. (2012) and Martin et al. (2015) only included evidence from RCTs in their reviews, this may have omitted studies that may help to strengthen the robustness and inclusivity of the checklists that had been developed at the time. Therefore, the following study types were included:

- Randomised controlled trials (RCTs), quasi-randomised and non-randomised controlled trials
- Controlled before-and-after studies (prospective studies with a concurrent control group allocated using a non-random method and with a baseline period of assessment of main outcomes).
- Single case experimental designs
- Non-controlled studies

Systematic reviews were excluded, although their reference lists were checked for possible papers. Studies that were a re-analysis or subgroup analysis, or a sub-study of an included primary study were included in the review, with separate data extraction occurring for individual papers and the content reported separately.

2.5.2 Types of participants

Studies were limited to people with MS. All types of MS, that is, relapsing-remitting, secondary progressive and primary progressive, were considered for inclusion in the review.

Studies involving participants with other neurological disorders (e.g., stroke, epilepsy, or as a result of a traumatic brain injury) were excluded unless a subgroup of people

with MS could be identified or with a *substantial number* of people with MS. The latter was operationalised as at least 75% of the participants were people with MS. This was done to limit clinical heterogeneity of the sample regarding diagnosis and the effect that this could have on data analysis and interpretation (Ryan, 2014).

Studies were included if participants were over 18 years, or if subgroup analyses were available for those over 18 years. Studies including participants aged 17 years and under were excluded, due to the diagnostic and therapeutic challenges that were often associated with paediatric MS (Banwell et al., 2007) and that were not common with adult MS.

2.5.3 Types of interventions

Cognitive rehabilitation was defined as a structured set of therapeutic cognitive activities, targeting memory, attention and executive function deficits, and occurring over more than one session. These programmes could be delivered in a range of settings (e.g., hospital or home-based) and formats (e.g., computer-based, individual, all group formats, blended formats).

2.5.4 Outcomes

Outcomes refer to “to the effectiveness of the activities in relation to the achievement of the intended goal” (Lavoie, 2004, p. 12). As noted by Guimarães and Sá (2012), there were two methods used to assess cognition in MS that are not based on structural or functional imaging techniques: that is, self-reports of MS patients and their family members and/or caregivers, and objective, neurocognitive batteries. Since the focus of this systematic review was on the effectiveness of cognitive rehabilitation on increasing function, studies were included if the primary or secondary outcomes were measures of changes in functional ability.

Examples of these were:

1. Objective neurocognitive/neuropsychological measures (batteries/tests) of memory, attention and executive function, and other cognitive performance.
    - Examples of batteries: Brief Repeatable Battery of Neuropsychological Tests (BRB-N) (Rao, 1990, Rao et al., 1991b) and Minimal Assessment of Cognitive Function in MS (MACFIMS) (Benedict et al., 2006) neuropsychological batteries
    - Examples of standardised, objective outcome measures for measuring a single domain of cognitive performance: the Wechsler Memory Scale (Wechsler, 1997), the Paced Auditory Serial Addition Test (Gronwall, 1977), and the Doors and People Test (Baddeley et al., 1994).
2. Self-report measures that assessed the degree of subjective memory, attention and executive function problems in everyday life, coping strategies for these problems, quality of life, function, mood, and fatigue.

Studies reporting outcomes assessing mood, fatigue and general function were also included, to take into account the often-reported relationship these variables have with self-reported cognitive impairments and the effect that this has on quality of life (Arnett and Strober, 2011, Rao et al., 1991a).

Studies that only reported structural and functional imaging outcomes (e.g., functional magnetic resonance imaging [fMRI] were excluded.

2.5.5 Search methods for identification of studies

The search strategy was not restricted by date or geographical location. However, only studies published in English and in peer-reviewed journals were included.

2.5.5.1 Electronic searches

The Joanna Briggs Institute (2014) recommendations for searching databases were followed in the preliminary stages of developing the search strategy. The process commenced with an initial limited search based on aspects of the inclusion criteria (Table 3), followed by an analysis of the text words within the title and abstract, as well as the article index terms and keywords. This stage helped to identify key search terms (words, phrases and synonyms) and specialist terminology, acronyms or useful keywords. A second search was then undertaken, using the keywords and index terms identified from step one. The aim was to minimise the risk of excluding principal keywords and index terms from the search strategy.

Following a similar method used by van Heugten et al. (2012), the findings of this search were compared to studies identified in the previous reviews (e.g., das Nair et al., 2016; Martin et al., 2015; Mitolo et al., 2015) to ensure that relevant articles had been identified in the search results. A subject librarian was then consulted to check the combining of search terms in the search strategy. Based on the results of the two previous stages, any missing search terms were incorporated into the final search strategy. This was an iterative process. The subject librarian also assisted in developing a search strategy for MEDLINE (Ovid) (Appendix 1). The MEDLINE (Ovid) search strategy was adapted for each database, using appropriate MESH headings, truncations and Boolean logic for each database.

Table 3 Initial limited search of the systematic review

Criteria	Keywords
Study design	Study design keywords were not included in the search strategy
Participants	Multiple sclerosis, MS, Demyelinating autoimmune disease$, Demyelinating disease$, Autoimmune diseases Cognition, Cognitive, Cognitive dissonance, Cognition Disorder, Metacognition, Attention /Concentration/Awareness, Attentional deficits/disorders/Distraction, Cognitive impairment, Memory, Mental processes, Executive function/ Planning/Organisation/Regulation, Neurological systems and disorders
Intervention	Rehabilitation, neurorehabilitation, cognitive rehabilitation, neuropsychological rehabilitations remediation, education, training, retraining, paging system, treatment, treatments, therapy, recovery, restitution, restoration, strategy, counselling, remediation Attention/concentration, distraction, cognition, executive/ planning/ organisation/ regulation, memory, mental processes
Outcomes	Outcome keywords were not included in the search strategy

Searches were conducted across a number of electronic database and alerts were set up to highlight new papers published in-between the initial search and the analysis.

The following ten databases were searched from time of inception to 1 May 2017:

- MEDLINE In-Process & Other Non-Indexed Citations (1946 to current)
- EMBASE (1974 to current)
- CINAHL (1982 to current)
- Applied Social Sciences Index and Abstracts (ProQuest) (1987 to current)
- ISI Web of Science: Social Sciences Citation Index (1956 to current)
- PsycINFO (1806 to current)

- Dissertations & Theses A&I (1743 to current)
- Dissertations & Theses - UK and Ireland (1716 to current)
- Allied and Complementary Medicine database (1985 to current)
- CAB Abstracts (1973 to current).

These databases covered a range of subjects of relevant topics, and they hosted the journals where studies related to cognitive rehabilitation in MS were usually published.

2.5.5.2 Hand searches and searching other resources

The reference lists of all included studies and previously published reviews (das Nair et al., 2016, Martin et al., 2015, Mitolo et al., 2015, Rosti-Otajärvi and Hämäläinen, 2014) were searched for relevant studies. The Cochrane Central Register of Controlled Clinical Trials (CENTRAL) (The Cochrane Library, latest issue) was searched to identify other relevant systematic reviews, to identify individual papers.

Hand-searching of the following online resources also occurred:

- UK Clinical Trials Gateway (https://www.ukctg.nihr.ac.uk/)
- The NIHR Clinical Research Network database
- Networked Digital Library of Theses & Dissertations

The specialist register GreyNet (http://www.greynet.org/) was searched for grey literature that may have been published in peer-reviewed journals.

2.5.6 Data collection

2.5.6.1 Selection of studies

The eligibility of the studies was judged by assessing the titles and abstracts (if available) against the pre-defined inclusion criteria. A hierarchy by which studies were excluded was developed and followed (Appendix 2).

Full-text copies of all potentially relevant studies or studies where there was uncertainty regarding their inclusion were obtained and the researcher and a second reviewer (20% of full-text copies) independently assessed whether they met the inclusion criteria. Any disagreements were resolved by discussion with a third reviewer.

2.5.6.2 Data extraction

Data extraction forms were developed for this stage. Data extraction was a two-step process:

1. Confirmation of inclusion of the full text article, with study characteristics extracted based on PICO (participants, intervention, comparators and outcomes).
2. As the aim of this review was to ascertain the content and/or description of cognitive interventions, particular attention was placed on the information reported in the papers pertaining the 'active ingredients' of the interventions, that is, the *essential* elements considered to influence the outcomes (Michie et al., 2009). Data pertaining to the theoretical basis and underlying assumptions of the cognitive rehabilitation interventions, as well as the extent to which the interventions were implemented as intended (i.e., fidelity) were extracted, as these factors influence and help to interpret the outcomes (Dijkers, 2015). For example, data included a description of intervention delivery (i.e., facilitator, the format of groups, the content of the sessions, whether the intervention was manualised, how fidelity was assessed, and the setting of homework tasks). To enable an assessment of the extent to which the description of interventions met the reporting guidelines suggested in the literature, relevant items from checklists identified in the literature and that applied to cognitive rehabilitation research were also included in the data extraction tools. These included the TIDieR checklist (Hoffmann et al., 2014),

findings from the systematic reviews by Martin et al. (2015) and van Heugten et al. (2012), the Publication Manual of the American Psychological Association's Journal Article Reporting Standards (JARS) (VandenBos et al., 2010), and the Western Journal of Nursing Research (Conn, 2012) checklist for the reporting of interventions. Details of the checklists are provided in Appendix 3.

Data from studies meeting the inclusion criteria were extracted independently by the researcher and a second reviewer (extracted data from 20% of included studies). This process was undertaken to assess the reliability of the data extraction by the primary researcher. The data extracted independently by the two reviewers was entered onto a data extraction form developed for the study, after which results were compared. Discrepancies between the two reviewers were agreed through discussion or arbitrated by a third reviewer if necessary.

Data from multiple reports were not combined into a single data collection form, nor was information from multiple forms combined at this stage, as suggested by Cochrane when extracting data from multiple reports of the same interventional study (Higgins and Green, 2011).

One reviewer checked a random selection (10%) of the data entered. Where corrections were required, a full audit trail and justification was conducted. This process was undertaken to establish the reliability of the data entry by the primary reviewer.

The various components of the intervention described in each paper were coded against the checklists. The content was recorded as complete (based on the description provided for each item) (i.e., full colour block), missing (white box), or partially reported (grey box). Data supplied in supplementary texts (e.g., available

online) were included in the coding and in assessing the quality of reporting of individual studies. As the aim of the review was to report on the aspects of interventions described in articles, authors were not contacted to provide additional or missing data.

2.5.7 Data analysis

A narrative synthesis process described by Popay et al. (2006) was followed for data analysis. The steps undertaken were as follows:

- A preliminary synthesis of the results – that is, a) tabulation of the included studies, identifying key details such as study design, cognitive deficit targeted and the intervention type, b) thematic analysis to identify key themes relating to the items described in the checklists, and c) content analysis to quantify the content of the reports into categories and to convert these to frequencies;
- An exploration of relationships within and between studies.

Assessment of the methodological quality (e.g., study design) or the generalizability of findings to different settings, measures and participants (Steckler and McLeroy, 2008) of the included studies was not undertaken, as the purpose of the review was to examine what was reported, rather than the quality of the studies themselves.

2.6 Results of the review

2.6.1 Results of the searches

Figure 4 presents the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al., 2009) flow diagram. The search strategy identified 16,618 articles for review. Of the 123 full text articles reviewed to check for eligibility for inclusion in the review, 69 were excluded (Appendix 4). The reasons for exclusion were: people with MS made up less than 75% of the study participants (n=4); the

intervention was not cognitive rehabilitation (n=34); the study design did not meet the inclusion criteria (n=22); the outcomes were not measures of changes in functional ability (n=7); and the study was not published in English (n=2).

2.6.2 Characteristics of the included studies

Appendix 5 provides specific details of the 54 included articles: 42 (78%) were primary studies; the rest of the articles were subgroup analyses (n=7; 13%) or follow-up studies (n=5; 9%) to the primary papers. Thirty-nine (72%) studies were RCTs or quasi-RCTs, nine (17%) were controlled before and after studies, five (9%) were before and after studies, and one (2%) used a single case experimental design.

Participants' ages ranged from 18 to 73 years, although in most (n=39; 72%) of the included articles, participants had a mean age between 40 and 50 years. Twenty-three (43%) articles included participants with remitting-relapsing multiple sclerosis only. The type of multiple sclerosis was not specified in seven (13%) articles. The remaining 24 (44%) articles had participants with two or more types of multiple sclerosis. The cognitive domains targeted in the rehabilitation programmes of the included studies are presented in Table 4.

Where similar items from different checklists were identified (that is, describing the same reporting information) the results of the coding/data extraction were merged by two reviewers (Appendix 6). Table 5 presents a summary of the findings of the quality of reporting of the included studies based on the merged checklist items.

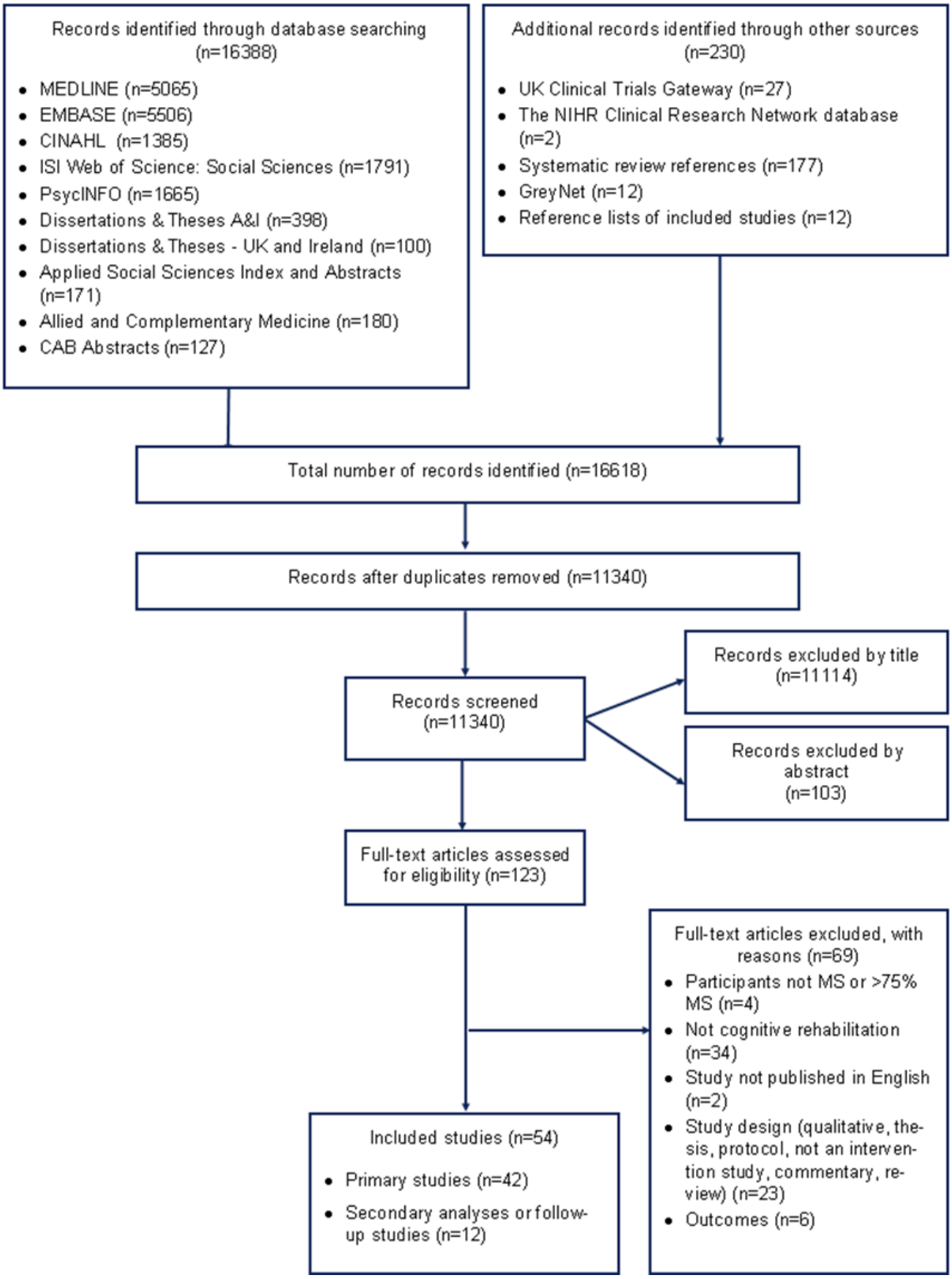


Figure 4 PRISMA flowchart of systematic review search results

Table 4 Characteristics of included studies by delivery mode and cognitive domain targeted in the intervention

Cognitive Domain	**Delivery Mode**		
	Individual	**Group**	**Blended**
Memory only	Allen et al. (1998), Ernst et al. (2013), Ernst et al. (2012) Gentry (2008), Pedulla et al. (2016), Vogt et al. (2009)	Carr et al. (2014), Chiaravalloti et al. (2012)	Martin et al. (2014)
Attention only	Amato et al. (2014), Cerasa et al. (2013), Plohmann et al. (1994), Plohmann et al. (1998)	-	-
Executive function only	Birnboim and Miller (2004), Fink et al. (2010)	-	Hanssen et al. (2015)
Combination	Altun et al. (2015), Bonavita et al. (2015), Brenk et al. (2008), Campbell et al. (2016), Charvet et al. (2015), De Giglio et al. (2015), De Giglio et al. (2016b), Ernst et al. (2015), Filippi et al. (2012), Gich et al. (2015) Hancock et al. (2015), Hildebrandt et al. (2007), Janssen et al. (2015), Jonsson et al. (1993), Lincoln et al. (2002), Mantynen et al. (2014), Mattioli et al. (2010), Mattioli et al. (2012), Mattioli et al. (2014), Mattioli et al. (2016) Mendozzi et al. (1998), Parisi et al. (2014), Perez-Martin et al. (2017), Rosti-Otajärvi et al. (2013a), Rosti-Otajärvi et al. (2013b), Sastre-Garriga et al. (2011), Shatil et al. (2010), Solari et al. (2004)	Brissart et al. (2013), Chiaravalloti et al. (2005), Chiaravalloti et al. (2013), Chiaravalloti and DeLuca (2015), Dobryakova et al. (2014), Leavitt et al. (2014), Shevil and Finlayson (2010), Tesar et al. (2005)	Pusswald et al. (2014), Stuifbergen et al. (2012)

Table 5 Summary of the reporting quality of the 54 included studies for selected reporting items

The broad aspect of reporting	No. (%) of studies in which item was reported completely*	No. (%) of studies in which item was reported partially complete*	No. (%) of studies in which item was not reported*	No. (%) of studies in which item was not applicable**
Demographic and clinical characteristics of the participants	54 (100%)	0	0	n/a
Theory/conceptual framework upon which the intervention is based	29 (54%)	21 (39%)	4 (7%)	n/a
Key elements of intervention, including active ingredients and mechanism of action	21 (39%)	29 (54%)	4 (7%)	n/a
Details of the intervention content i.e., what participants received	26 (48%)	24 (44%)	4 (7%)	n/a
Specific details about the procedures	16 (30%)	36 (66%)	2 (4%)	n/a
Level of professional training of the person who delivered the intervention	6 (11%)	12 (22%)	4 (7%)	32 (59%)**
Number of people who delivered the intervention	4 (7%)	3 (6%)	15 (28%)	32 (59%)**
Individual delivering intervention received training specific to the intervention	0	4 (7%)	18 (33%)	32 (59%)**
Competency of individual to deliver intervention assessed and achieved	2 (4%)	9 (17%)	11 (20%)	32 (59%)**
Delivery mode: Individual or group	24 (44%)	8 (15%)	22 (41%)	n/a
The intervention ‘dose’: intended and actual	17 (31%)	35 (65%)	2 (4%)	n/a
Materials	12 (22%)	32 (59%)	10 (19%)	n/a
Assessment of fidelity (delivery of the intervention)	2 (4%)	2 (4%)	18 (33%)	32 (59%)**
Adherence/compliance of participants to intervention	11 (20%)	8 (15%)	35 (65%)	n/a
Note: *Assessed against the description of the reporting item for the checklists used; **not applicable for computer-based interventions.				

2.6.2.1 Intervention details that were reported completely

Information relating to the characteristics of the participants (such as baseline demographic and clinical characteristics) was reported completely in all the included papers (reported in n=54 articles; 100%).

2.6.2.2 Intervention details that were reported partially complete

Who delivered the intervention?

The individuals who delivered the intervention were mostly described in terms of their professional training (n=18; 82%), with the majority being rehabilitation psychologists, psychologists or neuropsychologists.

If the individual who delivered the intervention was reported to have received training (n=4; 18%), no further information was provided. For example, one paper reported that “the facilitator (interventionist) was a master’s prepared nurse carefully trained prior to the initiation of the study” (Stuifbergen et al., 2012, p. 884). In the study by Altun et al. (2015), the authors reported that the psychologists were supervised by an experienced clinical psychologist, but it was unclear whether this meant psychologists received specific training (from the clinical psychologist or another individual).

None of the papers provided any details regarding the therapists’ competency level to deliver the intervention.

The intervention ‘dose’

The frequency of sessions (n=50; 93%), total number of sessions (n=33; 61%), and duration of the intervention (n=50; 93%) was often reported. However, the actual dose (i.e., exactly how much of the intervention participants received) was missing. Only 17 (32%) papers provided this information (e.g., in the form of descriptive statistics).

The key elements of the intervention, including active ingredients and mechanism of action

Only three papers made specific reference to the active ingredients of the intervention. For example, one paper reported the following: “The only difference between the groups was that only the treatment group was exposed to the active ingredients of the mSMT (imagery and context)” (Chiaravalloti et al., 2013, p. 2067). Eighteen (33%) papers reported the key elements of the intervention and the intended mechanism of action but did not make explicit mention of active ingredients. For example, one paper defined the intervention as: “ProCog-SEP program […] based on exercises drawn from facilitation/reorganization theories. This technique is defined by the use of preserved functions. It aims to teach the patient to use facilitation strategies to help these preserved functions, like mental imagery, or semantic cues” (Brissart et al., 2013, p. 554).

The majority (n=29; 54%) of the studies indicated the cognitive rehabilitation strategy but did not specify the intended mechanism of action or goal of the key elements. For example, one paper reported: “[…] this investigation focused specifically on training processing speed and working memory, the most fundamental cognitive deficits for multiple sclerosis patients” (Hancock et al., 2015, p. 114).

Procedures

Specific details about the intervention processes (i.e., ‘the methods section of a recipe’) as described in the TIDieR (Hoffmann et al., 2014) checklist, were only complete in 16 (30%) papers. Brissart et al. (2013) provided a detailed explanation of the steps undertaken during their intervention sessions. This included a description of activities that occurred before the session and how they explained intervention content to participants. This level of detail was incomplete in 36 (67%) of the papers.

Session-specific content

Session-specific content was reported incompletely in 24 (44%) of the papers. Articles often reported the cognitive rehabilitation approaches used in the intervention (e.g., compensatory or retraining) but often did not provide information pertaining to the specific content of each intervention session. For example, Lincoln et al. (2002) reported the intervention consisted of various internal and external memory strategies. However, specific details of what occurred during the six months participants received the intervention were missing. This information was reported completely in 48% of the included articles. For example, Perez-Martin et al. (2017) provided a detailed description of memory functions discussed in each session, the content of the booklets provided to participants, as well as visual image of some of the computerised tasks that were included in the intervention.

Intervention materials

The intervention materials were reported completely in 12 (22%) papers. For instance, one paper included an example of the patient score sheet used for one of the rehabilitation sessions. In 32 (59%) papers, the materials were not explicitly mentioned but could be inferred from the procedures. Ten (18%) papers did not provide this information.

2.6.2.3 Intervention details that were reported poorly

Intervention mode of delivery

The mode of intervention delivery (delivered individually or in a group) was often not clear. Only 24 (44%) papers mentioned this explicitly. In eight (15%) papers the delivery mode could be deduced if information about the setting (e.g., home-based) or format (e.g., computer-based) was reported. For example, if a paper reported that the intervention was delivered in the participants' homes the assumption was that the

intervention was individually delivered. In 22 (41%) papers, this information was missing altogether (i.e., mode of delivery, setting or format of delivery).

Facilitator and participant adherence to the intervention

Aspects of the fidelity of intervention delivery, such as therapist compliance to the intervention manual were reported poorly in 81% of relevant articles (i.e., not computer-based). The assessment and outcome of fidelity checks were reported in only two articles (Gentry, 2008, Martin et al., 2014). Regarding participant compliance with the intervention (e.g., completing homework), this was not reported in 35 (65%) of the included papers. This was reported entirely in 11 (20%) of papers. For example, Rosti-Otajärvi et al. (2013a) reported the mean number of exercises participants completed during the intervention as well as the proportion of homework completed.

Facilitator attributes

In the articles reporting interventions that were delivered by therapists (n=22; 41%), details pertaining to the number of people who delivered the intervention, intervention-specific training received and how competency to deliver the intervention was assessed and maintained were missing in up to 81% (n=18) of the included papers.

Specific to group interventions

The minimum and maximum number of people in the groups was only reported in one of the 14 group-based or blended studies. Four (29%) studies reported the maximum number of people in each group. The group size was not reported in nine (64%) papers.

2.6.2.4 Multiple study reports

There were mixed findings when the quality of reporting was compared across several papers reporting the same study. For example, more details about the procedures, the intervention dose, the setting and who delivered the intervention were provided in the one-year follow-up to the *Sclerosi Multipla Intensive Cognitive Training (SMICT)* trial (Mattioli et al., 2014) than in the original study (Mattioli et al., 2010) or the two-year follow-up study (Mattioli et al., 2016). However, the quality of the reporting for another trial was observed to be consistent when comparing the primary study (Chiaravalloti et al., 2005) to subsequent sub-group (Chiaravalloti et al., 2012) and secondary analysis(Leavitt et al., 2014) of the Story Memory Technique (mSMT) intervention.

2.6.3 Comparison of reporting across different checklists

2.6.3.1 Studies that did well on one checklist and not on others

Three papers (Hancock et al., 2015, Hanssen et al., 2015, Jonsson et al., 1993) performed 'well' (that is, provided more complete descriptions of the intervention, based on the description provided for each item, where applicable) on the TIDieR checklist. Two papers (Hanssen et al., 2015, Jonsson et al., 1993) reported the intervention materials, procedures and tailoring of the intervention completely. All three papers provided partial information of who delivered the intervention. For example, the papers mentioned research assistant or neuropsychologist but did not indicate what, if any, training they received or how many people delivered the intervention. All three papers did not report whether the intervention was modified (e.g., changes to the intervention provider or intervention material) during the study. For all papers, partial information was reported for the intervention dose, the skills and qualifications of the person who delivered the intervention. All three papers performed poorly on the Western Journal of Nursing checklist (Conn, 2012), particularly for items

relating to the conceptual frameworks of the intervention, intervention materials, intervention procedures (e.g., the timing of the intervention delivery) and intervention variations. These items were the most poorly reported across all checklists.

2.6.3.2 Studies that performed well on all checklists

None of the studies performed well (i.e., most aspects of the intervention reported completely) on all checklists, but two papers (Carr et al., 2014, Stuifbergen et al., 2012) were close to achieving this.

2.6.3.3 Studies that did not perform well on any of the checklists

Forty-four (82%) papers provided incomplete or missing reports of the session by session content of the interventions (for example, these four papers (Chiaravalloti et al., 2012, Ernst et al., 2015, Parisi et al., 2014, Vogt et al., 2009)). There was no apparent reason for this, nor commonality between the studies in this group, for instance, regarding mode of delivery (group or individual) or type of study (primary or secondary/sub-group analyses of a primary study.

2.6.3.4 Comparison of reporting according to publication year

Thirty-nine articles were published before 2015 and before publication of the TIDieR guideline (Hoffmann et al., 2014). Comparing these to the articles published after 2014, there were no discernible differences in the quality of reporting (i.e., aspects that were reported completely, incompletely, or were missing).

2.6.4 Summary of reporting of intervention content

Results of the merging of similar reporting items from the different checklists used for data extraction (Table 5) and from discussions with clinicians in the research group regarding what may be considered essential aspects of cognitive rehabilitation

content that need to be reported to enable both replication of these interventions and implementation in practice are presented in Table 6. This information would be used to inform the development of the round one questionnaire in the Modified Delphi consensus study in Study three (Chapter 4).

Table 6 Preliminary reporting items of aspects of cognitive rehabilitation reported in the articles included in the systematic review

Reporting Item	**Reporting Sub-item**
Key elements of the intervention, i.e., the theory underpinning the intervention, including active ingredients and mechanism of action	The cognitive rehabilitation strategies are taught, i.e., restitution, compensation or environmental modifications
	The intervention mechanism of action
	What are the goals of each element of the intervention, e.g., to improve function (specify what this is exactly)
Details of the intervention content, i.e., what participants received	
Specific details about the procedures	Session by session content
	Format of sessions
	Break
	Homework is given
	How are missed sessions are dealt with
	Is there any input from the family/caregiver
Who delivered the session (skills, training in general and specific to the intervention), how many there were	Professional attributes *relevant to the intervention*
	Professional attributes - the level of professional training
	Level of professional training specific to the intervention
	Competence in delivering the intervention
	Number of deliverers
The intervention delivery mode	Individual or group
	If group-based, the group size is provided
Delivery of the intervention - needs to be delivered in relation to a key event?	
Setting	Home-based or community (and details provided)
	Is the recruitment setting similar to intervention delivery setting?

Reporting Item	Reporting Sub-item
	Specific details related to the setting, e.g., a quiet room needed
The intervention 'dose'	The intended and actual duration of intervention (provide descriptive statistics)
	The intended and actual number of sessions (provide descriptive statistics)
	The intended and actual length of sessions (provide descriptive statistics)
	The intended and actual frequency of sessions (provide descriptive statistics)
Materials	Is the intervention manualised? Details of where to find the manual or who to contact
	Is a booklet/workbook provided for participants? And examples provided (or where to look, who to contact for further information
	Other info about materials, e.g., if computer- and home-based, details of who supplies the computers
Any modifications to the intervention between protocol development and delivery/write-up	Any changes to the dose or the content of the intervention, e.g., changes to the manual
Is the Intervention standardised – so all participants receive the same intervention	
Intervention tailored to the individual	If intervention tailored, and on what basis was this made/decided. Include details of how to main content validity of the intervention if tailored for all participants
Assessment of fidelity	How was this assessed
	Results – was the intervention delivered as planned?
Adherence/compliance of participants to intervention	How was this assessed
	Results – did the participant comply with the intervention (e.g., attend the minimum number of sessions).

2.7 Discussion

2.7.1 Summary of findings

The objectives of this study were to collate and summarise the reporting of aspects of cognitive rehabilitation for memory, attention and executive function for people with multiple sclerosis in scientific journals, assess the quality of reporting and to suggest ways in which this reporting could be improved. The review showed that, overall, the reporting of the content of cognitive rehabilitation was poor. Specifically, details needed to aid replication of the study were either reported incompletely or were missing. Information that was partially reported was: the essential elements of the intervention (including active ingredients and mechanism of action); the theory or conceptual framework for the intervention; details of the content, i.e., exactly what participants received and the intervention 'dose'. Information that was reported poorly was: how the intervention was delivered; facilitator attributes, whether the intervention was delivered as planned and whether participants adhered to the intervention. Also reported poorly in this study were aspects relating to group-based interventions, such as the group sizes. These characteristics of the intervention were consistent to those identified by Schulz et al. (2010) as the essential features of interventions (intervention content and delivery) that were important for replication and implementation of interventions.

There were no discernible differences in the quality of reporting of the same intervention across multiple study reports (i.e., the primary study compared to follow-up and/or secondary analyses). Regarding the checklists used, none of the included papers performed well on all the checklists, with items from the Western Journal of Nursing checklist (Conn, 2012) tending to be reported incompletely or not at all.

The findings are comparable with previous research that found 50 to 70 percent of non-pharmacological interventions were poorly reported (Glasziou et al., 2008, Hoffmann et al., 2013, Samaan et al., 2013). Specifically, information relating to the following was poorly reported:

- The theory/aims of the intervention (Martin et al., 2015).
- The content and intervention procedures (Glasziou et al., 2008, Hoffmann et al., 2013, Martin et al., 2015, van Heugten et al., 2012).
- The materials used (Glasziou et al., 2008, Hoffmann et al., 2013, Martin et al., 2015)
- Fidelity and adherence (van Heugten et al., 2012).

Complete descriptions of interventions are needed to enable replication by other researchers and for implementation into clinical practice (Dijkers, 2015). This viewpoint is supported by Cicerone et al. (2005) who argued that imprecise descriptions might lead to disagreements when interpreting the research evidence. Michie et al. (2009) stated that the 'active ingredients' or intervention components that influence outcomes of the intervention need to be described clearly in research studies. The researcher acknowledges that in complex interventions, some of the 'active' ingredients can only be hypothesised based on theory or previous research literature. In the review, only two papers (Chiaravalloti and DeLuca, 2015, Chiaravalloti et al., 2013, Leavitt et al., 2014) made specific reference to the active ingredients of their intervention, while 18 papers provided information on the intended mechanism of action. This is closely linked with the theory/conceptual framework upon which the interventions are based (only reported completely in 54% of the included studies). Cognitive rehabilitation is driven by cognitive, emotion, behavioural and learning models and theories (Wilson, 2017, Wilson, 2002). However, the actual contribution of each ingredient to the overall effect of the treatment can only be

understood if each of those ingredients was assessed and reported. This might be beyond the scope of some studies and hence is not featured in many of the papers.

There is evidence that checklists can improve the quality of reporting of interventions (Cobo et al., 2011, Kane et al., 2007, Plint et al., 2006, Smith et al., 2008). However, in a recent scoping review of systematic reviews of adherence to reporting guidelines by Samaan et al. (2013) of the 50 included reviews, 43 (86%) reported poor levels of adherence to reporting guidelines. The authors provided recommendations to improve adherence, including the use of *appropriate* reporting guidelines. Taken together with the existing literature, the findings from this review provided further evidence for the need for more domain/intervention-specific checklists (Dijkers, 2015, Glasziou et al., 2008, Hoffmann et al., 2013, Martin et al., 2015, Samaan et al., 2013, van Heugten et al., 2012).

2.7.2 Strengths and limitations of the study

One strength of this systematic review is that two reviewers independently assessed studies for inclusion and extracted data from the included studies on a proportion of eligible articles (achieving agreement, or disagreements were resolved by discussion with a third reviewer) to minimise the risk of errors. Furthermore, data synthesis and interpretation was discussed within the research group. A second strength was the inclusion of a variety of study designs in the search strategy. This provided a more comprehensive examination of the quality of reporting of cognitive rehabilitation in multiple sclerosis compared to previous reviews. However, one potential limitation of the review was that only published studies of interventions for memory, attention or executive dysfunction were included. While 70% of published cognitive rehabilitation studies in multiple sclerosis target the cognitive domains of memory, attention and

executive function (Mitolo et al., 2015), the studies included may not be representative of all cognitive rehabilitation research in MS.

2.7.3 Issues highlighted and suggestions for improving reporting checklists

Several issues became apparent during the data extraction and coding process. Disparities in the coding of different checklist items could be attributed to whether or not an item description was provided and the level of detail provided. Where no item descriptions were supplied, it was left to the reviewers to determine what was required for a specific checklist item. Thus, checklist items should be accompanied by clear and detailed descriptions, as well as with examples.

The coding process that was undertaken in this review highlighted the need for a checklist that is user-friendly, regarding the number of items contained within it and the way in which reporting items are presented. The researcher suggested a one-page checklist, whereby a tick-box is used to indicate whether or not a particular aspect of the intervention content has been reported.

The checklists used in this review tended to describe intervention components, such as ‘dose’ in medical terminology, which would not be appropriate for some rehabilitation interventions. For example, the Journal Article Reporting Standards (VandenBos et al., 2010) checklist includes an item that asks researchers to report how long any effects of the intervention were intended to last. The terminology of the proposed checklist should be appropriate for cognitive rehabilitation, such as the maintenance of strategies or skills targeted in the intervention, as suggested by Sohlberg and Mateer (2001). This may help towards ameliorating the difficulty

researchers face using multiple checklists in tandem to report on different aspects of their research.

This review followed Moher and colleagues' (2010) recommended steps for developing health research reporting guidelines and previous reviews by van Heugten and colleagues (2012) and Martin et al. (2015). These two reviews examined the content of cognitive rehabilitation interventions various neurological conditions, including multiple sclerosis. They also considered several cognitive domains (memory, attention, executive function, language, awareness and visuospatial functioning) and found the overall quality of reporting was poor. The review was unique as it focused solely on studies of the cognitive rehabilitation of memory, attention and executive function for people with MS.

In light of the evidence presented, a domain-specific reporting checklist (i.e., is *appropriate*) may facilitate better reporting of the content of cognitive rehabilitation for people with multiple sclerosis. For example, the checklist could include the rehabilitation setting (inpatient, outpatient, home-based), the practical details needed to administer the most important elements of the intervention (following fundamental approaches to cognitive rehabilitation to restore cognitive function, the use of compensatory strategies and devices, or environmental modifications (Mateer, 2005), and the materials used by both therapists and participants.

2.7.4 Review conclusion and implications of findings

Most studies did not adequately report key aspects of cognitive rehabilitation for memory, attention and executive function for people with multiple sclerosis. This may prevent the implementation of cognitive rehabilitation clinically. At the time this research was conducted, current reporting checklists were too general or used

terminology that was not appropriate for cognitive rehabilitation, but more suited to drug trials. Therefore, modifications to these or new checklists needed to consider clinicians who deliver cognitive rehabilitation to people with MS.

In this initial stage of the research, the aspects of cognitive rehabilitation for people with MS that were reported in scientific journals were examined. The next step of the research was to examine what *actually* occurred during the delivery of a cognitive rehabilitation programme for people with MS.

Chapter 3 Examining the content of a cognitive rehabilitation intervention, a video-based observational study – Study Two

3.1 Chapter Overview

Chapter 2 described the key details of cognitive rehabilitation interventions for memory, attention and executive dysfunction that were reported poorly in published articles, and the list of salient intervention reporting domains that was created. Additionally, the data extraction process highlighted shortcomings of existing reporting checklists. In light of this, recommendations were made on how a more appropriate reporting checklist for cognitive rehabilitation in MS might be developed. Having ascertained the quality of reporting in the research literature, the next step was to examine what occurred during treatment sessions in a cognitive rehabilitation intervention for MS. This study was therefore nested within a large-scale RCT evaluating the clinical and cost-effectiveness of Cognitive Rehabilitation for Attention and Memory in people with MS (CRAMMS) (Lincoln et al., 2015), which provided a unique opportunity to examine the detailed content of a group-based cognitive rehabilitation intervention. Details of CRAMMS were described in Chapter 1 (1.3.4.2).

Together with findings from the systematic review in Study one (Chapter 2), this examination of the *actual* content of a cognitive rehabilitation programme was intended to contribute towards the development of a comprehensive reporting checklist for cognitive rehabilitation in MS. The outcomes of both studies would contribute to the development of a reporting checklist for cognitive rehabilitation in MS in Study three.

3.2 Introduction

The degree to which interventions are implemented as intended is called 'implementation fidelity' (Carroll et al., 2007, Moore et al., 2015). The importance of examining implementation fidelity in trials of complex interventions was described in Chapter 1 (1.3.7.2). As cognitive rehabilitation is a 'complex intervention' (that is,

comprises multiple interconnecting components) (Craig et al., 2013), it was therefore important to ascertain whether all of the components of the intervention in CRAMMS were delivered consistently. This would allow a detailed evaluation of the intervention, highlight any potential areas for improvement, and facilitate better implementation into clinical practice.

The focus of this study was not on the theoretical underpinnings of treatment fidelity, but its practical application. Carroll et al.'s (2007) framework for examining implementation fidelity was followed. Within this framework, the evaluation of implementation fidelity relies on measuring adherence (Carroll et al., 2007). That is, whether or not the content, frequency, duration, and dosage of the implemented intervention are conducted as planned. The focus of the current study was on the 'content' sub-category of adherence. This incorporates the 'active ingredients', which are the salient elements that an intervention aims to deliver to recipients and which are likely to achieve positive outcomes (Carroll et al., 2007, Michie et al., 2009). These elements are often poorly reported in the cognitive rehabilitation for neurological disorders in general (Martin et al., 2015, van Heugten et al., 2012) and specifically in MS (Mhizha-Murira et al., 2017). The degree of adherence is quantifiable, for example by assessing how much of the content in the prescribed intervention manual was delivered and for how long (Carroll et al., 2007).

Borrelli (2011) summarised the various approaches available to assess the treatment fidelity in public health clinical trials, which could have been applied to the CRAMMS group-based intervention. These were:

- The audio recording of treatment sessions. This was done in studies such as das Nair et al. (2018) that examined the fidelity of intervention delivery using the audio-recordings of treatment sessions of a pre-surgical psychological intervention in people listed for total knee replacement surgery.

- Asking therapists to complete intervention component checklists following each session. For example, Thomas et al. (2016), Thomas et al. (2018) asked therapists who delivered a behavioural activation therapy to stroke survivors to complete a record form at the end of sessions, indicating the amount of time they had spent on different components of the intervention.
- Interviewing therapists to ascertain what was covered during the session. This was done in a study by Hasson et al. (2012). Repeated semi-structured interviews with key individuals who delivered a care-based model for frail older adults were conducted over the course of the study to highlight any issues and perceptions of the content of the intervention.
- The observation of video recordings of treatment sessions or the direct observation of treatment sessions by an independent researcher (the latter is an approach used in studies by O'Brien et al. (2013), Spillane et al. (2007)). For example, Hart et al. (2014a) used video recordings to describe the content of a learning and memory rehabilitation for people who had experienced a traumatic brain injury.
- Asking for participant feedback, via either interviews or questionnaire, as to what components of treatment they thought they received during sessions.

The use of observational methods to assess intervention implementation or process outcomes such as what was delivered during the intervention (fidelity) was consistent with the data collection methods suggested by MRC framework for process evaluations of complex interventions (Moore et al., 2015). There were advantages and disadvantages associated with each of these approaches. For example, asking therapists to record the intervention components delivered may serve to make intervention components more salient and may minimise the likelihood of parts being recorded as “not covered” (Borrelli (2011). However, with such post hoc feedback, there may also be a potential for recall bias. Audio and video recordings provide

objective ways to evaluate the delivery of treatment, with video recording also allowing evaluation of nonverbal behaviours (Borrelli, 2011). Disadvantages of these methods, however, include technical issues (e.g., equipment failure), as well as the likelihood of reactive effects, such as the Hawthorne effect, whereby the presence of recording equipment may affect the treatment interaction (Bowling, 2014).

3.3 Aim

This study aim was to gain an understanding of how the content of the CRAMMS intervention compared to what was planned.

3.4 Objectives

The overall objective of the study was to complete a detailed analysis of the actual content of the CRAMMS intervention. More specifically:

1. To determine what the CRAMMS APs delivered during the group sessions compared with what was prescribed in the intervention manual.
2. To examine what was discussed spontaneously between the group members and the APs during the intervention`.

3.5 Methods in observational research

Observation is used in research to gain insight into how people behave in complex situations (Bowling, 2014), and allows the behaviour to be described completely and accurately (Shaughnessy and Zechmeister, 2015). The different approaches to data collection and data analysis in observational research are briefly discussed here, to justify the choice of methods for this study.

Observational methods may be classified as direct or indirect (Shaughnessy and Zechmeister, 2015). Direct observation occurs when behaviours are observed as they happen, such as in participant or non-participant observation. An example of direct, non-participant observation in research is a study by O'Brien et al. (2013), in which direct observations of a group memory rehabilitation programme for people with neurological conditions (including MS) were used to determine the fidelity of the intervention. An independent researcher (observer) recorded what occurred during group sessions but did not participate in the group discussions.

As noted by Baker (2006), when the observer acts as a *non-participant* and *complete observer*, they do not participate or interact with those under observation. This method may thus enable social interaction to be captured with limited distractors. However, in practical terms, it may be challenging to ensure that reactive effects of an observer on group members' behaviours are non-existent, as the observer's very presence may lead to the assumption that they played a role in the therapeutic group setting. O'Brien et al. (2013) also identified this as a potential limitation of their study. Such reactive effects may be minimised through indirect (unobtrusive) observation, which occurs when evidence is retrospectively examined (e.g., via audio or video recordings).

With direct observation, there is also a risk of *inattentional blindness* on the part of the observer, which describes a failure to notice new and salient events, particularly when attention may be focused elsewhere (Shaughnessy and Zechmeister, 2015). A treatment session involving a group of individuals adds further complexity to such situations since in such a setting there are often concurrent multiple and complex interactions (Asan and Montague, 2014). Use of video recordings may remedy this, as videos can be viewed repeatedly, and by multiple observers, thus increasing the reproducibility of measurement of observations (Asan and Montague, 2014).

While reactivity effects may be lessened when employing video-based observation methods rather than direct observations, it is important to note that these effects are not necessarily eliminated. Lomax and Casey (1998) argued that the presence of a camera inevitably becomes part of the social world (e.g., treatment session) under investigation. They also stated that the process of *observing* results in the *observer* participating in what is being observed, to varying degrees, and that observations cannot occur without some level of 'participation'. It is therefore necessary to acknowledge that the presence of a camera in therapeutic sessions is itself a means of creating and defining these interactions.

3.5.1.1 Data collection in observational research

Unstructured observation is a qualitative, inductive method, beginning with the observations made. The imposition of definitions and structures on the data is postponed until a pattern is observed in the accumulated information (Bowling, 2014). Conceptual categories are subsequently developed from the data.

Structured observation is a quantitative deductive approach, whereby phenomena are defined a priori to test the theory. Structured observational schedules are prepared in advance of the observations made. In developing an observation schedule, the researcher begins with a conceptual definition, specifying what is to be observed and standardised with a measuring instrument. Observers follow set procedures when making observations (e.g., referring to a codebook with coding rules), which enables other researchers to replicate findings when making similar observations.

3.5.1.2 Sampling

Sampling is a form of structured observation, and the sampling carried out pertains to either the *people* under observation or the *time* at which the observations are carried out (Bryman, 2012). Situation, event and time sampling may be used to enhance the external validity of observational findings (Shaughnessy and Zechmeister, 2015).

