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# Self-management support for people with Multiple Sclerosis

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# ABSTRACT

## Background

Self-management programmes help people with long term conditions, such as Multiple Sclerosis (MS), manage symptoms, and contain utilization of health-care resources. However, the optimum level and type of support for people with MS (PwMS) to self-manage effectively is unknown. The research in this thesis set out to explore current self-management provision for PwMS, the experiences and perceptions of self-management support for PwMS from service user and provider perspectives, and to propose a best practice model of self-management support for PwMS.

## Methods

Following a scoping review of self-management programmes and self-management experiences of PwMS reported in the literature, a field study involving focus group interviews with health professionals providing self-management support for PwMS in three different services, and observation of those support services in action, was undertaken. Semi-structured interviews with eight PwMS receiving support from the three services explored their perceptions and experiences. Thematic analysis and synthesis of all findings informed a new ‘best practice’ model of support for PwMS to self-manage.

## Findings

The scoping review identified that published self-management programmes for PwMS focused mostly on fatigue management, interventions based on cognitive behavioural therapy/social cognitive theory to increase self-efficacy, and educational programmes, and insights into perceptions and experiences of self-management from the perspective of PwMS and health professionals were limited. The field study identified two important categories, *the service* and *self-management provision,* and themes of *diversity of care*, *physical activities*, *interactions with others*, *and self-management*. Themes identified from the interviews with PwMS were *MS journey*, *MS services*, and *self-management.* A model of best practice was created from synthesis and triangulation of all data from the review and empirical studies.

## **Conclusion**

A novel, comprehensive and holistic model of self-management support for MS has been proposed, which needs further refinement and co-production with key stakeholders prior to being tested for feasibility and acceptability.

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# CHAPTER 1 – INTRODUCTION

## 1.0 Introduction and overview of the thesis

My involvement with this research has been an exceptional journey both professionally and personally. The reason for choosing the topic of this research has a personal connection to me: a relative who is affected with Multiple Sclerosis (MS) was lacking the experience and skills required to enable him to self-manage his condition. The curiosity and the lack of my own experience in self-management opened my eyes to a new era which can enable people with MS (PwMS) to be in control in managing their disease. During this journey, I developed a deep understanding of my research topic and subsequently gained new skills that I can use in my clinical practice as a physiotherapist.

This first chapter of the thesis will introduce the topic of chronic disease, with a particular focus on Multiple Sclerosis (MS) as a long-term neurological condition, highlighting the psychosocial effects of MS at different stages of the disease, and strategies that help people to cope with MS. The concept of self-management will be introduced in terms of its history and definitions, and self-management programmes for chronic diseases in general. The chapter will set out the research aims and questions, and provide an overview of the work reported in the thesis. Chapter 2 will review the literature and evidence related to self-management programmes for people with MS (PwMS) and barriers to self-management. An overview of the methodologies underpinning the empirical studies is reported in chapter 3, and chapter 4. Chapter 5 provides a full description and analysis of the studies undertaken: a field study involving focus group interviews with three different services providing self-management support for PwMS and observation of the three services in action; and a series of individual semi-structured interviews with PwMS receiving support to self-manage. Chapter 6 presents a discussion of all the work in the thesis and presents a proposed best practice model of self-management support for PwMS, and provides a conclusion and recommendations for future research and clinical practice.

## 1.1 Chronic disease

The World Health Organisation (WHO) identified chronic diseases as illnesses with a long duration and slow progression in general. Examples of chronic diseases are heart disease, stroke, chronic respiratory diseases, diabetes, and cancer; such diseases are the primary cause of mortality in the world, and are the cause of 63% of all deaths (WHO, 2019). In addition, the WHO (2019) states that approximately 10 million people across the United Kingdom (UK) have a neurological condition; such conditions can be caused by damage to the brain, spinal cord and other parts of the nervous system (WHO, 2019). The most common neurological conditions are stroke, MS, Parkinson’s, epilepsy, muscular dystrophy, spinal cord injury (SCI), and spina bifida (Thomas et al., 2011).