Situation sampling involves sampling behaviour at different locations and under different circumstances. With event sampling, all occurrences of the behaviour are recorded within a specified time. Time sampling, which is interval-based, provides an *estimation* of the frequency or duration of behaviours, on the basis of the presence or absence of these behaviours during the time intervals (Bowling, 2014, Lane and Ledford, 2014). Time intervals are chosen randomly or systematically, with the aim of obtaining representative samples of the data (Shaughnessy and Zechmeister, 2015). Time-sampling has been used in studies examining the content of cognitive rehabilitation for people with MS. For example, O'Brien et al. (2013) employed a momentary time-sampling method, whereby the content of discussions and the type of activity occurring were recorded *in situ* on the minute (one observation and recording of discussions). The content of the observations were recorded qualitatively (transcribed verbatim), including which member of the group where talking. Smale et al. (2014) used interval time-sampling to record the content of treatment sessions within one minute. This meant that multiple observations and therefore recording of intervention content could occur within that period.

3.5.1.3 Data analysis in observational research

Spoken word, as recorded in structured observation, is rarely analysed directly, but is transformed into research data in the form of text (i.e., transcriptions) (Lemke, 2012). All analysis of such data is reductionist, as the research process reconstructs the

verbal data in order to make sense of it (Lemke, 2012). A plethora of analytical approaches are available, including quantitative coding and the counting of behaviours, conversation analysis of communication sequences, and qualitative interpretation of the content and meaning of communication (e.g., content analysis) (Parry et al., 2016). As Lemke (2012) noted, the choice of analytical method is context-specific, dependent on the research objectives in question.

3.5.1.4 Video observation in cognitive rehabilaition for MS

The use of video-based observational methods in healthcare research, specifically in rehabilitation research, has become increasingly widespread (Asan and Montague, 2014, Parry et al., 2016). Such methods are used not only to ascertain the content of intervention sessions but also to evaluate treatment fidelity.

A review of the literature suggested that although the use of video-based observations to examine the content of cognitive rehabilitation intervention is increasing, most of the evidence-base is from direct observational studies in other neurological conditions such as traumatic brain injury (Chouliara, 2013) or in MS (e.g., (O'Brien et al., 2013). Video-based observations to assess the content and intervention fidelity of rehabilitation interventions were also conducted in stroke (Skidmore et al., 2014) and brain injury research (das Nair et al., 2017, Hart et al., 2014a). There were no studies that examined the content of cognitive rehabilitation, specifically in MS, utilising video-based observational methods.

With respect to using videos to evaluate fidelity in delivery of interventions and specific to cognitive rehabilitation in MS is the study by Smale et al. (2014). The treatment integrity of an RCT of memory rehabilitation for people with MS was evaluated using time-sampling to objectively and systematically record the content of video recordings

of intervention sessions. Interval coding was used to record what occurred within one minute, based upon the core components of the sessions. All relevant components of the intervention manual that happened within the time interval were recorded, even if there were several components during one interval. The observer also transcribed verbatim what was discussed during the time interval. One limitation of this study was the small number of videos that were observed and coded (10 videos in total, one video randomly selected from each intervention session). It is unclear whether these were representative of the consistency of intervention delivery across all the sites. A second limitation of this study is that only one individual identified the main components of the intervention, which formed the basis of the fidelity assessment (these components were subsequently observed and recorded). Furthermore, there was no assessment of the reliability of the findings, as only one person coded the transcripts.

3.6 Methods of this study

3.6.1 Study design

This was a structured observational study of video recordings of the group cognitive rehabilitation sessions (i.e., the intervention arm), which were routinely collected as part of the CRAMMS trial. Structured observations were selected as these may provide a more reliable account of events, allow for better precision in the timing and ordering of events, and provide an accurate and pragmatic method of observing the complex social context of the CRAMMS group intervention. Video recordings of intervention sessions were chosen over interviews and retrospective self-reports (e.g., questionnaires) regarding what had occurred during the sessions. Video recordings provided a record of 'naturally occurring' interactions within the group intervention and provided more accurate information by limiting the risk of response and recall bias (Asan and Montague, 2014).

Video-based observation was also preferable to direct observation, whereby the researcher would have been present during the treatment sessions but would not have participated in the discussions. In practical terms, it would have been challenging to eliminate the reactive effects of the researcher on the group members' behaviours. This issue was noted in the initial preparatory stages of this study when the researcher directly observed one group (during 10 sessions) to check whether there were any differences between what was observed on video versus what was observed in person. While there were no observed differences in the quality of information between the two methods, on many occasions both participants and the APs involved the researcher in their discussions (e.g., by directing questions toward the researcher). The researcher's very presence led to the assumption that they were part of the 'in-group' and therefore played a role in the therapeutic group setting.

Video-based observations were thus selected in this study as the best way to ensure that a 'naturalistic' treatment session occurred without disturbance from an 'outsider' (i.e., the researcher). In the current study, participation by the researcher in the group intervention sessions and hence generation of the video data was minimal, with the researcher acting as a "complete observer" (Dallos, 2012).

As the CRAMMS trial protocol (Lincoln et al., 2015) specified that all group intervention sessions were to be recorded if there was consent from all participants, the video camera and by extension, the current research became a part of the "social world" (Lomax and Casey, 1998) of the cognitive rehabilitation sessions. This was done so that any influences of reactivity on the part of the APs who delivered the intervention or the participants were allayed. Furthermore, the presence of the video camera during all the sessions could have decreased participants' sensitivity and

therefore reactivity to it (Haidet et al., 2009, Latvala et al., 2000). Additionally, any reactive effects would have been the same for all the cognitive rehabilitation sessions.

3.6.2 Participants and setting

Participants were those who had given written informed consent for the use of video data from the CRAMMS treatment group sessions. This included the AP who facilitated the group sessions and the patients who were randomised to the cognitive intervention.

Five sites were involved in the CRAMMS trial. Group sessions took place at different settings, including community centres and university campuses. There were between four and six participants in each group, and an AP delivered the intervention according to the intervention manual.

3.6.3 Research Ethics

Ethical approval was granted by the Health Research Authority (HRA) West Midlands - South Birmingham Research Ethics Committee (reference 14/WM/1083).

Three levels of consent were available for video recording of the treatment sessions: (1) The participant was willing to be seen in the video recordings, (2) The participant did not want to be visible in the video recordings but consented to have audio data collected, or (3) The participant did not consent to have any data collected (audio and visual). Participants were informed that, should they withdraw from CRAMMS, data collected for this observational study up to the point of withdrawal could be used in the analysis.

All data were stored in accordance with the Data Protection Action (1998) and University of Nottingham regulations.

3.6.4 Description of the CRAMMS group intervention

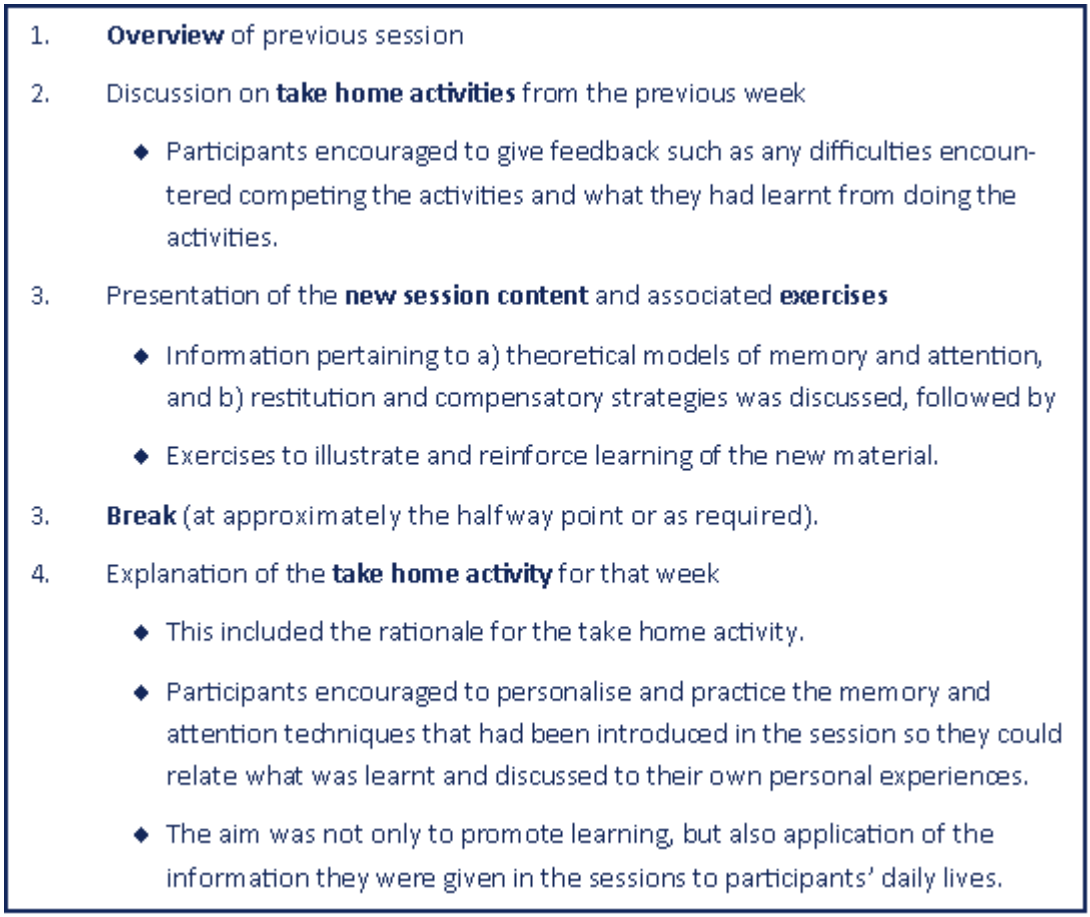
A description of the overall CRAMMS trial was provided in Chapter 1. The focus of this section and this study is on the content of the CRAMMS cognitive rehabilitation intervention.

The CRAMMS intervention incorporated a multitude of restitution (drill and practice) and compensatory rehabilitation strategies, as well as a 'generalisation' component (e.g., the take home activities). Generalisation is concerned with the association between the cognitive rehabilitation exercises to similar tasks and general daily functioning (Anderson et al., 2012). The intervention aimed to introduce participants to a broad range of different strategies that could help with attention and memory problems. Therefore, participants would have a "toolbox" of strategies from which to choose, dependent upon their needs and the aspects of cognitive function that they wanted to improve. Cicerone et al. (2005) argued that combining restitution training with compensatory strategy training increased the effectiveness of cognitive rehabilitation programmes.

The CRAMMS treatment manual was developed and piloted in a previous feasibility trial (Carr et al., 2014) and a similar intervention was delivered in a memory rehabilitation trial for people who had experienced a traumatic brain injury (das Nair et al., 2017).

The general format of each treatment session is presented in Figure 5. Being the introductory and concluding sessions, the formats of sessions 1 and 10 differed slightly. Each session had a specific overall theme (see Appendix 7), beginning with

introductions (session 1), memory theories and processes (session 2), attention theory and attention retraining/restitution (session 3), attention internal strategies (session 4), compensatory strategies (internal memory aids) (sessions 5 to 7), external memory aids (compensatory strategies) (sessions 8 and 9) and a review of the programme (session 10).



1. **Overview** of previous session
2. Discussion on **take home activities** from the previous week
   - Participants encouraged to give feedback such as any difficulties encountered competing the activities and what they had learnt from doing the activities.
3. Presentation of the **new session content** and associated **exercises**
   - Information pertaining to a) theoretical models of memory and attention, and b) restitution and compensatory strategies was discussed, followed by
   - Exercises to illustrate and reinforce learning of the new material.
3. **Break** (at approximately the halfway point or as required).
4. Explanation of the **take home activity** for that week
   - This included the rationale for the take home activity.
   - Participants encouraged to personalise and practice the memory and attention techniques that had been introduced in the session so they could relate what was learnt and discussed to their own personal experiences.
   - The aim was not only to promote learning, but also application of the information they were given in the sessions to participants' daily lives.

Figure 5 Overall format of CRAMMS group intervention sessions

The APs were encouraged to provide participants with a rationale for all the manual content and activities that took place during the sessions. This was to promote understanding and increase motivation to engage with the content. The APs were instructed to be flexible in terms of what was covered from session to session, and the time spent on the different activities that occurred in sessions depended on the needs of the group. However, all session-specific content was completed in a single

meeting rather than split across sessions. AP facilitator notes were provided to accompany the intervention manual, and for each activity, there was a suggested amount of time that APs should spend discussing these. APs were advised to use these times as approximations only, for time-keeping purposes, and to use their discretion as needed.

If participants missed a session, the APs invited them to attend the following meeting early in order to be given an overview of the missed content. It was emphasised to the APs during training, as well as during monthly supervision, of the need to be mindful of individual differences in the groups and to manage these effectively. For example, different rates of learning and interpersonal group member conflict. APs were instructed to video record all of the group sessions for which consent had been provided by all group members (the exception was when APs delivered their first group, to allow APs to become familiarised with the manual).

3.6.5 Study procedures

The overarching analytic frame used for data collection and analysis was content analysis. This research methodology describes a range of approaches used to assess the content of a wide range of raw data, either quantitatively or qualitatively. Specifically, this is a systematic method for classifying the manifest content of verbal, written, or visual communication into codes, which are grouped into categories that can be subsequently quantified and summarised (Elo and Kyngäs, 2008, Hsieh and Shannon, 2005, Kohlbacher, 2006). Manifest content refers to the content of communication that is obvious, and not the underlying meaning that needs to be deciphered (Graneheim and Lundman, 2004). Therefore, only visual or auditory content (i.e., what participants were doing or saying in the videos), and not what they were thinking, was the focus here.

As (Krippendorff, 2013) argued, qualitative and quantitative content analysis operate on a continuum, thus allowing researchers to move along it in order to gain better insight into the meaning of data. Taking this into consideration, a combination of Mayring's (2000) and (Krippendorff, 2013) definitions for content analysis was used in this study. Content analysis was defined as "An approach of systematic, rule guided qualitative […] analysis, which tries to preserve some methodological strengths of quantitative content analysis and widen them to a concept of qualitative procedure" (Mayring, 2000, p. 1). Content analysis would allow patterns to be identified through a systematic process of categorised coding (Hsieh and Shannon, 2005), resulting in replicable and valid conclusions about the data obtained (Krippendorff, 2013). The categories derived from codes with similar attributes would also be expressions of the manifest content (Erlingsson and Brysiewicz, 2017).

Directed content analysis as described by Hsieh and Shannon (2005) was used for data collection and analysis, the goal of which was to validate or conceptually develop or extend a theoretical framework or theory. Directed content analysis employs a deductive approach, whereby the initial coding framework is determined by the theoretical underpinnings of the variables under investigation, and/or by previous research findings. This is a more structured approach than conventional content analysis, which is more inductive as it does not utilise pre-conceived categories or is used when the exiting literature is limited (Hsieh and Shannon, 2005). It also differs from summative content analysis, which focuses on latent content and word use as it pertains to a specific topic (Hsieh and Shannon, 2005).

Directed content analysis provides a pragmatic way in which to reduce and organise the large amounts of data that are generated from the video recordings (Silverman, 2011). This method was advocated by Bellg et al. (2004), who stated the optimum

way to evaluate treatment delivery is by using pre-specified criteria to code the sessions of the intervention.

The procedures used for structured observation and content analysis are described in detail below. This procedure facilitated an examination of the salient themes and content of the sessions, and content of discussions between the APs and the participants. A flowchart of the process of content analysis of video recordings of the CRAMMS group sessions is shown in Figure 6.

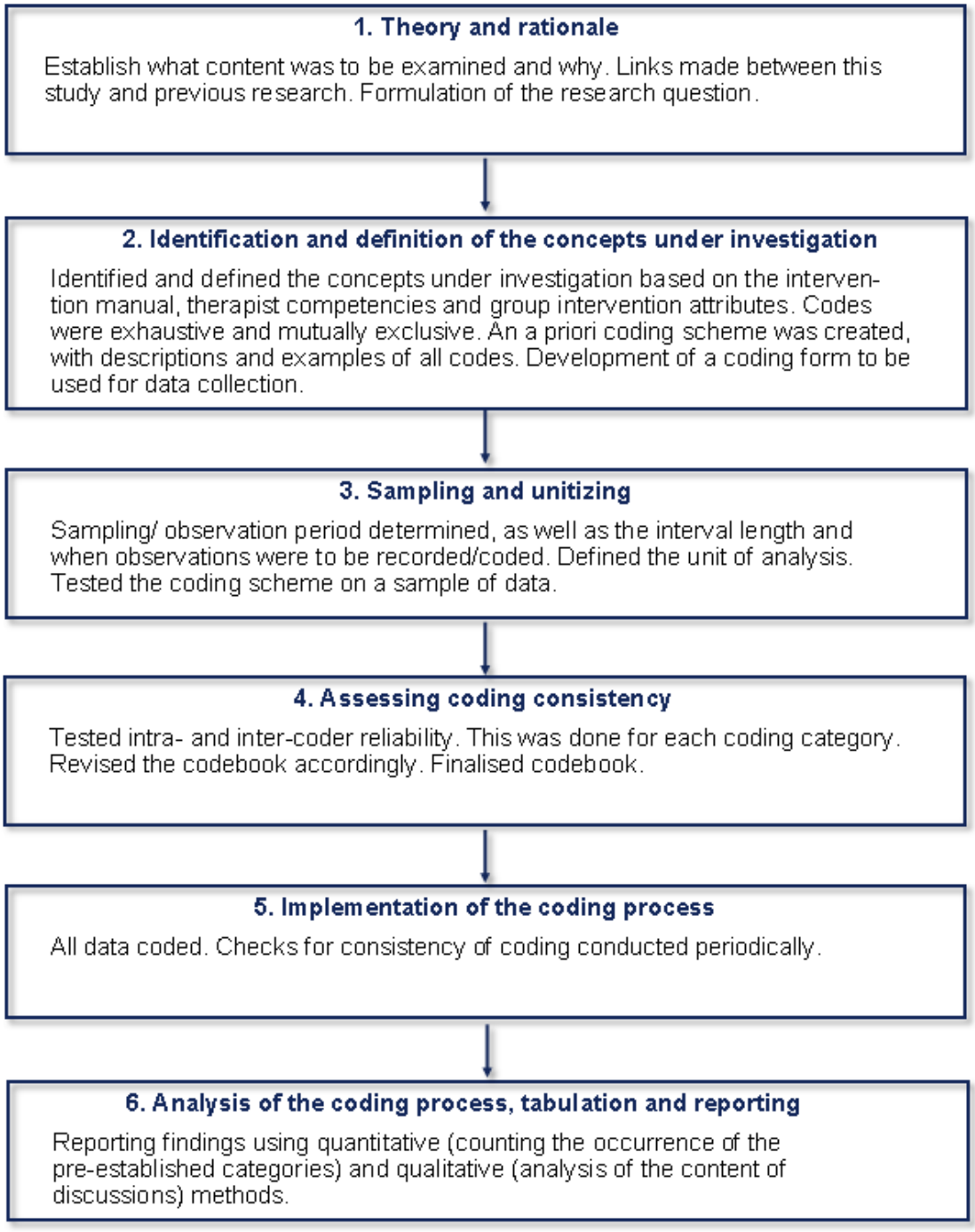


Figure 6 Process of content analysis of the CRAMMS group sessions

Based on Krippendorff (2013), Marvasti (2004), Neuendorf (2002), Zhang and Wildemuth (2017)

3.6.5.1 Rationale and theory

The treatment manual for the CRAMMS intervention served as the theoretical framework on which to base the initial data coding.

3.6.5.2 Development of the codebook: identification and definition of the categories under investigation

The development of the codebook, comprising a standardized and systematic set of instructions (Hsieh and Shannon, 2005), is an important step in directed content analysis. Well-structured and defined codes that reflect the constructs under investigation provide a way in which large amounts of textual data can be reduced into fewer, more manageable categories (Hamad et al., 2016). This was used to guide the analysis of the content of the video recordings and to help the coders make decisions about the nature of the content of the observations. This was important to ensure reliability and validity of coding and the replicability of the analyses (Krippendorff, 2013).

Utilising Krippendorff's (2013) description, the term 'coder' in this research was defined as an individual who was involved in stages of recording, transcribing and coding observations. As the coders were themselves observers, it was imperative to provide clear definitions of concepts, to provide clear examples of codes, and to create coding instructions that promoted consistency of decision-making.

As detailed earlier in this chapter, the CRAMMS intervention was a complex intervention, and thus it was important to consider the unique challenges that this posed when identifying the content, or 'active ingredients', of the various sessions of the intervention. Furthermore, as discussed in Section 3.6.4 above, APs were instructed to use the intervention manual flexibly in terms of time spent on session components, which had implications for the assessment of treatment fidelity in relation

to the trial protocol (Craig et al. (2013). At the codebook development stage, it was important for the researcher to understand the degree to which adaptation of the intervention manual was permitted so that the codebook could account for this.

Development of the codes was informed by:

- Previous studies by Carr et al. (2014) and das Nair et al. (2017), which also informed the development of the CRAMMS intervention manual.
- Components identified from the CRAMMS intervention treatment manual and discussions with the CRAMMS researchers about the main elements of the intervention. This was to establish the content validity of the codes.
- Initial observations of video-recordings of a sample of intervention sessions.

By involving key stakeholders in the codebook development, this ensured the rigour of the process, allowing for critiques of the categories (i.e., if they were exhaustive, mutually exclusive, etc.) before finalisation.

The codebook included all components of the intervention as per the intervention manual, with a distinction made between content that was session-specific (e.g., memory process in session 2) and content that applied to all sessions (e.g., learning about attention and memory). For the session-specific codes, intervention components that the CRAMMS researchers deemed most important, or which summarised the content of the session, were used. Some of these were considered most likely to be the ‘active ingredients’ of the sessions.

Content not related explicitly to the cognitive rehabilitation programme activities was coded as ‘other’. This category reflected activities that were expected as part of a group-based intervention, such as administrative tasks, information on the organisation of the sessions, and social chat.

The AP and participant codes related to the content of discussions, or activities that were expected to occur in the sessions. For the APs, these included therapist competency skills (e.g., group facilitation skills). For the participants, these could be describing problems with memory or attention, or engaging with the manual. Included was what was discussed by the APs (e.g., presenting memory and attention strategies) and the participants (e.g., describing memory and attention problems).

The initial codebook was piloted using the video recordings of 40 sessions (four videos per session), to ascertain any components that may have been omitted from the initial codebook and to determine if any other modifications were needed. This was an iterative process, with additional codes defined and indicators for the coding categories identified as required. This process was intended to ensure that the codes were objective, exhaustive, mutually exclusive, independent, and related to the research objectives. Codebook development, therefore, used two approaches: (1) deductive – as directed by the manual, and (2) inductive – with new codes derived from the content in the videos.

See Appendix 8 for an example of the coding sheet and Appendix 9 for the codebook.

3.6.5.3 Sampling of the videos and selection of events

The initial intention in this study was to use purposeful sampling to select 40 videos (i.e., four videos per session) of CRAMMS sessions, from across the five geographical sites, with sessions representing the beginning, middle and end of the 10-week group sessions. However, this was subsequently amended so that the sampling period chosen was the *complete* duration of *all* video recordings of the treatment sessions. This approach was undertaken for the following reasons:

- CRAMMS researchers no longer thought the intervention sessions could be separated into the 'start', 'middle' and 'end'. This was because the APs were instructed to use the manual flexibly, that is, to discuss content from any previous sessions, as needed.
- There were potentially 450 videos available for coding (45 groups x 10 sessions per group), and so coding only 40 of these would represent a very small sample, with implications for the generalisability of the results.
- Coding all of the videos would maximise the adequacy of the data and the thoroughness of the coding process in describing the content of the intervention, thus ensuring that the coding process was both exhaustive and exclusive.
- Coding all of the videos would counteract issues of therapist drift, as well as site and AP differences in the delivery of sessions.

Time-sampling (structured observation)

A time-sampling procedure, used in previous research (O'Brien et al., 2013, Smale et al., 2014), and derived from standard methods of structured observation (Bryman, 2012), was used to capture the minutiae of the content of discussions at one-minute intervals.

At the end of each minute, on the minute, two observations were made: (1) the person who was talking (i.e., AP or participant), and (2) the content of what was discussed. Rather than completing a verbatim transcription of the whole session, which would have been time consuming and would have resulted in a density of data that did not add to the analysis, only the specific phrases that were uttered on the minute were transcribed verbatim. The content of these utterances was then classified according to whether the discussion was related to cognitive rehabilitation (either generally, or with specific reference to the session being conducted) or not.

Defining the unit of analysis

In the context of data analysis, units can be conceptualised as independent elements that are whole, i.e., cannot be divided further during analysis. Unitizing allows distinctions to be made within a continuum of text that otherwise cannot be differentiated, and omits irrelevant information without loss of meaning (Krippendorff, 2013).

Recording or coding units were defined by their physical distinction (i.e., time units, with data being collected on the minute), while maintaining the overall meaning of utterances or sentences (e.g., minimising the coding of incomplete utterances or sentences) (Krippendorff, 2013). Where compound sentences were recorded (i.e., with the connectors '*and'* or '*or'*), only the first part of the sentence was transcribed and coded, as long as this made sense or was 'meaningful' as a standalone text. This was consistent with the procedure followed by Strijbos et al. (2006).

Moreover, the researcher endeavoured to provide transcripts that were comprehensive and clear, and therefore additional context was provided where necessary to minimise misinterpretation or confusion. For example, the text "let me get that" was accompanied with the description '[referring to bag on the floor]'. The content of the recorded discussions (in audio and text form) was coded and categorised separately. Transcribed statements were coded as specified in the codebook and using the additional supplementary codes identified through the previous analysis. See Table 7 for an example transcript with the codes.

Table 7 Example of observation sheet with transcripts and codes

Time (mins)	Manual Content: All sessions	Manual Content: Specific session	Other Content	Therapist activity	Patient activity	Text
1	D	2TA			FH	the work last week just helped to clarify that it was a useful [memory and attention strategy]
2	P	3R		SU		so [last week] we talked about distractions, too much information all at once
3		IO			DP	I have to be in the same situation or the same place for me to recognise them [people's faces]
4	L	M		EP		it [memory] helps us to build on previous experiences

Codes: *Manual content applicable to all sessions:* D = discussing take home activities; P = discussing the content of the previous intervention session. *Session specific codes:* IO = initial introductions in session 1; M = discussing what is memory; 3R = recapping the content of the previous intervention session (session 3); 2TA = discussing the take home activity from session 2. *Assistant psychologist activity codes:* EP = providing an explanation of memory and attention; SU = summarising the previous intervention session. *Participant activity codes:* DP = Describing problems related to memory and attention; FH = providing feedback on the take home activities.

3.6.5.4 Establishing validity and reliability

It is important for the measurement of observations to be both *reliable* and *valid*, so that they might serve as accurate representations of behaviours. As a means of measuring and recording the content of discussions during treatment sessions, it was important that the codebook represented a *valid* measure, and that the individuals (i.e., coders) who observed, recorded and coded behaviours did so in a *reliable* fashion.

Validity of the codebook

The validity of a measurement refers to whether or not that measurement tests what it is intended to test (McBurney and White, 2002). Content validity is a theoretical construct relating to the extent that the content of a measure or instrument appears to exhaustively include and assess the full range of domains that it is intended to appraise (Bowling, 2014). Thus, the codebook, and the categories/codes representing the different aspects of the treatment manual and the content of discussions was intended to have sufficient content validity.

As discussed in Section 3.6.5.1, the content validity of the codes and categories in the codebook was maintained by consulting with the CRAMMS researchers, the APs who delivered the sessions, and with experts who were familiar with cognitive rehabilitation. Additionally, further codes were added to the codebook following the viewing of 40 initial videos, so that the codebook contained activities that fully encapsulated aspects of cognitive rehabilitation for people with MS. This method was consistent with a study conducted by De Wit et al. (2007), in which the content validity of a scoring list was verified by watching existing recordings of therapy sessions, using a scoring list to code the behaviours, and asking experts to then confirm whether the list contained activities that encapsulated routine practice in rehabilitation of stroke survivors.

Reliability: Assessing coding consistency

Reliability refers to the extent to which the use of a measure results in the same outcome on different occasions (McBurney and White, 2002). Several types of reliability applied to the current research design: *Stability*, or *intra-coder* (test-retest) reliability, refers to the extent to which one individual's coding yields the same findings over time (Krippendorff, 2013). *Replicability*, or *inter-coder* reliability, refers to the degree to which a different coder codes the same information in the same manner (Krippendorff, 2013). Finally, *accuracy* in this context refers to the comparison of the codebook used in this research with another one that is considered the 'gold standard' (Campbell et al., 2013). Although the codebook was devised based on prior research and theory, it was impossible to compare this with previous codebooks, since the content of cognitive rehabilitation differs significantly between different programmes.

Lack of coding reliability in content analysis increases the probability of Type II errors (accepting a null hypothesis when its statement was false), and to a lesser extent Type I errors (rejecting a null hypothesis when its statement was true). As Strijbos et al. (2006) noted, the reliability of coding in content analysis is primarily influenced by two factors. First, the way in which coding categories are constructed and the number of codes used. This impacts on the *discriminant capability* of the codebook, that is, the extent to which text is coded simply and unambiguously using the coding scheme (Campbell et al., 2013). The coding categories must be mutually exclusive, with no overlapping boundaries. Secondly, reliability may also be affected by the way in which the unit of analysis is defined, and it is important that this unit of analysis is not too small.

Steps undertaken to establish intra-coder reliability of the coding

A random sample of videos was periodically checked for coding consistency throughout the observational period. Specific checks were made in the preparatory stages of codebook development, whereby after each iteration of the codebook any videos observed and coded up to that point were checked for coding consistency using the new codes. At the end of the data collection period, a random selection of videos (5%) that were coded at the start of data collection were also checked for consistency of coding.

Steps undertaken to establish inter-coder reliability

Inter-coder agreement was initially established through discussions between the researcher and the second data coder, who was not a member of the CRAMMS trial research group. Any coding discrepancies were then resolved through a process of discussion and consensus. This process also served to check the characteristics of the different codes used (e.g., to ensure that these were mutually exclusive). The same two coders then independently coded a different sample of text, and Cohen's kappa statistics were calculated to establish the degree of inter-coder reliability due to chance. The two coders used the codebook to code 10% of the video recordings (i.e., those that had not been coded during codebook development), to assess inter-coder reliability.

The most commonly used Cohen's kappa coefficients cut-offs, suggested by Landis and Koch (1977), signifying the strength of the agreement between two coders, are 0.01 to 0.20 (slight agreement), 0.21 to 0.40 (fair agreement), 0.41 to 0.60 (moderate agreement), 0.61 to 0.80 (substantial agreement), and 0.81 to 1.00 (almost perfect agreement). In the current study, the minimum threshold for the inter-coder reliability was 0.61 (Landis and Koch, 1977).

3.6.6 Data analysis

Since both quantitative and qualitative content analysis approaches were used in this study, the data generated from video observations were coded and subjected to content analysis (i.e., quantitative approach), and narrative analysis (qualitative approach) was then used to supplement this data further (Bowling, 2014).

3.6.6.1 Quantitative data

All statistical analyses were performed using the Statistical Package for Social Sciences (SPSS) version 25. All content and activity codes in the codebook were defined as nominal data. The presence or otherwise of the intervention manual codes in the coded data was used to assess intervention fidelity – to determine what was *delivered* during the sessions compared with what was specified in the treatment manual. To measure what was *discussed* during the intervention sessions, the number of observations per code was counted, and the proportion of time spent on these was calculated as a percentage of all observations (by session, site, or overall, as appropriate). To examine the consistency of observations between sites and by session number, the distribution of observations was compared. Codes representing similar attributes for each of the AP and therapist activities were grouped into categories that were expressions of the manifest content in the data (Erlingsson and Brysiewicz, 2017). These were used to summarise and report the findings.

3.6.6.2 Qualitative data

NVivo version 12 was used to identify patterns that emerged from the AP and participant activity categories (i.e., the content of discussions), consistent with directed content analysis (Hsieh and Shannon, 2005). Emergent patterns were used to substantiate findings from the quantitative data analysis. Illustrative quotations

were used to provide examples of the coding categories (see Table 7 for an example transcript with the codes).

At the time of conducting this phase of the research, the outcomes of the CRAMMS trial were unknown. The potential influence that knowledge of the findings may have had on data collection and analysis was thus minimal.

3.7 Results

Aspects of this research have been included in the CRAMMS NIHR Health Technology Assessment (HTA) report (Lincoln et al.).

3.7.1 Characteristics of CRAMMS trial participants

Table 8 presents the clinical and demographic characteristics of the CRAMMS trial participant. Those who were randomised to the intervention group were mostly (73%) women, of white ethnicity (97%), had remitting-relapsing MS (self-reported) and were not employed or in education (34%).

Across all five sites, the mean number of sessions attended by participants who received the CRAMMS intervention, including catch-up sessions, was 7.7 sessions. Nine APs were observed delivering the intervention in the video recordings.

Table 8 Baseline characteristics of the CRAMMS trial participants

Participant characteristics	**Cognitive Rehabilitation intervention group (n = 245)**
Mean [SD] age at randomisation (years)	49.9 [9.8]
Gender	
Men	67 (27%)
Women	178 (73%)
Ethnicity	
White	237 (97%)
Asian, Black or Mixed	8 (3%)
Mean [SD] participant reported time since MS diagnosis (years)	12.1 [8]
Type of MS (participant reported)	
Relapsing-remitting	159 (65%)
Primary progressive	22 (9%)
Secondary progressive	64 (26%)
Mean [SD] score Multiple Sclerosis Neuropsychological Screening Questionnaire (MSNQ)[a] (at baseline)	38.9 [7.1]
Mean [SD] score MS impact scale – psychological subscale	23.3 [5.8]
Mean [SD] years of education	14.2 [3.4]
Employment status	
Retired	80 (33%)
Not employed or in education	83 (34%)
Employed part time or full time	75(31%)
In education part time or full time	7 (3%)

[a]MSNQ - Scores range between 0 and 60 with higher scores indicating more cognitive problems. A score of 28 or more was required to be eligible for the study. [b]MS impact scale: psychological subscale scores range from 9 to 36. Higher scores indicating greater psychological impact of MS on everyday life.

3.7.2 Video recording of the group intervention sessions

Out of 45 intervention groups, 35 (78%) were recorded. There were 10 (22%) groups not recorded: two (4%) because one participant in the group did not want to be seen or heard on the video recording, six (13%) because it was the AP's first group and two (4%) for unknown reasons. Out of the 450 cognitive rehabilitation sessions that took place, 252 (56%) were fully recorded, 39 (9%) were partly recorded (e.g., due to

a camera fault or the battery dying during the session), and 159 (35%) were not recorded.

The distribution of video recording of cognitive rehabilitation sessions by session number and by the site is presented in Figure 7 and Table 9. Session 4 had the highest number of completed video recordings; session 1 had the lowest. Most groups were randomised at Site 1 (35%), and this site had the largest proportion of complete video recordings (41%). Site 5 had the most substantial proportion of complete video recordings with respect to the total number of possible videos (24 out of 30 sessions that were delivered at this site; 80%). Site 2 had the largest proportion of missing videos (73%).

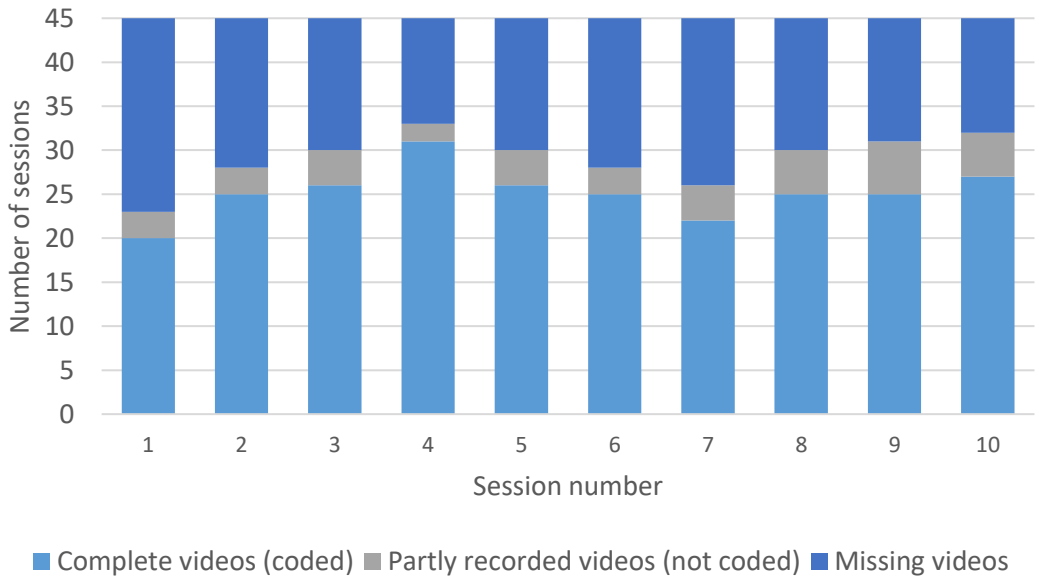


Figure 7 Distribution of video recordings of cognitive rehabilitation sessions, by session number

Table 9 Distribution of video recording of cognitive rehabilitation sessions, by site

	1	2	3	4	5	Total
Number of groups randomised to treatment (number of sessions)	16 (160)	7 (70)	11 (110)	8 (80)	3 (30)	45
Number of groups were consent to record videos was not given (number of sessions)	1 (10)	1 (10)	0	0	0	2
Number of complete video recordings available and analysed	105	7	74	42	24	252
Number of partly recorded videos (not observed/coded)	5	2	20	9	3	39
Number of missing videos*	40	51	16	29	3	139

*Not including sessions where there was no consent to video record the session

3.7.3 Inter-coder reliability

The second coder coded the transcripts from 26 (10%) of the total number of complete videos. These were randomly selected, based on the proportion of videos available for each session. For example, as there were 31 complete videos for session 4, a random selection of three videos were coded and included in the interrater reliability analysis. The paired observations (i.e., the code from the primary coder and the second coder for each observation point) for each of the five content categories (e.g., manual content, other content, participant activities and therapist) were entered as two variables (nominal data) into SPSS, and crosstabulated using the kappa statistic option. The results of the inter-coder reliability are presented in Table 10. The kappa score demonstrated *substantial* to *excellent* levels of agreement between the coders for all the categories.

Table 10 Inter-coder agreement on the content categories

Categories	**Cohen's kappa (κ)**	***P***
Manual content applicable to all sessions	0.98	<0.001
Session-specific manual content	0.99	<0.001
Other content not related to cognitive rehabilitation	0.89	<0.001
Therapist activities	0.83	<0.001
Participant activities	0.91	<0.001

3.7.4 Treatment fidelity findings

The findings pertaining to whether the intervention was delivered as planned (treatment fidelity) are now presented. It is important to note that due to the time sampling method used in the video observations, these findings represent *estimations* of the frequency or duration of the different activities that occurred during the CRAMMS intervention sessions. The percentage of time spent for each activity was estimated from the percent of observations in which a given activity was recorded. For example, if out of 100 observations 60 were for take home activities, the suggestion is that 60% of the time was spent discussing take home activities.

3.7.4.1 Time spent on intervention manual content versus activities unrelated to cognitive rehabilitation

A summary of the proportion of *actual* time spent on components of the intervention manual versus the timings proposed in the intervention manual for all sessions is presented in Figure 8. Time spent reviewing the take home activities from a previous session was 50% higher than proposed in the study protocol. The time spent discussing both internal and external memory aids was also higher than what was planned (at 15% and 31%, respectively). Time spent discussing the take home activity for the current session was almost 56% less than planned in the manual.

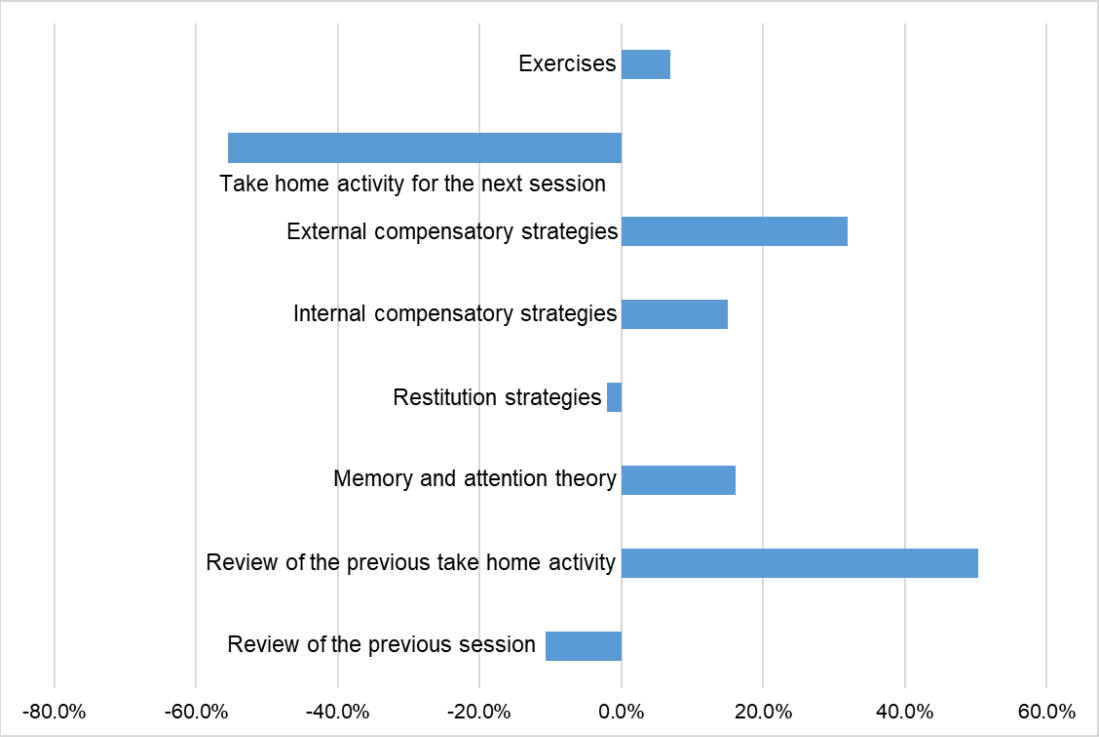


Figure 8 Actual time spent on intervention manual activities (actual time minus time approximations in the study protocol).

Bars on the right indicate that more time was *actually* spent on cognitive rehabilitation activities than suggested in the intervention manual. Bars on the left indicate that less time was actually spent cognitive rehabilitation activities than suggested in the intervention manual.

With reference to the types of activities that occurred during the intervention sessions, sessions one and ten had the highest proportion of time spent doing 'other' or non-cognitive rehabilitation activities (e.g., discussing the organisation of sessions or CRAMMS trial research processes such as the outcome assessments) at 24% and 19%, respectively (see Figure 9). Session 4 had the smallest proportion of 'other' activities at 9%. For all the sessions, between 76% and 91% of the time during sessions was spent doing activities related to the cognitive rehabilitation manual (Figure 9).

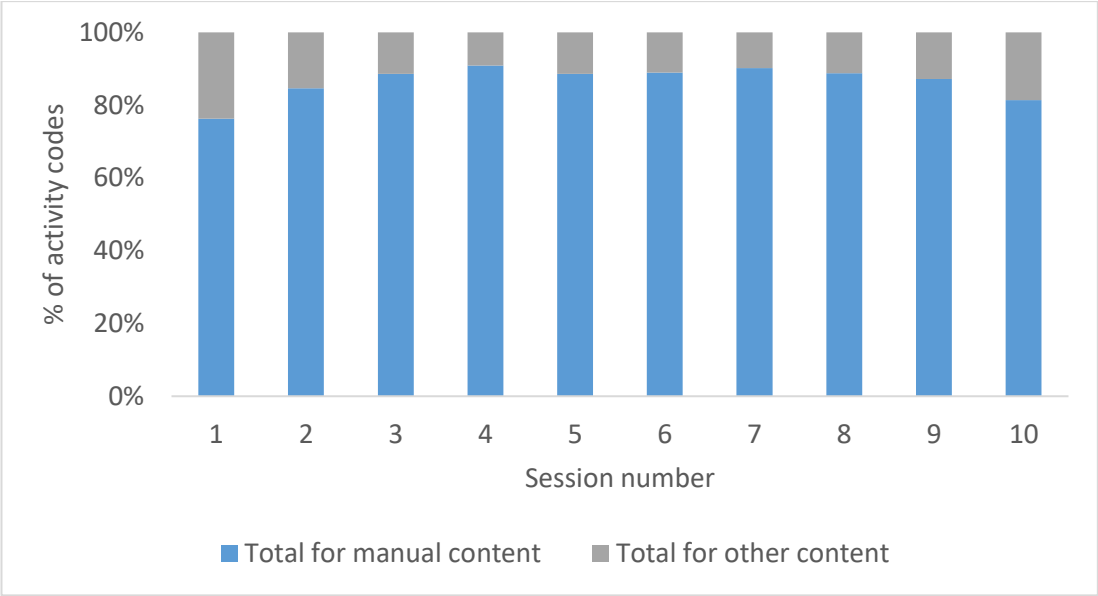


Figure 9 Coding of session-specific manual content and other content unrelated to cognitive rehabilitation by session number

Figure 10 illustrates the time spent on different activities according to the site. The proportion of time spent on activities related to cognitive rehabilitation ranged between 84% and 93%. The time spent on other activities unrelated to the intervention was comparable across all sites, with site 3 spending the most time on these activities at 16%.

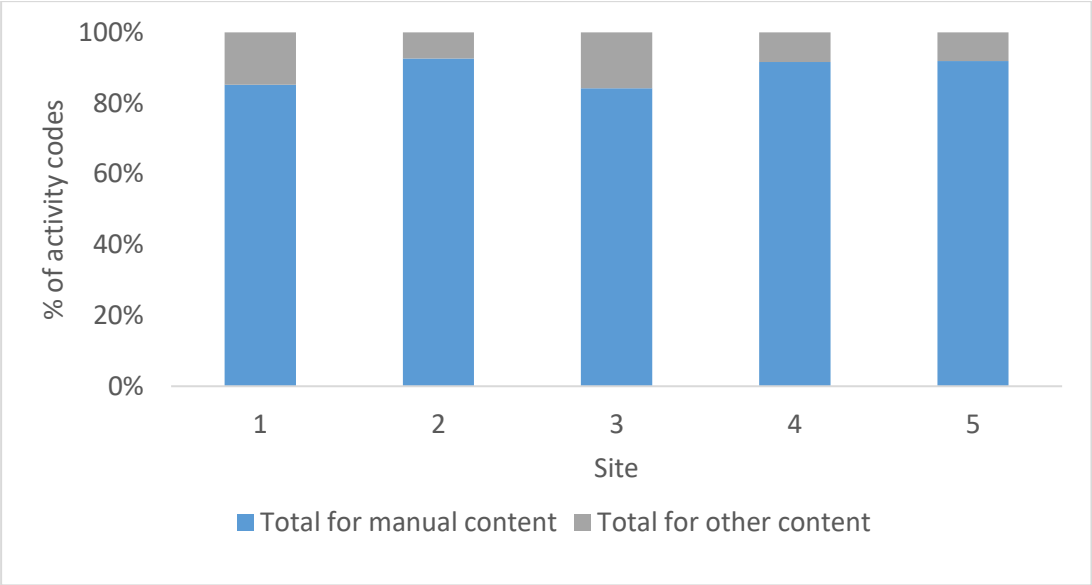


Figure 10 Coding of session-specific manual content and other content unrelated to cognitive rehabilitation by site

3.7.4.2 Time spent on intervention manual content applicable to all sessions

Examining the specific activities that occurred in all sessions and at all sites, almost 24% of the time was spent learning about strategies to address attention and memory problems, followed by reflecting on personal experience (14.3%) and discussing take home activities (12.9%). See Table 11. These findings were comparable across the sites, although site 2 spent more time learning about attention and memory strategies and less time discussing attention and memory compared to the other sites. Time spent on content unrelated to the intervention was less at just over 10% across all sites. Site 3 spent the most time discussing non-intervention content (12.4%) whereas sites two and five only spent 6.4% of their time on this content.

Table 11 Distribution of categories of applicable to all sessions by site

	Site 1 (n=7980)		Site 2 (n=543)		Site 3 (n=4921)		Site 4 (n=3019)		Site 5 (n=1806)		Total (N=18269)	
	n[1]	%[2]	n	%	n	%	n	%	n	%	n	%
Manual content categories applicable to all sessions												
Discussing take home activities	1034	13	67	12.3	675	13.7	349	11.6	239	13.2	2364	12.9
Learning about attention and memory	657	8.2	26	4.8	357	7.3	398	13.2	196	10.9	1634	8.9
Learning about memory and attention strategies	1981	24.8	165	30.4	1075	21.8	725	24	395	21.9	4341	23.8
Reflecting on personal experience	1074	13.5	82	15.1	738	15	375	12.4	346	19.2	2615	14.3
Summarising the previous session	467	5.9	17	3.1	133	2.7	107	3.5	67	3.7	791	4.3
Other content unrelated to cognitive rehabilitation categories												
Administrative processes												
Administrative tasks	30	0.4	0	0	12	0.2	3	0.1	2	0.1	47	0.3
Break	77	1	1	0.2	76	1.5	2	0.1	3	0.2	159	0.9
Housekeeping	44	0.6	1	0.2	27	0.5	28	0.9	8	0.4	108	0.6
Organisation of sessions	115	1.4	1	0.2	59	1.2	23	0.8	9	0.5	207	1.1
CRAMMS Research activities	71	0.9	0	0	21	0.4	36	1.2	8	0.4	136	0.7
Preparing materials	6	0.1	2	0.4	3	0.1	7	0.2	2	0.1	20	0.1
Living with MS												
Discussing hospital visits	21	0.3	0	0	11	0.2	2	0.1	1	0.1	35	0.2
Discussing living with MS	164	2.1	2	0.4	130	2.6	29	1	36	2	361	2
Discussing MS services	2	0	0	0	0	0	0	0	0	0	2	0
Social												
Laughter	3	0	0	0	11	0.2	7	0.2	2	0.1	23	0.1
Social chat	359	4.5	27	5	266	5.4	83	2.7	42	2.3	777	4.3
Other: Silences	1	0	0	0	5	0.1	0	0	0	0	6	0

n[1] = number of observations; %[2] = percentage of observations

Table 12 and Table 13 show the distribution of categories that applied to all intervention sessions by session number. Discussions on take home activities occurred in similar proportions as the sessions progressed, with the highest percentage of time spent on this in session 2. Sessions 2 and 3 also had the largest proportion of time spent on learning about memory and attention at 46% and 20%, respectively. The focus of these sessions was on introducing participants to aspects of memory such as encoding and consolidation (memory processes), memory storage (working memory) and retrieval, and attention (e.g., types of attention and distractors). The proportion of time spent on learning about memory and attention strategies increased from session 3 when techniques to improve attention were presented in sessions 3 and 4 (e.g., the 5Ws and the H strategy). The highest proportion of time spent on this activity was in session 5 (38.6%), when internal memory aids were introduced. This was consistently high as the intervention material moved onto external memory aids (sessions 8 and 9). Discussions on the previous sessions increased gradually as the sessions progressed. Reflections on personal experience progressively increased, with the highest proportion of time spent in sessions 9 and 10 (20%). This was in line with the goals of the sessions, which were to encourage participants to reflect on both their memory problems and their use of different strategies.

3.7.4.3 Time spent on activities unrelated to cognitive rehabilitation

The proportions of time spent doing the different activities unrelated to cognitive rehabilitation were comparable across all three sites (see Table 11). Five overall categories were identified for the various codes: administrative/organisational processes (e.g., the organisation of sessions), CRAMMS research processes (e.g., discussing outcome visits), living with MS (including accessing services), social (e.g., social chat) and other (e.g., silences). The most frequent non-intervention activity

observed in all the sites was social chat (4.3% across all sites), and this was highest at site 3 (5.4%). The second highest activity code was discussions on living with MS at 2% across all sites.

A similar pattern was observed for the engagement of 'other' activities by session number (Table 12 and Table 13). Engagement in social chat was the most frequently observed activity in all the sessions. This was comparable across all sessions, with the highest proportion observed in sessions 1 and 8. Living with MS was the second most frequently discussed activity in eight of the sessions, with the highest proportion of activity observed in session 1 (5.1%). In this session, participants were encouraged to introduce themselves and explain why they were participating in the study. In session 10, the second most frequently discussed topic was the CRAMMS research processes that would take place once the group sessions had ended. In this session, the APs were instructed to explain what would happen once the groups had stopped. For example, for participants to expect two outcome visits after the group sessions had ended.

Table 12 Distribution of categories of applicable to all sessions (session 1 to 5)

Manual content categories applicable to all sessions	Session 1		Session 2		Session 3		Session 4		Session 5	
	n	%	n	%	n	%	n	%	n	%
Discussing take home activities	44	3.2	332	18.7	328	17	360	15.2	232	12.5
Learning about attention and memory	46	3.3	816	46.1	392	20.4	68	2.9	43	2.3
Learning about memory and attention strategies	124	8.9	72	4.1	231	3.4	807	34.1	717	38.6
Reflecting on personal experience	144	10.4	151	8.5	293	15.2	229	9.7	245	13.2
Summarising the previous session	0	0	41	2.3	66	3.4	82	3.5	86	4.6
Other content categories unrelated to cognitive rehabilitation										
Administrative processes										
Administrative tasks	10	0.7	5	0.3	3	0.2	13	0.5	3	0.2
Break	23	1.7	3	0.2	33	1.7	26	1.1	10	0.5
Housekeeping	24	1.7	23	1.3	10	0.5	12	0.5	7	0.4
Organisation of sessions	69	5	25	1.4	11	0.6	14	0.6	11	0.6
CRAMMS Research activities	23	1.7	5	0.3	0	0	1	0	2	0.1
Group session procedures: Preparing materials	1	0.1	2	0.1	4	0.2	2	0.1	2	0.1
Living with MS										
Discussing hospital visits	7	0.5	4	0.2	1	0.1	0	0	2	0.1
Discussing living with MS	71	5.1	51	2.9	35	1.8	19	0.8	25	1.3
Discussing MS services	0	0	0	0	0	0	0	0	0	0
Social										
Laughter	1	0.1	0	0	3	0.2	2	0.1	3	0.2
Social chat	71	5.1	72	4.1	90	4.7	89	3.8	72	3.9
Other: Silences	2	0.1	1	0.1	0	0	0	0	0	0

Table 13 Distribution of categories of applicable to all sessions (session 6 to 10)

Manual content categories applicable to all sessions	Session 6		Session 7		Session 8		Session 9		Session 10	
	n	%	n	%	n	%	n	%	n	%
Discussing take home activities	182	10.1	242	14.6	210	11.7	213	12.4	221	11
Learning about attention and memory	107	6	81	4.9	4	0.2	0	0	77	3.8
Learning about memory and attention strategies	676	37.7	550	33.3	468	26.1	424	24.7	272	13.5
Reflecting on personal experience	236	13.1	199	12	373	20.8	343	20	402	20
Summarising the previous session	84	4.7	86	5.2	108	6	120	7	118	5.9
Other content categories unrelated to cognitive rehabilitation categories										
Administrative/ organisational processes										
Administrative tasks	4	0.2	2	0.1	2	0.1	2	0.1	3	0.1
Break	14	0.8	8	0.5	11	0.6	4	0.2	27	1.3
Housekeeping	5	0.3	7	0.4	13	0.7	3	0.2	4	0.2
Organisation of sessions	14	0.8	18	1.1	12	0.7	18	1	15	0.7
CRAMMS Research activities	1	0.1	4	0.2	2	0.1	1	0.1	97	4.8
Group session procedures: Preparing materials	5	0.3	1	0.1	2	0.1	0	0	1	0
Living with MS										
Hospital visits	1	0.1	1	0.1	3	0.2	9	0.5	7	0.3
Discussing living with MS	13	0.7	19	1.1	38	2.1	30	1.7	60	3
Discussing MS services	0	0	2	0.1	0	0	0	0	0	0
Social										
Laughter	0	0	1	0.1	0	0	3	0.2	10	0.5
Social chat	66	3.7	56	3.4	92	5.1	71	4.1	98	4.9
Other: Silences	1	0.1	0	0	0	0	0	0	2	0.1

3.7.5 Description of the session-specific CRAMMS intervention content

After collating the session-specific activity categories according to the overall theme of the discussions, findings showed the most frequently discussed topics pertained to internal compensatory strategies (28.5%) (Table 14). This included mnemonics, and strategies to improve encoding and retrieval (e.g., visual imagery). This corresponds with the number of sessions (three) that focused on this topic. Take home activities were the second most frequently discussed topic (20%). Overall, memory and attention were the focus of almost 41% of discussions during the intervention sessions.

Table 14 Summary of the overall categories for session-specific manual content, collated for all sessions and all sites

Activity category	n	%
CRAMMS group intervention procedures (e.g., the format of sessions)	757	5.5
External compensatory strategies (e.g., diary use)	1416	10.4
Participant feedback (e.g., uptake of strategies, perceived changes)	670	4.9
Internal compensatory strategies (including mnemonics and visual imagery)	3896	28.5
Memory and attention theory and processes	2030	14.8
Cognitive retaining/restitution strategies	319	2.3
Review of previous sessions	636	4.7
Take home activities	2769	20.2
Ways of coping with memory and attention problems (e.g., pacing and relaxation)	1189	8.7

A more comprehensive analysis of the session-specific activities is presented in the following section.

3.7.5.1 Time spent on session-specific intervention manual content

On examination of the session-specific activity categories, presented by the site in Table 15, all aspects in the intervention manual were discussed to some degree in the sessions. The only exceptions to this were the visual imagery story exercise in session 6 (only observed at site 3), and the second take home activity in session 4 (not observed at site 2). There was a change tin the intervention manual content for session 3 in the earlier months of the CRAMMS study session. The topic 'errorless learning' was replaced with 'learning' only. This meant that there were differences in what was observed in the videos from the earlier stages of the study versus the later ones. For sites 1, 3 and 5 the content of discussions contained both errorless learning and learning; site 2 only discussed learning and site 4 just discussed errorless learning. The proportion of time spent engaged in session-specific activities generally fluctuated across all sessions. What was consistent (apart from session 1) was the proportion of time spent involved in activities concerning the take home activities for that session, which were the lowest observed category of activity.

Table 15 Proportion of time spent on session specific activities according to site

Session-specific manual content activities	Site 1		Site 2		Site 3		Site 4		Site 5		Total	
	n	%	n	%	n	%	n	%	n	%	n	%
Session 1												
Introduction to others	68	11.5	n/a[a]	n/a[a]	35	6.7	17	6.2	n/a[a]	n/a[a]	120	8.7
Discuss format of session and memory programme	65	11.0	n/a[a]	n/a[a]	55	10.6	25	9.2	n/a[a]	n/a[a]	145	10.5
Establish group rules	21	3.5	n/a[a]	n/a[a]	17	3.3	19	7.0	n/a[a]	n/a[a]	57	4.1
Explore attention and memory	14	2.4	n/a[a]	n/a[a]	16	3.1	8	2.9	n/a[a]	n/a[a]	38	2.7
Things which forget	103	17.4	n/a[a]	n/a[a]	108	20.7	50	18.3	n/a[a]	n/a[a]	261	18.8
How feel when having difficulty with memory	32	5.4	n/a[a]	n/a[a]	19	3.6	26	9.5	n/a[a]	n/a[a]	77	5.6
Own techniques to help	67	11.3	n/a[a]	n/a[a]	73	14.0	32	11.7	n/a[a]	n/a[a]	172	12.4
Rating of effectiveness	29	4.9	n/a[a]	n/a[a]	24	4.6	38	13.9	n/a[a]	n/a[a]	91	6.6
Advice to share	12	2.0	n/a[a]	n/a[a]	5	1.0	8	2.9	n/a[a]	n/a[a]	25	1.8
What else want to know	11	1.9	n/a[a]	n/a[a]	3	0.6	6	2.2	n/a[a]	n/a[a]	20	1.4
Explanation of take home activity	26	4.4	n/a[a]	n/a[a]	14	2.7	11	4.0	n/a[a]	n/a[a]	51	3.7
Session 2												
Review session 1	39	5.4	n/a[a]	n/a[a]	7	1.5	9	2.5	10	4.3	55	3.5
Review of take home activity	105	14.5	n/a[a]	n/a[a]	92	20.1	40	11.1	21	9.1	237	15.1
What is memory	92	12.7	n/a[a]	n/a[a]	47	10.3	49	13.6	28	12.2	188	12.0
Processes involved in Memory	87	12.0	n/a[a]	n/a[a]	51	11.2	72	20.0	36	15.7	210	13.4
Case study task	16	2.2	n/a[a]	n/a[a]	2	0.4	3	0.8	23	10.0	21	1.3
Memory storage	126	17.4	n/a[a]	n/a[a]	44	9.6	47	13.1	26	11.3	217	13.8
Memory retrieval	35	4.8	n/a[a]	n/a[a]	42	9.2	57	15.8	29	12.6	134	8.5
Memory systems	57	7.9	n/a[a]	n/a[a]	40	8.8	21	5.8	18	7.8	118	7.5
Take home activity task 1	33	4.6	n/a[a]	n/a[a]	15	3.3	8	2.2	10	4.3	56	3.6
Take home activity Task 2	29	4.0	n/a[a]	n/a[a]	20	4.4	11	3.1	3	1.3	60	3.8
Session 3												

Session-specific manual content activities	Site 1		Site 2		Site 3		Site 4		Site 5		Total	
	n	%	n	%	n	%	n	%	n	%	n	%
Review session 2	35	4.4	8	11.4	5	1.0	15	5.4	5	1.9	55	3.4
Review take home activity	137	17.1	6	8.6	122	23.8	57	20.5	53	20.3	316	19.4
Different types attention	118	14.7	3	4.3	74	14.5	84	30.2	42	16.1	276	17.0
Different types of distractors	66	8.2	8	11.4	47	9.2	21	7.6	18	6.9	134	8.2
Attention exercise	65	8.1	5	7.1	40	7.8	25	9.0	19	7.3	130	8.0
Attention exercise plus distractor	95	11.8	9	12.9	64	12.5	30	10.8	28	10.7	189	11.6
Techniques to improve attention	145	18.1	20	28.6	78	15.2	21	7.6	66	25.3	244	15.0
Take home task 1	14	1.7	2	2.9	7	1.4	1	0.4	2	0.8	22	1.4
Take home task 2	29	3.6	2	2.9	11	2.1	2	0.7	1	0.4	42	2.6
Session 4												
Review session 3	62	6.5	8	5.5	8	1.3	17	4.3	5	2.0	87	4.4
Review take home activity	132	13.8	21	14.5	86	14.0	54	13.5	38	15.4	272	13.7
Story recall exercise	118	12.3	22	15.2	78	12.7	61	15.3	40	16.3	257	12.9
5W and the H	74	7.7	9	6.2	30	4.9	33	8.3	13	5.3	137	6.9
Story recall with 5W and the H	134	14.0	32	22.1	115	18.7	54	13.5	38	15.4	303	15.2
When difficult to pay attention	59	6.1	8	5.5	42	6.8	20	5.0	18	7.3	121	6.1
How attention improved	55	5.7	9	6.2	21	3.4	20	5.0	14	5.7	96	4.8
Strategies to remember	62	6.5	6	4.1	57	9.3	2	0.5	2	0.8	121	6.1
Case study handout	96	10.0	25	17.2	90	14.6	86	21.6	56	22.8	272	13.7
Techniques to improve attention - session 3 content	10	1.0	n/a[b]	n/a[b]	n/a[b]	n/a[b]	22	5.5	n/a[b]	n/a[b]	32	1.6
Take home task 1	15	1.6	1	0.7	8	1.3	4	1.0	6	2.4	27	1.4
Take home task 2	29	3.0	0	0.0	19	3.1	3	0.8	3	1.2	51	2.6
Session 5												
Review session 4	58	6.8	n/a[a]	n/a[a]	17	3.4	7	2.5	4	1.8	82	5.0
Review take home activity	125	14.6	n/a[a]	n/a[a]	92	18.5	64	22.9	30	13.3	281	17.0
Use of internal memory aids	85	9.9	n/a[a]	n/a[a]	41	8.3	36	12.9	27	12.0	162	9.8

Session-specific manual content activities	Site 1		Site 2		Site 3		Site 4		Site 5		Total	
	n	%	n	%	n	%	n	%	n	%	n	%
Rehearsal	66	7.7	n/a[a]	n/a[a]	39	7.9	23	8.2	21	9.3	128	7.7
Chunking	103	12.0	n/a[a]	n/a[a]	78	15.7	33	11.8	33	14.7	214	12.9
Categorisation	241	28.1	n/a[a]	n/a[a]	115	23.2	91	32.5	77	34.2	447	27.0
Exercise 3: Phone number	28	3.3	n/a[a]	n/a[a]	51	10.3	8	2.9	7	3.1	87	5.3
Take home task 1	9	1.1	n/a[a]	n/a[a]	5	1.0	1	0.4	2	0.9	15	0.9
Take home task 2	16	1.9	n/a[a]	n/a[a]	8	1.6	3	1.1	2	0.9	27	1.6
Session 6												
Review session 5	47	6.2	1	1.1	9	1.9	10	2.8	0	0.0	66	4.1
Review take home activity	68	9.0	8	9.2	53	11.4	45	12.5	16	12.3	166	10.4
Levels of processing	243	32.2	29	33.3	91	19.6	99	27.6	36	27.7	433	27.2
Visual imagery	139	18.4	17	19.5	66	14.2	78	21.7	20	15.4	283	17.8
Associations	58	7.7	9	10.3	22	4.7	25	7.0	16	12.3	105	6.6
Story method	76	10.1	9	10.3	79	17.0	54	15.0	29	22.3	209	13.1
First letter cues	17	2.3	1	1.1	16	3.4	11	3.1	3	2.3	44	2.8
Rhymes	15	2.0	1	1.1	11	2.4	6	1.7	1	0.8	32	2.0
Take home task 1	6	0.8	0	0.0	5	1.1	5	1.4	3	2.3	16	1.0
Take home task 2	15	2.0	3	3.4	8	1.7	4	1.1	1	0.8	27	1.7
Remember visual imagery story from Exercise 2	0	0.0	0	0.0	6	1.3	7	1.9	0	0.0	13	0.8
Session 7												
Review session 6	66	7.4	0	0.0	12	2.4	6	5.1	2	3.1	84	5.5
Review take home activity	144	16.2	14	16.9	107	21.4	25	21.4	11	16.9	276	18.2
Little and often strategy	135	15.2	16	19.3	97	19.4	21	17.9	9	13.8	253	16.7
PQRST method	231	26.0	18	21.7	151	30.2	42	35.9	22	33.8	424	28.0
Chocolate truffles - learning	84	9.5	11	13.3	30	6.0	0*	0*	13	20.0	114	7.5
Chocolate truffles - errorless learning	40	4.5	0*	0*	6	1.2	5	4.3	2	3.1	51	3.4

Session-specific manual content activities	Site 1		Site 2		Site 3		Site 4		Site 5		Total	
	n	%	n	%	n	%	n	%	n	%	n	%
Relaxation	53	6.0	12	14.5	35	7.0	7	6.0	2	3.1	95	6.3
Take home task 1	18	2.0	1	1.2	10	2.0	3	2.6	1	1.5	31	2.0
Take home task 2	12	1.4	3	3.6	10	2.0	3	2.6	1	1.5	25	1.6
Session 8												
Review session 7	64	7.9	3	3.8	19	4.4	17	6.9	5	2.3	100	6.6
Review take home activity	77	9.5	8	10.0	55	12.7	27	10.9	32	14.6	159	10.4
Diary use	328	40.4	30	37.5	179	41.3	91	36.7	83	37.9	598	39.3
Memory aids – internal and external	56	6.9	8	10.0	43	9.9	38	15.3	11	5.0	137	9.0
Positive attitude to memory aids	46	5.7	7	8.8	16	3.7	5	2.0	5	2.3	67	4.4
Pacing - Making the most of energy	102	12.6	18	22.5	68	15.7	54	21.8	54	24.7	224	14.7
Take home task	31	3.8	2	2.5	3	0.7	3	1.2	3	1.4	37	2.4
Session 9												
Review session 8	52	6.9	1	1.3	17	4.0	6	2.2	4	2.0	75	5.1
Review take home activity	103	13.7	5	6.4	43	10.1	36	13.4	27	13.8	182	12.4
Problems with external aids	287	38.2	36	46.2	168	39.6	143	53.4	77	39.3	598	40.8
Memory aids use in future	30	4.0	2	2.6	12	2.8	15	5.6	6	3.1	57	3.9
Case studies: making life a bit easier	93	12.4	20	25.6	79	18.6	38	14.2	49	25.0	210	14.3
Useful tips when using external memory aids	13	1.7	1	1.3	11	2.6	2	0.7	9	4.6	26	1.8
Take home task 1	16	2.1	2	2.6	11	2.6	5	1.9	5	2.6	32	2.2
Take home task 2	25	3.3	3	3.8	28	6.6	11	4.1	7	3.6	64	4.4
Session 10												
Review session 9	24	2.9	n/a[a]	n/a[a]	1	0.2	7	1.6	3	1.3	32	1.8
Review take home activity	143	17.1	n/a[a]	n/a[a]	80	16.0	66	15.1	41	17.5	289	16.2
Overview of sessions	170	20.3	n/a[a]	n/a[a]	127	25.3	118	27.0	42	17.9	415	23.2
Favourite strategies	93	11.1	n/a[a]	n/a[a]	57	11.4	66	15.1	36	15.4	216	12.1

Session-specific manual content activities	Site 1		Site 2		Site 3		Site 4		Site 5		Total	
	n	%	n	%	n	%	n	%	n	%	n	%
Reflecting on memory problems identified in session 1	132	15.8	n/a[a]	n/a[a]	90	18.0	71	16.2	50	21.4	293	16.4
Group feedback - Changes since the programme	92	11.0	n/a[a]	n/a[a]	36	7.2	33	7.6	49	20.9	161	9.0
Take home activity	5	0.6	n/a[a]	n/a[a]	1	0.2	2	0.5	0	0.0	8	0.4

n/a[a] This calculation was not possible as there were no videos available for the session. n/a[b] The session-specific manual content was from an earlier session. This was covered in this session as the time ran out in the previous session. *Note errorless learning was changed in the manual to 'learning' after a few groups had received the intervention. This is the reason it appears in some observations and not in others.

3.7.6 Assistant psychologist and participant activities

When coding observations as AP or participant activity codes, 49% of the codes were for AP activities and 51% were for participant activities.

There was variation in the proportion of codes across the sites (Figure 11). Site 4 had APs and participants engaged in activities on 56% and 44% of observations, and site 5 had participants involved in activities most of the time (63%) compared to the APs at 37%. The distributions of AP and participant activity codes by session number are presented in Figure 12. In the observations, APs were engaged in activities at a higher proportion than participants in session 1, 2 and 8. These were an introductory session, core session on memory theory and processes and the main session on diary use (external memory aid), respectively. This difference was more marked in session 2, whereby APs were engaged in activities for 64% of the observations. This session was more educational in format, aiming to provide participants with an understanding of how memory problems occur and a rationale for how to address these problems.

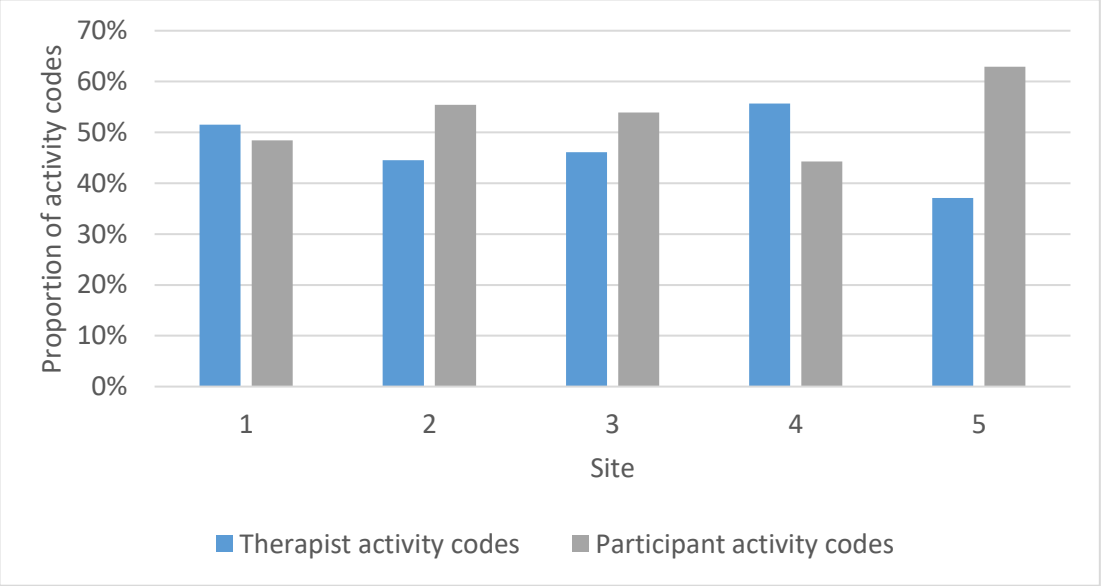


Figure 11 Distribution of assistant psychologist and participant activity codes by site

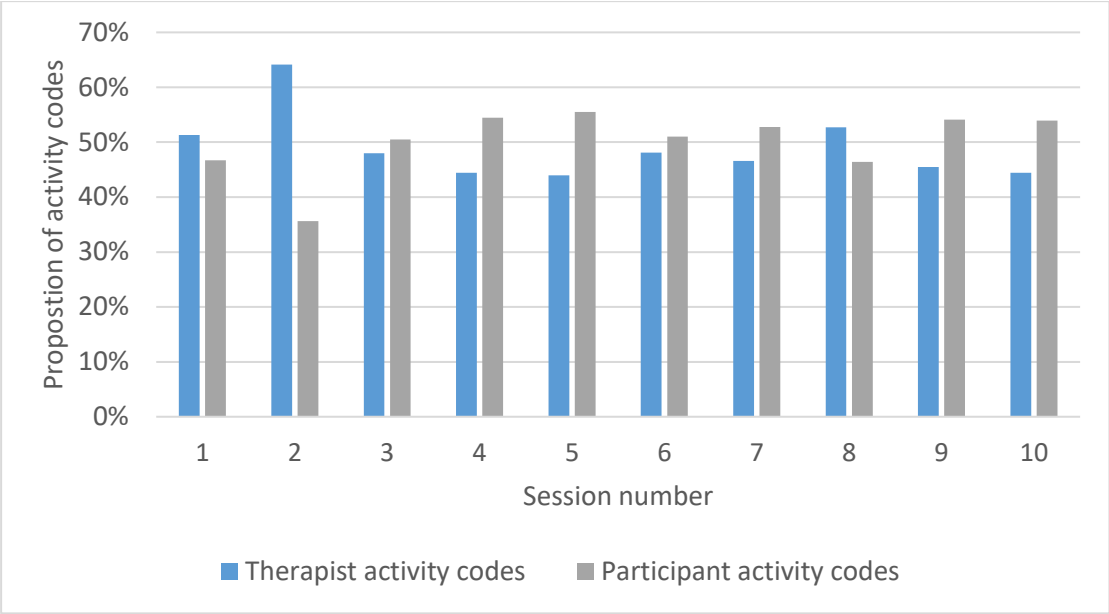


Figure 12 Distribution of assistant psychologist and participant activity codes by session number

3.7.6.1 Assistant psychologist activities

Table 16 presents the distribution of observed AP activities by site, grouped by overall category based on the activity codes. Comprehensive results for the activity codes for each of the categories by site are presented in Appendix 10. Overall, the most frequent activity for APs was 'presenting and discussing internal and external memory and attention strategies' (17%). Site 2 had the highest proportion of this activity (20%) and at site 5 this was lowest at 12% of the total time spent. This activity code fell under the category psychoeducation, which occurred in 33% of all observations. The second most frequent activity code was presenting and discussing educational material (11%), which was consistent across all sites. The third most frequent observed activity was providing an explanation for memory and attention, at 6% across sites. Site 2 was observed to engage in this activity for 1.5% of observations, which was less than at the other sites. Therapist group facilitation and competency skills were the second highest observed activity category (11.6%). This included the codes providing feedback (4%), paraphrasing other participants' contributions (1%), facilitating group discussions (3.5%), summarising cognitive rehabilitation activities (1.5%) and

providing encouragement (1.6%). The frequency of these activities was comparable across all the sites.

Table 16 Distribution of assistant psychologist activity categories by site

Therapist activity categories	Site 1 (n=7980)		Site 2 (n=543)		Site 3 (n=4921)		Site 4 (n=3019)		Site 5 (n=1806)		Total (N=18269)	
	n	%	n	%	n	%	n	%	n	%	n	%
Administrative/ organisational	278	3.4	5	1	141	2.8	111	3.7	26	1.4	561	3
Psychoeducation	2824	35.4	176	32.5	1482	30.1	1105	36.6	474	26.2	6061	33.1
Therapist facilitation skills	890	11.1	57	10.4	570	11.5	441	14.7	164	9.1	2122	11.6
Miscellaneous/ Other	82	1.1	3	0.6	34	0.7	23	0.8	4	0.3	146	0.8

The distribution of AP activity categories by session number is presented in Table 17. The frequency of activity categories varied across sessions, consistent with the central theme and objective of the individual sessions. APs were observed engaging in psychoeducational activities (e.g., providing an explanation of memory and attention) in all sessions. However, the frequency of activities related to psychoeducation was highest in session 2 at 43% overall (27% for providing an explanation for memory and attention). This session focused on memory theories. The frequency of activities relating to presenting different strategies (psychoeducation) increased as the sessions progressed, in line with the content of the manual which moved from theory (sessions one to three) to introducing strategies and their application (sessions 4 to 9). The most frequent occurrence of this activity was observed in session 8 (diary use) but was comparably high for sessions 4 to 9. APs were only observed discussing consent to video record the sessions three times across sessions. This was consistent with the research ethical protocol, where consent is sought before any activities occur. Similar to the occurrence of activities across sites, therapist competency skills were relatively comparable across all sessions but represented a lower proportion of observations in sessions 4 (7.4%) and

5 (6.3%). Both these sessions covered internal strategies such as the 5Ws and H (session 4) and chunking (session 5).

Anonymised illustrative quotations for each of the therapist activities codes are presented in Appendix 12.

Table 17 Distribution of assistant psychologist activities according to session number

Therapist activity categories	Session 1		Session 2		Session 3		Session 4		Session 5		Session 6		Session 7		Session 8		Session 9		Session 10	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Administrative/ organisational	203	14.7	49	2.8	40	2.2	34	1.4	26	1.5	30	1.7	26	1.5	26	1.5	15	0.9	112	5.4
Psychoeducation	240	17.3	762	43.1	610	31.7	829	35.1	667	36	673	37.5	586	35.4	644	35.9	580	33.8	470	23.4
Therapist facilitation skills	240	17.3	286	16.1	259	13.4	173	7.4	116	6.3	154	8.6	156	9.3	265	14.8	175	10.2	298	14.7
Miscellaneous/ Other	28	2	39	2.2	14	0.8	15	0.6	7	0.4	6	0.4	3	0.2	10	0.6	11	0.6	13	0.6

Content of assistant psychologist discussions

To examine the content of AP discussions further, a qualitative content analysis of the transcripts from the video observations was conducted. The findings are reported according to the overall category activities as previously discussed and presented in Table 16 and Table 17.

Figure 13 illustrates the most frequent words uttered by APs across all sites and for all sessions. The most frequent word was ‘remember’, followed by ‘memory’ and ‘think’.



Figure 13 Word cloud of most frequently words used words by the assistant psychologists (all sessions)

Administrative and organisational

Overall, this category comprised codes related to group procedural issues. These included APs informing participants of where toilet facilities were located (housekeeping), asking participants if they required a reminder text before a session (information about sessions), and preparing materials during sessions (e.g., handing out exercise material, including pens and paper).

Psychoeducation

As discussed previously, the most frequent activity APs were engaged in was presenting or discussing memory and attention strategies (17%). Examination of the transcripts of text for this code showed that the content of this discussions pertained to internal memory and external aids as a whole (40% and 29%, respectively), such as presenting the types of memory aids that would be classed as 'internal' or external'. For example:

> *"Internal memory aids, we'll be covering things like deep level processing, visualisation, story-making methods" (Site 4, Session 1)*

In almost 20% of discussions coded under this category, the content of the discussions was concerned with discussing cognitive rehabilitation strategies in relation to educational material (e.g., reviewing previous sessions or discussing take home activities). Also observed were discussions focusing on making linkages between the external and internal aids and memory and attention processes (6%). For example:

> *"We're linking encoding to retrieval [when using mnemonics as a memory aid]" (Site 5, Session 5)*

Providing an explanation of memory and attention was the third most frequently discussed activity by APs. The content of these discussions largely (69%) focused on theories of memory, including what memory and attention are, the processes involved, memory storage, retrieval and memory systems. For example:

"So long term storage is the point that we can go back to and we retrieve it at a later date or a later period in time" (Site 1, Session 2)

"As well as sustained attention, we've got divided attention which is like multi-tasking" (Site 2, Session 3)

APs often provided explanations of memory and attention in relation to the educational material (e.g., reviewing previous sessions or discussing take home activities), and when explaining how a particular strategy could help to improve problems with the processing of memory, providing encouragement. For example:

"it [internal memory aids] do take a bit of work for your brain but the idea is that work that your brain is doing is processing that information […] that work is going to help it go into long-term memory" (Site 3, Session 5)

"It's all about encoding, it has to be logical to yourselves [explaining memory processes in relation to PQRST strategy]" (Site 1, Session 7)

Therapist facilitation skills

The utilisation of therapist skills by the APs, such as facilitating group discussions and providing feedback were observed frequently in the text (3.5% and 3.7%, respectively). APs would often use group discussion facilitation prompts to prompt participant to discuss particular topics in more detail, or as a way of introducing new material or a different line of thinking to the group. For example:

"What type of retrieval is it, if I'm asking you to cover it up and do it [retrieve it] straightaway?" (Site 5, Session 2)

"If we didn't have diaries how else would you store the information do you think?" (Site 2, Session 8)"

In terms of providing encouragement and reassurance, the APs encouraged participants to persevere with strategies, particularly when they were finding it difficult to understand the application of some of the strategies presented.

"You will get there, using the first letters cues strategy is about practice, it's about having that motivation as well" (Site 1, Session 7)

"Some [strategies] are going to work for you, some will not, it's just the way your mind works" (Site 1, Session 5)

Miscellaneous/ other

This category comprised of social chat, discussions on the psychosocial impacts of living with MS and APs giving information related to memory that was not in the manual. The latter occurred in response to participants' queries about other neurological conditions or aspects of memory not specific to MS. For example, when asked by a participant whether addiction was connected to emotional memory:

"Addiction as far as I know is more to do with neurotransmitters such as dopamine" (Site 1, Session 2)

3.7.6.2 Participant activities

Table 18 presents the distribution of participant activities, grouped into overall categories, by site. The results for the activity categories and corresponding activity codes are presented in Appendix 13. Across all sites, the main category of activities

participants were observed engaging in were those related to the intervention content, that is, psychoeducation (41.7%). The main activity codes in this group were discussing and filling in educational material (17%). This sub-category consisted of the activity codes discussing educational material (12.8%), filling in educational material (1.3%) and providing feedback on the take home activities (3.1%). The observed frequency of these observations occurred consistently across sites, although site 2 spent a higher proportion of time discussing educational material (21.5%) than the other sites. The second most frequent activity was discussing memory and attention strategies (15.8%). This occurred consistently across sites. The third most frequent discussion topic for participants was discussing the memory and attention problems they experienced (7.5%). There was some variation in the frequency of this activity across sites, ranging from 5.6% at site 4 and 9.2% at site 5.

Table 18 Distribution of participant activity categories according to site

Participant activity categories	**Site 1 (n=7980)**		**Site 2 (n=543)**		**Site 3 (n=4921)**		**Site 4 (n=3019)**		**Site 5 (n=1806)**		**Total (N=18269)**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Administrative/ organisational	61	0.8	1	0.2	38	0.7	34	1.1	34	1.9	168	0.9
Living with MS	207	2.6	4	0.7	164	3.4	50	1.7	69	3.8	494	2.7
Psychoeducation	3090	39.3	268	49.4	2089	42.4	1149	38.1	968	53.6	7602	41.7
Psychosocial aspects of cognitive issues in MS	107	1.3	6	1.1	52	1.1	21	0.7	21	1.2	207	1.1
Miscellaneous/ Other	326	4.1	21	3.9	259	5.3	82	2.7	42	2.3	730	4

The observed occurrences of participant activity categories by session number are presented in Table 19, with the corresponding activity codes presented in Appendix 14. Overall, the occurrence of participant activities corresponded with the content and themes of the sessions. For example, as the theme of the sessions progressed from memory and attention theory to strategies to address these issues, this was reflected in the frequency of these activity categories. Discussions on the memory and attention problems experienced by participants were observed to occur at higher proportions in the initial sessions (one to three), which had a focus on these specific aspects of MS. The occurrence of discussion on strategies started increasing from session 4 (13.6%). This session focused on internal strategies to improve encoding and recall. There was a gradual increase in the occurrence of this activity code, peaking at session 9 (35.4%), which looked at ways of minimising potential problems associated with using external memory aids. Discussions on changes participants were experiencing (as a consequence of attending the group sessions), such as the increased and/or novel use of strategies they had been introduced to during the sessions were observed more frequently in sessions 8 to 10 (4.9% of observations).

Table 19 Distribution of participant activity categories according to session number

Participant activity categories	Session 1		Session 2		Session 3		Session 4		Session 5		Session 6		Session 7		Session 8		Session 9		Session 10	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Administrative/ organisational	16	1.2	13	0.8	2	0.2	3	0.1	2	0.2	6	0.4	5	0.3	3	0.3	7	0.4	111	5.4
Living with MS	93	6.7	45	2.5	33	1.8	22	0.9	25	1.3	14	0.8	25	1.6	126	7.1	38	2.2	73	3.6
Psychoeducation	411	29.6	471	26.6	839	43.6	1175	49.6	920	49.5	827	46	774	46.7	602	33.5	808	47	775	38.4
Psychosocial aspects of cognitive issues in MS	69	5	33	1.8	11	0.6	8	0.3	12	0.6	8	0.4	13	0.8	16	0.9	7	0.4	30	1.4
Miscellaneous/ Other	58	4.2	69	3.9	86	4.5	79	3.3	71	3.8	61	3.4	56	3.4	85	4.7	70	4.1	95	4.7

Content of participant discussions

The qualitative analysis of the content of participants' discussions is presented below, grouped under the overall category activities as discussed previously and shown in Table 18 and Table 19. Further examples of anonymised illustrative quotations for the different activity categories and codes are presented in Appendix 15.

Administrative/ organisational

In the earlier sessions, the content of participants' discussions in this activity category comprised mainly of discussions on housekeeping (e.g., asking when there would be a break) and the organisation of sessions (e.g., dates, rescheduling session due to public holidays or illness). Session 10 saw an increase in discussions on CRAMMS research activities once the group sessions were completed. Participants sought to gain clarification on what they could say (to avoid issues of unblinding) to a CRAMMS researcher who contacted them to arrange a feedback interview or conduct outcome assessments. For example,

> *"We're obviously not meant to tell them [the outcome assessor], but the person who's doing the interview then they're gonna [sic] know [that the participant attended the group sessions]" (Site 4, Session 10)*

Furthermore, in session 10 participants gave feedback on several aspects of the format of the intervention. Regarding session duration, participants indicated that the sessions needed to be longer, considering the quantity of information that was presented during the sessions:

> *"An extra half an hour would have made it [sessions] a little less frantic in a way" (Site 1, Session 10)*

"There's a lot in this book that's not been filled in, because we haven't had time […] we spent time recapping" (Site 3, Session 10)

Participants also spoke about the size of the groups, indicating that they comprised of the right number of people:

"I think this was a good sized group […] if you'd had 12-18 you might end up not talking to some of the people in that group within the time [..]" (Site 5, Session 10)

Participants spoke at length about the therapeutic benefits of a group format, regarding a shared experience and learning from other people who were in the same situation as they were. For example:

"[It] makes you feel better that it's not just you and you're not on your own with it, that's why I like coming here" (Site 1, Session 3)

"In terms of learning stuff, I'm learning from [AP] and from you [pointing to another participant]" (Site 3, Session 6)

"Doing something like this [group] can give you confidence" (Site 1, Session 10)

Living with MS

The content of participants' discussions consistently included mention of what impact MS had on their daily lives. This included other symptoms of MS (e.g., mobility and fatigue); financial implications, accessing support services; medication and contact with clinical staff (e.g., neurologists and MS nurses). For example, describing the impact the 'invisible' symptoms of MS on their life:

"I'm pleased it's [MS] invisible in many ways but it kind of is frustrating because people go 'me too' […] I know it's not you too, you're just tired not fatigued" (Site 3, Session 1)

Psychoeducation

This category included codes pertaining to discussing and filling in educational material, discussing cognitive rehabilitation strategies as they were presented in the different sessions as well as how participants were incorporating these into their daily lives. Additionally, feedback on the take home activities and questions relating to the intervention content were also grouped uner this category. Figure 14 illustrates the most frequent words discussed by participants for codes in this category.



Figure 14 Word cloud of the most frequent words discussed by participants for codes in the psychoeducation category

In relation to the educational material, participants described how the more theoretical aspects of the intervention content helped them to understand their memory and attention problems:

"It [learning about attention] was a penny dropping moment, otherwise I would have just carried on [not paying attention to things]" (Site 4, Session 10)

When engaging in discussions on memory and attention strategies, participants often reflected on the use of memory aids that they had previously used in their daily lives, and how effective these had been. For example:

"I find if I write it down [information at work] it reinforces it for me" (Site 3, Session 4)

"For me it works, visualisation, I suppose it's because I've done it for donkeys' years, it's not something new" (Site 4, Session 10)

Participants often discussed combining different internal and external strategies to help them remember. For example:

"So I could maybe, when I take them (medication), [I] make a note on the day […], maybe put my paracetamols on the diary" (Site 1, Session 6)

Discussions centred on internal memory aids such as the 5Ws and H, and the PQRST method suggested participants had divergent perceptions of these strategies. For example, some participants found them to be particularly useful strategies. For example:

"I think its [using 5Ws and H for take home activity] has helped me remember detail" (Site 3, Session 5)

"I think it's [5Ws and H strategy] very good if you want key facts and that, it depends on what it is [one wants to remember]" (Site 1, Session 4)

On the other hand, some participants found these strategies challenging, regarding their purpose and application:

"I don't think personally I'll get on with the PQRST one [strategy]; PQRST', I think it's too much to remember" (Site 1, Session 7)

"I can't figure out why I need that [PQRST]" (Site 4, Session 8)

Predominantly in session 10, participants described the perceived changes in their cognitive abilities, psychological well-being, and/or behaviour because of attending the sessions. For example, when explaining the increased use of compensatory strategies:

"Better [as a result of attending the group] I'm not memorising things better, but utilising things [memory and attention aids] better" (Site 1, Session 10)

"The first time I went shopping with that list in my head with all them pictures [using visualisation and categorisation], it were just unbelievable" (Site 3, Session 10)

Participants indicated they were more aware of their memory abilities because of attending the group sessions, with this self-appraisal leading to an increase in self-efficacy:

"I can see an improvement [after doing the intervention], I think the awareness is the main thing for me, being [more] aware" (Site 3, Session 10)

"It does give you confidence, this ten weeks [intervention]" (Site 3, Session 10)

Feedback on the take home activities that were assigned after each session sometimes consisted of participants expressing they had forgotten to do the tasks. Reasons for forgetting included distractions at home or not having someone at home to help them carry out some of the tasks (mainly for session 4):

"I didn't have someone to help me do the task [route finding activity]" (Site 1, Session 4)

Some participants also found some of the take home activities challenging to do or to understand the instructions:

"That, is very hard that, remembering in three separate hours [what take home activity asked them to do]" (Site 3, Session 10)

"It's not very clear [instructions for take home activity on page 32]; one is contradicting the other [instructions]" (Site 3, Session 3)

On the other hand, some participants found doing the take home activities consolidated the information they received during the sessions or helped them better understand their memory and attention problems:

"I think this [doing take home activities and trying out the strategies] is making a difference [to help with memory issues]" (Site 3, Session 7)

Psychosocial aspects of MS & support

This category comprised codes relating to the emotions that often accompanied memory and attention problems and ways in which participants tried to cope, social support from other group members and input from family members. Participants shared information on how they dealt with these issues mostly in session 1 and to a small degree in session 10.