Regardless of age of onset, whether the aetiology of the chronic disease is known, or whether its manifestation is considered primarily physical or psychological, people with chronic conditions and their families face a common set of challenges. For example, managing the symptoms, coping with disability, experiencing and coping with the emotional impact of the disease, managing medication regimens that are complex, difficulties in lifestyle adjustments, and gaining helpful medical care (Wanger et al., 2001).

### *1.1.1 Chronic disease management*

Chronic disease management is an essential on-going process in which the person with the chronic condition should participate continuously in a variety of practices related to health care, in order to obtain effective treatment of that chronic illness (Holman & Lorig, 2004). Holman and Lorig (2004) state that many people with chronic disease are well informed about the effect of that disease and its therapies, and must implement that knowledge in order to guide management of that condition over time. Therefore, in order to accomplish effectiveness and efficiency in treatment, it is suggested that the expert patient and health professional must contribute complementary knowledge and authority in the process of health care (Holman & Lorig, 2004).

There has been an increased recognition of the need for individuals with chronic diseases to participate actively in and commit to their treatment regimens (Newman at al., 2001). Historically, clinicians have played the main role in choosing their patient’s treatment regimens. However, more recently, the importance of direct involvement of service users in managing their long-term condition is clearly recognised, and these processes are referred to variously as education, psycho-education, or, more recently, self-management interventions (Newman et al., 2001). The Department of Health (DOH) in the UK stated that findings of research and practical experience in North America and Britain showed that people with a chronic disease need not be passive recipients of care. They can be key decision-makers in the treatment process by ensuring sufficient knowledge of their condition that can empower them to take some responsibility for its management (DOH, 2000). Indeed, by working in partnership with their health and social care professionals, the person with a chronic condition will have greater control over their lives (DOH 2000).

This was also highlighted in the NHS Long Term Care Plan (2019), in which health care leaders agreed to develop a long term plan to enable patients get the most from the NHS to help them manage their conditions/diseases in the future. The plan was developed by NHS experts, including frontline health care professionals and patients' groups. The plan allowed people with different conditions to have more control over their treatment and the care they received. This is achieved by the collaboration between general medical practitioners (GPs) and community services, to expand the services provided to people with different health conditions.

The Kings Fund Document on NHS Long Term Plan (The Kings Fund, 2019) welcomed the idea of moving from one-size-fits-all and highlighted the importance of embracing a tailored approach to support people with different health conditions. They emphasized the importance of training professionals and using expert patient approach. This will help empower staff and connect different services with communities. They also focused on the shared responsibility in making informed choices in regard to service user’s health

The idea of chronic illness as a disease course that only changes in relation to physiological factors has changed; research over the past two decades has suggested that chronic illness can affect the person psychologically and in terms of their sense of well-being (Lorig & Holman, 2003). Turner (2000) explained that psychological factors might be related to the physical impairments or physical changes that a person with chronic illness might encounter. Furthermore, some chronic illnesses may disturb sleep, alter appetite, and cause fatigue, consequently affecting mood, leading into depression and anxiety (Turner, 2000). In addition, the change of social circumstances due to the chronic course of a disease might be another factor leading to psychological impairment, lack of employment, financial strain, and lack of emotional support.

It is therefore suggested that research should investigate interventions that integrate self-management into chronic illness care and take into consideration the outcomes directly related to individuals coping with illness, such as quality of life (Rae-Grant et al., 2011).

### *1.1.2 Self-management*

Self-management of long-term conditions is considered to be a complex and evolving construct, as it is a more person-centred perspective in terms of medical disease management and treatment compliance. It is a multidimensional construct in general, incorporating elements of illness treatment management, relationships with health care providers, and general coping or quality of life (QOL) (Bishop et al., 2008). Self-management involves actions taken by people to recognise, treat and manage their own health which can be carried out independently or in partnership with health care professionals (NHS, 2019). The main aim of self-management programmes is to enhance health outcomes by supporting medical care, rather than replacing it (Walker et al., 2003) and has been shown to enable people to decrease pain, and to share in decision making about the disease treatment (Kralik et al., 2004).