When describing their memory and attention problems, participants said they had issues remembering (e.g., names, faces), were forgetful (e.g., to take medication, of where they had parked their car), found it difficult to pay attention, and were easily distracted. For example:

> *"I can recognise faces but it's names that I can't remember" (Site 4, Session 4)*
>
> *"I am given amitriptyline to sleep but I forget to take it" (Site 1, Session 1)*
>
> *"I could be watching TV and I hear a noise or a bang it gets my attention and I get distracted from the TV" (Site 3, Session 1)*

The most common emotion participants associated with their memory and attention problems was frustration, due to not being able to retrieve information from their memory:

> *"I tend to get worked up and stressed out as I'm frustrated as I should be able to remember these things" (Site 1, Session 1)*

In order to cope with their memory and attention problems, participants indicated they tended to avoid certain situations in which their memory would be tested:

"You avoid those situations [in which they forget, find it difficult to get their words out] because you're embarrassed or you think it's going to affect someone who's with you" (Site 3, Session 1)

Miscellaneous/ other

This category mainly consisted of participant social chat. In a minimal number of instances participants asked questions about memory that were unrelated to the intervention content. For example,

"How do you know all these Wi-Fi connections are not causing problems with memory to your brain?" (Site 1, Session 9)

3.8 Discussion

3.8.1 Summary of findings

The quantitative content analyses results showed that the cognitive rehabilitation delivered during the CRAMMS intervention sessions was consistent with that described in the treatment manual, suggesting high adherence to the content of the intervention as specified in the manual. A number of factors supported this. First, the finding that at least 75% of the time during the intervention sessions was spent engaged in activities related to the CRAMMS intervention manual (i.e., cognitive rehabilitation) than those unrelated to the intervention manual. Qualitative analysis of the content of discussions provided further details of what was discussed. This showed that both APs and participants predominantly discussed topics that were directly related to the intervention (e.g., the psychoeducational aspects). On the part of the therapists, this indicated that 'therapist drift', when over time therapists stray

from the treatment protocol (Bellg et al., 2004) was minimal. From this, it was deduced that participants who attended the group sessions received cognitive rehabilitation and not another intervention.

The second source of support came from observations of the individual cognitive rehabilitation sessions and the observed frequency of activities relating to the entire manual. All but two (out of 93) session-specific activities were observed to occur during the sessions (e.g., a very brief exercise from session 6 was not observed in sites 1, 2 and 5), or in a later session in two instances. The latter did not affect the assessments of treatment fidelity, since the intervention delivery protocol allowed for a certain degree of flexibility in the content discussed within the sessions, as long as all the components of the intervention were delivered to the participants. Therefore, the overall categories of the intervention were all delivered by the APs.

As discussed previously in the background section on complex interventions and fidelity in Chapter 1, Carroll et al. (2007) suggested a conceptual framework for implementation fidelity, or adherence, which included details of the content of the intervention, coverage, frequency and duration of the intervention. Content referred to the key components of the intervention, or its 'active ingredients' or essential components; the frequency, duration, and coverage of intervention delivery refer to the 'dose' of the intervention (Carroll et al., 2007). All these are quantifiable factors. The authors argued that for fidelity to be considered high, implementation of the intervention has to meet the criteria (as per the protocol) for each of these aspects of adherence. Using this model to evaluate the delivery of the CRAMMS intervention provides further support for the suggestion that the implementation fidelity of this intervention was high. Specifically: (1) almost all components of the intervention were delivered; (2) therapist drift was minimal; (3) overall, the 'dose' of the intervention was in line with the protocol, which allowed for a degree of flexibility on the amount of time

spent on aspects of the intervention, in line with participant needs. For example, therapists were encouraged to spend time explaining concepts to CRAMMS participants if necessary. More time was spent on almost all the core components of the intervention, such as discussions on the different strategies and the take home activities.

Whilst quantitative analysis of the activity codes gave an indication of the presence or absence of these codes, and the degree to which they were discussed (measured as time spent), qualitative analysis of the activity codes allowed for a more in-depth examination of what was discussed in relation to the various intervention components. Relating to the specific types of conversations, APs responded to the purpose of each session, spending more time explaining theoretical models of memory and attention in some sessions and in others focusing more on presenting and explaining strategies. An examination of the psychoeducation activity category showed that not only did APs present memory and attention theory and processes and the different internal and external strategies, they frequently made links between the two. Therefore bridging the gap between more theoretical aspects of the intervention and the applied and more practical elements. The discussions from participants indicated they found this to be an essential aspect of intervention delivery, further reinforced by the take home activities. This finding was supported by research evidence suggesting the support of a therapist, as opposed to cognitive rehabilitation programmes that were delivered at home via a computer, had a significant impact on outcomes (Sporner, 2013).

Qualitative content analysis of the participant activity codes suggested that most of the strategies were well received, although participants experienced some difficulty understanding the potential benefits of some of the internal aids. The mixed perceptions of internal memory aids may be attributed to participants' unfamiliarity

with some of the strategies (e.g., the PQRST). This is supported by findings from a study by Evans et al. (2003). Based on interviews with 94 people with acquired brain injury, less than 10% used internal memory strategies such as first letter mnemonics, rhymes and alphabet searching.

There was also mixed engagement with some of the take home activities. Overall, non-completion of these in some sessions may be an indication of participant engagement with the content. Feedback in the final session indicated that some participants experienced some changes due to attending the group. These included improvements in memory and attention abilities due to increased awareness and understanding of how to apply the different strategies. Moreover, participants expressed increased self-efficacy through a better understanding of memory and attention and the issues that can arise, or participants' perceptions of their abilities. Often, this was attributed to the 'shared' experience that the group setting provided.

This finding was consistent with previous research evidence suggesting that group-based cognitive rehabilitation have been associated with a range of advantages. In a study by Miotto and Evans (2005), following a group-based attention and goal management cognitive rehabilitation intervention people exhibiting impairments in executive function at baseline showed significant improvements in this cognitive domain compared to an information-only (i.e., given a leaflet) group and a group that received physiotherapy.

Meta-syntheses of qualitative research on cognitive rehabilitation in people with MS conducted by das Nair et al. (2015b) and Klein et al. (2017) identified the key themes of sense of community and social support, and shared learning as contributing factors for the perceived benefits of group-based cognitive rehabilitation in MS. The therapeutic qualities of group interventions are based on their curative properties, which are the main facilitators of change within the individuals (Yalom and Leszcz,

2005). Universality, whereby group members no longer feel alienated, is based on the assumption that no human experience occurs exclusively to one individual, and there is always an element of inter-individual commonality (Yalom and Leszcz, 2005). Hence, there is a perception of shared life experience and identification within the group (Murphy and Johnson, 2006). This could encourage learning, modelling and role-playing (i.e., imitative behaviour) (Yalom and Leszcz, 2005).

As discussed in the methods Section 3.5, the purpose of this study was not to 'infer' the current CRAMMS intervention findings onto other cognitive rehabilitation programmes for people with MS but to provide a description of the content of the intervention. Additionally, direct comparisons with previous research are not possible, as the coding scheme used in the current study differed to those used in previous studies with people with MS (O'Brien et al., 2013, Smale et al., 2014) and those used in traumatic brain injury (TBI) population groups (das Nair et al., 2017). Therefore, it is necessary to interpret the current findings as they are discussed with respect to previous research. Similar to the present study, the most frequent activities observed in these studies were those related to cognitive rehabilitation, such as discussing strategies to help with memory problems. For example in the study by Smale et al. (2014), which informed the development of the CRAMMS intervention, the most frequently observed content related to memory strategies, including case examples and exercises (58% of the total content). In their cluster randomised controlled trial examining the treatment fidelity of a group memory rehabilitation for people with TBI by das Nair et al. (2017), a similar proportion of therapist facilitation skills was observed across all sessions and sites (11.3% compared to 11.6% in this study). Furthermore, similar to the current study 'presenting and discussing memory strategies' was the most frequently observed rehabilitation activity (35.8%).

The content of CRAMMS was consistent with recommendations for cognitive rehabilitation for attention and memory, as summarised in Table 1 (Chapter 1, section 1.3.4). For example, Fish (2017) summarised that the rehabilitation of attention deficits involved: 1) psychoeducation to explain the nature of attention; 2) the exploration of attention through exercises; 3) the introduction of attention strategies (internal and external, e.g., reducing distractors); and 4) behavioural modification and ongoing assessment of this through 'real' world tasks (e.g., take home activities). This aligned with CRAMMS sessions 4 and 5.

3.8.2 Limitations and strengths of this study

3.8.2.1 Limitations

One potential limitation of this study was the time-sampling interval used. In Lane and Ledford's (2014) systematic review on the accuracy and reliability of different time-sampling intervals, medium interval lengths of 30-59 seconds were usually found to provide an accurate estimate of behaviours within an observation period, with better accuracy for smaller intervals (2-29 seconds) and worse for larger intervals (>59 seconds). However, due to the large number of videos to observe, with each treatment video recording lasting between 60 to 90 minutes, a one-minute interval between observations was chosen. This was to meet the study objective of completing a comprehensive analysis of the content of the CRAMMS intervention, without compromising the reliability of the data collection by increasing the number of data observations.

Although the inter-coder reliability was high, one could argue that this was based on the transcriptions and not the video observations per se. In their study, a precursor to the CRAMMS trial, O'Brien et al. (2013) followed a similar procedure, whereby observations were recorded in situ by one researcher. A second coder, using the

coding scheme, then coded this text data. To ameliorate the potential issues of the transcripts not reflecting the observations in the current study, the researcher endeavoured to provide transcripts that were complete and clear as a standalone, providing context where possible to minimise misinterpretation or confusion. Furthermore, a proportion of transcripts were checked against the videos to ensure the accuracy of the transcriptions. Moreover, by checking the coding of observations carried out earlier in the data collection process and correcting for any errors, the researcher ensured the consistency and stability, and therefore the intra-coder reliability of the coding process. Additionally, the researcher became very experienced in observations and coding, thus also increasing the consistency of the data collection and analysis.

It is important also to take into consideration that the findings of this study are based on the availability of complete video recordings of the CRAMMS treatment sessions (56% of potential recordings). This is particularly important when comparing site-specific findings - Site 2 had a larger proportion of missing videos (73%) while Site 5 had the most substantial number of complete video recordings (80%). Therefore, any site-specific differences may be a characteristic of the completely recorded treatment sessions.

Another limitation is that only the *content* of communication, specifically the obvious and visible manifest content of communication to describe what occurred during the treatment sessions was the focus of this study. This provided a foundational description of the CRAMMS intervention (i.e. *what happened*). Further analysis of the video recordings to interpret the underlying meaning or latent content of discussions (Graneheim and Lundman, 2004) or an examination of the quality of interactions between APs and participants using an approach such as conversation analysis could

serve to answer follow-up questions such as *'in what way'* or *'how'* (Erlingsson and Brysiewicz, 2017) did the discussions occur.

3.8.2.2 Strengths

One major strength of this study is that all available video sessions were coded. This circumvented potential issues regarding the sampling of the videos and therefore the comprehensiveness of the coding process. This was a limitation of the studies by O'Brien et al. (2013), Smale et al. (2014), as the objective of the coding was to maximise 'code saturation' (Hennink et al., 2016) and 'theoretical sufficiency'. This was done to indicate the adequacy of the data and the fullness of the coding process (Charmaz, 2006, Dey, 2007) in describing the content of CRAMMS intervention, thus ensuring the coding process was both exhaustive and exclusive (Neuendorf, 2002). The researcher recognises these terms are ordinarily used to describe grounded theory methodology. These were deemed appropriate for this study.

The most significant limitation to using directed content analysis is by only using pre-defined codes when recording observations and important events may be missed entirely if relevant codes did not exist for these. As Atkinson (1992, p. 459) pointed out, it was important to avoid falling fowl to a 'conceptual grid', whereby the framework for code developed was informed solely by existing cognitive rehabilitation theory and models or previous research. Therefore, the data collected would only reflect this framework. This limitation was negated in the current study, as the development of the codebook was not reliant solely on a priori knowledge, but an iterative process involving various stakeholders. This was a limitation of the Smale et al. (2014) study, whereby the components of the sessions were decided upon by one individual.

Examining the activity codes for both APs and participants, both quantitatively and qualitatively, allowed for a complete account of what exactly was discussed during the cognitive rehabilitation sessions. This led to a more detailed knowledge of what occurred during the delivery of cognitive rehabilitation for people with MS than previously known. The definition of content analysis and the methods used in this study were consistent with Hamad et al.'s (2016) proposed "The combined content-analysis (CCA) model" for content analysis. Under this model, the authors argue that content analysis methodology is better understood as a mixed-methods design, combining both quantitative (deductive, theoretical-level) and qualitative (inductive, data level) methods to data collection and analysis. The mixed-methods approach to content analysis is suitable when several methods are required to answer more than one research question or when it is beneficial to combine both methods to address a question (Hamad et al., 2016). This model aligned with the current study, as a *quantification* and a *description* of the content of treatment was required to meet the research questions.

The research methods used in study two were consistent with the literature. For example in their systematic review that identified the measures used to monitor the fidelity of intervention delivery and to describe the reporting of implementation characteristics in behaviour change interventions, Walton et al. (2017) found that 17 (39%) of included studies used observational methods and 20 (46%) assessed fidelity by comparing the delivery of intervention components to what was planned.

3.8.3 Conclusion and implications of findings

The findings of this study support the conclusion that all aspects of the content of the CRAMMS intervention were delivered as intended in the intervention manual, although there were some variations for time spent on different intervention content.

Therefore, an evaluation of the effectiveness of the CRAMMS can be attributed to what was described in the intervention manual. The content of the AP discussions revealed that a significant proportion of their time was spent discussing topics directly related to the intervention manual or performing therapist facilitation skills that are essential aspects of group-based interventions. Participant discussions highlighted that the clinical presentation of MS (including cognitive problems) and the psychosocial impact of this on their daily lives were intertwined. Overall, participant feedback on the content of the intervention was positive, although some participants found the internal strategies challenging to grasp. With regards to the delivery of the intervention, findings suggested the participants perceived the group favourably. There were some issues expressed concerning the duration of the individual intervention sessions.

Researchers and clinicians may want to consider the format of intervention delivery; not only is the content of an intervention important, but so are the potential psychosocial aspects and benefits of group rehabilitation. Adaptations of the timings of the intervention content, the duration of intervention sessions and some internal strategies can also be made before replication or implementation of the CRAMMS intervention in clinical practice.

The current study and the systematic review findings comprised the first stage in the process for the development of a reporting checklist for cognitive rehabilitation interventions in MS. As the quality of reporting and the content of a cognitive rehabilitation intervention had been established, the next stage was to ascertain which aspects of these interventions clinicians perceived as ‘essential’ to be included in published studies. This would facilitate implementation of these interventions in routine practice.

Chapter 4 Developing a reporting checklist, a consensus on cognitive rehabilitation – Study Three

4.1 Chapter overview

This chapter presents a Modified Delphi consensus process for the development of a reporting checklist for cognitive rehabilitation in MS, which was the final study.

As reported in Chapter 2, a systematic review of the aspects of the content cognitive rehabilitation of attention, memory and executive function were either poorly reported or missing from the published studies. These included how the interventions were delivered (e.g., face-to-face or in a group setting), descriptions of the content of each of the sessions, and the mechanism of change and/or active ingredients of the intervention. Moreover, the review processes underscored the need for a checklist that was accessible, in terms of the number of items contained within it and the way in which items were presented. Furthermore, the terminology used within the checklist should be appropriate for cognitive rehabilitation.

In Chapter 3, analysis of the video recordings of interventions sessions indicated that the CRAMMS intervention was delivered as planned (the delivery of the intervention adhered to the content as planned in the intervention manual), and the most frequent discussions for both assistant psychologists and participants referred to memory and attention strategies. Therefore, the outcomes of these studies established: (1) What was reported in research studies of cognitive rehabilitation in MS and (2) What actually occurred during treatment sessions in one cognitive rehabilitation trial.

These findings were integrated and became the starting point for the development of the initial list of reporting statements, which were used in the first round of the modified Delphi consensus study.

4.2 Introduction

The importance of reporting guidelines that are appropriate for an intervention (i.e., constructs, context and language) and clincial population were discussed in Chapter 1. The specific relevance of the issue to cognitive rehabilitation was supported by the findings of the systematic review in Chapter 2, whereby several problems with the reporting checklist used during data extraction were identified, and recommendations suggested. Therefore, the development of a clinician-informed, evidence-based checklist may enable researchers to report key aspects of complex cognitive rehabilitation interventions and may enhance the implementation of such research in clinical practice. This study followed Moher et al.'s (2010) recommended steps for developing health research reporting guidelines. A reporting guideline is defined as "a checklist, flow diagram, or explicit text to guide authors in reporting a specific type of research, developed using explicit methodology" (Moher et al., 2010, p. 1).

4.3 Aim

The aim was to develop a clinician-informed, evidence-based reporting checklist, appropriate for a multi-disciplinary team, to improve the translation of cognitive rehabilitation from research to clinical practice.

4.4 Objectives

The focus was the development of a reporting checklist that was specific to intervention type (cognitive rehabilitation) and clinical population (people with MS). The specific objectives of this study were:

- To conduct a Modified Delphi study to identify key aspects of the content of cognitive rehabilitation programmes that need to be specified in MS research papers.

- To develop a reporting checklist for researchers to use when reporting the content of cognitive rehabilitation interventions for people with MS.

4.5 Consensus methods

The development of guidelines in health research is often based on the experience and option of a group of individuals with knowledge of the subject area (Murphy et al., 1998). As Murphy et al. (1998) summarised, the three main approaches to formal consensus development methods that are relevant to health research are:

- The nominal group technique
- The consensus development conference
- The Delphi method

A summary of the differences and similarities between these approaches, modified from Murphy et al. (1998), is presented in Table 20. The Delphi method was considered appropriate for this study as it allowed for questionnaires to be sent to potential participants, did not require face-to-face contact and allowed experts in the area to be involved in the process.

4.5.1 The Delphi method

The Delphi technique is a questionnaire-based iterative approach to gain consensus on an issue among a group of experts in their field. 'Expert' is defined as an individual who is informed on a particular topic (McKenna, 1994). The technique has been used extensively in medical, health and social science research (Coole et al., 2015, Keeney et al., 2001, Pezaro and Clyne, 2015, Waters et al., 2014), as well as for the development of a number of reporting guidelines (Boutron et al., 2005, Hoffmann et al., 2014, Moher et al., 2011, Phillips et al., 2016, Slade et al., 2016). For example, a Delphi study was conducted during the preliminary stages in the development of the

CONSORT statements for reporting RCTs. Experts were tasked to ascertain the importance of potential checklist items for inclusion in a final checklist (Hopewell et al., 2008).

Table 20 Characteristics of consensus development methods

	Nominal group technique	**Consensus development conference**	**Delphi method**
Participants in the consensus development	Expert in the field	Public	Expert in the field
Anonymity of individual judgements maintained	Yes	No	Yes
Participants received feedback on group decisions	Yes	No	Yes
Type of contact between group members	Face-to-face	Face-to-face	Online
Aggregation of judgements	Explicit, e.g., calculating the mean of individual judgements	Implicit, e.g., majority vote	Explicit, e.g., calculating the mean of individual judgements

Modified from Murphy et al. (1998)

There are four key characteristics of the Delphi method (von der Gracht, 2012). These are:

1) Anonymity

As the questionnaires are not completed face-to-face, it minimises the potential for the effect of negative social influences that are common with group interactions, such as conformity, conflict and groupthink, and the potential for more vocal or senior participants dominating the consensus process (Jones and Hunter, 1995, Keeney et al., 2001, Murphy et al., 1998).

2) Iteration

The process involves sequential rounds of questions (in questionnaire format), as each stage builds upon the findings from the previous step. This iterative process enables participants to revise their opinion based on group response (Jones and Hunter, 1995).

3) Controlled feedback

Between rounds, a summary of the group's response is communicated to participants. Also included is the participant's response, which they can evaluate to inform their response in the subsequent round (Keeney et al., 2001, McKenna, 1994).

4) Group response

Consensus is calculated based on the pre-specified degree of consensus within the group being the aim of each round (Waters et al., 2014). Descriptive statistics such as the frequency distributions or the mean of ratings are used to identify patterns of agreement between group members (McKenna, 1994).

A "classic" Delphi often starts with qualitative interviews, with open-ended questions, allowing panellists freedom in how they respond (Keeney et al., 2001). This often results in a large number of items generated, which may or may not be relevant to the research questions. A classic Delphi usually consists of four rounds, which can be time consuming and increases the risk of attrition of participants from the study. It is therefore not uncommon for the methods to be modified, to guarantee that the focus aligns with the research and to improve the efficiency of study conduct.

The Delphi approach was chosen for this study for the following reasons:

- The process of developing a checklist based on expert-consensus did not lend itself to a specific method of analysis but would benefit from more subjective judgements from experts (as well as the fact panellists with a range of experience and levels of expertise were contacted) (McKenna, 1994).
- The recruitment of clinicians and researchers into the study was not to be limited to the UK context since cognitive rehabilitation is delivered globally. This method brings together individuals from diverse geographical locations (Keeney et al., 2001).
- The organisation of face-to-face meetings or video conferencing was impractical, considering cost, time and logistical factors.

4.6 Methods for this study

Recommendations by Diamond et al. (2014) for what to report in Delphi studies were used to report the methods and results of this study. The overall methodological criteria they recommend included clear study objectives, description of the participants and comprehensive details pertaining to the Delphi processes and results.

4.6.1 Study design

A “modified” Delphi approach (McKenna, 1994) was undertaken, with findings from the systematic review (Chapter 2) and content analysis of the CRAMMS intervention (Chapter 3) integrated. These informed the development of the initial list of reporting statements for the questionnaire used in the first round of the study. Three rounds were planned a priori, to minimise issues with retention and low response rates that are common in Delphi studies with many rounds (Keeney et al., 2001). Additionally, as the objective of this study was to prioritize reporting statements, three rounds were adequate (i.e., any reporting statements that did not reach consensus in its

importance was assumed not to be important, compared to other statements). This modified approach, therefore, met the research aims.

Basing the statements for round one the results of the systematic review was an acceptable and common modification of the Delphi process (Hsu and Sandford, 2007, Moher et al., 2010). This approach had been previously used in the development of other reporting guidelines (Phillips et al., 2014, Slade et al., 2016) and was recommended as the first step to developing reporting guidelines (Moher et al., 2010). The addition of findings of the content analysis of the CRAMMS intervention provided an additional, unique perspective. Consequently, the initial statements were not only grounded on what was reported in the literature but also on what *actually* took place in a cognitive rehabilitation programme for people with MS.

4.6.2 Ethical approval

This study was reviewed and approved by the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee (FMHS ref no: 92-1707) (Appendix 16).

4.6.3 Recruitment of the expert panel

4.6.3.1 Definition of expert

A maximum variation purposive sampling method, appropriate for recruiting participants for consensus groups (List, 2004), was used to select a multi-disciplinary group of participants. This is a non-probability sampling technique, whereby individuals are selected based on their assumed knowledge on the topic (Hasson et al., 2000, Palinkas et al., 2015).

Experts for this study were defined as clinicians and researchers who had knowledge and practical experience of delivering cognitive rehabilitation to people with MS and had the time and willingness to participate in the study. The debates surrounding the use of the word 'expert' in Delphi studies, and how this influences the identification of participants, were acknowledged (Keeney et al., 2001, Trevelyan and Robinson, 2015).

A heterogeneous group of individuals who delivered cognitive rehabilitation was considered appropriate to allow for different perspectives to be explored (Keeney et al., 2001). The experts invited to take part in this study were:

1) Clinicians (i.e., clinical psychologists, neuropsychologists, MS nurses, occupational therapists, physiotherapists and rehabilitation physicians) who delivered cognitive rehabilitation for people MS. They were asked to participate in the consensus to determine what they would need to be reported in trials of cognitive rehabilitation to enable them to deliver the trial intervention in clinical practice.
2) Researchers conducting research in cognitive rehabilitation for people with MS, who also delivered cognitive rehabilitation to people with MS. They were invited to identify what details they considered necessary for papers to report, in order to replicate the intervention in other studies as well as deliver that intervention to people with MS.

4.6.3.2 Sample size and sampling frame

There were no clear recommendations regarding the sample size for Delphi studies. In a systematic review that examined the reporting of Delphi study processes, sample sizes ranged from less than 10 to over 100 participants (Diamond et al., 2014). In Delphi studies, sample size calculations are largely dependent on the desired

composition of the group, that is, homogenous or heterogeneous (Murphy et al., 1998). In the current study, the clinicians and researchers formed a homogenous group on the basis they all had knowledge of cognitive issues in MS and cognitive rehabilitation. Murphy et al. (1998) suggested that for homogeneous groups a sample of between six and twelve participants was sufficient to maintain the reliability of the process. A minimum of ten participants was recommended (Okoli and Pawlowski, 2004), with larger samples not necessary to preserve the reliability of the Delphi consensus process (Jones and Hunter, 1995, Murphy et al., 1998). In light of this, the aim was to ensure 10 to 15 participants, representing different professionals, completed all three rounds of the study. Thus, the aim was to recruit up to 20 experts, to take into account attrition between rounds, which has been reported to be between 30-50% (Boutron et al., 2005, Phillips et al., 2014, Shariff, 2015, Slade et al., 2016). The sampling frame is presented in Table 21. Clinical Psychologists and Occupational Therapists were oversampled as they were the clinicians who predominantly delivered cognitive rehabilitation to people with MS.

Table 21 Sampling Frame – Profession and number of experts who were to be recruited into the study

Clinical background	**Clinicians who delivered cognitive rehabilitation to people with MS**	**Researchers who delivered cognitive rehabilitation**
Clinical Psychologist	3	3
MS Nurse Specialist	2	2
Occupational Therapist	3	3
Physiotherapist	1	1
Rehabilitation Physicians	1	1

4.6.3.3 Identification and recruitment of the expert panel

Experts were identified as providing cognitive rehabilitation through the MS Society website and local clinicians' knowledge. Corresponding authors of studies included in the systematic review were also invited. Potential modified Delphi participants' contact details were accessed via publicly available information, such as NHS websites, the MS Society website, and researcher contact details found in published papers.

After identification of the experts from each of the professional groups, formal invitations to participate were sent via email. A Participant Information Sheet was also included (Appendix 17).

Those who did not respond to the initial invitation were emailed again seven days after the initial invitation. If they did not respond the second time, another expert from the same or similar professional background was selected and invited. The same procedure was followed until the required sample was achieved.

Experts were asked to confirm they were involved in the delivery of cognitive rehabilitation to people with MS when they responded to the initial invitation email. Experts were asked to respond to the invitation to take part in the study and to return the questionnaires. Completion and subsequent return of questionnaires was taken as informed consent. Return of completed questionnaires also inferred as consent for the use of anonymised data and non-identifiable data in the analysis and any publications as detailed in the participant information sheet.

The experts were informed their responses would remain confidential within the PhD research group. Participants were provided with ways to contact the researcher directly (email and telephone), should they need clarification on any aspect of the

research process before completing the questionnaires. Participants received copies of the findings of the study if they requested this.

Experts were informed that participation in the study was voluntary and that they were free to withdraw at any point without giving a reason. Participants were asked to contact the researcher if they wished to withdraw and were then removed from the list of participants. Participants were made aware (via the information sheet) that should they withdraw the data collected up to that point could not be erased and may still be used in the final analysis.

4.6.4 Development of the initial statements for Round One

The initial list of reporting statements was based on the findings of the systematic review in study one (Chapter 2) and content analysis of the CRAMMS group video sessions in study two (Chapter 3). The aspects of cognitive rehabilitation that were reported in research trials of cognitive interventions from systematic review were grouped into broad categories and sub-categories exemplifying the content of cognitive rehabilitation for people with MS (Table 6, Chapter 2). These items were integrated and consolidated with findings from the content analysis and generated into statements (as opposed to merely describing the aspect of cognitive rehabilitation). The categories from the systematic review were used to organise the initial reporting statements into reporting domains. During this process, checks were conducted to ensure the initial reporting statements were relevant to cognitive rehabilitation (e.g., theory and content) and specifically to MS.

For example, the systematic review found that the key elements of the intervention, including the intended mechanism of action, were often poorly reported. In the content analysis of CRAMMS sessions, there were frequent discussions on the association

between the various external and internal aids to memory and attention processes. Additionally, explanations of how the strategies were intended to improve problems with the processing of memory. The following reporting statements were derived from these findings:

- The theoretical framework used and mechanism of change: describes how the intervention is intended to work by identifying change mechanisms or the underpinning theories of cognitive rehabilitation. For example, whether the intervention is proposed to enable persons to adapt to their cognitive disability, establishing new patterns of cognitive activity or reinforce previously learned patterns of behaviour.
- The cognitive rehabilitation approaches or strategies that underpin the intervention: describes the techniques used to facilitate improvement in cognitive problems. For example, drill and practice exercises to restore cognitive function, and behaviour change to facilitate adaptation.

4.6.5 Modified Delphi procedure

Figure 15 illustrates flow through the study. Participants were involved during the active rounds of the modified Delphi. From recruitment, there were three rounds of the study. To enable efficient and timely data collection from an international pool of participants, the initial questionnaire was circulated to panellists in Microsoft Word format. This format was chosen over other methods such as Bristol Online Survey and Survey Monkey as some organisations block access to these external websites.

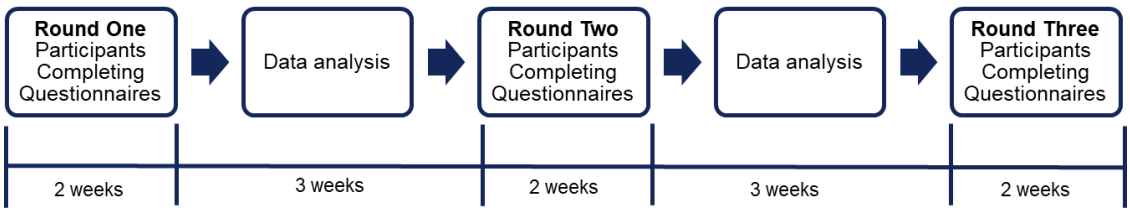


Figure 15 Duration of the study and participant involvement

4.6.5.1 Definition of consensus

The meaning of 'consensus' was defined beforehand to minimise bias (Waters et al., 2014). As there is significant variation in the ways in which consensus has been assessed in the Delphi research literature, a standardized definition does not exist. Measures of consensus have included a specified number of rounds, a certain level of agreement (e.g., between 60 and 90% agreement among participants), cut-offs and descriptive statistics such as the mean or median (Holey et al., 2007, Keeney et al., 2010, von der Gracht, 2012). The use of a predefined level of agreement was considered appropriate as this enabled the consensus among the expert panel to be quantified. Additionally, the level of agreement was argued to be meaningful when Likert scales were used to rate the degree of agreement (von der Gracht, 2012). A threshold of 70% was considered appropriate for this study, as recommended by Keeney et al. (2010). This signified the level of agreement of the importance of a statement for inclusion in the reporting checklist after all three rounds had been completed. The threshold was consistent with other similar research using a modified Delphi technique to develop reporting checklists (Slade et al., 2016).

4.6.5.2 Rating of reporting statements

The initial checklist was circulated to panellists by email, with the document in Microsoft Office Word format. Participants were asked to select one response using the following 4-statement Likert scale: (4) very high importance – essential statement for inclusion in a reporting checklist, (3) high importance – statement likely to require inclusion in a reporting checklist, (2) moderate importance – possible consideration for inclusion in a reporting checklist, (1) low importance – not to be included in a reporting checklist. By not offering a midpoint response, respondents had to decide whether to include or exclude a statement (i.e., a positive or negative evaluation).

Participants were also given the opportunity to add statements and provide comments for each statement in a free text box. Asking experts for comments served to address common limitations of Delphi studies, as highlighted by Avella (2016). First, it provided experts with the opportunity to elaborate on their opinions and ensured they were not constrained from suggesting additional reporting checklists. Second, researcher bias was minimised by ensuring the researcher played a role of facilitator (as opposed to imposing their preconceptions on participants) during the Delphi process (Avella, 2016). Participants were also encouraged to make changes to statements or to indicate whether the given statement should be considered in the first instance.

4.6.5.3 Round one

The initial draft questionnaire for round one was pilot tested to determine the accessibility of the questionnaire and the time taken to complete it. The questionnaire consisted of 38 reporting statements. Attached to this was a sheet requesting demographic information (e.g., professional role, years of experience, country, and organisational affiliation), to enable reporting on the characteristics and level of representativeness of the participants (Appendix 18).

4.6.5.4 Round two

Participants were provided with descriptive feedback (frequencies and percentages) for each statement along with any statements that had achieved consensus. Statements that reached at least 70% consensus in round one were supplied as a summary sheet of statements. This was done to minimise attrition (by reducing the length of the questionnaire) and to manage the number of statements. These were not the most important reporting statements per se, but merely reached consensus at this early stage. Any statements that reached consensus (70% and over agreement)

were not taken forward. Pre-specified criteria were used to retain statements that did not reach consensus in Round one (described in 4.6.5.4). New statements derived from participants' comments in Round one were also added to the Round two questionnaire. All statements were presented in a different order in the Round two questionnaire. Participants were asked to rate each statement using the 4-statement Likert scale as in Round one. Participants, therefore, had the option of revising their own judgments/opinions in light of others' opinions. However, they did not have to do so. After completing the rating exercise, participants again had the opportunity to provide further statements.

4.6.5.5 Round three

The procedure for Round two was repeated in Round three.

There was one reminder following each Delphi round, which was sent seven days after the questionnaire was first sent. Participants were provided with a further seven days to respond, and the Delphi round closed 14 days after the initial questionnaire was sent.

4.6.6 Between rounds data analysis

A study advisory group consisting of the researchers and a Public and Patient Involvement (PPI) member met after each round was completed to discuss the study's progress and interpretation of the findings.

The total number of completed questionnaires (number of participants) was recorded. Both quantitative and qualitative data were generated from each round.

4.6.6.1 Quantitative data analysis

The rating for each statement for respondent was recorded on a spreadsheet and exported to SPSS version 22 for analysis. As the data generated were ordinal, descriptive statistics (percentage agreement, frequency of responses for the total number of respondents for that round) were calculated for each statement.

Statements that achieved a consensus level of less than 50% were excluded from the questionnaire in the subsequent round.

At the completion of the third round, all statements were described as either: 1) The statement met consensus for inclusion in the reporting checklist or 2) The statement did not achieve consensus, which suggested it should not be included in the reporting checklist.

4.6.6.2 Qualitative data analysis

Participants' free text comments/opinions from each round were analysed using content analysis. This was to identify categories (i.e., reporting domains) within experts' responses, and to collapse or combine these into additional reporting statements in the next round, if appropriate (Keeney et al., 2010).

After each round, the researcher (under the guidance of the advisory group) provided an anonymised summary of the experts' opinions from the previous round. For each statement, this included a summary of the ratings (i.e., proportions) for each response as selected by other respondents. Additionally, a questionnaire consisting of revised statements and additional statements, and statements where consensus was not achieved were sent to participants in the next round, with the wording modified.

4.6.6.3 Criteria for retaining statements following round one and round two

Statements that reached consensus (i.e., a level of agreement of at least 70% for the rating 'essential for inclusion in a reporting checklist') were removed from the questionnaire. Statements that had a level of agreement of between 50% and 69% for the rating 'very high importance – essential statement for inclusion in a reporting checklist' were retained for the next round, either as they were or amended based on experts' feedback. Statements not meeting this criterion (i.e., received a response of less than 50%) were carefully examined and discussed during the advisory group meetings, with comments from participants carefully considered and discussed focusing on the key aspects of descriptions of the content of cognitive rehabilitation and what a clinician would need to know. Any statements not meeting these criteria were excluded from the questionnaire. The objective was to develop a reporting checklist that captured the essential elements to be reported, but that was not overly long and onerous to adhere to for researchers. Participants were encouraged to read the feedback before responding again to the statements.

4.6.6.4 Criteria for checklist development

At the final stage of checklist development, statements were filtered based on the level of agreement they had achieved in the rounds. Statements with at least 80% level of agreement were ranked using their means (level of importance) (Keeney et al., 2010). This formed the priority list of reporting statements. Those statements that had achieved between 70% and 79% level agreement were also ranked by their means and comprised the list of reporting items that needed to be reported once those in the priority list had been included. This procedure was chosen to ensure the reporting statements that achieved the highest level of agreement (highest

percentage) and the highest level of importance (highest mean rating) were prioritised in the final reporting checklist.

The modified Delphi process does not require assessment of test-retest reliability, as it is expected that experts will change their responses between rounds, based on group feedback (Okoli and Pawlowski, 2004). In this study, construct validation occurred through the advisory group's interpretation of the findings from rounds one to three, and the initial draft reporting checklist was sent to some of the Delphi panellists to check the content (interpretation) and formatting of the developed checklist.

4.7 Results

4.7.1 Participant recruitment and response rate

The initial uptake for the Delphi study was 45%, with 18 out of the 40 experts who were invited to participate accepting the invitation (Figure 16). Of these 18 participants, four withdrew over the course of the study. Response rates were 100% (n=18) in round one, 83% (n=15) in round two and 78% (n=14) in round three. Fourteen participants responded to all three rounds. The study was completed within five months.

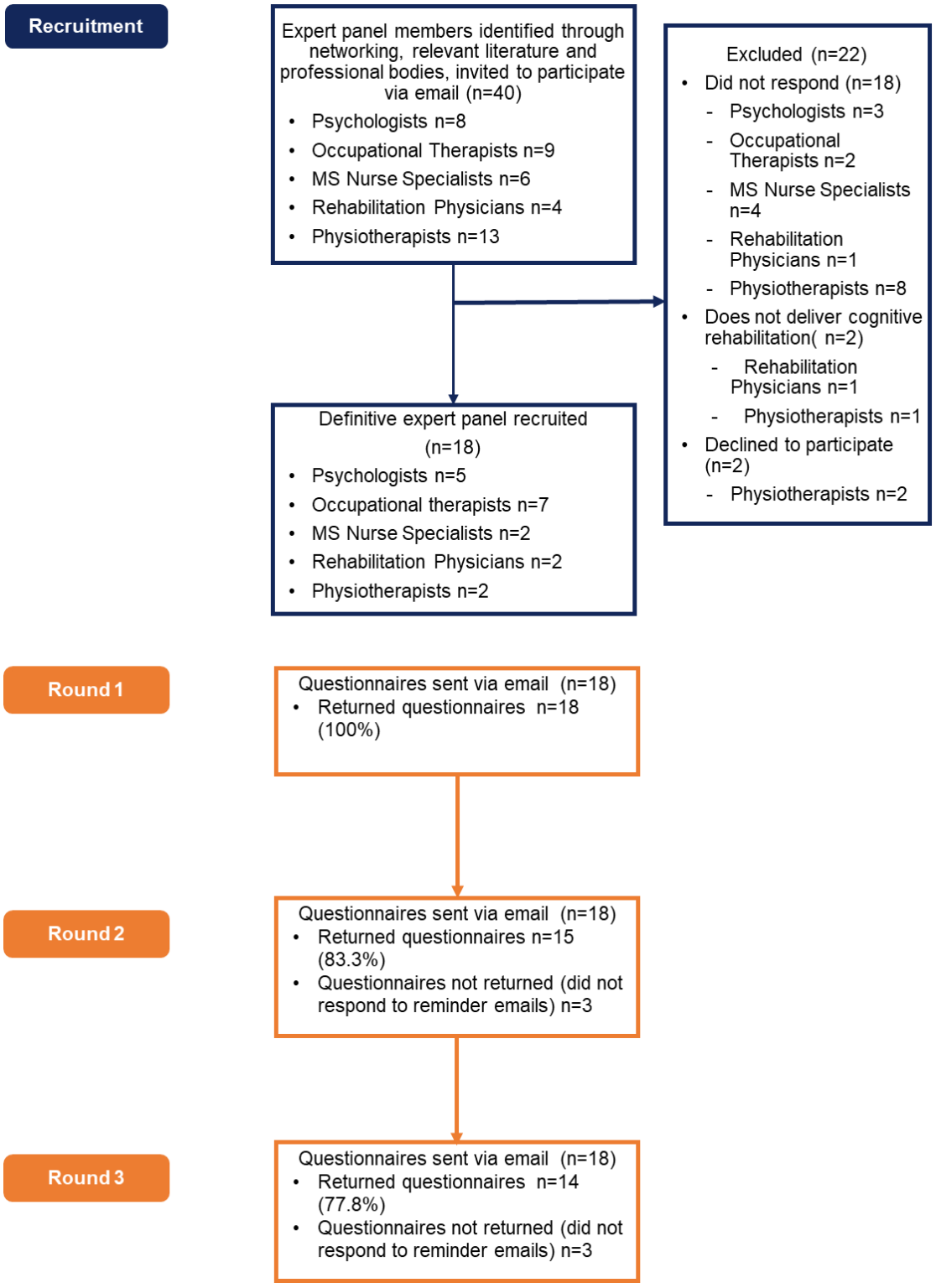


Figure 16 Flowchart of Delphi study recruitment and data collection

4.7.2 Expert panel participant characteristics

The majority of experts were occupational therapists (33%). The median length of experience in delivering cognitive rehabilitation was 15 years. Half of the experts delivered cognitive rehabilitation to people with MS in hospitals or secondary care settings, with the majority (55%) located in the United Kingdom (See Table 22).

Table 22 Characteristics of 18 Delphi participants from Round one

Characteristic	**n[1]**	**%[2]**
Occupation		
Occupational therapist	6	33
MS nurse specialist	2	11
Neuropsychologist	2	11
Clinical psychologist and neuropsychologist	2	11
Physiotherapist	2	11
Rehabilitation physician	2	11
Researcher who also delivered cognitive rehabilitation	1	6
Other	1	6
Length of experience in delivering cognitive rehabilitation to people with MS (yrs)		
Median (IQR)	15.00 (5.88-20.00)	
Range	0* - 32	
Organisation where experts deliver cognitive rehabilitation to people with MS		
Hospital or secondary care	9	50
University or research setting	6	33
Community service	2	11
Charity or third sector	1	6
Setting where experts deliver cognitive rehabilitation to people with MS		
Public or government	15	83
Other	3	17
Location of experts' clinical practice		
UK	10	55
Australia	3	16
Malaysia	2	11
Finland	1	6
The Netherlands	1	6
USA	1	6

*Experience delivering cognitive rehabilitation under 1 year; n^1 = number of experts, $\%^2$ = percentage of experts

4.7.3 Summary of rounds

Eight reporting domains were presented in the round one questionnaire. These domains were identified from the suggested items to include in the checklist, based on findings from systematic review presented in Table 6 (Chapter 2).

A summary of the results of scoring for each round is presented in Table 23. This provides the following information:

- The total number of reporting statements participants were asked to rate.
- The number of statements that reached consensus (at least 70%) agreement for the rating 'essential statement for inclusion in a reporting checklist'.
- Statements that received 50-69% agreement and were revised and retained for the next round based on experts' comments. Examples are provided in Table 24 and Appendix 20.
- Statements that did not reach consensus and were excluded.
- New statements that were generated from experts' comments.

All three rounds of this study served to identify and prioritise the reporting domains the expert panel agreed were essential for inclusion in a reporting checklist.

Table 23 Summary of results from all three rounds

Round	One	Two	Three
Total number of statements for rating	38	23	14
Number (%) of statements that reached consensus (≥70%)	10 (26%)	13 (57%)	6 (43%)
Number (%) of statements that reached ≥50% but less than 70% and were amended and retained for the subsequent round	17* (45%)	9 (39%)	7 (50%)‡
Number (%) of statements that did not reach consensus ≥50% but were revised and retained for the subsequent round based on comments	1 (3%)	1 (4%)	n/a
Number (%) of statements that did not reach consensus (≤50%) and were excluded	10 (26%)	0	1 (7%)
Number of new statements generated from comments	1	2	n/a
Number (%) of experts who provided comments	11 (61%)	7 (30%)	6 (43%)

*Some of these statements were amended and split into two statements in the following round, based on participants' comments (n=4 in round one, n=5 in round two); ‡Statements could have been considered for amendment if the study had not terminated after round three

Table 24 Example of changes made to a reporting statement that had achieved 50-69% agreement in both round one and round two

Round one Statement	Round one Statement Description	Round two Statement	Round two Statement Description	Comments	Amendments		Justification
					Statement	Statement Description	
Reporting domain: Name of the intervention							
Brief name or acronym	Reports the name of intervention, which includes the target population.	Brief name or acronym	a. The title of the paper reflects the content of the intervention. b. The title of the paper reflects the target population.	Occupational Therapist: Rating of "high importance" for 1a and both 2 and 3 for 1b - I would add abstract because to find the papers in a systematic search free text words are based on what is written in the abstract; Rehab Physician: Rating of "moderate importance" for 1a and 4 for 1b - content of intervention can be in the abstract.	Brief name or acronym	a. The title of the paper reflects the content of the intervention. b. The abstract of the paper reflects the content of the intervention.	Checking whether the issue is with 'target population' or the 'title/abstract'

4.7.4 Summary of the results

A detailed analysis of the outcome of each round is presented in Appendix 19, Appendix 21 and Appendix 22.

4.7.5 Statements achieving consensus for inclusion in the reporting checklist

At the end of round three 29 statements, representing nine reporting domains, achieved at least 70% consensus in rounds one to three (Table 25). Some domains were reworded based on experts' comments in the current study (e.g., to provide clarity) and there was a new reporting domain suggested by experts. The reporting domains were:

- Content of the intervention sessions (n=2)
- Intervention delivery (n=5)
- Intervention materials (n=3)
- Key elements of the intervention (n=4)
- Modifications to the intervention (n=3)
- Name of the intervention (n=1)
- Number of sessions, frequency and duration of the intervention (n=7)
- Participant characteristics (n=3)
- Unintended consequences of the intervention (new reporting domain suggested by the expert panel) (n=1)

The level of agreement (consensus) was between 71.4% and 100%. The level of importance (mean ratings) ranged between 3.40 and 4.00. The statement and descriptor *"The aims of the cognitive rehabilitation - Reports the aim of the intervention, i.e., what it is hypothesised to achieve. For example, to improve function"* received the highest level of importance, with all 18 participants in round one rating it

as essential for inclusion in a reporting checklist (i.e., 100% level of agreement and level of importance of 4). This statement was from the reporting domain ‘key elements of the intervention’.

Table 25 Statements that achieved a rating of at least 70% for 'essential for inclusion in a reporting checklist' in round one to three, grouped by reporting domain

Round	Reporting domain	Statement	Description	No. of respondents who gave this rating/Total no. of respondents	Percentage of respondents who gave 'essential' rating (level of agreement)	Level of importance (mean rating)
Two	Content of the intervention sessions	Details of the session content	The paper describes the content of the sessions, e.g., the topics covered or the theme of the session	12/15	80.0	3.73
Two		Activities for participants outside of the intervention sessions	The paper reports whether the homework is to enable them to try out strategies in their own environment	11/15	73.3	3.6
One	Intervention delivery	How the intervention is delivered – the mode of delivery	Reports whether the intervention is delivered individually or in a group, or a combination of the two.	17/18	94.4	3.94
One		Media used to deliver the intervention	a. Reports whether the intervention is delivered face-to-face, over the telephone, or is computer-based.	13/18	72.2	3.72
One		Media used to deliver the intervention	b. If a mixture, reports which elements are delivered using which formats.	13/18	72.2	3.72
Two		Specific details about delivery of group interventions	The paper reports if the intervention is delivered in a group, reports the mean group size.	12/15	80.0	3.87

Round	Reporting domain	Statement	Description	No. of respondents who gave this rating/Total no. of respondents	Percentage of respondents who gave 'essential' rating (level of agreement)	Level of importance (mean rating)
Three		The setting where the intervention is delivered	The paper describes where the intervention is delivered e.g. at home, a hospital/community setting or a mixed setting	11/14	78.6	3.64
Two	Intervention materials	A manual is used by facilitators to deliver the intervention	The paper reports whether a manual is used to guide the intervention.	12/15	80.0	3.73
Two		Equipment used during intervention delivery	The paper reports whether specific equipment is required to deliver the intervention e.g. a touch-screen computer.	11/15	73.3	3.4
Three		Intervention materials given to participants	The paper reports where the workbook can be obtained	10/14	71.4	3.5
Three	Key elements of the intervention	The theoretical framework used	The paper describes how the intervention is intended to work by identifying the underpinning theories of cognitive rehabilitation. For example: is treatment based on drilling practice i.e. restitution or behaviour change i.e. compensation	11/14	78.6	3.79

Round	Reporting domain	Statement	Description	No. of respondents who gave this rating/Total no. of respondents	Percentage of respondents who gave 'essential' rating (level of agreement)	Level of importance (mean rating)
One		The aims of the cognitive rehabilitation	Reports the aim of the intervention, i.e., what it is hypothesised to achieve. For example, to improve function.	18/18	100.0	4
One		The cognitive rehabilitation approaches or strategies that underpin the intervention	Describes the techniques used to facilitate improvement in cognitive problems. For example, to restore cognitive function, the use compensatory strategies and devices, and environmental modifications.	14/18	77.8	3.78
One		The essential elements of the intervention	Reports on what are considered to be the most important elements of the intervention i.e. the 'active ingredients	14/18	77.8	3.72
One	Modifications to the intervention	The intervention is tailored to the individual	Reports whether the intervention is tailored to individual need, e.g., whether cognitive rehabilitation is based on results of assessment of cognitive deficit (e.g., objective test and/or self-report).	13/18	72.2	3.72
Two		The same intervention is	The paper reports whether the same intervention is delivered to all participants	11/15	73.3	3.73

Round	Reporting domain	Statement	Description	No. of respondents who gave this rating/Total no. of respondents	Percentage of respondents who gave 'essential' rating (level of agreement)	Level of importance (mean rating)
		delivered to all participants				
Two		Any modifications made to the intervention as described in the protocol	The paper reports whether any changes to the intervention have been made that deviate from the protocol.	12/15	80.0	3.53
Three	Name of the intervention	Brief name or acronym	The abstract of the paper reflects the content of the intervention	12/14	85.7	3.86
Two	Number of sessions, frequency and duration of the intervention	The total number of intervention sessions	The paper reports descriptive statistics to underpin the total number of intervention sessions such as mean (standard deviation), median (interquartile range).	13/15	86.7	3.87
Two		The duration of the intervention	The paper reports descriptive statistics to underpin the duration of the intervention such as mean (standard deviation), median (interquartile range)	12/15	80.0	3.6
Two		The length of individual	a. The paper reports the amount of time it takes to deliver the intervention.	11/15	73.3	3.6

Round	Reporting domain	Statement	Description	No. of respondents who gave this rating/Total no. of respondents	Percentage of respondents who gave 'essential' rating (level of agreement)	Level of importance (mean rating)
Two		intervention sessions	b. Reports the actual length of intervention content sessions e.g., "It takes approximately 1.5h per session".	11/15	73.3	3.67
One		The duration of the intervention	Reports the time period over which the intervention is delivered including the actual duration of the intervention, e.g., "The intervention lasted 10 weeks".	15/18	83.3	3.83
One		The total number of intervention sessions	Reports how many sessions of the intervention were delivered including the actual number of sessions, e.g., "The intervention had 8 sessions".	15/18	83.3	3.83
One		The frequency of intervention sessions	Reports how often were the sessions delivered including the actual frequency of sessions, e.g., "Sessions were held weekly".	14/18	77.8	3.78
Two	Participant characteristics	The intervention is to be delivered with respect to specific clinical presentations	The paper reports whether the intervention needs to be delivered with respect to specific clinical presentations. For example, cognitive profile and functional performance in everyday life skills	13/15	86.7	3.87

Round	Reporting domain	Statement	Description	No. of respondents who gave this rating/Total no. of respondents	Percentage of respondents who gave 'essential' rating (level of agreement)	Level of importance (mean rating)
Three		The demographic characteristics of the participants	The paper provides details of the demographic characteristics of the participants. For example: age, gender, ethnicity	10/14	71.4	3.64
Two		Age of the participants	The paper reports the average age of the sample	12/15	80.0	3.67
Three	Unintended consequences of the intervention	Possible harm caused by the intervention	The paper reports whether there were any unintended negative consequences of delivering the intervention	10/14	71.4	3.57

4.7.6 Statements excluded from the reporting checklist

Eleven statements were removed from all three rounds, as they did not meet the predefined threshold for consensus and/or through the content analysis of the free text comments (Table 26). The level of agreement for these statements ranged from 22.2% to 44.4% and the level of importance (mean rating) ranged between 3.00 and 3.33. The excluded statements represented the following reporting domains:

- Participant characteristics (n=1)
- Content of the intervention (n=2)
- Number of sessions, frequency and duration of the intervention (n=2)
- Intervention materials (n=1)
- Facilitator attributes (n=4)

All reporting statements pertaining to facilitator attributes (e.g., the professional background of the person who delivers the intervention) were excluded from the following round as they achieved less than 50% agreement (range 22.2% to 38.9% agreement). A further seven statements had between 50% to 69% agreement in round three and did not meet the threshold for inclusion in a reporting checklist.

Table 26 Reporting statements excluded (>50% level of agreement for 'essential' rating)

Round statement was excluded	Reporting domain	Statement	Statement description	Percentage of participants who gave this rating (level of agreement)	Mean rating (level of importance)
One	Participant characteristics	Type of MS Diagnosis	Reports MS diagnosis targeted by the intervention, if applicable.	44.4	3.17
One		Time since diagnosis of MS	Reports min, max (range) since the people with MS were first diagnosed, if applicable.	44.4	3.22
One	Content of the intervention	Management of missed sessions	How 'missed' sessions are managed, e.g., whether 'catch-up' sessions are offered.	22.2	3.0
Three		How the sessions are structured	The paper describes the sequence of events in each session. For example: welcome, recap of the previous session, overview of the topic, setting homework topics and summary	42.9	3.29
One	Number of sessions, frequency and duration of the intervention	The length of individual intervention sessions	Reports descriptive statistics such as mean (standard deviation), median (interquartile range).	33.3	3.33
One		The frequency of intervention sessions	Reports descriptive statistics, e.g., mean (standard deviation), median (interquartile range).	38.9	3.28

Round statement was excluded	Reporting domain	Statement	Statement description	Percentage of participants who gave this rating (level of agreement)	Mean rating (level of importance)
One	Intervention materials	Materials given to participants	Reports whether information is provided as to how clinicians can access the manual.	38.9	3.29
One	Facilitator attributes	The professional background of the person who delivers the intervention	Reports the professional background of the intervention facilitators, e.g., psychologist, nurse, occupational therapist.	33.3	3.28
One		The level of professional training of the person delivering the intervention	Reports the level of professional training of the facilitators, e.g., assistant psychologist, nurse specialist, Band 7 occupational therapist, board certified, etc.	27.8	3.06
One		The person delivering the intervention has attained key competencies	Reports how the facilitators' delivery competence was assessed and/or monitored.	22.2	3.00
One		The number of facilitators who deliver the intervention	Reports the number of facilitators needed to deliver the intervention, e.g. minimum required.	38.9	3.11

4.7.7 Expert justifications and comments: results of content analysis of the experts' comments

There was no apparent association between the number of experts' comments, the rating of importance or the level of agreement for the reporting statements. For descriptive purposes, the experts' comments were consolidated into four categories (see Table 27):

- The comment reinforced the experts' rating of the reporting statement
- The comment provided to clarify a reporting statement (e.g., wording)
- The comment used to describe the importance of the reporting statement for implementation and/or replication of cognitive rehabilitation.
- The suggestion of an additional reporting statement and/or reporting domain.

Eleven (61%) participants provided comments in round one, either alongside individual statements (14 comments) or at the end of the questionnaire (four comments). Seventeen comments were made regarding suggestions for additional reporting criteria. The majority of the statement-specific comments were for the reporting domain 'participant characteristics'. No comments were given for the reporting domain 'intervention delivery', 'number of sessions, frequency and duration of the intervention' and 'facilitator attributes'. Comments for statements in the reporting domain 'participant characteristics' resulted in the amendment of two statements and a new statement in round two. Content analysis of the additional reporting criteria showed that the reporting domain 'characteristics of the participants' (n=8 comments) generated the most comments, followed by a new domain 'outcomes of the intervention' (n=4 comments). The advisory group met to discuss the comments and their relevance to descriptions of the *content* of cognitive rehabilitation. Out of the 17 suggested reporting statements proposed by experts, eight (47%) did not meet the

criteria. Eight suggestions led to the amendment of existing statements and one comment resulted in an additional reporting statement.

Table 27 Summary of number and type of comments provided by Delphi participants for the different reporting domains

Reporting domain	**Number of comments made by experts, by type of comment**			
	Reinforcing rating	**Clarify statement**	**Relevance to implementation of cognitive rehabilitation**	**Suggested additional reporting statement**
Name of the intervention	3	2		
Participant characteristics	6	1	3	12
Key elements of the intervention	4	1	2	2
Content of the intervention	1	5	6	
Intervention delivery	1	3	5	1
Number of sessions, frequency and duration of the intervention	3		4	1
Intervention materials	5	1		
Modifications to the intervention	2		2	2
Facilitator attributes				1
Unintended consequences of the intervention	2			1

Other reporting domains suggested: funding (n=1), patient perspectives of cognitive rehabilitation (n=1)

Seven (47%) of the 15 participants provided comments in round two. All reporting domains received comments in this round. The majority of the statement-specific comments were for the reporting domain'. Comments for statements resulted in the amendment of nine statements in round two. The content analysis of the additional reporting criteria showed that the reporting domain 'characteristics of the participants' generated the most comments. The advisory group met to discuss the comments and their relevance to descriptions of the *content* of cognitive rehabilitation. Of the four suggested reporting criteria, three (75%) met this criterion. Two suggestions led to the addition of two reporting statements to the round three questionnaire. These were 'unintended consequences of the intervention' and 'the intervention is tailored to the individual'.

Six (43%) of the 14 participants provided comments in round three, either alongside individual statements or at the end of the questionnaire. All reporting domains received comments, with the majority of the statement-specific comments related to the reporting domain 'content of the intervention'. The advisory group met to discuss the comments and their relevance to descriptions of the *content* of cognitive rehabilitation. Of the four suggested additional reporting criteria, three (75%) had been included in earlier rounds and had achieved consensus. One suggested additional reporting criteria 'facilitator attributes' had been included in round one, receiving less than 50% agreement on the rating of 'very high importance'. The reporting domain was excluded from the round two questionnaire.

Examples of the content analysis of the participant comments (e.g., suggested additional reporting statements) are presented in Appendix 20.

4.7.8 Changes in experts' ratings based on feedback of the group's responses

Regarding how participants rated statements with respect to the feedback they received between rounds and in the specific questionnaires, 13 out of 21 (62%) in round one and 5 out of 12 (42%) in round two went on to achieve consensus in the following round. This signified an increase in the percentage of respondents rating the statement as 'high importance' to 'very high importance – essential for inclusion in a reporting checklist.' The average change in percentage increase was 13.3%.

4.7.9 Development of the cognitive rehabilitation in MS reporting checklist

Out of the 29 reporting statements that met the threshold for consensus, 13 (45%) statements, representing eight reporting domains had an agreement level of at least 80% (Table 25). The mean (i.e., level of importance) of these statements ranged between 3.53 and 4.00. The 16 statements with a level of agreement of between 70% and 79% also represented eight reporting domains and had a mean level of importance ranging from 3.40 to 3.79.

The advisory group met to discuss the statements that had reached consensus. The wording of reporting domains, statements, and their descriptions were amended for clarification, to reduce ambiguity on the meaning of descriptions, keeping the substance as agreed through the Delphi process. The reporting domains were constructed in an order that aimed to reflect the processes involved in describing research studies (i.e., commencing with the name of the intervention and ending with unintended consequences). The draft checklist was sent to a small number of experts from the panel who had responded in all three rounds of the study for sense checking, agreement of the phrasing and format of the reporting checklist. The experts were

advised that any suggestions for amendment needed to maintain the *substance* of the reporting statements, as agreed through the Delphi process. One rehabilitation physician, two clinical psychologists (one clinician and one researcher/clinician) and one occupational therapist provided comments on the final checklist.

The overall feedback from the selected experts was that the checklist provided a clear and comprehensive picture of what is essential and what is important to report in published papers. It will be a useful tool for publishing cognitive rehabilitation studies for people with MS. One expert suggested that, due to to the limitations in the number of words allowed in different journals, aspects of the content of cognitive rehabilation could be reported in an appendix. Another expert commented on the distinction made between reporting statements labelled 'essential' and 'desirable'. The expert identified the importance of emphasizing that the statments in the 'desirable' list were essentail for implementation of cognitive rehabilitation. On the basis of this feedback, the list of reporting statments was relabelled as *'Priority 1*' and *'Priority 2'* statments. The latter group was to be reported once those in the *Priory 1* list had been included in the study write-up. The final reporting checklist is presented in Appendix 23.

Table 28 presents an example of the application of the reporting checklist developed in this study, using the CRAMMS intervention (Chapter 3) as an example.

Table 28 Description of the CRAMMS intervention using the checklist for cognitive rehabilitation in multiple sclerosis

Table 1 of Priority reporting statements		
Statement	**Statement description**	**Descriptive text**
Reporting domain: Name		
Intervention name stated in the abstract	Abstract of the paper reports the content/focus of the intervention	CRAMMS (cognitive rehabilitation for memory and attention in MS)
Reporting domain: Aims		
Aims of the cognitive rehabilitation	Report the aim of the intervention (i.e., what it is hypothesised to achieve, e.g., to improve function by reducing the cognitive, emotional, behavioural and psychosocial issues as a consequence of MS)	Cognitive rehabilitation encompasses a structured set of therapeutic activities designed to retrain memory and attention for people with MS who experience problems in these cognitive area. This is to help improve function in these cognitive areas, as well as help them cope better with their memory and attention problems.
Reporting domain: Content		
Details of the session content	Describe the content of the sessions (e.g., the topics covered or the theme of the session)	The topics covered in each session were as follows: Session 1 – introduction to the intervention Session 2 – introduction to memory and memory process Session 3 to 4 – introduction to attention and restitution (drill and practice) Session 5 to 7 - internal memory aids e.g., rehearsal and visualisation

Table 1 of Priority reporting statements		
Statement	**Statement description**	**Descriptive text**
		Sessions 8 to 9 – presentation of external memory aids and effective use of these Session 10 – review of the programme
Reporting domain: Delivery		
Format of intervention delivery	Report whether the intervention is delivered individually or in a group, or a combination of the two	The intervention was delivered in a group format.
	If the intervention is delivered in a group, report the mean group size	The mean treatment group size (allocated at randomisation) was 5.4.
Reporting domain: Timeframe		
Number of intervention sessions	Report descriptive statistics to underpin the total number of intervention sessions participants received, such as mean (standard deviation), median (interquartile range)	The mean number of participants attended was 7.7 (SD=3.5), including catch-up sessions and 7.0 (SD=3.4) excluding catch up sessions.
	Report how many sessions of the intervention were delivered including the actual number of sessions (e.g., “The intervention had 8 sessions”)	The intervention comprised of 10 sessions.
Reporting domain: Target population		

Table 1 of Priority reporting statements		
Statement	**Statement description**	**Descriptive text**
Intervention to be delivered with respect to specific clinical presentations	Report whether the intervention needs to be delivered with respect to specific clinical presentations (e.g., cognitive profile and functional performance in everyday life skills)	*Reported cognitive problems* - as determined by a cut-off score of >27 on the patient version of the Multiple Sclerosis Neuropsychological Screening Questionnaire (MSNQ) (Benedict et al., 2003). The cut-off was based on the original validation study by Benedict et al. (2003) with 50 participants with MS. The cut-off was used to identify those with cognitive impairment on a neuropsychological test battery. *Cognitive deficits* - BRBN scoring not more than one standard deviation below the mean of healthy controls, corrected for age and years of education
Age of the participants	Report the average age	Mean age at randomisation: control group 48.9 years (SD=10), intervention group (cognitive rehabilitation) 48.9 years (SD=9.8)

4.8 Discussion

4.8.1 Summary of findings

This modified Delphi aimed to develop a reporting checklist for cognitive rehabilitation in MS, based on evidence and informed by clinicians. By identifying and prioritising the aspects of cognitive rehabilitation for people with MS that clinicians who deliver these programmes need to see reported in research studies, this may facilitate the implementation of these interventions in clinical practice.

This modified Delphi study achieved all its objectives. The response rate was high, with 14 (78%) respondents completing all three rounds of the study. The expert panel was representative of key stakeholders in the delivery of cognitive rehabilitation. The final number of experts fell within the minimum of ten participants recommended for Delphi studies (Jones and Hunter, 1995, Murphy et al., 1998, Okoli and Pawlowski, 2004). For example in their systematic review of 100 studies that used the Delphi methods, Diamond et al. (2014) found that the highest proportion of studies (40%) had between 11 and 25 participants in the final round.

The reporting domains that achieved consensus did not seem unexpected for inclusion in a reporting checklist for cognitive rehabilitation in MS. It would be difficult to implement the interventions in practice or replicate them without adequate description of: (1) the name of the intervention, (2) participant characteristics, (3) how interventions are delivered, (4) specific details about the content of sessions, (5) intervention materials, (6) intervention timeframes, (7) modifications made to the intervention and (8) unintended consequences. To some extent these domains had been included in relevant reporting guidelines such as the TIDieR (Hoffmann et al., 2014), the Publication Manual of the American Psychological Association's Journal Article Reporting Standards (JARS) (VandenBos et al., 2010), and the Western

Journal of Nursing Research (Conn, 2012) checklist for the reporting of interventions. These domains had also been suggested in the systematic reviews by Martin et al. (2015) and van Heugten et al. (2012). Moreover, the reporting domains aligned with essential intervention characteristics that should be described to aid replication and implementation that were recommended by Schulz et al. (2010).

A comparison of previously developed reporting guidelines and checklists and the one developed in this study is provided in Appendix 24. The most significant difference between the reporting statements in the checklist developed in this study and previous checklists is the degree of *specificity* to cognitive rehabilitation interventions and to neurological conditions such as MS. For example, the theoretical framework (drill and practice or behaviour change) and approaches to cognitive rehabilitation (restitution or compensation strategies) are included in the current checklist. These were not specified in the existing reporting checklists.

One difference observed between these guidelines and the reporting domains suggested in this study was the exclusion of the facilitator attributes category. Reporting statements in this category did not achieve the minimum level of consensus, suggesting these were not essential to facilitate replication or implementation of cognitive rehabilitation in MS. However, it is important to acknowledge the context-dependent differences in who delivers cognitive rehabilitation. For example, variations in clinical pathways and access to specialist cognitive rehabilitation across the UK were observed in the survey conducted by Klein et al. (2018). Larger team size (consisting of a range of health professional) and the receipt of post-registration training was found to correlate with greater confidence clinicians expressed in managing cognitive problems in MS (Klein et al., 2018). However, by providing aspects of cognitive rehabilitation identified as most important for implementation and replication in this study, the aim is that this will allow clinicians

to make informed decisions on whether these interventions are appropriate for their patients, the setting and self-assessed expertise (or knowledge) they have to deliver these interventions.

Another difference was the omission of 'mechanism of action' (or moderating variables within the intervention that affected desired outcomes) from the included reported statements in this study. This differed from items included in both the TIDieR (Hoffmann et al., 2014), the JARS reporting standards (VandenBos et al., 2010) (VandenBos et al., 2010)and the Western Journal of Nursing Research checklist (Conn, 2012). The opinions of the expert panel for this statement were split 50-50 between 'essential' and 'high importance'. Comments from the expert panel suggested that although a proposed mechanism of action should always be included, in practice the 'exact' mechanism was often unknown. The implication is that reporting of mechanisms of actions could potentially be based on assumptions and not precisely how the aspects of the cognitive rehabilitation had an effect on desired outcomes.

An interesting finding was, whereas there was unequivocal agreement that the aims of the cognitive rehabilitation should be included in the reporting checklist (i.e., all experts rated this statement as 'essential'), there were differences in the opinions regarding other statements in the 'key elements of the intervention' reporting domain. These included the theoretical framework used, the cognitive rehabilitation strategies underpinning the intervention and the essential, or 'active ingredients' of the intervention. Experts commented that as remediation or compensatory effect was sometimes difficult to distinguish clinically, they appreciated that it might be difficult for researchers to report with certainty the theoretical framework underpinning the cognitive rehabilitation programme. This finding was consistent with Candy et al.'s (2018) assertion that the complexity of cognitive rehabilitation and researchers' lack

of clarity on the minutiae of the intervention could lead to an oversimplification of descriptions.

As noted in the data extraction process of the systematic review (Chapter 2, section 2.7.3) the discrepancies in coding using the different checklist items were attributed to whether or not item descriptions were provided, and if so, how detailed this information was. The reporting checklist developed in this study addresses these issues by providing clear descriptions for each statement, including examples. Instructions accompanying the checklist make it clear that all reporting statements (in both tables) should be reported. This was a limitation of the Western Journal of Nursing reporting guidelines (Conn, 2012). This guideline advised, "not all items will be relevant for all interventions". The ambiguity of which items were most *important* and *relevant* for reporting could lead to further incomplete reporting, as researchers 'choose' what to report (also taking into account journal word limits). Another advantage of the developed reporting checklist is that it utilises wording that is specific to the principles of cognitive rehabilitation, specific to MS, but can also be generalised to other neurological conditions. For example, the replacement of the word 'dose' (medical model), and specifying the cognitive rehabilitation techniques such as restitution, compensation, and environmental modifications.

4.8.2 Limitations and strengths

4.8.2.1 Limitations

The initial reporting checklist for round one was developed based on the findings of the systematic review (Chapter 2) and content analysis of a cognitive rehabilitation intervention (Chapter 3) through the identification of reporting items that were considered to relate to descriptions of the *content* of cognitive rehabilitation. Bias may

have been introduced to this modified Delphi through the selection of these reporting items. However, this was ameliorated in the following ways:

- Experts were encouraged to provide comments on the reporting statements presented in round one and subsequent rounds and propose additional reporting statements. A large proportion of experts commented in round one (61%). Subsequently, new reporting statements were incorporated, and existing statements amended on the basis of this feedback.
- The advisory group (consisting of the researcher, the supervisory team and a PPI member) met to discuss the findings of each round and to interpret the synthesis of experts' comments. This ensured the decision to incorporate or exclude experts' feedback was not made by one individual.

Moreover, only 26% of reporting statements in round one, based solely on the findings of the systematic review and the content analysis, met the criteria for inclusion in the final reporting checklist.

The findings of this study were influenced by the perspectives of the researcher, the advisory group and the experts, who were clinicians and researchers who delivered cognitive rehabilitation to people with MS. Consequently, this formed a heterogeneous group, representing a broad spectrum of geographical location, experience, knowledge, and opinion of cognitive rehabilitation for people with MS. Furthermore, this group was seen to reflect the key characteristics of the individuals who would be influenced by the standard of reporting of cognitive rehabilitation and its implementation in practice. Although this is a strength of the research, it is important to interpret the results and the content of the final reporting checklist as the majority opinion and belief and within the context of the composition of the expert panel (Murphy et al., 1998, von der Gracht, 2012). That is, mostly neuro- and clinical psychologists and occupational therapists who delivered cognitive rehabilitation to

people with MS, had a median of 15 years' experience and were predominantly from the UK.

4.8.2.2 Strengths

A strength of the conduct and reporting of this study was that it aligned with Diamond et al.'s (2014) quality indicators for Delphi studies. For example, the study objectives, the sampling of participants, definitions of consensus and the maximum number of rounds were stated a priori and reported in this chapter. The low attrition rate observed in this study ensured that the original sampling frame was maintained. Therefore, consensus for the final reporting checklist statements was based upon the proportions of clinicians who ordinarily deliver cognitive rehabilitation in practice (more likely to be neuro- and clinical psychologists and occupational therapists in the UK). Additionally, as the initial list of reporting statements were grounded on cognitive rehabilitation theory (i.e., what had been reported in the literature and what occurred during treatment sessions of the CRAMMS trial), this minimised the occurrence of ambiguous statements that were not relevant to cognitive rehabilitation. This was one of the pitfalls of conducting Delphi studies that Stevenson (2010) and Dijkers (2015) had identified.

4.8.3 Conclusions and implications

This modified Delphi study completed the second stage in the development process for the reporting checklist for cognitive rehabilitation in MS. The systematic review (Chapter 2) and content analysis of the CRAMMS intervention session (Chapter 3) had examined what had been previously reported in published studies, and what *actually* occurred during sessions of cognitive rehabilitation. The findings of this modified Delphi study determined a consensus opinion regarding what clinicians consider as the most important characteristics of cognitive rehabilitation interventions

that would inform the delivery of these programmes. Researchers should ensure these aspects of cognitive rehabilitation are reported completely in published studies. This may increase the clinical uptake of these interventions and reduce the gap between research and implementation.

Chapter 5 Final Discussion

5.1 Chapter overview

This chapter provides the final discussion and conclusions of this research. It brings together the findings from the studies reported in the three previous chapters. It provides a summary and synthesis of the results; discusses the strengths and limitations of the research; provides an interpretation of the findings within the wider research context and discusses the research and clinical implications of the work. Conclusions are proposed and further areas of work are identified.

5.2 Introduction

The research presented in this thesis pertained to the overall aim of exploring avenues to increase the clinical impact of trials of cognitive rehabilitation, through the development of a consensus checklist for the reporting of the content of cognitive interventions for people with MS. The specific aims of this research corresponded to the three studies. In summary, the study-specific aims were:

a) To produce a 'state of the science' systematic review of how cognitive rehabilitation for people with MS was reported in scientific journals (study one, Chapter 2).
b) To complete a detailed analysis of the actual content of a large-scale RCT of cognitive rehabilitation in MS (CRAMMS), to examine what the CRAMMS therapists delivered and what therapists and participants discussed during the treatment sessions (study two, Chapter 3).
c) To reach clinician- and researcher-consensus on the content of cognitive rehabilitation interventions for people with MS that should be reported in the research literature (study three, Chapter 4).

The overarching design of the research was exploratory mixed-methods. The exploratory nature of the research aims and objectives required a combination of

quantitative and qualitative research approaches. An iterative and convergent process was undertaken (Moseholm and Fetters, 2017), with the findings of the first two studies informing the third study.

5.3 Summary of findings from the three studies

The findings of the systematic review in study one indicated there was great variation in the comprehensiveness of descriptions of the content and conduct of the interventions. Intervention details that were reported partially complete related to the intervention 'dose', the active ingredients of the interventions and the mechanisms through which these 'ingredients' influence outcomes. The intervention details that were poorly reported were how the interventions were delivered, details pertaining to the training and monitoring of facilitators and intervention fidelity. There were no discernible differences in the comprehensiveness of reporting intervention details across different papers reporting the same study.

In study two, video-based observation and content analysis of the group-based CRAMMS intervention sessions demonstrated that adherence to the intervention manual content (i.e., intervention fidelity) was very high. That is, the content of the intervention had been delivered as planned. Analysis of the assistant psychologist and participant discussions demonstrated support for a multidimensional approach to cognitive rehabilitation. Participants attributed perceived improvements in their participation in daily activities (i.e., increased function) and greater self-efficacy (self-awareness and self-confidence) to manage their cognitive problems to this multidimensional approach. Analysis of participants' discussions highlighted the perceived psychosocial and therapeutic benefits the group-based format of CRAMMS.

The findings from the systematic review and content analysis were integrated to inform the initial questionnaire in round one of the modified Delphi study (study three). The outcome of this study was the development of a domain-specific reporting checklist for MS. Based on the pre-specified criteria, consensus was achieved for 29 reporting statements. These statements were subsequently grouped according to how the expert panel rated their importance, forming a Priority 1 and 2 list of reporting statements.

Taken together, the findings from the three strands achieved the overall research aim, which was to identify the key aspects of cognitive rehabilitation interventions in MS that need to be reported in scientific papers that would enable implementation in practice and develop a reporting checklist based on these factors.

5.4 Comparison of key findings to other research

The two key themes that emerged from all three strands of the research were: *content* of cognitive rehabilitation and the *delivery* of cognitive rehabilitation in MS. The *content* of cognitive rehabilitation relates to, for example, the cognitive rehabilitation approach undertaken and the topics discussed in the sessions. The procedural or process-related aspects of interventions (i.e., its *delivery*) include intervention timeframes such as the amount of time it takes to deliver the session-specific content.

There are similarities between these themes and those identified by Schulz et al. (2010) in their intervention taxonomy of features of interventions that could inform the design, conduct and reporting of interventions. Consistent with the findings of the current research, intervention characteristics such as the mode of delivery and overall strategies of the intervention were identified in the taxonomy. Davidson et al. (2003) also identified similar intervention characteristics that needed to be reported in

research papers that were included in the current research (e.g., the intervention setting and the content of the intervention sessions). An interesting finding was that the experts in study three did not identity facilitator attributes as 'essential' for inclusion in the reporting checklist, which was not consistent with the factors suggested by both Davidson et al. (2003) and Schulz et al. (2010).

The key difference between the aspects of interventions described by Davidson et al. (2003) and Schulz et al. (2010) and the reporting checklist developed in this thesis is its specificity to cognitive rehabilitation and MS. For example, the intervention content explicitly states the theoretical underpinnings (e.g., drill and practice or behaviour change) of cognitive rehabilitation. An advantage of the cognitive rehabilitation reporting checklist is that it was developed with the goal of facilitating implementation of cognitive rehabilitation within clinical services.

The *appropriateness* of reporting guidelines is one of the main recommendations suggested by Samaan et al. (2013) following an examination of the factors associated with adherence to reporting guidelines. The cognitive rehabilitation reporting checklist meets this recommendation. Its appropriateness was achieved through the *identification* of and *prioritising* the features of cognitive rehabilitation interventions in MS that clinicians would need to have reported in scientific papers to facilitate the *implementation* of these interventions in practice. This argument is further supported when comparing the reporting checklist developed in this research to the reporting checklists used in the systematic review (study one) (Appendix 24). None of the other reporting checklists and guidelines capture all aspects of cognitive rehabilitation interventions that experts have identified as essential for inclusion in a reporting checklist, to aid implementation of the intervention in clinical practice. Moreover, similar to the limitations of Davidson et al.'s (2003) and Schulz et al.'s (2010) intervention descriptions described above, none of the reporting checklists such as

the TIDieR (Hoffmann et al., 2014) capture aspects *specific* to cognitive rehabilitation. This specificity, through familiarity with the key terms (e.g., restitution and compensatory approaches), could prompt researchers to better report or capture the nuances of cognitive rehabilitant in their published papers. Does this mean we need a unique checklist for each intervention? Perhaps not. It would be impractical to require researchers to follow individual checklists for every type of intervention trial conducted. However, cognitive rehabilitation is a specialised and large enough field to warrant such a bespoke checklist, just as 'psychotherapy' would warrant a similar unique checklist (albeit, there may be some overlaps with the cognitive rehabilitation checklist).

Another issue with existing checklists that has been identified in the literature is concerned with the descriptions accompanying the reporting statements or items. In their systematic review to ascertain whether the description of complex, non-pharmacological interventions has improved, Candy et al. (2018) compared the reporting of intervention between 2002-2007 versus 2010-2015, based on the items in the CONSORT (Hopewell et al., 2008) and TIDieR (Hoffmann et al., 2014) reporting guidelines. The authors commented "[...] some items [in the TIDieR guidelines] remained open to differences in interpretation" (Candy et al., 2018, p. 6). The current research sought to minimise any ambiguity in the wording of the reporting statements (and their accompanying descriptions) included in the final checklist by checking these with a representative group of clinicians and researchers who had participated in the modified Delphi study. It was particularly important to gain feedback from researchers as they represent the individuals who will use the reporting checklist when writing research papers. The feedback was positive, with experts stating that the reporting checklist provided a clear, comprehensive and useful tool for publishing cognitive rehabilitation studies for people with MS.

The iterative and sequential nature of this research programme enabled the exploration of how to improve the reporting of cognitive reporting interventions. This did not only focus on the content of the reporting checklist, but also its presentation and usability. The data extraction process in study one (Chapter 2) identified a number of issues with existing checklists and guidelines. Following this, the objective was to develop a reporting checklist that did not befall the same issues.

In summary, the reporting checklist developed in this research serves to meet the following requirements:

- To provide clear reporting criteria with adequate descriptions and/or examples of what to report. This is to minimise subjective interpretation by researchers when reporting this information in published papers.
- To use language that aligns with terms and constructs relevant to cognitive rehabilitation. For example, specifying the theoretical underpinnings of the interventions and the cognitive rehabilitation approaches.
- To develop a reporting checklist that is concise but includes the key aspects of interventions that needed to be reported. The task of reporting these characteristics should not be an onerous undertaking.
- To make it explicit to authors that all reporting domains should be included in research papers. This is to reduce any ambiguity on which reporting criteria to prioritise, or not.

Despite promising results for cognitive rehabilitation (see reviews by Goverover et al. (2018) and Gromisch et al. (2018)), cognitive function in MS is still not routinely assessed and managed. Kalb et al. (2018) conducted a series of consensus meetings and literature searches to provide insight into the barriers and facilitators of cognitive screening and management of cognitive problems in people with MS. Although education, early screening, and provision of interventions such as cognitive

rehabilitation to help manage cognitive deficits are identified as ‘standard care’ for the management of cognitive deficits in MS, optimal care is not being achieved for a number of reasons. This includes issues clinicians have with accessing information relating to cognitive rehabilitation strategies. To overcome this barrier, Kalb et al. (2018) recommend an increase in the quantity and quality of the information pertaining to the management of cognitive issues in MS available to clinicians and encourage raising awareness of the different ways in which cognitive issues can be managed (e.g., through cognitive rehabilitation). In addition, a UK-based survey to ascertain clinical practice for the assessment and management of cognitive deficits in people with MS by Klein et al. (2018) found that cognitive rehabilitation is offered secondary to other forms of rehabilitation (e.g., to help with mobility issues). Less than 50% of healthcare professionals (e.g., occupational therapists, neuropsychologists, MS Nurses) working with people with MS stated they developed and implemented cognitive rehabilitation strategies as part of routine care.

Taken together, it is apparent there is still ‘a gap’ between research and clinical practice for cognitive rehabilitation in MS.

There is some overlap between the overall themes of intervention content and intervention delivery that were identified in this research and the phases of intervention development and implementation of the MRC framework (Campbell et al., 2000, Craig et al., 2013) that were presented in Chapter 1. Arguably, precise and comprehensive descriptions of cognitive rehabilitation interventions in the published literature are not only important for dissemination and implementation, but also play a moderating role within the iterative phases of the MRC framework. Without adequate reporting of intervention characteristics such as the underlying theory, the main components, feasibility, processes, and permissible adaptation, this may have

a negative impact on the overall outcome. The role that reporting of cognitive rehabilitation may play in each of these areas is discussed in the following sections.

5.4.1 Content of cognitive rehabilitation interventions

Content-specific aspects of cognitive rehabilitation such as the aims of the intervention, the theoretical framework underpinning the intervention and the cognitive rehabilitation approaches, or strategies used in the intervention were considered vital for implementation by clinicians and were included in the reporting checklist developed in this research. However, these aspects of the intervention were reported incompletely in published studies (study one), often with no explicit explanation for how the intervention features were hypothesised to affect the outcomes provided. Based on this, a researcher or clinician may not be able to ascertain what an intervention entailed beyond the cognitive rehabilitation approaches described. Ambiguity pertaining to what participants received and/or how the intervention characteristics may help to improve the daily lives of people with MS in the intervention could affect decisions on whether to replicate or implement the intervention in practice.

Using the CRAMMS intervention as an example of the application of cognitive rehabilitation, this highlighted the challenges associated with identifying the key elements of a complex intervention and may be a possible reason why these details were reported poorly in the research literature. Active ingredients, and particularly mechanisms of action, often cannot be observed directly or require different methods of assessment. Due to the multidimensional nature of cognitive rehabilitation programmes (e.g., different approaches and formats of delivery) and therefore the content of these interventions, there are several possible active ingredients and mechanisms of action. Therefore, the active ingredients can only be hypothesised

(e.g., through theory or existing research). Furthermore, the active ingredients may not necessarily be specific to the content of the intervention but could be attributed to:

- The format of delivery (e.g., group format and the perceived benefits of the shared experience).
- The manner in which the intervention material is presented (e.g., each participant is provided with a manual to take keep).
- The quality intervention delivery such as therapist competency skills (e.g., providing reassurance and encouragement).
- The didactic provision of a theoretical foundation of memory and attention before strategies are introduced and applied.

The complexity of identifying the active ingredients in complex cognitive rehabilitation interventions was supported by findings from study three. When examining the placement of reporting statements from the reporting domain 'aims', the aims of the intervention (associated with the outcomes such as improving function) were rated unanimously as essential to include in the reporting checklist. However, aspects such as the theoretical framework of the intervention and the active ingredients received a mixture of ratings that meant they were grouped under the 'Priority 2' group of reporting statements. Candy et al. (2018) suggested that the poor reporting of active ingredients in the studies they reviewed could be attributed to researchers' lack of clarity of what these elements are, the result of which was either an oversimplification or omission of these details. The current research findings support these claims. Comments accompanying the ratings for these factors suggested that the *exact* details might not be known. For example, as the effect of restitution or compensatory approaches is often difficult to distinguish clinically (Jacoby and Ahissar, 2013), more importance is placed on whether or not the study aim and outcomes are adequately explained.

In cognitive rehabilitation for people with MS, the mechanisms of action may include different aspects of information processing (increased awareness of cognitive deficits and strategies), learning (e.g., procedural, emotional, procedural), increased self-efficacy, readiness for change and motivation (Brown et al., 2016, Hart et al., 2014b). Therefore, it would be difficult to isolate the essential or the most important variables, particularly by describing the content of the intervention as conducted in study two of this research. Of particular note is the omission of the intervention 'mechanism of action' (i.e., the unmeasurable processes through which the intervention variables that have an effect on outcomes) from the final reporting checklist. In study three of the research, experts indicated that as these processes were often unknown, therefore including these in a reporting checklist was not of paramount importance (i.e., to effect implementation decisions). Experts indicate that it is more important to know the specific themes or topics covered in the intervention sessions, as well as any activities (such as 'homework') that accompany the intervention sessions.

The challenges of identifying and reporting the key components of cognitive rehabilitation interventions, particularly the concepts of 'active ingredients' and mechanisms of action highlighted in this research is debated in the literature. Sumowski et al. (2018) and Simons et al. (2016) argue that there is a need for further development of the 'science' of cognitive rehabilitation. The authors emphasise that a review of the theoretical models of MS-related cognitive deficits, as well as mechanisms of action was required. Some aspects of cognitive rehabilitation interventions may be reported incompletely due to researchers' uncertainty on what these are exactly (e.g., the mechanisms of action), which is supported by the findings in this thesis.

An examination of recently published studies of cognitive rehabilitation in people with MS (Mani et al., 2018, Messinis et al., 2017, Rilo et al., 2018, Stuifbergen et al., 2018)

also lends support to the issues researchers may have in identifying and therefore reporting the main components of interventions. For example, Mani et al. (2018) described the intervention as “a compensatory, problem-based, and integrated approach based on learning theory and an information processing model to enhance general cognitive function” (Mani et al., 2018, p. 591). Although the theoretical underpinnings of intervention and the aims (i.e., to increase “general function” (Chouliara and Lincoln, 2016)) is identified, a description of which components of the intervention are considered the ‘active ingredients’ and the mechanism of action is missing.

A possible solution is the Rehabilitation Treatment Specification System (RTSS) (Van Stan et al., 2019). The RTSS focuses on the actions taken by interventionists to achieve specific change or function in a participant. Treatments are comprised of several treatment components, each with a tripartite structure (i.e., treatment target, ingredients and mechanism of action), as described in the RTT. The RTSS emphasises the role that volition on the part of the treatment recipient plays in determining outcomes (Van Stan et al., 2019).

The RTSS may be beneficial in the initial stages of theorising and modelling of cognitive rehabilitation interventions in MS (Phase 1 of the MRC framework). By identifying the treatment component, this would facilitate the generation of hypotheses on reasons why the treatment was effective, or not. However, the issue of how each ingredient or component of the intervention contributes to the outcomes can still only be understood if each ingredient is assessed and the findings reported. Although Whyte et al. (2018) suggest the RTSS could be used to report the different components (including the underlying theory) and outcomes (i.e., the measurable target) of an intervention at various stages in the development and evaluation of interventions, it is understood that this might be beyond the scope of most cognitive

rehabilitation in MS research studies. The majority of these studies are Phase II (exploratory) and Phase III (evaluation) (Goverover et al., 2018, Mitolo et al., 2015) and not preclinical (theory exploration) and Phase I (modelling through the identification of essential components). The researcher is in agreement with Whyte et al. (2018) in that the RTSS (Van Stan et al., 2019) might be more useful at the theory development phases. Therefore, more research concerned with theory and modelling of these aspects of cognitive rehabilitation may be needed.

However, the problem of identifying the active ingredients and potentially the mechanisms of action in cognitive rehabilitation remains. In the content analysis study, an evaluation of these factors was not possible as it would require more than observation to understand what these components are. The issue is further compounded by the fact that most of these factors described above are internal to the individual and therefore might not be measurable.

Sumowski et al. (2018) suggest that structural and neuroimaging outcomes may help to identify the mechanisms of action in cognitive rehabilitation programmes. This is supported by findings from a systematic review by Prosperini et al. (2015), which examined functional and structural brain plasticity changes following cognitive rehabilitation in people with MS. Ten studies where included in the narrative review (n=162), and there were consistent task-related fMRI findings showing increased activation of the cingulated cortex in six of the included studies. As this region of the brain is related to emotion as well as learning and memory, the authors suggested this linked behavioural outcomes to motivational learning. Motivational learning may be a potential mechanism of action in cognitive rehabilitation. However, the small sample sizes of the included studies and conflicting research evidence concerning the regions correlated with increased brain activation following different cognitive rehabilitation approaches targeting differing cognitive domains. For example, in their

RCT (n=8), Chiaravalloti et al. (2012) found increased activation in the frontal ad temporal lobe following context and visual imagery (memory retraining) cognitive rehabilitation using functional magnetic resonance imaging (fMRI). Furthermore, neuroimaging studies often conflicting structural brain changes (increased or reduced brain activation) (Sumowski et al., 2018) (or different sites of activation) (Prosperini et al., 2015) even when there are objective and self-reported changes (i.e., improvements) in function (Piqueras, 2015).

Alternatively, metacognitive approaches such as Think Aloud (Ball, 2005) could help identify the active ingredients and potential mechanisms of action in cognitive rehabilitation, especially when they are internal (e.g., motivation and self-efficacy). A similar approach was used by Birnboim (1995) to facilitate metacognitive learning in people who had experienced a traumatic brain injury.

The results of such research could be added to the reporting checklist, specifying to further expand the examples provided for the main components of the intervention that influence cognitive rehabilitation outcomes.

5.4.2 Delivery of cognitive rehabilitation

The evaluation of complex interventions, such as cognitive rehabilitation, is dependent on the study design (e.g., RCTs conducted with low risk of bias), the outcomes, and the intervention processes (Craig et al., 2013, Michie et al., 2009). The findings of the review in study one demonstrated that intervention processes were often poorly reported in the literature. This included information relating to the mode of delivery, the fidelity of intervention delivery, the intervention 'dose' and facilitator attributes. The findings were consistent with previous research (Glasziou et al., 2008, Martin et al., 2015, van Heugten et al., 2012). Based on the information provided in

the articles, it would be difficult to compile a definitive, stepped process of how to deliver the intervention.

The evaluation of intervention fidelity in the content analysis study provided insight into the processes involved in the implementation of cognitive rehabilitation. The contribution of this study to the outcome of this research is supported by the argument made by Simons et al. (2016), in that current gaps in treatment theory knowledge may be lessened through improvements in the reporting of both intervention content and processes.

Adherence and intervention timeframes (i.e., intervention fidelity) are important as they enable both researchers and clinicians to ascertain whether an intervention is appropriate for the setting and the needs of the person with MS. However, participant adherence to the intervention activities such as attendance completion of take home activities could not be deduced conclusively from the video-based of intervention sessions in study two. The findings of study two highlighted potential areas for improvement (e.g., increasing the length of sessions) before the CRAMMS intervention is replicated or implemented in clinical practice.