Self-management is considered to be a strategy to take an action and is defined in terms of three tasks: firstly, caring for the disease in terms of medication, treatment, visiting physicians, and caring for the type of exercise and diet; secondly, controlling and engaging in one’s normal life activities; and thirdly, coping emotionally in terms of with living with the disease, realizing, and establishing a new sense of future (Bishop et al., 2008).

The term “self-management” refers to the activities people undertake to create order, discipline and control in their lives (Kralik et al., 2004). This sense of control comes from the person’s own beliefs in his/her ability to act in specific ways or change certain thinking patterns; this control is called self-efficacy (Bandura, 1986). Individuals with chronic illness develop generalised expectancies about their capability to manage their own disease; therefore, persons with greater expectations for management of their disease are more likely to have greater self-efficacy (Walker et al., 2003). Self-efficacy plays a crucial role in social cognitive theory, from which many recent programmes supporting self-management for patients with chronic health conditions are derived (Lau-Walker & Thompson, 2009). The social cognitive theory reflects a psychological model of behaviour initially derived from the work of Albert Bandura in 1986 (Lau-Walker & Thompson, 2009). It refers to the idea that people have the ability to control their own behaviour and the environment in a specific goal-directed fashion (Bandura, 2001).

Perceived control, or self–efficacy, is defined as a person's self-assessment of the ability to have the power in taking control over his or her life (Bishop et al., 2008). Higher levels of perceived control have been directly related to decreased anxiety and depression, better physical health, declined deterioration in activities of daily living, and higher levels of subjective well-being (Bishop et al., 2008). Accordingly, this critical element of psychosocial adaptation to chronic illness is correlated with a variety of positive health outcomes and adaptive procedures among people with chronic illnesses (Bishop et al., 2008).

People who are diagnosed with chronic long-term conditions begin to make sequences of adjustments over time (Kralik et al., 2004). It is suggested that structured self-management education programmes might not have an immediate effect on changing behaviour, due to differences in individual responses attached to social, cultural, emotional and psychological needs (Corben & Rosen, 2005). Taking a role in the active self-management of a condition is affected by many factors involving the length of time since the condition had been diagnosed, the disease level of severity, age, social support, and educational level (Corben & Rosen, 2005). However, due to the concept that chronic conditions vary in the extent to which they obstruct both social and psychological worlds, and therefore result in what might be essential for optimum self-management, many individuals find optimum self-management is usually hard to accomplish, as shown by low rates of adherence to treatment guidelines (Newman et al., 2004).

There are various models and approaches to self-management interventions (Newman et al., 2004). The educational approach was one of the earliest, providing patients with information in a traditional academic format (Newman et al., 2004). Whilst knowledge might be essential, it is often not enough to make a change in behaviour. Therefore, attention was turned towards psychology, where three theoretical models were elaborated (Newman et al., 2004). These three models were clarified by Newman et al. (2004) and were based on the social cognitive theory; expectation is a key role, where an individual's confidence influences his or her ability to perform the behaviour.

The first model is the stress coping model, which proposes coping strategies to control stress associated with the condition, and the self-management intervention from this model influences improved coping. In addition, there is a transtheoretical model, based on the readiness-to-change concept, which refers to how readily individuals are prepared to change their behaviour; interventions based on this theory mainly focus on the individual’s desire to change, and the approach is adapted due to differences in participants' motivation to change behaviour (Newman et al., 2004). A third model of self-management was introduced in the literature based on cognitive behavioural therapy (CBT) theory (Beck, 1976); CBT deals with links between thoughts and feelings that may drive behaviours, and uses cognitive restructuring to help people make behavioural changes (Hewlett et al., 2011). Hewlett at al. (2011) introduced an intervention self-management programme including skills such as problem-solving, goal-setting, self-monitoring of activity, rest and energy management, aimed to help people turn cognitive and behavioural changes into improved well-being.

In summary, the purpose of self-management is to support and help people to keep well according to their needs and from their own perspectives (Lorig & Holman, 2003). Hence, self-management is a strategy for coping with long-term conditions, such as MS.