It is important to note that in study two only the *quantity* and not the *quality* of intervention delivery was examined. As indicated by Bellg et al. (2004) and Borrelli (2011), other aspects of intervention fidelity that could influence outcomes include how participants engage with and respond to the contents and delivery of the intervention, and whether the therapists deliver the intervention competently. As the objective of the study was to describe the content cognitive rehabilitation programme in study two, these aspects were not monitored.

Although the duration of the treatment was included in the reporting checklist, the researcher understands the complexities of 'time' and 'duration' factors in rehabilitation research. Whyte et al. (2018) for a more nuanced quantification of intervention 'dose'. For example, a treatment may last six months in that 10 sessions are delivered followed by a top up, but that is not equivalent to a treatment equally spaced over a 6 months period. Therefore, 'duration' may be difficult to interpret (and be less meaningful clinically), requiring a more nuanced quantification. Taken together, information pertaining to the number of sessions, the frequency of sessions and descriptive statistics pertaining to the period of time over which the intervention is delivered may be more meaningful. These aspects of intervention timeframes are included in the reporting checklist developed in this research.

5.4.3 Implementation of cognitive rehabilitation in MS

The challenges and issues associated with the dissemination and implementation of research evidence (e.g., cognitive rehabilitation) in healthcare practice (Curtis et al., 2017, Kristensen et al., 2016) and the associated strategies (Nilsen, 2015, Proctor et al., 2013) are beyond the current scope. These include factors such as behaviour change (i.e., on the part of healthcare professionals and organisations) that influence adoption of interventions (Bauer et al., 2015) and the importance of the contextual factors on the success of implementation of interventions (Moore et al., 2015, Wells et al., 2012).

However, the aim is that the reporting checklist for cognitive rehabilitation developed in this research will enable one aspect of implementation. That is, the effective communication of aspects of cognitive rehabilitation interventions in research papers to enable healthcare providers to assess the suitability of cognitive rehabilitation for their setting and patient group. These include intervention characteristics such as the

adaptability and complexity of the intervention and any associated costs, as identified by Damschroder et al. (2009) in the CFIR framework. As discussed, the reporting checklist developed in this research was developed with the goal of implementation of cognitive rehabilitation in MS. Therefore, the aim is that the reporting checklist will aid facilitation of interventions by enabling clinicians to:

- Assess the adaptability of the cognitive rehabilitation for their setting and patient group
- Evaluate the complexity of the intervention
- Examine the presentation of the intervention
- Assess whether the intervention can be tested on a small scale
- Determine any costs associated with the intervention

The researcher notes that there are other factors to consider when evaluating the comprehensiveness of reporting of cognitive rehabilitation in published papers. An examination of the literature (Candy et al., 2018, Samaan et al., 2013) highlights that barriers to adequate reporting include:

- Journal word limits.
- Whether or not journals insist that research authors adhere to reporting guidelines.
- Intellectual property restrictions concerning the publication of marketed material (e.g., intervention materials, including computer software).

5.5 Strengths and limitations of the research

Although the strengths and limitations of each of the specific three studies have been described (sections 2.7.2, 3.8.2 and 4.8.2), it is important to recognise that there are also strengths and limitation overall.

5.5.1 Limitations

One limitation of the research is that in the content analysis the quantity of the intervention was assessed and not the quality of interactions between the APs and the participants. As Easton (2010) highlights, and consistent with a critical realist epistemology, observations are unable to lead to a complete understanding of social interactions. Approaches such as conversation analysis, which examines the sequence of communication (Parry et al., 2016) have been used to assess the nature of interactions between healthcare professionals and patients based on video observation (Arnold et al., 2010). Alternatively, the competency of APs or other healthcare professional to deliver cognitive rehabilitation (e.g., group facilitation skills) could be examined to determine the quality of delivery.

Whilst the reporting checklist arguably provides more *appropriate* and *specific* details compared to existing checklists and guidelines, a potential limitation is that it could be perceived as an oversimplification of the content of complex cognitive rehabilitation interventions. As the focus of the research was on the *most important* aspects of cognitive rehabilitation that needed to be reported in published papers, this was achieved. Furthermore, as an example, the checklist has been used to describe the CRAMMS example. Further piloting of the checklist (i.e., in single studies and systematic reviews) would highlight areas that need to be refined as well as determine the applicability of the checklist.

Another potential limitation of the research is the focus on the cognitive domains of memory, attention and executive function in studies one and two. However, study three and therefore the outcome of this research was not specific to these cognitive domains, but to all cognitive issues that are experienced by people with MS.

5.5.2 Strengths

This research was based upon a comprehensive mixed method approach, founded on the guidance for developing reporting guidelines (Moher et al., 2010). Overall, findings were consistent across all three studies, which support confidence in the reliability of the research outcomes. The comprehensiveness of the final reporting checklist was enhanced by the inclusion of data collected in the CRAMMS study. This was unique, as gaining real-world insight into the content and conduct of a cognitive rehabilitation programme complemented the systematic review findings.

The reporting checklist for cognitive rehabilitation in MS developed in this research has a number of advantages. First, both single studies and systematic reviews can use the checklist to report the content of these interventions. The reporting checklist can be used to when planning systematic reviews (to identify intervention components that may drive research questions), in the data extraction stages (to develop the data extraction form) and to structure the reporting of the content of the intervention (e.g., in a summary table).

The second strength of the reporting checklist is that although it was designed in relation to MS, the contents of the checklist pertain to the cognitive rehabilitation of other neurological conditions, such as stroke. Incomplete reporting of intervention details is also an issue in stroke rehabilitation (Hoffmann et al., 2015, Walker et al., 2017). Bernhardt et al. (2017a) and Bernhardt et al. (2017b) reported the findings of the first Stroke Recovery and Rehabilitation Roundtable, the aim of which was to bring together stroke and rehabilitation experts to develop an agreed framework upon which the development, conduct and reporting of stroke research would be based. Identified within this framework was the need to improve the reporting of the intervention timeframes (i.e., the start and the end) (Bernhardt et al., 2017a) and participant clinical

presentations such as the time since stroke onset (Bernhardt et al., 2017b). The cognitive rehabilitation-reporting checklist could support this endeavour.

5.6 Implications of the research findings

5.6.1 Contribution to academic knowledge

Each phase of the research is independent and original. The systematic review was the first to examine the quality of reporting of cognitive rehabilitation in MS, specific to memory, attention and executive function deficits. The content analysis study used video-based observations in a multi-site cognitive rehabilitation in MS trial. The large number of intervention session videos included in the analysis contributed to the comprehensiveness of the coding process, which is unique. It is believed that the development of the reporting checklist using findings from *both* the systematic review and content analysis study makes a methodological contribution to the current research approach recommended by Moher et al. (2010).

5.6.2 Implications for research

The main implication arising from this research is that future research can use the reporting checklist to facilitate the complete reporting of cognitive rehabilitation interventions. This will enable replication of the intentions in studies as well as synthesis of research findings in systematic reviews. A second implication is that the checklist may encourage researchers to identify the main components of the interventions, including the underlying theories, essential elements and the hypothesized mechanisms of action. This would contribute to the theory development and modelling of cognitive rehabilitation, as suggested by the MRC framework, as well as predicted outcomes of these interventions.

5.6.3 Implications for clinical practice

The clinical implications of this research are indirect. If researchers use the checklist to adequately report the content of cognitive rehabilitation programmes, this may contribute to the decision-making processes of whether or not to implement cognitive rehabilitation for use in MS clinical practice. Details such as the adaptability, complexity and any associated intervention costs can be considered alongside other factors that influence implementation of research into clinical practice. Interventions that are well-described enable staff to deliver them clinically as originally intended (and evaluated) in research.

5.7 Future research

There were a number of suggestions for future research highlighted throughout the thesis.

Future research to explore the quality of delivery of cognitive rehabilitation programmes is needed. The video-recordings of the CRAMMS intervention sessions could be observed again, but with focus placed on how the APs engaged with both the participants and the treatment manual. The level of competency would be rated (e.g., to what extent is the AP displaying knowledge of the intervention material – excellent, adequate or poor). Together with findings of the quantity/content described in this research, results of the quality of delivery may be used to determine to what extent these factors influence rehabilitation outcomes. For example, through a regression analysis. This has wider implications for the evaluation and the implementation of cognitive rehabilitation (i.e., determining whether quantity or quality of delivery was important to determine positive outcomes).

The intervention's active ingredients and/or mechanisms of action should be investigated to inform the theory development and modelling processes in cognitive rehabilitation, which are important for both intervention evaluation and implementation. Once identified, these intervention components can be included in the reporting checklist. This has direct implications for the quality of reporting of these interventions, which could inform both Phase I theory development and Phase IV implementation processes. A 'Think Aloud' protocol would be used to ascertain from both therapists and participants their thought processes whilst they engaged with the intervention content. By gaining insight into cognitive processes, this could identify the key aspects of the intervention and mechanisms (e.g., knowledge attainment, motivation) that have an effect on outcomes but cannot be observed directly. Consequently, the reporting checklist would be revised in light of this new knowledge.

5.8 Final conclusion

The aim of this research was to explore avenues to increase the clinical impact of trials of cognitive rehabilitation in MS. Cognitive rehabilitation interventions for people with MS that have been evaluated for clinical and cost-effectiveness can only be adapted for clinical practice if they are described accurately and in detail. The development of the checklist will aid researchers to describe succinctly their interventions in sufficient detail such that they can be replicated in further research, synthesised in systematic reviews or adapted for implementation in clinical practice. This will ensure that the quality and integrity of the intervention is maintained, and nothing is lost in the translation from the lab setting to clinical setting, to provide maximum benefit to people with MS.

The evidence-based, clinician-informed checklist developed in this research should be regarded as the first step towards the implementation of such research in clinical practice.

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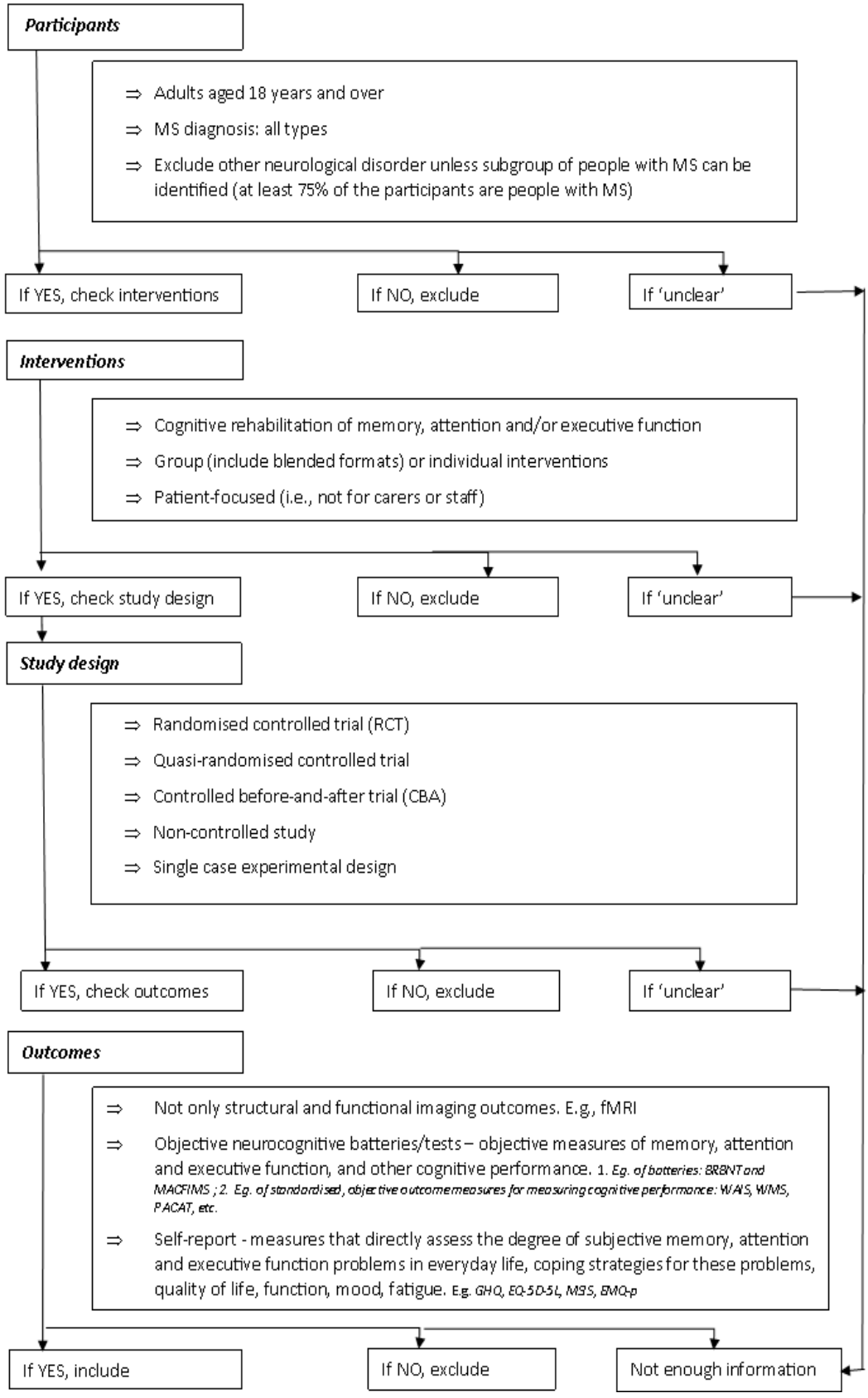
Appendices

Appendix 1 MEDLINE (Ovid) search strategy (Chapter 2)

1. exp Multiple Sclerosis/
2. exp demyelinating autoimmune diseases, cns/
3. "autoimmune diseases of the nervous system"/
4. multiple sclerosis.ab,ti.
5. 1 or 2 or 3 or 4
6. exp *Cognition Disorders/ or exp *Cognition/
7. exp *Cognitive Dissonance/
8. exp *Mild Cognitive Impairment/
9. exp *Metacognition/
10. exp *Awareness/
11. exp *Attention/
12. exp *Memory/ or exp *Memory Disorders/
13. mental processes/ or exp *executive function/
14. (cogniti* or neuropsychol* or memor* or7 attenti* or execut* or metacognit* or aware* or concentrat*).ab,ti.
15. 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14
16. 5 and 15
17. exp *Neurological Rehabilitation/ or exp *Rehabilitation/ or exp *Rehabilitation Research/
18. exp *Cognitive Therapy/
19. exp *Neuropsychology/
20. exp Therapy, Computer-Assisted/

21. exp Computers/
22. exp Neuropsychological Tests/
23. (interven* or train* or re?train* or computer?assisted therap* or rehabilit* or neurorehab* or neuropsych* rehab* or restitut* or remediat* or restorat* or retrain* or train* or recover* or treat* or guid* or instruct* or teach* or stimulat* or exerci* or strateg* or counsel* or therap* or intervent* or manage*).ab,ti.
24. 17 or 18 or 19 or 20 or 21 or 22 or 23
25. (attent* or memor* or cognit* or cogniti* disorder* or concentrat* or awar* or alert* or distract* or executive function).ab,ti.
26. 24 and 25
27. 16 and 26

Appendix 2 Hierarchy for excluding articles (Chapter 2)



Appendix 3 Checklists used for data extraction (Chapter 2)

TIDieR (Hoffman et al., 2014)	
Item	Item description
Brief name Name/phrase describing Intervention	Intervention name and full explanation of any abbreviations or acronyms, or One or two line statement about the intervention
Why Rationale, theory, or goal of elements essential to Intervention	Aim is to provide information on the essential elements of the intervention. This could be referred to as the 'active ingredients', i.e. The intervention components that are associated with its effect on the outcomes Include a description of the mechanism of action of the active components of the intervention
What – materials Physical or informational, for participants or providers. Info on where accessed (online appendix, url, etc.)	Physical and information materials that were used as part of the intervention The list of materials can be comparable to ingredients for a recipe Examples include materials given to participants, training materials for the intervention facilitators/providers A description of materials may include a description of the procedures
What – procedures Describe procedures, activities, and/or processes used in Intervention, incl. Enabling or support activities	Similar to the 'methods' section of a recipe. Involves the intervention materials (i.e., ingredients). A description of what happens to the intervention 'ingredients' 'procedure' includes the sequence of steps to be followed, along with the actual intervention itself Examples of activities include 'referral, screening, case finding, assessment, education, treatment sessions, telephone contact' (p. 5) Support activities refers to 'implementation activities', i.e., additional activities that enable or support the occurrence of the intervention

TIDieR (Hoffman et al., 2014)	
Item	Item description
Who provided For each Intervention provider, describe expertise, background and training given	Intervention provider characteristics can affect the outcomes Includes the number of providers who were involved in delivering the intervention or in the intervention process Their discipline (e.g. Psychologist, research assistant, trainer) Pre-existing specific skills, experience and expertise Additional training specific to the intervention that providers were given before and/or during the study Whether providers degree of competence was monitored, how this was done and what was done if their competence was found to be lacking If providers were reimbursed for their time or given other incentives
How Describe modes of delivery (e.g., face-to-face, internet, telephone) and whether delivered individually or in a group	To specify if intervention was delivered to one participant at a time or to a group (includes group size) If relevant stipulate who initiated contact with study participants, if sessions were interactive (e.g., 'participants and therapists typed free text into the computer, with messages sent instantaneously' (p. 5)) or not ('messages were sent in an automated fashion' (p. 5)) Indicate intervention delivery aspects that are considered to be essential or be influential to the outcome
Where Describe type(s) of location(s) where Intervention occurred, incl. Necessary infrastructure or relevant features	Intervention may have been delivered in location whether participants were recruited or data were collected If not the case, this should be specified. Information may include the country, hospital or primary care facility, the healthcare system or context, the availability of particular facilities or equipment

TIDieR (Hoffman et al., 2014)	
Item	Item description
	These details may have an impact on aspects of intervention feasibility, and provider/participant adherence. Important for intervention replication.
When and how much Describe no. of times Intervention was delivered, over what time period incl. No. Of sessions, their schedule, duration, intensity or dose	For interventions with a number of sessions, information on the session schedule, and whether the number of sessions, their schedule and/or intensity was fixed or could change under specific conditions (and a description of what these were) Details on the timing of the intervention in relation to other key events e.g., how long after diagnosis, or another crucial event. The amount or dose that participants receive as part of the intervention may differ from the amount initially intended. This information is usually reported in the results section, and the details provided.
Tailoring If Intervention was planned to be personalised, titrated or adapted, describe what, why, when and how.	Participants may not receive an identical intervention due to, e.g., participants' preference, skills, or situation. Tailoring may be an intrinsic part of the intervention e.g., increasing the intensity of an exercise. A brief description of the rationale and guide for tailoring should be given. Any variables or constructs used to assess participants should be included in the description. Authors to state at which point tailoring occurred. Any materials used, e.g., flowcharts, algorithms, should be included (or referenced)
Modifications Describe changes if Intervention was modified during course of study (what, why, when and how).	This does not refer to tailoring at the participant level, but to modifications that take place at the study level

TIDieR (Hoffman et al., 2014)	
Item	Item description
	Include a description of what was modified, a reason for why this happened, when the modification took place, and how the modified intervention was different from the original one May include modifications to the intervention provider or intervention materials A description of any changes made between the published protocol/pilot study and the primary paper It is important to note this, as they enable the reader to identify any issues and prevent the repetition or errors when attempting the replicate the intervention
How well – planned If Intervention adherence or fidelity was assessed, describe how and by whom, and describe any strategies used to maintain/improve fidelity	Fidelity can have an effect on how successful an intervention is, and refers to the extent to which the intervention was delivered in the manner in which it was intended. Terms to describe this concept include treatment integrity, participant or provider adherence, and implementation fidelity A description of 'how well' the intervention was delivered or received (e.g., how many participants did the exercises, how many exercises they did, and for how long). It goes beyond the receipt of intervention (e.g., the number of participant who were issued with the intervention exercises Fidelity can refer to several parts of the intervention, including provider training, intervention delivery, and intervention receipt Measures, strategies, or tools used to determine fidelity should be described Materials used to assess or maintain fidelity should be described or referenced

TIDieR (Hoffman et al., 2014)	
Item	Item description
How well - actual If Intervention adherence or fidelity assessed, describe extent to which intervention was delivered as planned	Provide a description of the extent to which the intervention that was delivered differed from the intervention intended This information is useful to explain the results of the study, reduce misinterpretation of the study outcomes, and provide vital information to be used in modifications of the intervention. If fidelity is found to be lacking, this can highlight the ned for future studies and/or strategies to improve adherence This may include elements of the study that participants disliked. Reporting of intervention fidelity will be dependent on the assessment measures.

van Heugten et al.		
Item	**Aim**	**Item description (if available)**
Intervention characteristics (process, structure, context)	Treatment activity: Frequency, intensity, duration	Total, planned and actual
	Individual or group	
	Involvement of caregivers/others	Is information pertaining to the involvement of the caregiver in treatment available
	Direct or contextual treatment	Direct therapy or applied in daily life
	Treatment context Organisation (healthcare setting)	
	Theoretical basis	Content of the experimental treatment
	Treatment resources Physical (equipment)	In studies using medical or other devices (e.g., prisms, software programs or virtual reality programs), information should include the

van Heugten et al.		
Item	**Aim**	**Item description (if available)**
		type of device used. In such situations, further information is not necessary, for instance, type of prisms or a software program
	Knowledge (of staff)	Discipline(s) of the therapists involved
	Skills of staff	Information about the necessary experience, knowledge or skills of the staff

Martin et al., 2015		
Code	**Sub-code**	**Description of code (if available)**
Dose	Number of sessions	Overall number of sessions
	Length of sessions	Length of each session
	Frequency of sessions	
	Duration of programme	Overall duration of the group programme
Group	Size	Size, or size range of the group
	Diagnosis	Specific diagnosis that is related to the cognitive problems
Aim/focus of programme	Original	Original programme developed by the authors
	Adapted	Programme adapted from previous research
	Manualised	Manual-based programme, and is manual available
	How was manual developed/adapted	
	If adapted, are clear refs given to the original programme	
	Session by session content reported	Clear description of the topics covered in each group session
	How are missed sessions dealt with	
Facilitator	Who facilitated	Details on who ran the group sessions e.g., occupational therapist, clinical neuropsychologist or research assistant **and** if any specific form of training was given to the facilitators
	How many facilitators where there	

Martin et al., 2015		
Code	**Sub-code**	**Description of code (if available)**
	What kind of training did they receive	
Format of sessions	General format of session reported (overview, summary, etc.)	Step by step description, from the beginning of the session (e.g., recap of previous session) to ending session with a summary
	Booklet/materials given	
	Break	
	Was homework set	

Journal Article Reporting Standards (JARS): reporting standards for studies with an experimental manipulation or intervention (intervention-specific)	
	Article section and topic
Method	
Experimental manipulations or interventions	Details of the interventions or experimental manipulations intended for each study condition, including control groups, and how and when manipulations or interventions were actually administered, specifically including the following:
	Content of the interventions or specific experimental manipulations Summary or paraphrasing of instructions, unless they are unusual or compose the experimental manipulation, in which case they may be presented verbatim
	Method of intervention or manipulation delivery Description of apparatus and materials used and their function in the experiment Specialised equipment by model and supplier
	Deliverer: who delivered the manipulations or interventions Level of professional training
	Level of training in specific interventions or manipulations
	Number of deliverers and, in the case of interventions, the mean, SD, and range of number of individuals/units treated by each
	Setting: where the manipulations or interventions occurred

Journal Article Reporting Standards (JARS): reporting standards for studies with an experimental manipulation or intervention (intervention-specific)	
	Article section and topic
	Exposure quantity and duration: how many sessions, episodes, or events intended to be delivered, how long they were intended to last
	Time span: how long it took to deliver the intervention or manipulation to each unit
	Activities to increase compliance or adherence (e.g., incentives)
	Use of language other than English and the translation method
Units of delivery and analysis	Unit of delivery: how participants were grouped during delivery
Participant flow	Total number of groups (if intervention was administered at the group level) and number of participants assigned to each group
Treatment fidelity	Evidence on whether the treatment was delivered as intended
Baseline data	Baseline demographic and clinical characteristics of each group
Discussion	Discussion of results taking into account the mechanism by which the manipulation or intervention was intended to work (causal pathways) or alternative mechanisms
	If an intervention is involved, discussion of the success of and barriers to implementing the intervention, fidelity of implementation

Western Journal of Nursing Research checklist	
Attribute	**Examples of details to include**
Previously developed intervention	Person(s) responsible for developing original intervention with full citation to publications/sources
	Description of modifications to previously developed intervention
Conceptual framework on which intervention is based	Conceptual framework name and/or description
	Developer of conceptual framework, if applicable (cite original sources over secondary sources)

Western Journal of Nursing Research checklist	
Attribute	**Examples of details to include**
	Modifications to the original conceptual framework for this project
	Specific links between conceptual model key constructs and intervention attributes
	Any conceptual framework suggested intervention components not included in the tested intervention
	Conceptual model-specific mediating constructs or moderating variables measured in this study
Intervention components	Specific details of what treatment subjects' received when they received the intervention
	Descriptive information about any materials provided to subjects, for example, readability of print content
	Nonspecific intervention components, that is, intervention active factors/components that are not specified or suggested by the conceptual framework that differ between treatment and control subjects
	"Common" factors, that is, those usually found in most nursing intervention studies such as therapeutic relationships that differ between treatment and control subjects
	Any intervention or attention provided to control or comparison subjects to clarify active components of the intervention
Timing of intervention delivery	Provide rationale and description of delivery timing
	Identify if the intervention was delivered in relationship to some index event such as following medical procedure or diagnosis
Intervention dose	Total number of doses
	Strength of dose, that is, the amount/volume/duration per individual dose
	Dose frequency, that is, time elapsed between doses
	Treatment duration, that is, minutes, hours, days, weeks, or months over which the entire intervention was delivered
Mode of delivery	Face-to-face
	Mediated, for example, telephone, surface mail, email, Internet, DVD
Intervention target and recipient	Target: person or social unit (e.g., family) that will be potentially affected by the intervention

Western Journal of Nursing Research checklist	
Attribute	**Examples of details to include**
	Recipient: individuals who receive the intervention; interventions often are delivered directly to patients, but in some cases health care providers or families receive an intervention intended to benefit someone besides the recipient·
	Description of any compensation such as gifts or honoraria intervention targets/recipients receive to participate in the study
Delivery setting	Physical setting: for example, home, diabetes clinic, inpatient hospital room
	Social setting: individual, family, researcher formed groups or existing groups such as coworkers or church members
	Researcher groups should include information on group size and how groups were formed
Intervention variations related to group or individual attributes	Standardized interventions identical for all participants
	Interventions with planned variations Targeted interventions, that is, interventions matched to group characteristics, such as different interventions for women vs. men Tailored interventions, that is, interventions matched to individual characteristics Basis of tailoring Decision points for tailoring Strategies to ensure content validity
	Discussion of treatment fidelity
	Discussion of unplanned deviations in content and dose
Interventionist	Personal attributes relevant to the study (eg, age, gender, ethnicity)
	Professional attributes, including profession, credentials, and formal education
	Intervention delivery competence Intervention training Verification of competency

Appendix 4 Characteristics of excluded studies (Chapter 2)

Reason for exclusion: People with MS make up less than 75% of study participants	
Author	**Year**
das Nair and Lincoln	2012
Gunduz et al.	2012
van der Putten et al.	1999
Wilson et al.	2001
Reason for exclusion: not cognitive rehabilitation	
Author	**Year**
Allen et al.	1995
Anderson et al.	2017
Basso et al.	2008
Basso et al.	2006
Beckwith et al.[a]	2015
Benedict et al.	2000
Blankespoor et al.	2017
Bogosian et al.	2016
Bombardier et al.	2008
Cabrera-Gómez et al.	2010
Canellopoulou and Richardson	1998
Charvet et al.	2017
Chiaravalloti and Deluca	2002
Chiaravalloti et al.	2003
das Nair et al.	2016
Dobryakova et al.	2016
Foley et al.	1987
Goverover et al.	2011
Goverover et al.	2008
Goverover et al.	2009
Hildebrandt et al.	2006
Jongen et al.	2016
Lee et al.	2017
Mattioli et al.	2016
McGuire et al.	2015
Mendoza et al.	2001

Mills and Allen	2000
Moore et al.	2008
Rodgers et al.	1996
Sumowski et al.	2010
Tesar et al.	2003
Thaut et al.	2014
Thomas et al.	2010
Wassem and Dudley[a]	2003
Reason for exclusion: study design	
Author	**Year**
Aldrich et al.	1995
Ben Ari et al.	2013
Cerasa et al.	2014
Charvet et al.	2016
Chiaravalloti	2011
Chiaravalloti and DeLuca	2015
D'Amico et al.	2016
de Giglio et al.	2016
Dobrushina et al.	2016
Foley et al.	1994
Gich et al.	2015
Hancock et al.	2013
Iaffaldano et al.	2016
Johnson et al.	2009
Lincoln et al.	2003
Lincoln et al.	2015
Longley et al.	2012
Mattioli et al.	2010
Nurova et al.	2014
Perez et al.	2016
Shevil et al.	2008
Stuifbergen et al.	2011
Reason for exclusion: Outcomes	
Author	**Year**
Ernst et al.	2015

Ernst et al.	2016
Hubacher et al.	2015
Huiskamp et al.	2016
Parisi et al.	2014
Shevil and Finlayson	2009
Smale et al.	2015
Other reasons for exclusion: Not published in English	
Author	**Year**
Brissart et al.	2010
Hildebrandt et al.	2003

[a]Although cognitive rehabilitation was included in programme, any effects would be difficult to separate from the rest of the programme

Appendix 5 Characteristics of the included studies (Chapter 2)

N=54. *MS type:* RRMS – relapsing remitting MS; PPMS – primary progressive MS; SPMS – secondary progressive MS; chronic progressive – CPMS; progressing relapsing – PRMS; *Study status* – 1: primary study; 2: secondary; 3: follow-up study.

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
Allen et al. (1998)	39.6 (8.71)	Non-specific MS	Before and after	Memory	Individual, computer-based	Computer-based imagery-based mnemonic strategy training 2 or 3 times a week; 30 minutes, 5 sessions	Objective	1
Altun et al. (2015)	36 (7.19)	RRMS	Before and after	Attention, sustainable attention, information processing speed, and verbal and visual memory	Individual, Computer-based	Different screens used, based on cognitive domains. For example, memory screen had tasks such as identification of objects and deduction exercises. 8 weeks, once a week for 1 hour	Both	1
Amato et al. (2014)	18–55 years (inclusion criteria)	RRMS	RCT	Attention	Individual, home-based, computer-based	Based on the Attention Processing Training program (APT). Focus is on restorative exercises. 3 months, twice a week, 1 hr	Both	1
Birnboim and Miller (2004)	45.5 (9.25)	Non-specific MS	Before and after	Executive function	Individual, computer-based	Strategy training, awareness and	Both	1

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
						learning application to daily life. 6 months, weekly, I hour, approximately 24 sessions		
Bonavita et al. (2015)	49 (8)	RRMS	CBA	Attention and information processing speed	Individual, computer-based	Short-term cognitive training based on RehaCom. 8 weeks, twice a week, 50 minutes	Objective	1
Brenk et al. (2008)	43.5(8.9)	Non-specific MS	CBA	Non-specific, but targets memory and attention	Individual	Non-specific cognitive training (restitution). 6 weeks, 5 days per week (10-15 minutes a day) or 1 day (all session units).	Both	1
Brissart et al. (2013)	42.5 (5.17);	RRMS	CBA	Memory and executive function	Group	Group proctor-SEP Cognitive Program - aims to teach the patient to use facilitation strategies to help preserved functions. 6 months, twice a week	Objective	1
Campbell et al. (2016)	47.37 (8.23)	RRMS, SPMS	RCT	Working memory, visuospatial memory, divided attention	Individual, home-based, computer-based	Restitution. Cognitive training to improve/increase brain activation of specific brain areas	Both	1

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
						and thus improve neural efficiency. Three times a week, 45 minutes.		
Carr et al. (2014)	34-72 (range)	PPMS, SPMS, RRMS, benign	RCT	Memory	Group	Group memory rehabilitation programme combining restitution and compensation strategies. 10 weeks, once a week for 1.5 hrs. Mean number of sessions 7.9 (0.23).	Self-report	1
Cerasa et al. (2013)	31 (9.2)	RRMS	RCT	Attention	Individual, clinical center, computer-assisted	Software RehaCom - computer-based intensive attention training program. 6 weeks, twice a week for 1 hr.	Both	1
Charvet et al. (2015)	19-55 years (inclusion criteria)	RRMS	RCT	Working memory and processing speed	Individual, computer-based	Computer-based, active adaptive cognitive remediation program focusing on training common areas of impairment in multiple sclerosis. 12 weeks, 5 days a week for 30 min. Intervention group	Both	1

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
						averaged 25.7 (8.3) hours.		
Chiaravalloti et al. (2005)	45.14 (13.78)	RRMS, PPMS and SPMS	RCT	Memory and learning	Group	Story Memory Technique (mSMT) focusing on approving the acquisition of info through context and imagery) into long-term memory. 4 weeks, twice a week for 45 minutes, 8 sessions in total.	Both	1
Chiaravalloti et al. (2012)	49.25 (9.33)	RRMS	RCT	Memory	Group	Engagement of imagery procedures to facilitate learning and use of context to organize incoming information. 5 weeks, twice a week for 45-60 minutes.	Objective	2
Chiaravalloti et al. (2013)	48.13 (10.17)	RRMS, PPMS, SPMS, PRMS	RCT	Memory and learning	Group	Modified Story Memory Technique (mgmt.) focusing on approving the acquisition of info through context and imagery) into long-term memory.	Both	2

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
						5 weeks, twice a week for 45-60 minutes.		
Chiaravalloti and DeLuca (2015)	48.13 (10.17)	RRMS, PPMS, SPMS, PRMS	RCT	Memory and learning	Group	Modified Story Memory Technique (mSMT) focusing on approving the acquisition of info through context and imagery) into long-term memory. 5 weeks, twice a week for 45-60 minutes.	Objective	2
De Giglio et al. (2015)	43.9 (8.4)	RRMS	RCT (waiting list control)	Attention, working memory, processing speed and executive function	Individual, home-based, computer-based	Computer and videogame-based training. 8 consecutive weeks, 30 minutes a day for 5 days a week.	Objective	1
De Giglio et al. (2016a)	43.2 (8.2)	RRMS	RCT (waiting list control)	Attention, working memory, processing speed and executive function	Individual, home-based, computer-based	Computer and videogame-based training. 30 minutes a day for 5 days a week.	Objective	2

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
Dobryakova et al. (2014)	40 (5.66)	RRMS and PPMS	RCT	Memory and learning	Group	Modified Story Memory Technique (mSMT) focusing on approving the acquisition of info through context and imagery) into long-term memory. 5 weeks, twice a week. 10 sessions in total.	Objective	3
Ernst et al. (2012)	37.25 (5.5)	RRMS	CBA	Autobiographical memory	Individual	Mental visual imagery (MVI)-based exercises – compensatory. Once a week for 3 hours. At least 6 sessions (to qualify as 'completed' programme).	Objective	1
Ernst et al. (2013)	42.96 (10.94)	RRMS	CBA	Autobiographical memory	Individual	An MVI (mental visual imagery)-based cognitive facilitation programme – compensatory. >6 weeks, once a week for 2 hrs.	Objective	1
Ernst et al. (2015)	42 (10.37)	RRMS	RCT	Executive function, autobiographical memory	Individual	Mental visual imagery (MVI)-based exercises.	Objective	1

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
						Six session, each two hours, once or twice a week.		
Filippi et al. (2012)	44.8 (28-60)	RRMS	RCT	Attention and information processing and executive functions	Individual, computer-based	Domain-specific cognitive training. Computer software – RehaCom package. 12 weeks, three times a week, 1 hr.	Objective	1
Fink et al. (2010)	44.8 (8.2)	RRMS	CBA	Executive function	Individual	Ease executive deficits by self-training and receiving feedback. 6 weeks, 5 times a week, 25-30 (exercises: total a week 100-120 min); 1.5 hrs (psychologist).	Both	1
Gentry (2008)	50 (37-73)	RRMS, PPMS, SPMS, CPMS	Before and after	Memory	Individual, home based	PDA, compensatory assistive technology/strategy. 12 sessions. 1 session per week.	Both	1
Gich et al. (2015)	45.5 (9.6)	RRMS and SPMS	RCT	Memory and executive function	Individual, computer-based	Cognitive rehabilitation programme based on the restoration of function. 6 months, once a week for 1.25 hrs.	Both	1

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
						Attendance rate was 84.3%.		
Hancock et al. (2015)	50.65 (6.32)	RRMS, SPMS, PPMS	RCT	Processing speed and working memory	Individual, home-based, computer-based	Computerized cognitive training (Posit Science). 6 weeks, 6 days per week for 30 minutes.	Objective	1
Hanssen et al. (2015)	53.9 (33-70)	PPMS, RRMS, SPMS	RCT	Executive function	Blended	Goal attainment. Psychoeducation, learning strategies. 4 week for 2hrs.	Self-report	1
Hildebrandt et al. (2007)	42 (25-55)	RRMS	RCT	Memory and working memory	Individual, home-based, computer-based	Home-based cognitive training program, designed to increase frequency and intensity of training. 6 weeks, 5 times a week for 30 minutes.	Both	1
Janssen et al. (2015)	49.43 (6.4)	RRMS	RCT (waiting list control)	Attention, working memory, executive functioning and processing speed	Individual	Cognitive training through multimodal videogame-based learning strategies: Hybrid-variable priority training (HVT) program. 8 weeks (10-week window), 20, 1 hour sessions.	Objective	1

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
Jonsson et al. (1993)	46.1 (7.3)	RRMS, secondary CPMS and primary CPMS course	RCT	Memory and attention (concentration)	Individual	Compensation (internal and external memory aids), substitution, direct training (puzzles, etc.) and neuropsychotherapy. Three times a week, 1-1.5 hrs, mean number of treatment hours 17.2.	Both	1
Leavitt et al. (2014)	49.72 (9.98)	RRMS, PPMS, SPMS, PRMS	RCT	Memory and learning	Group	Modified Story Memory Technique (mSMT) focusing on approving the acquisition of info through context and imagery) into long-term memory. 10 sessions.	Objective	2
Lincoln et al. (2002)	43 (10)	SPMS, RRMS, including benign, PPMS	RCT	Range of cognitive deficits (dependent of participants' needs), including memory	Individual	Identification of individual needs. Compensatory techniques includes training in use of external memory aids (diaries, calendars, notebooks) and internal memory aids (visual mnemonics).	Self-report	1

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
Mantynen et al. (2014)	43.5 (8.7)	RRMS	RCT	Attention and working memory	Individual, computer-based	Strategy-oriented computer-based attention and working memory retraining, psychoeducation and teaching compensatory strategies. 13 weeks, once a week for 1 hr. 11 to 85 (mean 31.6) sessions.	Both	1
Martin et al. (2014)	45.2-48.3	Not stated	RCT	Memory	Blended: 2 individual sessions and 10 group sessions	Compensatory (external memory aids) or restitution (encoding and retrieval practice, and attention-retraining exercises e.g. Letter and number cancellation. 10 weeks, once a week for 1.5 hrs, 10 sessions.	Both	2
Mattioli et al. (2010)	42 (41-53)	RRMS	RCT	Attention, information processing, executive function	Individual, computer-based	RehaCom computer-based intensive training. 3 months, three times a week for 1 hr.	Both	1

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
Mattioli et al. (2012)	45.46(10.48)	RRMS	RCT	Attention, information processing and executive function	Individual, computer-based	Intensive neuropsychological training. 3 months, three times a week for 1 hr. approximately 36 sessions per patient.	Both	1
Mattioli et al. (2014)	45 (38-50)	RRMS	RCT	Attention/speeded information, executive function and memory	Individual, computer-based	Domain-specific cognitive training (based on individual cognitive impairment). 15 weeks, twice a week for 1 hr. Mean 26.32 (10.19) number of sessions.	Objective	3
Mattioli et al. (2016)	44.8 (8.69)	RRMS	RCT	Memory, attention/speeded information processing and executive function	Individual, computer-based	Domain-specific cognitive training (based on individual cognitive impairment). 15 weeks, twice a week for 1 hr.	Both	3
Mendozzi et al. (1998)	45.38-47.92	RRMS or secondary CPMS	Quasi-RCT	Memory and attention	Individual, computer-based	Memory training (encoding) and attention tasks. Average of 8 weeks, twice a week for 45 min. 15 sessions in total.	Objective	1

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
Parisi et al. (2014)	43.6 (25-58)	Non-specific MS	RCT	Attention, information processing and executive function	Individual, computer-based	Domain-specific cognitive training. Computer software – RehaCom package	Both	3
Pedulla et al. (2016)	47.5 (9.3)	RRMS, SPMS	RCT	Working memory	Individual, home-based, computer	Computer-based adaptive cognitive training. 8 weeks, once a day, 5 sessions a week each 30 min. 40 sessions in total. Adherence was 87%	Objective	1
Perez-Martin et al. (2017)	44.93 (9.89)	RRMS, PPMS, SPMS	RCT	Memory, attention, processing speed and executive function	Individual, home-based, computer-based	Multi-domain computer-assisted cognitive rehabilitation supported by home-based work. 12 weeks, once a week for 60-75 minutes. 12 sessions in total.	Both	1
Plohmann et al. (1994)	39.7 (10.09)	RRMS, CPMS	CBA (waiting list control)	Attention	Individual, computer-based	Retraining, restitution. 4 weeks, 4 sessions per week for 45-60 min. 16 sessions.	Both	1

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
Plohmann et al. (1998)	44.6 (11.4)	Primary CPMS, Secondary CPMS, RRMS	SCED	Attention	Individual, computer-based	Four attention training programme; focus on two of most affected/diminished attention areas - specific and nonspecific training. Unclear: Three or 6 week, for 40 min. 12 sessions.	Both	1
Pusswald et al. (2014)	42.6 (1.0)	RRMS, SPMS, PPMS	RCT	Divided attention. Cog rehab included memory retraining	Blended: Individual (home-based computer training) and group psychosocial counselling	Cognitive functional training and psychosocial counselling focusing on restitution training and compensation strategies. 5 weeks, three times a week for 30 min.	Both	1
Rosti-Otajärvi et al. (2013a)	43.5 (8.7);	RRMS	RCT	Attention and working memory	Individual, computer-based	Strategy-oriented computer-based attention and working memory retraining, psychoeducation and teaching compensatory strategies. 13 weeks, once a week for 1 hr. mean number of sessions	Both	2

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
						31.6 (14.1) (range 11–85).		
Rosti-Otajärvi et al. (2013b)	43.7 (8.7)	RRMS	RCT	Attention and working memory	Individual, computer-based	Strategy-oriented computer-based attention and working memory retraining, psychoeducation and teaching compensatory strategies. 13 weeks, once a week for 1 hr. Mean number of sessions 32.1 (14.3).	Self-report	3
Sastre-Garriga et al. (2011)	50.73 (10.88)	RRMS, PPMS, SPMS	CBA	Attention, executive function and memory	Individual, computer-based	Intervention targeted worse affected cognitive domain. RehaCom Training. 5 weeks. 4 times a week.	Objective	1
Shatil et al. (2010)	43.75 (12.15)	RRMS and PRMS	CBA	Non-specific: it is composed of 15 evaluation tasks measuring a wide range of cognitive abilities such as memory, attention and eye-hand coordination	Individual, computer-based, home-based	CogniFit Personal Coach (CPC), a home-based, computerized, individualized cognitive training program. 12 weeks, three times a week for 20-30 min.	Both	1

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
Shevil and Finlayson (2010)	52.4 (10.3)	Non-specific MS	Before and after	Memory, attention, information processing and executive function	Group	Internal and external compensatory strategies (e.g. mnemonics, incorporating a day planner or digital recorder and organizing spaces). 5 weeks, once a week for 2 hours. Inclusion criteria: participants able to attend at least 4 out of 5 session.	Both	1
Solari et al. (2004)	46.2 (9.2)	RRMS, PRMS, CPMS	RCT	Memory and attention	Individual, computer-based	RehaCom; computer-based memory and attention retraining. 8 weeks, twice a week for 45 min. Number of sessions 16 (7-16).	Both	1
Stuifbergen et al. (2012)	47.95 (8.76)	Non-specific MS	RCT	Attention, Memory, Problem solving, executive skills	Blended	MAPSS-MS: group sessions focusing on compensatory strategies and individual-based computer-assisted cognitive training program. 2 months. Group: Once a week;	Both	1

First author, year published	Age (years; Mean (SD) or Median [interquartile range] or range)	Type of multiple sclerosis	Study design	Cognitive domain	Format of intervention delivery	Intervention technique	Outcomes (objective, self-report, or both)	Study status
						Individual: three times a week. Group: 2 hrs. Individual: 45 min. Group: mean number of sessions 6.1 (1.4).		
Tesar et al. (2005)	45.3 (9.2)	RRMS and SPMS	RCT	Memory and learning	Group, computer-based	Direct functional training and teaching of compensation strategies relevant to everyday life. 4 weeks, once a week for 1 hr. 12 sessions.	Both	1
Vogt et al. (2009)	43.2 (8.8)	RRMS, SPMS and CPMS	Quasi-RCT	Working memory	Home-based, computer-based, individual	High intensity, computer-based, working memory training – BrainStim. 4-8 weeks, 2-4 times a week for 45 min. 16 sessions (nearly 100% completed all sessions)	Both	1

Appendix 6 Assessment of the quality of reporting in the included studies (Chapter 2)

Information was reported completely, as per reporting item description	
Information was reported incompletely, as per reporting item description	
Information was not reported	
Reporting item not applicable (e.g., for computer-based interventions)	NA

Study IDs: Allen et al. (1998);[1] Altun et al. (2015);[2] Amato et al. (2014);[3] Birnboim and Miller (2004);[4] Bonavita et al. (2015);[5] Brenk et al. (2008);[6] Brissart et al. (2013);[7] Campbell et al. (2016);[8] Carr et al. (2014);[9] Cerasa et al. (2013a);[10] Charvet et al. (2015);[11] Chiaravalloti et al. (2005);[12] Chiaravalloti et al. (2012);[13] Chiaravalloti et al. (2013);[14] Chiaravalloti and DeLuca (2015);[15], De Giglio et al. (2015);[16] De Giglio et al. (2016);[17] Dobryakova et al. (2014);[18] Ernst et al. (2012);[19] Ernst et al. (2013);[20] Ernst et al. (2015);[21] Filippi et al. (2012);[22] Fink et al. (2010);[23] Gentry (2008);[24] Gich et al. (2015);[25] Hancock et al. (2015);[26] Hanssen et al. (2015);[27] Hildebrandt et al. (2007);[28] Janssen et al. (2015);[29] Jonsson et al. (1993);[30] Leavitt et al. (2014);[31] Lincoln et al. (2002);[32] Mantynen et al. (2014);[33] Martin et al. (2014);[34] Mattioli et al. (2010);[35] Mattioli et al. (2012);[36] Mattioli et al. (2014);[37] Mattioli et al. (2016);[38] Mendozzi et al. (1998);[39] Parisi et al. (2014);[40] Pedulla et al. (2016);[41] Perez-Martin et al. (2017);[42] Plohmann et al. (1994);[43] Plohmann et al. (1998);[44] Pusswald et al. (2014);[45] Rosti-Otajärvi et al. (2013a);[46] Rosti-Otajärvi et al. (2013b);[47] Sastre-Garriga et al. (2011);[48] Shatil et al. (2010);[49] Shevil and Finlayson (2010);[50] Solari et al. (2004);[51] Stuifbergen et al. (2012);[52] Tesar et al. (2005);[53] Vogt et al. (2009)[54]

ID	Broad aspect of reporting													
	Clinical characteristics of participants	Theoretical framework of the intervention	Intervention active ingredients & MoA	Intervention session content	Intervention procedures	Level of professional training of facilitator	No. of people who delivered the intervention	Intervention-specific facilitator training	Competency to deliver intervention	Individual or group delivery	Intended and actual intervention 'dose'	Intervention materials	Assessment of fidelity of delivery	Adherence/ compliance of participants
1						NA	NA	NA	NA				NA	
2						NA	NA	NA	NA				NA	
3						NA	NA	NA	NA				NA	
4						NA	NA	NA	NA				NA	
5						NA	NA	NA	NA				NA	
6														
7														
8						NA	NA	NA	NA				NA	
9														
10						NA	NA	NA	NA				NA	

ID	Broad aspect of reporting													
	Clinical characteristics of participants	Theoretical framework of the intervention	Intervention active ingredients & MoA	Intervention session content	Intervention procedures	Level of professional training of facilitator	No. of people who delivered the intervention	Intervention-specific facilitator training	Competency to deliver intervention	Individual or group delivery	Intended and actual intervention 'dose'	Intervention materials	Assessment of fidelity of delivery	Adherence/ compliance of participants
11						NA	NA	NA	NA				NA	
12														
13														
14														
15														
16						NA	NA	NA	NA				NA	
17						NA	NA	NA	NA				NA	
18														
19														
20														
21														
22						NA	NA	NA	NA				NA	
23														
24														
25						NA	NA	NA	NA					
26						NA	NA	NA	NA				NA	
27													NA	
28						NA	NA	NA	NA				NA	
29														
30														
31														
32														
33						NA	NA	NA	NA				NA	
34														

ID	Broad aspect of reporting													
	Clinical characteristics of participants	Theoretical framework of the intervention	Intervention active ingredients & MoA	Intervention session content	Intervention procedures	Level of professional training of facilitator	No. of people who delivered the intervention	Intervention-specific facilitator training	Competency to deliver intervention	Individual or group delivery	Intended and actual intervention 'dose'	Intervention materials	Assessment of fidelity of delivery	Adherence/ compliance of participants
35						NA	NA	NA	NA				NA	
36						NA	NA	NA	NA				NA	
37						NA	NA	NA	NA				NA	
38						NA	NA	NA	NA				NA	
39						NA	NA	NA	NA				NA	
40						NA	NA	NA	NA				NA	
41						NA	NA	NA	NA				NA	
42						NA	NA	NA	NA				NA	
43						NA	NA	NA	NA				NA	
44						NA	NA	NA	NA				NA	
45														
46						NA	NA	NA	NA				NA	
47						NA	NA	NA	NA				NA	
48						NA	NA	NA	NA				NA	
49						NA	NA	NA	NA				NA	
50														
51						NA	NA	NA	NA				NA	
52														
53						NA	NA	NA	NA				NA	
54						NA	NA	NA	NA				NA	

Appendix 7 Main themes of CRAMMS intervention sessions (Chapter 3)

Session theme	Description of session content
Session 1: Introduction to the programme	An introduction to group members, format of the sessions. Discussing problems participants experienced with memory and attention, and the strategies they had been using to help with these problems.
Session 2: Memory and memory problems	Memory theory: introducing participants to how memories are created stored and retrieved. explanations of how problems with memory can occur
Session 3: Attention I	Attention theory; including the different types of attention, distractors and how attention can be improved
Session 4: Attention II	Presenting ways in which participants can be more mindful of what they are doing in terms of encoding and recall, story recall picking out important information and discarding irrelevant information. That is, the 5Ws (what, when, who, where, why) and H (how) strategy.
Session 5: Introducing Internal Memory Aids I	The first session on internal memory strategies: - Session 5: rehearsal, chunking and categorisation. - Session 6: visual imagery, associations, story method, first letter cues, rhymes - Session 7: the little and often strategy, the PQRST (preview, question, read, state and test) method, which facilitates deeper level processing of information. This session also had a focus on the importance of relaxing on memory and attention. The aim of these sessions was to motivate participants to engage with internal memory aids
Session 6: Internal Memory Aids II	
Session 7: Internal Memory Aids III	
Session 8: Introduction to External memory Aids and Diaries	This was the second part to compensatory strategies, introducing participants to external memory aids. This session focused on effective diary use. Participants were also presented with psychosocial tips in terms of pacing and development a positive attitude to memory aids.
Session 9: External memory Aids II	This was the second session on external memory aids, focusing on potential problems associated with using external memory aids and how to minimise these.
Session 10: Review of the Programme and Fine-tuning	This was the final session, with a focus on providing a summary of what had been discussed in previous sessions as well as enabling participants to seek clarification on any aspects of the intervention they still struggled with. Family members were encouraged to attend this session. Participants were encouraged to continue using the strategies after the groups had ended.