## 1.2 Multiple Sclerosis

Multiple Sclerosis (MS) is a progressive disease of the central nervous system in which the immune system destroys the myelin sheath of axons, leading to altered neural conduction and ultimately damage to neurons; this in turn causes altered bodily function and activity limitation. MS affects around 100,000 people in the UK each year, with a peak incidence between the ages of 20-40 years (McCabe et al., 2009). It affects women more than men and there is no cure; only symptomatic relief is available (McCabe & Mckern, 2002). Furthermore, MS usually follows an unpredictable course which is characterized by exacerbations and remissions (Kroencke & Denney, 1999), affecting independence in activities of daily living and loss of participation in previous life activities. The importance of understanding the possible triggers for an exacerbation is considered to be one of the ways to adapt and cope with the new life with MS (Fawcett & Lucas, 2006).

Stokes and Stack (2011) classified MS into four types:

- Benign MS: where the person experiences a couple of relapses, separated by considerable time, allowing complete recovery with no sign of any disability.
- Relapsing-remitting MS: the course of disease is described by recurrent separated relapses, interrupted by periods of remission when recovery is either partial or complete.

- Secondary progressive MS: after the recurrent relapses and remissions, the disease enters a phase of progressive deterioration, with or without clear identification of relapses, where disability increases.
- Primary progressive MS: characterised by progressive and cumulative neurological deficit without remission or clear exacerbation.

### *1.2.1 Symptoms of MS*

Symptoms of MS are variable and can include: fatigue; speech and swallowing problems; pain; spasticity; bladder and bowel problems; general muscle weakness; double vision and nystagmus; optic neuritis; difficulties in maintaining balance; dizziness; tremor; cognition; and depression (Stokes & Stack, 2011). Although each individual with MS has his or her unique symptoms, the experience of some symptoms like pain and fatigue is likely to be common among PwMS (Fawcett & Lucas, 2006).

The unpredictable nature of physical, cognitive, and psychological symptoms experienced by PwMS makes it a difficult disease for individuals to cope with. The type of MS (benign, primary, relapsing-remitting, secondary progressive), the severity of symptoms and the duration of the illness, coupled with level of social support, are factors which may affect the ability of PwMS to cope effectively with the disease. This can impact on their general sense of well-being and quality of life by limiting interaction and engagement in usual activities (participation).

### *1.2.2 Psychosocial effects of MS*

Not engaging in social roles, through self-imposed withdrawal from social situations as well as through becoming socially isolated as a result of the loss of independence, is related to a decline in well-being and psychological adaptation (Mohr & Cox, 2001). It is suggested that 80-90% of PwMS have the relapsing-remitting form, but it is not always easy to detect which form of MS is initially presented; this uncertainty will add more stress to that experienced by recently diagnosed PwMS (Fawcett & Lucas, 2006).

With consideration of psychosocial problems, PwMS experience an increased level of emotional distress when compared to other patient groups with a similar degree of physical disability (Pakenham et al., 1997). There are two stages that can be identified that present significant psychosocial challenges for PwMS: firstly, the stage of accepting the reality of the disease; and secondly, knowing the best way to live with it (Brassington & Marsh, 1998).

When recently diagnosed with a chronic illness, some people might experience various stages of grief including denial, anger, and sadness (Nash, 2013). Therefore, in the early stages of MS, immediately after being diagnosed, grief may be a common reaction. PwMS and their partners are likely to experience a significant emotional burden due to the diagnosis; in one study, around 50% of PwMS and their partners had clinically relevant levels of either anxiety or distress (Janssens et al., 2003). This high emotional stress can be due to several reasons: people may compare their health status before and after they became ill, and PwMS in the early stage of diagnosis are more likely to focus on the loss of functional ability rather on actual functional ability; some PwMS will have already experienced the effects of their symptoms; or some may experience or feel uncertainty about the consequences of these early limitations for their future (Janssens et al., 2003).

### *1.2.3 Coping with MS*

Coping strategies reflect the way in which people react to stressful situations (Pakenham et al., 1997). PwMS adopt various coping strategies to help them to adjust; the disease-related changes to mood, emotions and behaviour may lead to negative feelings (McCabe et al, 2004), and a feeling of lack of control, which in turn may lead to both helplessness and depression. Accordingly, depression may subsequently increase MS-related autoimmune activity (Mohr & Cox, 2001).