Appendix 8 Example coding sheet from video observations (Chapter 3)

Site and Group No:				Session number:		
Date of session:				Duration of session:		
Start of recording:				Start of session:		
Time (mins)	Manual Content All sessions	Manual Content Specific session	Other Content	Therapist activity	Patient activity	Text
1						
2						
3						
4						
5						
6						
7						
8						
9						

Appendix 9 CRAMMS Video Analysis Codes (Chapter 3)

Directed content analysis: a priori coding scheme

Activities and content of discussions of therapists and participants

Therapist Activities

Activity	Description
Discussing consent to video the session	Gaining verbal consent to video the individual intervention sessions
Providing encouragement/ reassurance	Encouragement: the therapist provides encouragement enabling participants to explore their feelings and thoughts more completely and to continue talking. Reassurance: the therapist validate participants' experiences, by letting them know that many people with MS also feel and think in similar ways.
Providing explanation of memory and attention	Providing and explanation of memory and attention problems, including specific (i.e., mention of page numbers) and non-specific references to content in the intervention manual.
Facilitating group discussion (non-specific prompts)	Therapist guides the group's discussions and manages the sessions to ensure they stay relevant to the objectives of the sessions. Additionally, the therapist enables and empowers the group to engage in all aspects of the sessions. This includes providing prompts to further conversations (e.g., asking participants to elaborate on points they make), handling conflict in a group
Providing general information related to memory	Providing general information related to memory which is not covered in educational material
Presenting/ discussing educational material	Presenting and/or discussing specific content in the intervention manual, including prompts and task materials *When not to use:* If discussing educational material related to strategies, use code 'presenting/discussing cognitive rehabilitation strategies'
Providing feedback	Providing feedback on intervention manual specific questions, homework, tasks completed during the sessions
Paraphrasing other participants' contributions	Repeating back the important parts of what participant has said without changing the meaning of what they said *When not to use:* Summarising of e.g., sessions, manual content
Presenting/ discussing cognitive rehabilitation strategies	Presenting, explaining and/or discussing memory and attention strategies. This includes reference to specific pages in the manual (i.e., reference to page numbers), or making non-specific references to content in the manual.

Activity	Description
	When not to use: If discussing educational material unrelated to strategies, use code 'presenting/discussing educational material'
Summarising cognitive rehabilitation activities	Therapist briefly summarises the current session (at the end of a lengthy section or at the end of the session) or a previous session. The aim is to organise participants' thinking.
CRAMMS research activities/ research processes	Providing an explanation of CRAMMS research activities or research process, for example recruitment, randomisation, feedback interviews, outcome visits. *When not to use:* Discussing aspects of the group intervention e.g., the format, administrative issues.
Discussing housekeeping e.g., making drinks, breaks, toilets	Discussing fire exits, no smoking policy, toilets, drinks, breaks *When not to use:* Discussing organisation of sessions and administrative issues, travel arrangements
Providing/discussing information about the organisation sessions, venue, group, etc.	Providing information about the frequency of sessions, dates, venue (including room changes), the members of the group, sending reminders to participants (a few days before each sessions) *When not to use:* Discussing housekeeping such as discussing fire exits, when breaks are scheduled, toilet facilities and access to the building. Discussing travel expenses (i.e., reimbursement)
Discussing MS e.g., diagnosis, living with MS, impact on family and/or caregivers	When therapist contributes to and/or engages with participant discussions centred around MS and living with MS
Preparing materials	Activities relating to tasks e.g., distributing pictures, sheets of paper for content-specific exercises, distracting participants during tasks (part of the task to learn about e.g., different types of distractors)
Therapist Social chat	Therapist discussing topics unrelated to the intervention and/or content of the manual, which are social in nature. This includes therapist initiating the chat or are engaging in a conversation initiated by a participant
Discussing travel expenses	Discussing the reimbursement of travel expenses *When not to use:* Discussing the organisation of sessions, venue

Participant Activities

Activity	Description
Asking for clarification/ further information related to intervention content	Asking the therapist questions related (directly or indirectly) to the content of the intervention *When not to use:* The sentence is not phrased as a question and/or is not specific to the content of the intervention
Asking questions unrelated to intervention content	Asking the therapist questions unrelated (directly or indirectly) to the content of the intervention *When not to use:* The sentence is not phrased as a question and/or is related to the content of the intervention
Discussing the CRAMMS group intervention - format	Feedback on the intervention format: e.g., groups, how it was delivered, feedback on the assistant psychologist running the groups, the frequency of sessions and their duration *When not to use:* When discussing manual content, such as the strategies that were covered, explanations of memory and attention
Describing emotions and coping strategies	Describing how they feel about their memory and attention problems. Discussing how they cope to deal with any (negative) emotions associated with their memory and attention problems that are unrelated to specific memory and attention strategies. For example, avoiding social settings if they feel they are unable to keep up with the conversation or likely to forget people's names *When not to use:* Describing memory and/or attention problems without an emption attached to the description Making specific reference to internal and external memory strategies in relation to memory and attention problems
Describing problems related to memory and attention	Describing the memory and attention problems they experience in their day to day life *When not to use:* When discussing cognitive rehabilitation strategies they use to address/minimise the memory and attention problems they have
Discussing cognitive rehabilitation strategies	Discussing memory and attention strategies. This includes reference to specific pages in the manual (i.e., reference to page numbers), or making non-specific references to content in the manual. *When not to use:*

Activity	Description
	If discussing educational material unrelated to strategies, use code 'presenting/discussing educational material'
Input from family/carers	When family members and/or carers who are attending the sessions are discussing the impact of the intervention on the person with MS
Feedback on take home activities	Providing any comments, criticism and opinion of the take home activities.
Giving advice/sharing	Participants sharing with others/ giving advice on how to cope with MS (all the issues associated with the condition) in relation to accessing support (e.g., income support, adaptations to the home, applying for disability badges). *When not to use:* When discussing hospital visits e.g., annual reviews with the neurologist, seeing the MS nurse
Discussing use of strategies in relation to improvements in memory and attention as a result of the intervention	Discussing use of memory and attention strategies that participants are now using as a result of attending the group intervention, and/or improvements in these cognitive domains as a result of attending the groups. This includes reference to specific pages in the manual (i.e., reference to page numbers), or making non-specific references to content in the manual. *When not to use:* When discussing the general problems that they have with memory and attention
Discussing educational material	Discussing specific content in the intervention manual, including discussing tasks/exercises. *When not to use:* If discussing/filling in educational material related to strategies, use code 'discussing cognitive rehabilitation strategies' rather than this code If providing feedback on take home activities When there are silences during tasks (filling in or reading material in the manual). Code as 'filling in educational material'
Discussing CRAMMS research activities/ research process e.g., outcome visits	Discussing CRAMMS research activities or research process, for example recruitment, randomisation, feedback interviews, outcome visits. *When not to use* When discussing aspects specific to the group intervention
Housekeeping	Discussing fire exits, no smoking policy, toilets, drinks, breaks *When not to use:*

Activity	Description
	Discussing organisation of sessions and administrative issues, travel arrangements
Hospital visit discussion	Discussing hospital visits with neurologist, MS nurse, and other healthcare providers. Including annual check-up dates, personal experience of these visits
Discussing information about the organisation of sessions, venue, group, etc.	Discussing the frequency of sessions, dates, venue (including room changes), the members of the group, travel expenses (e.g., mileage, bus tickets). *When not to use:* Discussing travel expenses. E.g., “I only live in [place] so I'm fine [in terms of getting travel expenses reimbursed].
Discussing living with MS e.g., symptoms, diagnosis, living with MS, impact on family and/or caregivers	Participant discusses living with MS *When not to use:* Discussing hospital visits with neurologist, MS nurse, and other healthcare providers. Including annual check up Explicitly discussing memory and attention problems and the impact this may have on family, employment, etc. Use code “Describing problems related to memory and attention”
Filling in educational material	Activities related to tasks e.g., distributing pictures, sheets of paper for content-specific exercises, when completing these tasks, filling in educational material. *When not to use:* When there are silences unrelated to the intervention manual
Participant social chat	Discussing topics unrelated to the intervention and/or content of the manual, which are social in nature. *When to use:* Discussing holiday plans Discussing pets
Travel expenses	Discussing the reimbursement of travel expenses. *When not to use;* Discussing the organisation of sessions, venue

Content of the discussions: manual-specific and other

Other Content (not cognitive rehabilitation, unrelated to treatment)

Activity	Description
Administration	Discussing administrative tasks such as Handing out manuals Handing out pens Discussing travel expenses, including arranging taxis, parking, reimbursing travel expenses
Break	To be used when there is a break in the session and the video is still recording *When not to use:* Therapist is announcing that it is time for a break. Use 'housekeeping' code
CRAMMS Research activities	Discussing CRAMMS research activities or research process, for example recruitment, randomisation, feedback interviews, outcome visits. *When not to use:* Discussing aspects of the group intervention e.g., the format, administrative issues
Housekeeping	Discussing fire exits, no smoking policy, toilets, drinks, breaks *When not to use:* Discussing organisation of sessions and administrative issues, travel arrangements
Hospital visits	Discussing hospital visits e.g., annual reviews with the neurologist, MS nurses, occupation therapists
Organisation of sessions	Discussing the organisation of sessions, e.g., the venue, dates of sessions and group members. Discussing the videotaping of sessions. *When not to use*: When discussing housekeeping such as breaks, location of toilets, housekeeping, mobility and access issues
Laughter	Laughter, when there is no distinguishable dialogue *When not to use:* When there is laughter but there is also intelligible chat
Living with MS	Discussing living with/ general information MS e.g., symptoms such as fatigue *When not to use:* When discussing the organisation of sessions e.g., venue (room) Discussing cognitive deficits (e.g., memory and attention issues) associated with MS, in relation to their personal lives (e.g., quality of life, emotions) How participants cope with these memory and attention issues
MS services	Discussing accessing MS services that provide support
Preparing materials	Preparing materials for tasks e.g., handing out paper, props (e.g., pictures)

Activity	Description
Silences	There is no one talking
Social chat	Discussing topics unrelated to MS or the intervention *When not to use:* When preparing, filling in or reading material related to the manual/intervention

Treatment manual content all sessions: applies to all ten sessions of the intervention

Activity	Description
Discuss take home activities	Discussion on take home activities *When not to use:* When discussing memory and attention, and memory and attention strategies
Learn about attention and memory	When discussions are about memory and attention theory, the importance of memory and attention to daily life, what types of memory and attention problems there are *When not to use:* When discussing memory and attention strategies in relation to memory and attention problems
Learn about strategies to address attention and memory problems	When discussions are about the different external and internal strategies that can be used to help minimise/address the different memory and/or attention issues *When not to use:* When solely discussing memory and attention problems
Previous session	Making reference to the content of a previous session
Reflect on personal experience	Reflection of memory and attention problems, and/or the use of memory strategies, as they relate to their personal life and/or personal experiences

Session-specific codes

(In order as per manual content format)

Session 1– Introduction to the Programme

Activity and description
Introduction to others
Discuss format of session and memory programme
Establish group rules
Explore attention and memory
Discussion; Things which participants forget
Discussion: how participants feel when having difficulty with memory
Discussion: participants' own techniques to help to help with memory and/or attention problems
Rating of effectiveness of own techniques/strategies
Advice to share
What else want to know?
Explanation of take home activity

Session 2 – Memory and Memory Problems

Activity
Repeat introductions
Review of take home activity
What is memory
Processes involved in Memory
Case study task - Sensory memory
Memory storage - Explanation of working memory and long-term memory
Memory retrieval - Explanation of immediate recall/Delayed recall /Distractors
Memory systems explanation
Take home activity task 1
Take home activity Task 2

Session 3 - Attention

Activity
Review session 2
Review take home activity -
Different types attention - sustained/divided attention
Different types of distractors - internal and external distractors
Attention exercise- Newspaper exercise
Attention exercise plus distractor
Techniques to improve attention - How participants improve their attention skills
Take home task 1
Take home Task 2

Session 4– Attention II

Activity
Review session 3
Review take home activity
Story recall exercise
Introduction to 5W and the H – Who, What, Where, When, Why and How?
Story recall with 5W and the H – Who, What, Where, When, Why and How?
Discussion on instances where participants find it difficult to remember information
Discussion: How attention improved
Discussion of useful attention strategies to remember as presented in the intervention manual
Exercise 3 based on the 5Ws and the H
Take home task 1
Take home Task 2

Session 5 – Introducing Internal Memory Aids

Activity
Review session 4
Review take home activity
Use of internal memory aids - What is meant by internal memory aids
Discussion: Rehearsal and repetition strategies
Chunking and exercise:
Categorisation and exercise:
Exercise : Recall of telephone number
Take home task 1
Take home Task 2

Session 6 – Internal Memory Aids II

Activity
Review session 5
Review take home activity
Levels of processing The difference between deep-level and shallow-level processing
Visual imagery
Associations
Story method
First letter cues
Rhymes
Exercise 3: Remember visual imagery story from Exercise 2
Take home task 1
Take home Task 2

Session 7 –Internal Memory Aids III

Activity
Review session 6

Activity
Review take home activity
Little and often strategy:
PQRST method
Chocolate truffles – errorless learning or learning
Relaxation
Take home task 1
Take home Task 2

Session 8 - Introduction to External Memory Aids & Diaries

Activity
Review session 7
Review take home activity
Memory aids – internal and external
Diary use – using a diary effectively; useful tips when using a diary
Pacing - Making the most of your energy: Pacing Activity (3Ps)
Positive attitude - Developing a positive attitude to memory aids
Take home task

Session 9 – External Memory Aids II

Activity
Review session 8
Review take home activity
Problems with external aids:
Memory aids use in future? What prevents you from using these? Problems and possible solutions
Case studies: Making Life a Bit Easier
Useful tips when using external memory aids
Take home task 1
Take home Task 2

Session 10 – Review & Fine-tuning

Activity
Review session 9
Review take home activity
Overview of sessions
Favourite strategies
Problems from session 1 - Reflecting on memory problems
Group feedback - Changes since the programme
Take home activity

Appendix 10 Distribution of assistant psychologist activity categories and corresponding codes by site (Chapter 3)

Therapist activity categories	Site 1 (n=7980)		Site 2 (n=543)		Site 3 (n=4921)		Site 4 (n=3019)		Site 5 (n=1806)		Total (N=18269)	
	n	%	n	%	n	%	n	%	n	%	n	%
Administrative/ organisational	**278**	**3.4**	**5**	**1**	**141**	**2.8**	**111**	**3.7**	**26**	**1.4**	**561**	**3**
Consent to video the session	3	0	0	0	0	0	0	0	0	0	3	0
Discussing housekeeping	40	0.5	1	0.2	21	0.4	27	0.9	8	0.4	97	0.5
Discussing travel expenses	29	0.4	0	0	10	0.2	2	0.1	2	0.1	43	0.2
Providing information about sessions	123	1.5	2	0.4	88	1.8	38	1.3	7	0.4	258	1.4
Discussing CRAMMS research activities	58	0.7	0	0	21	0.4	25	0.8	5	0.3	109	0.6
Preparing materials	25	0.3	2	0.4	1	0	19	0.6	4	0.2	51	0.3
Psychoeducation	**2824**	**35.4**	**176**	**32.5**	**1482**	**30.1**	**1105**	**36.6**	**474**	**26.2**	**6061**	**33.1**
Providing explanation: memory and attention	437	5.5	8	1.5	237	4.8	271	9	110	6.1	1063	5.8
Presenting/ discussing cognitive rehabilitation strategies	1484	18.6	110	20.3	708	14.4	508	16.8	208	11.5	3018	16.5
Presenting/ discussing educational material	903	11.3	58	10.7	537	10.9	326	10.8	156	8.6	1980	10.8
Therapist facilitation skills	**890**	**11.1**	**57**	**10.4**	**570**	**11.5**	**441**	**14.7**	**164**	**9.1**	**2122**	**11.6**
Facilitating group discussion	258	3.2	19	3.5	202	4.1	126	4.2	38	2.1	643	3.5
Paraphrasing other participants' contributions	84	1.1	14	2.6	69	1.4	62	2.1	10	0.6	239	1.3
Providing encouragement/ reassurance	162	2	4	0.7	51	1	46	1.5	29	1.6	292	1.6
Providing feedback	250	3.1	16	2.9	197	4	150	5	54	3	667	3.7
Summarising cognitive rehabilitation activities	136	1.7	4	0.7	51	1	57	1.9	33	1.8	281	1.5
Miscellaneous/ Other	**82**	**1.1**	**3**	**0.6**	**34**	**0.7**	**23**	**0.8**	**4**	**0.3**	**146**	**0.8**
Living with MS	6	0.1	0	0	3	0.1	2	0.1	1	0.1	12	0.1
Providing general memory information (not manual)	36	0.5	0	0	15	0.3	11	0.4	1	0.1	63	0.3
Therapist Social chat	40	0.5	3	0.6	16	0.3	10	0.3	2	0.1	71	0.4

Appendix 11 Distribution of assistant psychologist activity categories and corresponding codes by session number (Chapter 3)

Therapist activity categories	Session 1		Session 2		Session 3		Session 4		Session 5		Session 6		Session 7		Session 8		Session 9		Session 10	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Administrative/ organisational	203	14.7	49	2.8	40	2.2	34	1.4	26	1.5	30	1.7	26	1.5	26	1.5	15	0.9	112	5.4
Consent to video the session	1	0.1	0	0	0	0	1	0	0	0	0	0	1	0.1	0	0	0	0	0	0
Discussing CRAMMS research activities	23	1.7	4	0.2	0	0	0	0	1	0.1	1	0.1	0	0	1	0.1	0	0	79	3.9
Discussing housekeeping	23	1.7	18	1	9	0.5	10	0.4	7	0.4	5	0.3	7	0.4	12	0.7	3	0.2	3	0.1
Discussing travel expenses	9	0.6	3	0.2	3	0.2	12	0.5	3	0.2	4	0.2	2	0.1	2	0.1	2	0.1	3	0.1
Providing information about sessions	147	10.6	21	1.2	11	0.6	9	0.4	11	0.6	8	0.4	14	0.8	9	0.5	10	0.6	18	0.9
Preparing materials	0	0	3	0.2	17	0.9	2	0.1	4	0.2	12	0.7	2	0.1	2	0.1	0	0	9	0.4
Psychoeducation	240	17.3	762	43.1	610	31.7	829	35.1	667	36	673	37.5	586	35.4	644	35.9	580	33.8	470	23.4
Providing explanation of memory and attention	39	2.8	483	27.3	218	11.3	62	2.6	30	1.6	70	3.9	71	4.3	20	1.1	4	0.2	66	3.3
Presenting educational material	133	9.6	217	12.3	259	13.5	255	10.8	168	9.1	189	10.5	189	11.4	151	8.4	214	12.5	205	10.2
Presenting cognitive rehabilitation strategies	68	4.9	62	3.5	133	6.9	512	21.7	469	25.3	414	23.1	326	19.7	473	26.4	362	21.1	199	9.9
Therapist facilitation skills	240	17.3	286	16.1	259	13.4	173	7.4	116	6.3	154	8.6	156	9.3	265	14.8	175	10.2	298	14.7
Facilitating group discussion	130	9.4	94	5.3	95	4.9	44	1.9	27	1.5	29	1.6	32	1.9	71	4	76	4.4	45	2.2
Paraphrasing other participants' contributions	29	2.1	52	2.9	28	1.5	23	1	10	0.5	19	1.1	9	0.5	33	1.8	15	0.9	21	1
Providing encouragement	46	3.3	36	2	14	0.7	10	0.4	16	0.9	34	1.9	45	2.7	43	2.4	16	0.9	32	1.6
Providing feedback	22	1.6	64	3.6	91	4.7	59	2.5	53	2.9	65	3.6	60	3.6	102	5.7	58	3.4	93	4.6
Summarising cognitive rehabilitation activities	13	0.9	40	2.3	31	1.6	37	1.6	10	0.5	7	0.4	10	0.6	16	0.9	10	0.6	107	5.3

Therapist activity categories	Session 1		Session 2		Session 3		Session 4		Session 5		Session 6		Session 7		Session 8		Session 9		Session 10	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Miscellaneous/ Other	28	2	39	2.2	14	0.8	15	0.6	7	0.4	6	0.4	3	0.2	10	0.6	11	0.6	13	0.6
Living with MS	6	0.4	4	0.2	0	0	1	0	0	0	0	0	0	0	1	0.1	0	0	0	0
Providing general memory information (not manual)	10	0.7	28	1.6	9	0.5	3	0.1	3	0.2	1	0.1	1	0.1	2	0.1	5	0.3	1	0
Therapist Social chat	12	0.9	7	0.4	5	0.3	11	0.5	4	0.2	5	0.3	2	0.1	7	0.4	6	0.3	12	0.6

Appendix 12 Assistant psychologist activities - illustrative text (Chapter 3)

Therapist activity categories	Example text
Consent to video the session	*"We've also got our camera running if that's ok?"*
Discussing CRAMMS research activities/ research processes	*"it's [outcome assessment] supposed to be completely unbiased so they [outcome assessor] don't know what group you're in"*
Discussing housekeeping e.g., making drinks, breaks, toilets	*"I'm not aware of any fire alarms today, any testing"*
Discussing living with MS	*"at the end of the day it is your MS and you need to feel comfortable and feel like you're getting benefits from the medication"*
Discussing travel expenses	*"if you give me a receipt for a taxi or if you want me to pay for petrol or anything I can do that the following week"*
Facilitating group discussion (non-specific prompts)	*"Do you have troubles remembering where you've parked?"*
Paraphrasing other participants' contributions	*"she [participant] said that for her it was distracting to always think where the toilet is"*
Preparing materials	*"if I give you these images [hands materials out]"*
Presenting/ discussing educational material	*"on the second page I think there should be 76 [Es to count as part of a task on distractors]*
Presenting/ discussing cognitive rehabilitation strategies	*"categorisation is particularly more useful in the short-term, for example for shopping lists"*
Providing encouragement/ reassurance	*"it takes practice and it takes skill to use them [strategies] in the first place, just try them"*
Providing explanation of memory and attention	*"if we process it [information] well enough in those 15 to 30 seconds we can then push that along into long term memory"*
Providing feedback	*"I don't think it's a problem of memory, I think its again distraction, you were probably doing something else focusing on something else"*
Providing general information related to memory not included in manual	*"addiction as far as I know is more to do with neurotransmitters such as dopamine [participant had asked if addiction was to do with emotional memory]"*
Providing/discussing information about the organisation of sessions.	*"I will let you know that next week I am on annual leave so there will be another lady [other AP's name] coming to run the group"*
Summarising cognitive rehabilitation activities	*"just to summarise, we've gone through two weeks of attention strategies"*
Therapist Social chat	*"I think it's a miracle if you can decipher what I'm writing to be honest [referring to their handwriting on the whiteboard]"*

Appendix 13 Distribution of participant activity categories and corresponding activity codes according to site (Chapter 3)

Participant activity categories	Site 1 (n=7980)		Site 2 (n=543)		Site 3 (n=4921)		Site 4 (n=3019)		Site 5 (n=1806)		Total (N=18269)	
	n	%	n	%	n	%	n	%	n	%	n	%
Administrative/ organisational	61	0.8	1	0.2	38	0.7	34	1.1	34	1.9	168	0.9
Discussing CRAMMS research activities	10	0.1	1	0.2	1	0	9	0.3	3	0.2	24	0.1
Discussing CRAMMS group format - feedback	33	0.4	0	0	21	0.4	17	0.6	29	1.6	100	0.5
Housekeeping	4	0.1	0	0	6	0.1	1	0	0	0	11	0.1
Information about sessions, venue, group	14	0.2	0	0	8	0.2	6	0.2	2	0.1	30	0.2
Travel expenses	0	0	0	0	2	0	1	0	0	0	3	0
Living with MS	207	2.6	4	0.7	164	3.4	50	1.7	69	3.8	494	2.7
Discussing living with MS (not cognition-specific)	200	2.5	4	0.7	160	3.3	50	1.7	69	3.8	483	2.6
Hospital visit discussion	7	0.1	0	0	4	0.1	0	0	0	0	11	0.1
Psychoeducation	3090	39.3	268	49.4	2089	42.4	1149	38.1	968	53.6	7602	41.7
Asking questions (intervention content)	38	0.5	1	0.2	33	0.7	26	0.9	8	0.4	106	0.6
Discussing educational material	801	10	117	21.5	619	12.6	410	13.6	397	22	2344	12.8
Feedback on take home activities	264	3.3	15	2.8	179	3.6	68	2.3	36	2	562	3.1
Filling in educational material	164	2.1	5	0.9	31	0.6	13	0.4	17	0.9	230	1.3
Describing memory and attention problems	571	7.2	41	7.6	423	8.6	163	5.4	166	9.2	1364	7.5
Discussing cognitive rehabilitation strategies	1257	15.8	87	16	773	15.7	451	14.9	310	17.2	2878	15.8
Discussing use of strategies (intervention)	33	0.4	2	0.4	31	0.6	18	0.6	34	1.9	118	0.6

Participant activity categories	Site 1 (n=7980)		Site 2 (n=543)		Site 3 (n=4921)		Site 4 (n=3019)		Site 5 (n=1806)		Total (N=18269)	
	n	%	n	%	n	%	n	%	n	%	n	%
Psychosocial aspects of cognitive issues in MS	107	1.3	6	1.1	52	1.1	21	0.7	21	1.2	207	1.1
Giving advice/sharing	9	0.1	0	0	4	0.1	4	0.1	0	0	17	0.1
Input from family/carers	3	0	0	0	0	0	0	0	0	0	3	0
Describing emotions and coping strategies	95	1.2	6	1.1	48	1	17	0.6	21	1.2	187	1
Miscellaneous/ Other	326	4.1	21	3.9	259	5.3	82	2.7	42	2.3	730	4
Participant social chat	320	4	21	3.9	259	5.3	81	2.7	42	2.3	723	4
Asking questions (not intervention content)	6	0.1	0	0	0	0	1	0	0	0	7	0

Appendix 14 Distribution of participant activity categories and corresponding activity codes, by session number (Chapter 3)

Participant activity categories	Session 1		Session 2		Session 3		Session 4		Session 5		Session 6		Session 7		Session 8		Session 9		Session 10	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Administrative/ organisational	16	1.2	13	0.8	2	0.2	3	0.1	2	0.2	6	0.4	5	0.3	3	0.3	7	0.4	111	5.4
Discussing CRAMMS research activities	5	0.4	1	0.1	0	0	1	0	1	0.1	0	0	1	0.1	0	0	1	0.1	14	0.7
Discussing CRAMMS group format	0	0	0	0	1	0.1	0	0	0	0	3	0.2	2	0.1	1	0.1	2	0.1	91	4.5
Housekeeping	1	0.1	5	0.3	1	0.1	2	0.1	0	0	0	0	0	0	1	0.1	0	0	1	0
Information about sessions	9	0.6	5	0.3	0	0	0	0	1	0.1	3	0.2	2	0.1	1	0.1	4	0.2	5	0.2
Travel expenses	1	0.1	2	0.1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Living with MS	93	6.7	45	2.5	33	1.8	22	0.9	25	1.3	14	0.8	25	1.6	126	7.1	38	2.2	73	3.6
Discussing living with MS (not cognition-specific)	90	6.5	43	2.4	32	1.7	22	0.9	25	1.3	14	0.8	24	1.5	125	7	35	2	73	3.6
Hospital visit discussion	3	0.2	2	0.1	1	0.1	0	0	0	0	0	0	1	0.1	1	0.1	3	0.2	0	0
Psychoeducation	411	29.6	471	26.6	839	43.6	1175	49.6	920	49.5	827	46	774	46.7	602	33.5	808	47	775	38.4
Asking questions) (intervention content)	10	0.7	37	2.1	20	1	11	0.5	4	0.2	12	0.7	4	0.2	0	0	1	0.1	7	0.3
Discussing educational material	33	2.4	75	4.2	225	11.7	463	19.6	366	19.7	361	20.1	409	24.7	54	3	98	5.7	260	12.9
Feedback on take home activities	1	0.1	42	2.4	106	5.5	157	6.6	44	2.4	42	2.3	52	3.1	38	2.1	29	1.7	51	2.5
Filling in educational material	6	0.4	4	0.2	98	5.1	53	2.2	25	1.3	8	0.4	23	1.4	0	0	12	0.7	1	0
Describing memory and attention problems	214	15.4	226	12.8	279	14.5	169	7.1	114	6.1	90	5	61	3.7	75	4.2	54	3.1	82	4.1

Participant activity categories	Session 1		Session 2		Session 3		Session 4		Session 5		Session 6		Session 7		Session 8		Session 9		Session 10	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Discussing cognitive rehabilitation strategies	147	10.6	87	4.9	111	5.8	322	13.6	367	19.8	314	17.5	225	13.6	422	23.5	608	35.4	275	13.7
Discussing use of strategies (intervention)	0	0	0	0	0	0	0	0	0	0	0	0	0	0	13	0.7	6	0.3	99	4.9
Psychosocial aspects of cognitive issues in MS	69	5	33	1.8	11	0.6	8	0.3	12	0.6	8	0.4	13	0.8	16	0.9	7	0.4	30	1.4
Giving advice/sharing	8	0.6	4	0.2	0	0	1	0	0	0	0	0	0	0	2	0.1	0	0	2	0.1
Input from family/carers	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3	0.1
Describing emotions and coping strategies	61	4.4	29	1.6	11	0.6	7	0.3	12	0.6	8	0.4	13	0.8	14	0.8	7	0.4	25	1.2
Miscellaneous/ Other	58	4.2	69	3.9	86	4.5	79	3.3	71	3.8	61	3.4	56	3.4	85	4.7	70	4.1	95	4.7
Asking questions (not intervention content)	1	0.1	3	0.2	1	0.1	0	0	0	0	0	0	1	0.1	0	0	1	0.1	0	0
Participant social chat	57	4.1	66	3.7	85	4.4	79	3.3	71	3.8	61	3.4	55	3.3	85	4.7	69	4	95	4.7

Appendix 15 Participant activity categories - illustrative text (Chapter 3)

Participant activity categories	Example text
Asking for clarification/ further information related to intervention content	*"Is encoding understanding the process sort of thing?"*
Asking questions unrelated to intervention content	*"How do you know all these Wi-Fi connections are not causing problems with memory to your brain?"*
Describing emotions and coping strategies	*"I won't shy away from it [memory or attention problem] but I'll try and hide it, add a bit of humour to it"*
Describing problems related to memory and attention	*"I can recognise faces but it's names that I can't remember"*
Discussing CRAMMS research activities/ research process e.g., outcome visits	*"The researcher [outcome assessor, who is blinded to treatment allocation], we're obviously not meant to tell them [that they were in the intervention group], but the person who's doing the interview then they're gonna know?"*
Discussing educational material	*"I didn't know what that was [pointing to image of a hot dog in the treatment manual as part of a categorisation strategy exercise]"*
Discussing living with MS and impact of family, quality of life etc.	*"that's another thing with this illness, your family don't understand, you look fine but you aren't"*
Discussing cognitive rehabilitation strategies	*"grouping [categorisation strategy] it would work quite well, but when you've got randoms [items] that's there, there are problems"* *"I like the story method and chunking I find is really good"* *"I can never remember what 'PQRST' stands for"*
Discussing the CRAMMS group intervention format	*"it's been really useful meeting with other people with MS"* *"I liked how we [group members] bounced stuff off each other and I think that's made it easier to take in [intervention content]"* *"my feedback would be the content [of the manual], it seems that the time is little […] we are struggling with memory"* *"an extra half an hour would have made it [sessions] a little less frantic in a way"* *"I think this was a good sized group […] if you'd had 12-18 you might end up not talking to some of the people in that group within the time [..] and you're aware of what am I saying [...] and I*

Participant activity categories	Example text
	was surprised how easy it was to forget about the camera being on as well"
Discussing use of strategies in relation to improvements in memory and attention as a result of the intervention	*"[I wanted more attention paid on internal memory aids] some of the external memory aids [discussed] are antiquated [gave examples, of Filofax, personal organiser, Dictaphones]"*
Feedback on take home activities	*"remembering to do the homework [difficult part of the programme]"* *"it [take home activity[was more or less a recap of what we'd done in the session"* *"I did the first one [take home activity] but I didn't do the second one because I was at work yesterday"*
Filling in educational material	*"[participants writing down 'what is memory and why it is important' on page 15 of the manual]"*
Giving advice/sharing	*"so going to that [MS group] they pass on information like car and medical insurance"*
Hospital visit discussion	*"I stopped [going to see the registrar instead of the neurologist], I said I'm not coming becomes some months you see the registrar and it's a bit pointless, you ask him stuff and he'll say I'll ask Dr so and so"*
Housekeeping	
Information about sessions, venue, group, etc.	*"Why no session on the 8th and the 15th?"*
Input from family member/carer	*"he [participant] likes it [the changes made to the calendar as a result of learning about using external memory aids] but I [partner] needs to get used to it that's all"*
Participant social chat	*"Is that wind or….? [discussing weather]"* *"I was named after a Scottish friend of my mother's"*
Travel expenses	*"I only live in [place] so I'm fine [in terms of getting travel expenses reimbursed]"*

Appendix 16 Ethical Approval for Modified Delphi study (Chapter 4)

University of Nottingham
UK | CHINA | MALAYSIA

Email: FMHS-ResearchEthics@nottingham.ac.uk

Faculty of Medicine & Health Sciences
Research Ethics Committee
c/o Faculty PVC Office
School of Medicine Education Centre
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Nottingham, NG7 2UH

15 August 2017

Jacqueline Mhizha-Murira
PhD Student
c/o Professor Avril Drummond
Deputy Head of School (Research and Knowledge Exchange) and Professor of Healthcare Research
School of Health Sciences
A Floor, South block link
Queen's Medical Centre (QMC)
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Dear Ms Mhizha-Murira

Ethics Reference No: 92-1707 **– please always quote**	
Study Title: A consensus on reporting of cognitive rehabilitation for multiple sclerosis.	
Short Title: Cog rehab consensus	
Chief Investigator/Supervisor: Professor Avril Drummond PhD, MSc, FCOT, Dip COT Deputy Head of School (Research and Knowledge Exchange) and Professor of Healthcare Research, School of Health Sciences, Professor Roshan dasNair, PhD,Professor of Clinical Psychology & Neuropsychology, Division of Psychiatry and Applied Psychology, Institute of Mental Health	
Lead Investigators/student: Jacqueline Mhizha-Murira, PhD Student, School of Health Sciences.	
Type of Study: PhD project, Delphi Consensus, mixed methods, questionnaire	
Proposed Start Date: 01/09/2017	**Proposed End Date:** 01/03/2018 6 mths
No of Subjects: 20	**Age:** 18+years
School: Health Sciences, Medicine	

Thank you for submitting the above application which has been considered by the Committee at its meeting on 18 July 2017 and the following documents were received:

- Cog Rehab Consensus: FMHS REC Application form and supporting documents version 1.0: 04/07/2017.

These have been reviewed and are satisfactory and the study has been given a favourable opinion.

A favourable opinion is given on the understanding that the conditions set out below are followed:

1. You should follow the protocol agreed and inform the Committee of any changes using a notification of amendment form (please request a form).
2. You must notify the Chair of any serious or unexpected event.
3. An End of Project Progress Report is completed and returned when the study has finished (please request a form).

Yours sincerely



Professor Ravi Mahajan
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix 17 Modified Delphi Participant Information Sheet (Chapter 4)

A CONSENSUS ON REPORTING OF COGNITIVE REHABILITATION FOR MULTIPLE SCLEROSIS

Researchers: Jacqueline Mhizha-Murira (PhD Student, School of Health Sciences, University of Nottingham, UK), Avril Drummond (Director of Research and Professor of Healthcare Research, School of Health Sciences, University of Nottingham, UK), Roshan das Nair (Professor of Clinical Psychology & Neuropsychology, School of Medicine, University of Nottingham, UK)

Participant Information Sheet (Delphi Study)

Final Version 1 04.07.2017

We would like to invite you to take part in a research study about reporting cognitive rehabilitation in Multiple Sclerosis. Before you decide whether to take part, it is important for you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study of you wish. Please ask us if there is anything that is not clear or if you would like more information

What is the purpose of the study?

Memory, attention and executive dysfunction are commonly reported cognitive problems by people with multiple sclerosis (MS) and can severely affect quality of life of the individual, their family and carers. Although the effectiveness of cognitive rehabilitation programmes has been evaluated in clinical trials, inadequate reporting of the content of the interventions may prevent clinical implementation.

This MS Society-funded research aims to increase the clinical impact of trials of cognitive rehabilitation. We want to do this by developing a clinician-informed, evidence-based checklist to guide researchers to better report cognitive rehabilitation studies.

In preparation for this consensus, we conducted a systematic review to summarise the key aspects of cognitive rehabilitation for memory, attention and executive dysfunction in MS, currently reported in research studies. We also consulted people who deliver cognitive rehabilitation to establish what needs to be reported to enable them to roll-out an intervention. The questionnaire is therefore based on published literature and current clinical opinion.

Why have I been invited to take part?

You have been identified as an individual with expertise in this area. We are keen to hear your views on the aspects of cognitive rehabilitation interventions that should be included in a reporting checklist.

What happens if I agree to take part in the study?

If you choose to take part we will ask you to rate a series of statements about the content of cognitive rehabilitation in MS. This is done online and over three rounds and these will be sent to you by e-mail after you have registered your interest to take part. Your consent will be implied by completion and return of these questionnaires.

At each round you will be able to review and modify your initial ratings based on the group opinion if you wish to do so. The first round should take 30 minutes to complete.

After we analyse the first round results, you would be asked to complete a second questionnaire that would include a summary of the responses from all panel members along with your responses to the earlier round. You would then be asked for your views again.

The overall aim will be to reach consensus on the aspects of cognitive rehabilitation interventions that need to be reported in research studies.

At no point will you be identified to the other participants.

When will the study take place?
We aim to start the Delphi study on 1st September 2017 and circulate the final results by 1st March 2018.

Do I have to take part in this research study?
It is up to you to decide. You can contact the researchers if you would like to know more about the study. You are free to withdraw at any time, without giving a reason. Consent will be implied by completing and returning the questionnaires. If you change your mind after completing the first questionnaire you can simply withdraw by ignoring any additional e-mails and questionnaires that we send you.

Will it cost me anything to take part?
No, but you will need some time to complete each round. Some employers may expect you to participate in the study in your own time.

Will taking part in the study be kept confidential?
Yes. We will follow established ethical and legal practices, and any personal information will be handled in confidence. All information which is collected about you during the course of the research will be kept strictly confidential, stored in a secure and locked office, and on a password protected database. All other data (research data) will be kept securely for 7 years in keeping with University protocol. After this time the data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain confidentiality. Only members of the research team will have access to the raw data.

What will happen if I don't want to carry on with the study?
Your participation is voluntary and you are free to withdraw at any time, without giving any reason. If you withdraw, the information collected until then cannot be erased and this information may still be used in the project analysis.

What if there is a problem?
If you have any concerns about any aspect of this study, you can initially approach the lead investigator Professor Avril Drummond. If you remain unhappy and wish to complain formally, you should then contact the FMHS Research Ethics Committee Administrator, c/o The University of Nottingham, Faculty PVC Office, B Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH. E-mail: FMHS-ResearchEthics@nottingham.ac.uk

Will anyone else know that I am taking part in the study?
Members of the study steering group may know that you are taking part in the study, but other members of the Delphi panel will not be informed of your participation. All the data collected by the research team will be confidential.

What will happen to the results of the research study?
It is intended that the results will be published formally in scientific journals and be used to inform the development of a reporting checklist for cognitive rehabilitation. We will send you a summary of the results if you wish by registering your interest with the lead investigator at the contact details below. You will not be identified in any reports/publications unless you consent to be acknowledged.

Who is organising and funding the research?
The University of Nottingham is organising the study. The study is being funded by the UK MS Society.

Who has given permission for the study to be carried out?
This study has been reviewed and approved by the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee (FMHS ref no: 92-1707).

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Appendix 18 Modified Delphi study Round one questionnaire (Chapter 4)

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Reporting Checklist for Cognitive Rehabilitation in Multiple Sclerosis

Researchers: Jacqueline Mhizha-Murira (PhD Student, School of Health Sciences, University of Nottingham, UK), Avril Drummond (Director of Research and Professor of Healthcare Research, School of Health Sciences, University of Nottingham, UK), Roshan das Nair (Professor of Clinical Psychology & Neuropsychology, School of Medicine, University of Nottingham, UK)

Round 1 – Introduction

Thank you for participating in this Delphi Consensus. The aim is to reach an agreement on the aspects of cognitive rehabilitation interventions that should be reported in research studies. This is to facilitate the implementation of cognitive rehabilitation for people with multiple sclerosis (MS) in clinical practice. This consensus questionnaire will be conducted in three rounds.

In preparation for this consensus, we conducted a systematic review to summarise the aspects of cognitive rehabilitation for memory, attention and executive dysfunction in MS that are currently reported in research studies. We also informally consulted people who deliver cognitive rehabilitation to establish what needs to be reported to enable them to roll-out an intervention in clinical settings. The questionnaire is therefore based on published literature and current clinical opinion.

It should take 30 minutes to complete this questionnaire.

MS Society
This research is funded by the UK MS Society

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Round 1 – About You - Demographic Information

1. *In what role do you deliver cognitive rehabilitation to people with MS? Please choose one.*
   ☐MS Nurse Specialist
   ☐Clinical Psychologist
   ☐Neuropsychologist
   ☐Physiotherapist
   ☐Occupational therapist
   ☐Researcher who delivers cognitive rehabilitation
   ☐Neurologist
   ☐Rehabilitation Medicine Consultant
   ☐Other *(please specify)*

   _____

2. *For approximately how long have you been delivering cognitive rehabilitation to people with MS?*
   Years _____ Months _____

3. *Please indicate the organisation you are employed by (e.g., Healthcare Trust), where you deliver cognitive rehabilitation. Please choose one.*
   ☐General practice/primary care
   ☐Community service
   ☐Hospital/secondary care
   ☐University/research setting
   ☐Charity or third sector
   ☐Other *(please specify)*

   _____

4. *Please indicate the setting. Please choose one.*
   ☐Private
   ☐Public/government
   ☐Other *(please specify)*

   _____

5. *Where is your clinical practice?*
   Country of practice _____

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Round 1 – Reporting Statements

In your opinion, how important are the following reporting criteria to inform your delivery of cognitive rehabilitation to your MS patients? Think about what you would like to see in a scientific paper reporting on cognitive rehabilitation.

	To select your response please click inside <u>one</u> box for each statement	*Very high importance – essential for inclusion in a reporting checklist*	*High importance – likely to require inclusion in a reporting checklist*	*Moderate importance – possible consideration for inclusion in a reporting checklist*	*Low importance – not to be included in a reporting checklist*	Please type any comments for each statement *(optional)*
Reporting Domain: *Name of the intervention*						
Statement	**Description**					
1. Brief name or acronym	Reports the name of intervention, which includes the target population.	☐	☐	☐	☐	
Reporting domain: Participant characteristics						
Statement	**Description**					
2. Age of the participants	Reports age (descriptive statistics e.g. min, max, range) of the sample.	☐	☐	☐	☐	
3. Type of MS Diagnosis	Reports MS diagnosis targeted by the intervention, if applicable.	☐	☐	☐	☐	

	To select your response please click inside one box for each statement	*Very high importance – essential for inclusion in a reporting checklist*	*High importance – likely to require inclusion in a reporting checklist*	*Moderate importance – possible consideration for inclusion in a reporting checklist*	*Low importance – not to be included in a reporting checklist*	Please type any comments for each statement *(optional)*
4. Time since diagnosis of MS	Reports min, max (range) since the people with MS were first diagnosed, if applicable.	☐	☐	☐	☐	
5. The intervention is to be delivered with respect to specific clinical characteristics	Reports whether the intervention needs to be delivered with respect to specific clinical characteristics e.g. time since diagnosed with MS, time since last relapse.	☐	☐	☐	☐	
Reporting domain: Key elements of the intervention						
Item	**Description**					
6. The aims of the cognitive rehabilitation	Reports the aim of the intervention, i.e., what it is hypothesised to achieve. For example, to improve function.	☐	☐	☐	☐	

	To select your response please click inside one box for each statement	*Very high importance – essential for inclusion in a reporting checklist*	*High importance – likely to require inclusion in a reporting checklist*	*Moderate importance – possible consideration for inclusion in a reporting checklist*	*Low importance – not to be included in a reporting checklist*	Please type any comments for each statement *(optional)*
7. The theoretical framework used or mechanism of change	Describes how the intervention is intended to work by identifying change mechanisms or the underpinning theories of cognitive rehabilitation. For example, whether the intervention is proposed to enable persons to adapt to their cognitive disability, establishing new patterns of cognitive activity or reinforce previously learned patterns of behaviour.	☐	☐	☐	☐	
8. The cognitive rehabilitation approaches or strategies that underpin the intervention	Describes the techniques used to facilitate improvement in cognitive problems. For example, to restore cognitive function, the use compensatory strategies and devices, and environmental modifications.	☐	☐	☐	☐	
9. The essential elements of the intervention	Reports on what are considered to be the most important elements of the intervention i.e. the 'active ingredients.	☐	☐	☐	☐	

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To select your response please click inside one box for each statement		*Very high importance – essential for inclusion in a reporting checklist*	*High importance – likely to require inclusion in a reporting checklist*	*Moderate importance – possible consideration for inclusion in a reporting checklist*	*Low importance – not to be included in a reporting checklist*	Please type any comments for each statement *(optional)*
Reporting domain: Content of the intervention						
Item	**Description**					
10. Details of session content	Describes the content of the sessions, e.g., the topics covered or the theme of the session. Also describes the sequence of sessions.	☐	☐	☐	☐	
11. How the sessions are structured	Describes the sequence of events in each session. For example: welcome, recap of the previous session, overview of the topic, scheduled break, summary.	☐	☐	☐	☐	
12. Activities for participants outside of the intervention sessions	Reports whether participants receive homework, and how often.	☐	☐	☐	☐	
13. Management of missed sessions	How 'missed' sessions are managed, e.g., whether 'catch-up' sessions are offered.	☐	☐	☐	☐	

To select your response please click inside one box for each statement		*Very high importance – essential for inclusion in a reporting checklist*	*High importance – likely to require inclusion in a reporting checklist*	*Moderate importance – possible consideration for inclusion in a reporting checklist*	*Low importance – not to be included in a reporting checklist*	Please type any comments for each statement *(optional)*
Reporting domain: Intervention delivery						
Item	**Description**					
14. How the intervention is delivered – the mode of delivery	Reports whether the intervention is delivered individually or in a group, or a combination of the two.	☐	☐	☐	☐	
15. Specific details about delivery of group interventions	If the intervention is delivered in a group, reports the mean group size (including the recommended minimum and maximum number of participants).	☐	☐	☐	☐	
16. Media used to deliver the intervention	a. Reports whether the intervention is delivered face-to-face, over the telephone, or is computer-based.	☐	☐	☐	☐	
	b. If a mixture, reports which elements are delivered using which formats.	☐	☐	☐	☐	
17. The setting where the intervention is delivered	Describes where the intervention is delivered e.g. at home or a hospital/community setting.	☐	☐	☐	☐	

	To select your response please click inside one box for each statement	*Very high importance – essential for inclusion in a reporting checklist*	*High importance – likely to require inclusion in a reporting checklist*	*Moderate importance – possible consideration for inclusion in a reporting checklist*	*Low importance – not to be included in a reporting checklist*	Please type any comments for each statement *(optional)*
18. Family and caregiver input	Reports whether input from family/caregiver is needed/required during delivery of the intervention.	☐	☐	☐	☐	
Reporting domain: Number of sessions, frequency and duration of the intervention						
Item	**Description**					
19. The duration of the intervention	a. Reports the time period over which the intervention is delivered including the actual duration of the intervention, e.g., "The intervention lasted 10 weeks".	☐	☐	☐	☐	
	b. Reports descriptive statistics such as mean (standard deviation), median (interquartile range).	☐	☐	☐	☐	
20. The total number of intervention sessions	a. Reports how many sessions of the intervention were delivered including the actual number of sessions, e.g., "The intervention had 8 sessions".	☐	☐	☐	☐	
	b. Reports descriptive statistics such as mean (standard deviation), median (interquartile range).	☐	☐	☐	☐	

	To select your response please click inside one box for each statement	*Very high importance – essential for inclusion in a reporting checklist*	*High importance – likely to require inclusion in a reporting checklist*	*Moderate importance – possible consideration for inclusion in a reporting checklist*	*Low importance – not to be included in a reporting checklist*	Please type any comments for each statement *(optional)*
21. The length of individual intervention sessions	a. Reports the minimum and maximum amount of time it takes to deliver the intervention including the actual length of sessions, e.g., "It takes approximately 1.5h per session".	☐	☐	☐	☐	
	b. Reports descriptive statistics such as mean (standard deviation), median (interquartile range).	☐	☐	☐	☐	
22. The frequency of intervention sessions	a. Reports how often were the sessions delivered including the actual frequency of sessions, e.g., "Sessions were held weekly".	☐	☐	☐	☐	
	b. Reports descriptive statistics e.g., mean (standard deviation), median (interquartile range).	☐	☐	☐	☐	
Reporting domain: Intervention materials						
Item	**Description**					
23. A manual is used by facilitators to deliver the intervention	Reports whether a manual is used to deliver the intervention, and where to access the manual.	☐	☐	☐	☐	

	To select your response please click inside one box for each statement	*Very high importance – essential for inclusion in a reporting checklist*	*High importance – likely to require inclusion in a reporting checklist*	*Moderate importance – possible consideration for inclusion in a reporting checklist*	*Low importance – not to be included in a reporting checklist*	Please type any comments for each statement *(optional)*
24. Materials given to participants	a. Reports whether a booklet/workbook is provided for participants.	☐	☐	☐	☐	
	b. Reports whether information is provided as to how clinicians can access the manual.	☐	☐	☐	☐	
25. Special equipment used during intervention delivery	Reports whether specific equipment is required to deliver the intervention e.g. a touch-screen computer.	☐	☐	☐	☐	
Reporting domain: Modifications to the intervention						
Item	**Description**					
26. Any modifications made to the intervention as described in the protocol	Reports whether any changes to the dose or the content of the intervention have been made that deviate from the protocol, e.g., changes made to the manual.	☐	☐	☐	☐	

	To select your response please click inside one box for each statement	*Very high importance – essential for inclusion in a reporting checklist*	*High importance – likely to require inclusion in a reporting checklist*	*Moderate importance – possible consideration for inclusion in a reporting checklist*	*Low importance – not to be included in a reporting checklist*	Please type any comments for each statement *(optional)*
27. The same intervention is delivered to all participants	Reports whether the intervention is standardised.	☐	☐	☐	☐	
28. The intervention tailored to the individual	Reports whether the intervention is tailored to individual need, e.g., whether cognitive rehabilitation is based on results of assessment of cognitive deficit (e.g., objective test and/or self-report).	☐	☐	☐	☐	
Reporting domain: Facilitator attributes						
Item	**Description**					
29. The professional background of the person who delivers the intervention	Reports the professional background of the intervention facilitators, e.g. psychologist, nurse, occupational therapist.	☐	☐	☐	☐	

	To select your response please click inside one box for each statement	*Very high importance – essential for inclusion in a reporting checklist*	*High importance – likely to require inclusion in a reporting checklist*	*Moderate importance – possible consideration for inclusion in a reporting checklist*	*Low importance – not to be included in a reporting checklist*	Please type any comments for each statement *(optional)*
30. The level of professional training of the person delivering the intervention	Reports the level of professional training of the facilitators, e.g. assistant psychologist, nurse specialist, Band 7 occupational therapist, board certified, etc.	☐	☐	☐	☐	
31. The person delivering the intervention has attained key competencies	Reports how the facilitators' delivery competence was assessed and/or monitored.	☐	☐	☐	☐	
32. The number of facilitators who deliver the intervention	Reports the number of facilitators needed to deliver the intervention e.g. minimum required.	☐	☐	☐	☐	

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1. *Are there any additional reporting criteria that are important to inform your delivery of cognitive rehabilitation to your MS patients?*

(Please List)

i. _____
ii. _____
iii. _____
iv. _____
v. _____

2. Any further comments?

_____
_____
_____
_____
_____

Thank you for taking the time to submit your answers. We will be in contact with the results of Round 1 shortly.

If you have any queries please contact:
Jacqueline Mhizha-Murira
Email address: jacquelinemhizha-murira1@nottingham.ac.uk
Telephone number: 00 44 115 82 30890

Appendix 19 Round one ratings for Delphi reporting statements (Chapter 4)

Statements reaching consensus, retained for round two and excluded (N=38)

Statement	Statement description	Rating of importance for inclusion in a reporting checklist				Mean rating	Consensus/ Retain/ Exclude
		Very high importance (4)	High importance (3)	Moderate importance (2)	Low importance (1)		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
Name of the intervention							
Brief name or acronym	Reports the name of intervention, which includes the target population.	8 (44.4)	6 (33.3)	4 (22.2)	0	3.22	Retain*
Participant characteristics							
Age of the participants	Reports age (descriptive statistics e.g. min, max, range) of the sample.	11 (61.1)	4 (22.2)	3 (16.7)	0	3.44	Include[ǂ]
Type of MS Diagnosis	Reports MS diagnosis targeted by the intervention, if applicable.	8 (44.4)	7 (38.9)	1 (5.6)	2 (11.1)	3.17	Exclude[ł]
Time since diagnosis of MS	Reports min, max (range) since the people with MS were first diagnosed, if applicable.	8 (44.4)	7 (38.9)	2 (11.1)	1 (5.6)	3.22	Exclude[ł]
The intervention is to be delivered with respect to specific clinical characteristics	Reports whether the intervention needs to be delivered with respect to specific clinical characteristics e.g. time since diagnosed with MS, time since last relapse.	9 (50.0)	6 (33.3)	2 (11.1)	1 (5.6)	3.28	Retain[ǂ]

Statement	Statement description	Rating of importance for inclusion in a reporting checklist				Mean rating	Consensus/ Retain/ Exclude
		Very high importance (4)	High importance (3)	Moderate importance (2)	Low importance (1)		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
Key elements of the intervention							
The aims of the cognitive rehabilitation	Reports the aim of the intervention, i.e., what it is hypothesised to achieve. For example, to improve function.	18 (100.0)	0	0	0	4.00	Consensus
The theoretical framework used or mechanism of change	Describes how the intervention is intended to work by identifying change mechanisms or the underpinning theories of cognitive rehabilitation. For example, whether the intervention is proposed to enable persons to adapt to their cognitive disability, establishing new patterns of cognitive activity or reinforce previously learned patterns of behaviour.	9 (50.0)	9 (50.0)	0	0	3.50	Retain[‡]
The cognitive rehabilitation approaches or strategies that underpin the intervention	Describes the techniques used to facilitate improvement in cognitive problems. For example, to restore cognitive function, the use compensatory strategies and devices, and environmental modifications.	14 (77.8)	4 (22.2)	0	0	3.78	Consensus

Statement	Statement description	Rating of importance for inclusion in a reporting checklist				Mean rating	Consensus/ Retain/ Exclude
		Very high importance (4)	High importance (3)	Moderate importance (2)	Low importance (1)		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
The essential elements of the intervention	Reports on what are considered to be the most important elements of the intervention i.e. the 'active ingredients.	14 (77.8)	3 (16.7)	1 (5.6)	0	3.72	Consensus
Content of the intervention							
Details of session content	Describes the content of the sessions, e.g., the topics covered or the theme of the session. Also describes the sequence of sessions.	11 (61.1)	5 (27.8)	2 (11.1)	0	3.50	Retain[‡]
How the sessions are structured	Describes the sequence of events in each session. For example: welcome, recap of the previous session, overview of the topic, scheduled break, summary.	9 (50.0)	5(27.8)	4 (22.2)	0	3.28	Retain[‡]
Activities for participants outside of the intervention sessions	Reports whether participants receive homework, and how often.	10 (55.6)	6 (33.3)	2 (11.1)	0	3.44	Retain[‡]
Management of missed sessions	How 'missed' sessions are managed, e.g., whether 'catch-up' sessions are offered.	4 (22.2)	10 (55.6)	4 (22.2)	0	3.00	Exclude[ł]

Statement	Statement description	Rating of importance for inclusion in a reporting checklist				Mean rating	Consensus/ Retain/ Exclude
		Very high importance (4)	High importance (3)	Moderate importance (2)	Low importance (1)		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
How the intervention is delivered – the mode of delivery	Reports whether the intervention is delivered individually or in a group, or a combination of the two.	17 (94.4)	1 (5.6)	0	0	3.94	Consensus
Specific details about delivery of group interventions	If the intervention is delivered in a group, reports the mean group size (including the recommended minimum and maximum number of participants).	9 (50.0)	7 (38.9)	1 (5.6)	1 (5.6)	3.33	Retain[‡]
Media used to deliver the intervention	Reports whether the intervention is delivered face-to-face, over the telephone, or is computer-based.	13 (72.2)	5 (27.8)	0	0	3.72	Consensus
Media used to deliver the intervention	If a mixture, reports which elements are delivered using which formats.	13 (72.2)	5 (27.8)	0	0	3.72	Consensus
The setting where the intervention is delivered	Describes where the intervention is delivered e.g. at home or a hospital/community setting.	10 (55.6)	7 (38.9)	0	1 (5.6)	3.44	Retain[‡]
Family and caregiver input	Reports whether input from family/caregiver is needed/required during delivery of the intervention.	9 (50.0)	7 (38.9)	1 (5.6)	1 (5.6)	3.33	Retain[‡]
Number of sessions, frequency and duration of the intervention							

Statement	Statement description	Rating of importance for inclusion in a reporting checklist				Mean rating	Consensus/ Retain/ Exclude
		Very high importance (4)	High importance (3)	Moderate importance (2)	Low importance (1)		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
The duration of the intervention	Reports the time period over which the intervention is delivered including the actual duration of the intervention, e.g., “The intervention lasted 10 weeks”.	15 (83.3)	3 (16.7)	0	0	3.83	Consensus
he duration of the intervention	Reports descriptive statistics such as mean (standard deviation), median (interquartile range).	11 (61.1)	7 (38.9)	0	0	3.61	Retain[‡]
The total number of intervention sessions	Reports how many sessions of the intervention were delivered including the actual number of sessions, e.g., “The intervention had 8 sessions”.	15 (83.3)	3 (16.7)	0	0	3.83	Consensus
The total number of intervention sessions	Reports descriptive statistics such as mean (standard deviation), median (interquartile range).	10 (55.6)	8 (44.4)	0	0	3.56	Retain[‡]
The length of individual intervention sessions	Reports the minimum and maximum amount of time it takes to deliver the intervention including the actual length of sessions, e.g., “It takes approximately 1.5h per session”.	11 (61.1)	7(38.9)	0	0	3.61	Retain[‡]

Statement	Statement description	Rating of importance for inclusion in a reporting checklist				Mean rating	Consensus/ Retain/ Exclude
		Very high importance (4)	High importance (3)	Moderate importance (2)	Low importance (1)		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
The length of individual intervention sessions	Reports descriptive statistics such as mean (standard deviation), median (interquartile range).	6 (33.3)	12 (66.7)	0	0	3.33	Exclude[ł]
The frequency of intervention sessions	Reports how often were the sessions delivered including the actual frequency of sessions, e.g., "Sessions were held weekly".	14 (77.8)	4 (22.2)	0	0	3.78	Consensus
The frequency of intervention sessions	Reports descriptive statistics e.g., mean (standard deviation), median (interquartile range).	7 (38.9)	9 (50.0)	2 (11.1)	0	3.28	Exclude[ł]
Materials							
A manual is used by facilitators to deliver the intervention	Reports whether a manual is used to deliver the intervention, and where to access the manual.	10 (55.6)	6 (33.3)	1 (5.6)	1 (5.6)	3.39	Retain[ǂ]
Materials given to participants	Reports whether a booklet/workbook is provided for participants.	9 (50.0)	8 (44.4)	0	1 (5.6)	3.39	Retain[ǂ]
Materials given to participants	Reports whether information is provided as to how clinicians can access the manual.	7 (38.9)	9 (50.00	0	1 (5.6)	3.29	Exclude[ł]
Modifications to the intervention							

Statement	Statement description	Rating of importance for inclusion in a reporting checklist				Mean rating	Consensus/ Retain/ Exclude
		Very high importance (4)	High importance (3)	Moderate importance (2)	Low importance (1)		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
Special equipment used during intervention delivery	Reports whether specific equipment is required to deliver the intervention e.g. a touch-screen computer.	10 (55.6)	5 (27.8)	1 (5.6)	2 (11.1)	3.28	Retain[‡]
Any modifications made to the intervention as described in the protocol	Reports whether any changes to the dose or the content of the intervention have been made that deviate from the protocol, e.g., changes made to the manual.	12 (66.7)	3 (16.7)	2 (11.1)	1 (5.6)	3.44	Retain[‡]
The same intervention is delivered to all participants	Reports whether the intervention is standardized.	12 (66.7)	6 (33.3)	0	0	3.67	Retain[‡]
The intervention is tailored to the individual	Reports whether the intervention is tailored to individual need, e.g., whether cognitive rehabilitation is based on results of assessment of cognitive deficit (e.g., objective test and/or self-report).	13 (72.2)	5 (27.8)	0	0	3.72	Consensus
Facilitator attributes							
The professional	Reports the professional background of the intervention	6 (33.3)	11 (61.1)	1 (5.6)	0	3.28	Exclude[ł]

Statement	Statement description	Rating of importance for inclusion in a reporting checklist				Mean rating	Consensus/ Retain/ Exclude
		Very high importance (4)	High importance (3)	Moderate importance (2)	Low importance (1)		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
background of the person who delivers the intervention	facilitators, e.g. psychologist, nurse, occupational therapist.						
The level of professional training of the person delivering the intervention	Reports the level of professional training of the facilitators, e.g. assistant psychologist, nurse specialist, Band 7 occupational therapist, board certified, etc.	5 (27.8)	9 (50.0)	4 (22.2)	0	3.06	Exclude[i]
The person delivering the intervention has attained key competencies	Reports how the facilitators' delivery competence was assessed and/or monitored.	4 (22.2)	10 (55.6)	4 (22.2)	0	3.00	Exclude[i]
The number of facilitators who deliver the intervention	Reports the number of facilitators needed to deliver the intervention e.g. minimum required.	7 (38.9)	6 (33.3)	5 (27.8)	0	3.11	Exclude[i]
n (%)[1] = total number of experts who gave the right (percentage of total number of respondents for that round). *Statement retained for the following Round because although <50% agreement, this statement received a significant amount of comments from							

Statement	Statement description	Rating of importance for inclusion in a reporting checklist				Mean rating	Consensus/ Retain/ Exclude
		Very high importance (4)	High importance (3)	Moderate importance (2)	Low importance (1)		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
participants about rephrasing/modifying. ‡ Statement retained for the following Round as it received ≥50%<70% agreement. The statement's description was amended in light of participants' comments. ǂ Statement excluded from the following Round as it received less than 50% agreement on level of agreement							

Appendix 20 Example of results of content analysis for comments in round one and round two (Chapter 4)

Participants' responses to the question *"Are there any additional reporting criteria that are important to inform your delivery of cognitive rehabilitation to your MS patients?"*

Round	Reporting criteria suggested by participants	Overall theme/reporting domain	Suggested new or revised reporting criteria
One	A well described hypotheses how key elements of the intervention are linked to theoretical based feasible outcomes (Occupational Therapist)	Key elements of the intervention and intervention outcomes	"The aims of the cognitive rehabilitation - Reports the aim of the intervention, i.e., what it is hypothesised to achieve. For example, to improve function." "The theoretical framework used: The paper describes how the intervention is intended to work by identifying the underpinning theories of cognitive rehabilitation. For example, whether the intervention is proposed to enable persons to adapt to their cognitive disability, establishing new patterns of cognitive activity or reinforce previously learned patterns of behaviour."
One	Outcome measures used and when and how participants were asked to complete them. (Occupational Therapist)	Outcomes	Advisory group agreed this did not pertain to descriptions of the content of the intervention and/or would not be useful to inform the delivery of cognitive rehabilitation
One	Baseline cognitive testing status. (Psychologist)	Participant characteristics	"The intervention is to be delivered with respect to specific clinical presentations: The paper reports whether the intervention needs to be

Round	Reporting criteria suggested by participants	Overall theme/reporting domain	Suggested new or revised reporting criteria
			delivered with respect to specific clinical presentations. For example, cognitive profile and functional performance in everyday life skills" and "The demographic characteristics of the participants: The paper provides details of the demographic characteristics of the participants."
One	Cultural context/influence in application of rehabilitation (Rehab Doctor)	Participant characteristics	Advisory group agreed this did not pertain to descriptions of the content of the intervention
One	MS organisation endorsements. (Psychologist)	Funding	Advisory group agreed this did not pertain to descriptions of the content of the intervention
Two	Presence of other MS complications- e.g. Spasticity, visual impairment, sensory impairment, presence of psychological illness etc. But I assume these would be covered well in study criteria (Rehab Physician)	Participant characteristics	Advisory group agreed this suggestion was captured in the statement 'The intervention is to be delivered with respect to specific clinical presentations
Two	The possible harm that can be caused by the intervention should be in. (Occupational Therapist))	Unintended consequences of the intervention	New statement:
Two	Please keep in mind that cognitive rehabilitation on daily functional level needs to be tailored and		New statement: "The intervention is tailored to the individual - The paper reports whether the intervention is tailored to

Round	Reporting criteria suggested by participants	Overall theme/reporting domain	Suggested new or revised reporting criteria
	personalised to be effective in daily life. It might require different formulations of words (Occupational Therapist):		individual need, e.g., whether cognitive rehabilitation is based on results of assessment of cognitive deficit (e.g., objective test and/or self-report)”

Appendix 21 Round two ratings for Delphi reporting statements (Chapter 4)

Statements reaching consensus, retained for round three and excluded (N=23)

Statement	Statement description	Ratings				Mean rating	Consensus/ Retain/ Exclude
		Very high importance	High importance	Moderate importance	Low importance		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
Name of the intervention							
Brief name or acronym	a. The title of the paper reflects the content of the intervention.	10 (66.7%)	2 (13.3%)	3 (20%)	0	3.47	Retain[‡]
Brief name or acronym	b. The title of the paper reflects the target population.	9 (60%)	5 (33.3%)	1 (6.7%)	0	3.53	Retain[‡]
Participant characteristics							
Age of the participants	The paper reports the average age of the sample	12 (80%)	1 (6.7%)	2 (13.3%)	0	3.67	Consensus
The demographic characteristics of the participants	The paper provides details of the demographic characteristics of the participants.	9 (60%)	4 (26.7%)	2 (13.3%)	0	3.47	Retain[‡]
The intervention is to be delivered with respect to specific clinical presentations	The paper reports whether the intervention needs to be delivered with respect to specific clinical presentations. For example, cognitive profile and functional performance in everyday life skills.	13 (86.7%)	2 (13.3%)	0	0	3.87	Consensus
Key elements of the intervention							

Statement	Statement description	Ratings				Mean rating	Consensus/ Retain/ Exclude
		Very high importance	High importance	Moderate importance	Low importance		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
The theoretical framework used	The paper describes how the intervention is intended to work by identifying the underpinning theories of cognitive rehabilitation. For example, whether the intervention is proposed to enable persons to adapt to their cognitive disability, establishing new patterns of cognitive activity or reinforce previously learned patterns of behaviour.	10 (66.7%)	5 (33.3%)	0	0	3.67	Retain‡
Content of the intervention							
Details of the session content	The paper describes the content of the sessions, e.g., the topics covered or the theme of the session.	12 (80%)	2 (13.3%)	1 (6.7%)	0	3.73	Consensus
How the sessions are structured	The paper describes the structure of each session in terms of timings and breaks.	7 (46.7%)	6 (40.0%)	2 (13.3%)	0	3.33	Retain*
Activities for participants outside of the intervention sessions	a. The paper reports whether participants receive homework.	10 (66.7%)	4 (26.7%)	1 (6.7%)	0	3.60	Retain‡

Statement	Statement description	Ratings				Mean rating	Consensus/ Retain/ Exclude
		Very high importance	High importance	Moderate importance	Low importance		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
Activities for participants outside of the intervention sessions	b. The paper reports whether the homework is to enable them to try out strategies in their own environment.	11 (73.3%)	3 (20.0%)	0	1 (6.7%)	3.60	Consensus
Intervention delivery							
Specific details about delivery of group interventions	The paper reports if the intervention is delivered in a group, reports the mean group size.	13 (86.7%)	2 (13.3%)	0	0	3.87	Consensus
The setting where the intervention is delivered	Describes where the intervention is delivered e.g. at home or a hospital/community setting.	9 (60%)	5 (33.3%)	0	1 (6.7%)	3.47	Retain[‡]
Family and caregiver input	The paper reports whether there was input from family/caregiver during delivery of the intervention.	8 (53.3%)	5 (33.3%)	2 (13.3%)	0	3.40	Retain[‡]
Number of sessions frequency and duration of the intervention							
The duration of the intervention	The paper reports descriptive statistics to underpin the duration of the intervention such as mean (standard deviation), median (interquartile range).	11 (73.3%)	3 (20%)	0	1 (6.7%)	3.60	Consensus

Statement	Statement description	Ratings				Mean rating	Consensus/ Retain/ Exclude
		Very high importance	High importance	Moderate importance	Low importance		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
The total number of intervention sessions	The paper reports descriptive statistics to underpin the total number of intervention sessions such as mean (standard deviation), median (interquartile range).	13 (86.7%)	2 (13.3%)	0	0	3.87	Consensus
The length of individual intervention sessions	a. The paper reports the amount of time it takes to deliver the intervention.	11 (73.3%)	3 (20.0%)	0	1 (6.7%)	3.60	Consensus
The length of individual intervention sessions	b. Reports the actual length of intervention content sessions e.g., “It takes approximately 1.5h per session”.	12 (80%)	2 (13.3%)	0	1 (6.7%)	3.67	Consensus
Intervention materials							
A manual is used by facilitators to deliver the intervention	a. The paper reports whether a manual is used to guide the intervention.	12 (80%)	2 (13.3%)	1 (6.7%)	0	3.73	Consensus
A manual is used by facilitators to deliver the intervention	b. The paper reports where a copy of the manual can be accessed.	9 (60%)	6 (40%)	0	0	3.60	Retain[‡]

Statement	Statement description	Ratings				Mean rating	Consensus/ Retain/ Exclude
		Very high importance	High importance	Moderate importance	Low importance		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
Intervention materials given to participants	The paper reports whether a workbook is provided for participants.	10 (66.7%)	4 (26.7%)	0	1 (6.7%)	3.53	Retain[‡]
Equipment used during intervention delivery	The paper reports whether specific equipment is required to deliver the intervention e.g. a touch-screen computer.	11 (73.3%)	1 (6.7%)	1 (6.7%)	2 (13.3%)	3.40	Consensus
Modifications to the intervention							
Any modifications made to the intervention as described in the protocol	The paper reports whether any changes to the intervention have been made that deviate from the protocol.	12 (80%)	0	2 (13.3%)	1 (6.7%)	3.53	Consensus
The same intervention is delivered to all participants	The paper reports whether the same intervention is delivered to all participants.	11 (73.3%)	4 (26.7%)	0	0	3.73	Consensus

n (%)[1] = total number of experts who gave the right (percentage of total number of respondents for that round). *Statement retained for the following Round because although <50% agreement, this statement received a significant amount of comments from participants about rephrasing/modifying; [‡] Statement retained for the following Round as it received ≥50%<70% agreement. The statement's description was amended in light of participants' comments; [ł] Statement excluded from the following Round as it received less than 50% agreement on level of agreement

Appendix 22 Round three ratings for Delphi reporting statements (Chapter 4)

Statement reaching consensus and excluded (N=14)

Statement	Statement description	Ratings				Mean rating	Consensus/ Retain/ Exclude
		Very high importance	High importance	Moderate importance	Low importance		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
Content of the intervention							
Details of session content	The paper describes how the content of the intervention is tailored and personalised for each individual	7 (50%)	4 (28.6%)	2 (14.3%)	1 (7.1%)	3.21	Retain[‡]
How the sessions are structured	a. The paper describes the sequence of events in each session. For example: welcome, recap of the previous session, overview of the topic, setting homework topics and summary	6 (42.9%)	6 (42.9%)	2 (14.3%)	0	3.29	Exclude[ł]
How the sessions are structured	b. The paper describes the format of each session. For example: welcome, recap of the previous session, overview of	9 (64.3%)	3 (21.4%)	1 (7.1%	1 (7.1%)	3.43	Retain[‡]

Statement	Statement description	Ratings				Mean rating	Consensus/ Retain/ Exclude
		Very high importance	High importance	Moderate importance	Low importance		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
	the topic, setting homework topics and summary						
Key elements of the intervention							
The theoretical framework used	The paper describes how the intervention is intended to work by identifying the underpinning theories of cognitive rehabilitation. For example: is treatment based on drilling practice i.e. restitution or behaviour change i.e. compensation.	11 (78.6%)	3 (21.4%)	0	0	3.79	Consensus
Intervention delivery							
The setting where the intervention is delivered	The paper describes where the intervention is delivered e.g. at home, a hospital/community setting or a mixed setting.	11 (78.6%)	2 (14.3%)	0	1 (7.1%)	3.64	Consensus

Statement	Statement description	Ratings				Mean rating	Consensus/ Retain/ Exclude
		Very high importance	High importance	Moderate importance	Low importance		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
Family and caregiver input	a. The paper reports whether there was input from family/caregiver during delivery of the intervention.	8 (57.1%)	3 (21.4%)	3 (21.4%)	0	3.36	Retain[‡]
Family and caregiver input	b. The paper reports what the input of family/caregiver was during the intervention.	8 (57.1%)	5 (35.75)	0	1 (7.1%)	3.43	Retain[‡]
Name of the intervention							
Brief name or acronym	a. The title of the paper reflects the content of the intervention.	9 (64.3%)	2 (14.3%)	2 (14.3%)	1 (7.1%)	3.36	Retain[‡]
Brief name or acronym	b. The abstract of the paper reflects the content of the intervention.	12 (85.7%)	2 (14.3%)	0	0	3.86	Consensus
Participant characteristics							
The demographic characteristics of the participants	The paper provides details of the demographic characteristics of the participants. For	10 (71.4%)	3 (21.4%)	1 (7.1%)	0	3.64	Consensus

Statement	Statement description	Ratings				Mean rating	Consensus/ Retain/ Exclude
		Very high importance	High importance	Moderate importance	Low importance		
		n (%)[1]	n (%)[1]	n (%)[1]	n (%)[1]		
	example: age, gender, ethnicity						
Intervention materials							
A manual is used by facilitators to deliver the intervention	The paper reports where the manual can be obtained.	9 (64.3%)	5 (35.7%)	0	0	3.64	Retain[‡]
Intervention materials given to participants	a. The paper reports whether a workbook is provided for participants.	9 (64.3%)	3 (21.4%)	1 (7.1%)	1 (7.1%)	3.43	Retain[‡]
	b. The paper reports where the workbook can be obtained.	10 (71.4%)	2 (14.3%)	1 (7.1%)	1 (7.1%)	3.50	Consensus
Unintended consequences of the intervention							
Possible harm caused by the intervention	The paper reports whether there were any negative unintended consequences of delivering the intervention.	10 (71.4%)	3 (21.4%)	0	1 (7.1%)	3.57	Consensus

n (%)[1] = total number of experts who gave the right (percentage of total number of respondents for that round). [‡] Statement could be considered for inclusion ≥50%<70% agreement. But as this was the final round statement was excluded.
[ł] Statement excluded as it received less than 50% agreement on level of agreement

Appendix 23 Reporting checklist for cognitive rehabilitation in MS (Chapter 4)

Essential reporting statements: it is ***essential*** for statements in both Table 1 and Table 2 to be reported in scientific reports of cognitive rehabilitation for people with MS. This may enable clinicians to implement these interventions in clinical practice. **Please note:** when using the checklist, the statements in the first table have priority (i.e., should be checked off first) before those in the second table.

Priority 1 reporting statements		
Statement	**Statement description**	**Reported ✓**
Reporting domain: Name		
Intervention name stated in the abstract	Abstract of the paper reports the content/focus of the intervention	
Reporting domain: Aims		
Aims of the cognitive rehabilitation	Report the aim of the intervention (i.e., what it is hypothesised to achieve, e.g., to improve function by reducing the cognitive, emotional, behavioural and psychosocial issues as a consequence of MS)	
Reporting domain: Content		
Details of the session content	Describe the content of the sessions (e.g., the topics covered or the theme of the session)	
Reporting domain: Delivery		
Format of intervention delivery	Report whether the intervention is delivered individually or in a group, or a combination of the two	
	If the intervention is delivered in a group, report the mean group size	
Reporting domain: Timeframe		
Number of intervention sessions	Report descriptive statistics to underpin the total number of intervention sessions such as mean (standard deviation), median (interquartile range)	
	Report how many sessions of the intervention were delivered including the actual number of sessions (e.g., “The intervention had 8 sessions”)	
Length of individual intervention sessions, specifically covering intervention content	Report the actual length of intervention content-specific sessions (e.g., “It takes 1.5h per session”)	
Intervention duration	Report the time period over which the intervention is delivered including the actual	

	duration of the intervention (e.g., "The intervention lasted 10 weeks")	
Reporting domain: Materials		
Manual used by facilitators to deliver the intervention	Report whether a manual is used to guide the intervention	
Reporting domain: Modifications		
Modifications made to the intervention as described in the research protocol	Report whether any changes are made to the intervention that deviate from the research protocol	
Reporting domain: Target population		
Intervention to be delivered with respect to specific clinical presentations	Report whether the intervention needs to be delivered with respect to specific clinical presentations (e.g., cognitive profile and functional performance in everyday life skills)	
Age of the participants	Report the average age	

Priority 2 Reporting Statements		
Statement	**Statement Description**	**Reported ✓**
Reporting domain: Aims		
Theoretical framework used	Describe how the intervention is intended to work by identifying the underpinning theories of cognitive rehabilitation (e.g., is treatment based on drill and practice i.e. restitution, or behaviour change i.e. compensation)	
Cognitive rehabilitation approaches or strategies that underpin the intervention	Describe the techniques used (e.g., to restore cognitive function, the use of compensatory strategies and devices, and environmental modifications)	
Essential elements of the intervention	Report on what are considered to be the most important elements of the intervention (i.e. the 'active ingredients')	
Reporting domain: Content		
Activities for participants outside of the intervention sessions	Report whether homework is to try out strategies in own environment	
Reporting domain: Delivery		
Setting where the intervention is delivered	Describe where the intervention is delivered (e.g. home, hospital/community setting or mixed setting)	

Priority 2 Reporting Statements		
Statement	**Statement Description**	**Reported ✓**
Media used to deliver the intervention	Report whether the intervention is delivered face-to-face, over the telephone, or is computer-based	
	If a mixture of delivery formats, report which elements are delivered using which formats	
Reporting domain: Timeframe		
Frequency of intervention sessions	Report how often sessions were delivered, including the actual frequency of sessions (e.g., "sessions were held weekly")	
Overall length of sessions	Report total amount of time to deliver intervention sessions, including intervention specific content (e.g., welcome, housekeeping, breaks)	
Details of the duration of the intervention	Report descriptive statistics to underpin the duration of the intervention such as mean (standard deviation), median (interquartile range)	
Reporting domain: Materials		
Intervention materials given to participants	Report where the workbook can be obtained	
Equipment used during intervention delivery	Report whether specific equipment is required to deliver the intervention (e.g., touch-screen computer)	
Reporting domain: Modifications		
Same intervention is delivered to all participants	Report whether the same intervention is delivered to all participants	
Intervention is tailored to the individual	Report whether the intervention is tailored to individual needs (e.g., whether cognitive rehabilitation is based on results of assessment of cognitive deficit i.e., objective tests and/or self-report)	
Reporting domain: Target population		
Demographic characteristics of the participants	Provides details of the demographic characteristics of the participants (e.g., gender, ethnicity)	
Reporting domain: Unintended consequences		
Possible harm caused by the intervention	Report any negative unintended consequences of delivering the intervention	

Appendix 24 Comparison of reporting checklist developed in this research to checklists used in the systematic review (Chapter 4)

✓ In checklist or guide; x not in checklist; N/A group-based interventions

Priority 1 reporting statements

Cognitive rehabilitation in MS Reporting Statement	Statement description	TIDieR (Hoffmann et al., 2014)	van Heugten et al. (2012)	Martin et al. (2015)	JARS (VandenBos et al., 2010)	Western (Conn, 2012)
Reporting domain: Name						
Intervention name stated in the abstract	Abstract of the paper reports the content/focus of the intervention	✓	x	x	✓	x
Reporting domain: Aims						
Aims of the cognitive rehabilitation	Report the aim of the intervention (i.e., what it is hypothesised to achieve, e.g., to improve function)	x	✓	x	x	x
Reporting domain: Content						
Details of the session content	Describe the content of the sessions (e.g., the topics covered or the theme of the session)	*x*	x	✓	x	x
Reporting domain: Delivery						
Format of intervention delivery	Report whether the intervention is delivered individually or in a group, or a combination of the two	✓	✓	N/A	✓	x
	If the intervention is delivered in a group, report the mean group size	x		✓	✓	x
Reporting domain: Timeframe						
Number of intervention sessions	Report descriptive statistics to underpin the total number of	*x*	x	*x*	x.	x

Cognitive rehabilitation in MS Reporting Statement	Statement description	TIDieR (Hoffmann et al., 2014)	van Heugten et al. (2012)	Martin et al. (2015)	JARS (VandenBos et al., 2010)	Western (Conn, 2012)
	intervention sessions such as mean (standard deviation), median (interquartile range)					
	Report how many sessions of the intervention were delivered including the actual number of sessions (e.g., “The intervention had 8 sessions”)	✓	x	✓	✓	x
Length of individual intervention sessions, specifically covering intervention content	Report the actual length of intervention content-specific sessions (e.g., “It takes 1.5h per session”)		✓	✓	✓	x
Intervention duration	Report the time period over which the intervention is delivered including the actual duration of the intervention (e.g., “The intervention lasted 10 weeks”)			✓	✓	✓
Reporting domain: Materials						
Manual used by facilitators to deliver the intervention	Report whether a manual is used to guide the intervention	*x*	x	✓	x	x
Reporting domain: Modifications						
Modifications made to the intervention as described in the research protocol	Report whether any changes are made to the intervention that deviate from the research protocol	✓	x	x	✓	✓
Reporting domain: Target population						
Intervention to be delivered with respect to specific clinical presentations	Report whether the intervention needs to be delivered with respect to specific clinical presentations (e.g., cognitive profile and	x	✓	*x*	x	✓

Cognitive rehabilitation in MS Reporting Statement	Statement description	TIDieR (Hoffmann et al., 2014)	van Heugten et al. (2012)	Martin et al. (2015)	JARS (VandenBos et al., 2010)	Western (Conn, 2012)
	functional performance in everyday life skills)					
Age of the participants	Report the average age	x	x	x	x	✓

Priority 2 reporting statements

Statement	Statement Description	TIDieR (Hoffmann et al., 2014)	van Heugten et al. (2012)	Martin et al. (2015)	JARS (VandenBos et al., 2010)	Western (Conn, 2012)
Reporting domain: Aims						
Theoretical framework used	Describe how the intervention is intended to work by identifying the underpinning theories of cognitive rehabilitation (e.g., is treatment based on drill and practice i.e. restitution, or behaviour change i.e. compensation)	x	x	x	x	x
Cognitive rehabilitation approaches or strategies that underpin the intervention	Describe the techniques used (e.g., to restore cognitive function, the use of compensatory strategies and devices, and environmental modifications)	x	x	x	x	x
Essential elements of the intervention	Report on what are considered to be the most important elements of the intervention (i.e. the 'active ingredients')	✓	x	x	x	✓
Reporting domain: Content						
Activities for participants outside of the intervention sessions	Report whether homework is to try out strategies in own environment	x	x	✓	x	x
Reporting domain: Delivery						

Statement	Statement Description	TIDieR (Hoffmann et al., 2014)	van Heugten et al. (2012)	Martin et al. (2015)	JARS (VandenBos et al., 2010)	Western (Conn, 2012)
Setting where the intervention is delivered	Describe where the intervention is delivered (e.g. home, hospital/ community setting or mixed setting)	✓	x	x	✓	✓
Media used to deliver the intervention	Report whether the intervention is delivered face-to-face, over the telephone, or is computer-based	✓	x	N/A	x	x
	If a mixture of delivery formats, report which elements are delivered using which formats	x	x	N/A x	x	x
Reporting domain: Timeframe						
Frequency of intervention sessions	Report how often sessions were delivered, including the actual frequency of sessions (e.g., "sessions were held weekly")	✓	✓	✓	✓	✓
Overall length of sessions	Report total amount of time to deliver intervention sessions, including intervention specific content (e.g., welcome, housekeeping, breaks)	x	x	x	✓	x
Details of the duration of the intervention	Report descriptive statistics to underpin the duration of the intervention such as mean (standard deviation), median (interquartile range)	x	✓	x	x	x
Reporting domain: Materials						
Intervention materials given to participants	Report where the workbook can be obtained	x	✓	x	x	x
Equipment used during intervention delivery	Report whether specific equipment is required to deliver the intervention (e.g., touch-screen computer)	✓	✓	x	✓	x
Reporting domain: Modifications						

Statement	Statement Description	TIDieR (Hoffmann et al., 2014)	van Heugten et al. (2012)	Martin et al. (2015)	JARS (VandenBos et al., 2010)	Western (Conn, 2012)
Same intervention is delivered to all participants	Report whether the same intervention is delivered to all participants	✓	x	N/A	x	✓
Intervention is tailored to the individual	Report whether the intervention is tailored to individual needs (e.g., whether cognitive rehabilitation is based on results of assessment of cognitive deficit i.e., objective tests and/or self-report)	✓	x	N/A	x	✓
Reporting domain: Target population						
Demographic characteristics of the participants	Provides details of the demographic characteristics of the participants (e.g., gender, ethnicity)	x	✓	x	✓	x
Reporting domain: Unintended consequences						
Possible harm caused by the intervention	Report any negative unintended consequences of delivering the intervention	x	✓	x	✓	x