Sahler and Carr (2009) stated that coping strategies are divided into three major categories: active coping, passive coping, and avoidance. They highlighted that active coping can be described as gathering information, having social support, prioritizing tasks, problem solving, and accepting help from family and friends. On the other hand, passive coping examples were described as distraction by others and relying on other people to solve their problems. Avoidance can be described as denial; this is when people decide there is no stressor in their life and therefore no need to change behaviour, perception, or emotional response (Sahler and Carr, 2009).

Coping resources may be actual characteristics of the environment that enable people to cope with stress; for example, access to money, availability of social support, in addition to individual internal factors that aid coping efforts, such as optimism, hardiness, and self-efficacy (Bowling et al., 2010). The active coping category of problem-solving, which resembles Lazarus and Folkman's (1984) problem-focused coping strategy, includes actions such as planning, prioritising, and applying effort that aims to correct the situation rather than passively allowing the stressor to continue (Allen & Leary, 2010). Thus, active or problem-focused coping involves fixing the problem at hand. Research suggests that problem-solving or problem-focused coping is useful or beneficial when people are willing to take action to correct the problem (Allen & Leary, 2010).

There are several factors that can have an impact on how PwMS can apply self-management skills, and this is likely to change at different stages of their illness journey. For example, a person seeking help when he/she had previously been independent may experience a lack of confidence, lack understanding about MS, and be unable to find the most appropriate ways to manage symptoms successfully. According to the Multiple Sclerosis Trust in the UK, people who are most likely to successfully self-manage their MS should: have a good base of information and understanding of the MS disease process; be able to control the effects of MS on their physical, emotional, social and working life; be able to adjust to their good and bad days, using pacing activities, and prioritising tasks through adopting a learning strategy; and finally, be able to make decisions and take action (MS Trust, 2013). This was also reflected by Ellis et al. (2017) who described the traits of the “good” self-manager as:

- remoralised, for example, taking responsibility;
- knowledgeable at obtaining information and reducing risks to physical health;
- being active in informed decision making.

However, this might raise a question about whether these coping strategies can fit all people to make them good self-managers.

### *1.2.4 Costs of long-term care in MS*

A key element for policy makers and advice organizations is the cost to society of long-term neurological conditions. Cost of illness studies can evaluate the economic burden of particular diseases, and can be used by related organisations such as policy makers to assign research and service funding. The majority of NHS costs for MS are attributed to hospital inpatient and out-patient treatments that generally relate to acute stage management only (O’Hara et al., 2002). PwMS and their families experience problems obtaining information about the disease; therefore, there appears to be an information gap about the disease. However, O'Hara et al. (2002) suggested that one way of ensuring cost effective continuity of care, in a way that encourages client empowerment, might be to provide people with knowledge and information needed to seek strategies which are beneficial to their health. Moreover, such information should contain discussion of self-care based on patient priorities. This can be obtained by an information booklet that explains self-care. However, this contradicts Chaplin et al. (2012), who suggested that an information booklet is not sufficient to fill this gap.

Relatively high cost estimates of MS disease were established and published over the past 10 years, in a variety of countries across the world (Trisolini et al., 2010). Moreover, MS forces significant economic burdens that can be classified into two types: type one, which is a personal burden on PwMS and their families; type two, is the general economic burden on society (Trisolini et al., 2010).

## 1.3 Purpose of the research in the thesis

The purpose of the research reported in this thesis was to explore self-management support for PwMS, with specific research objectives:

### *1.3.1 Primary research objective*

The primary research objective was to explore how PwMS can be best supported to self-manage their condition.

### *1.3.2 Specific research questions*

- What self-management programmes for PwMS have been reported in the literature, and what is the content of those programmes, and to what are the experiences of PwMS who have received these programmes?
- What are the characteristics (such as the underpinning philosophy, the nature and extent of support provided, the ‘uniqueness’, the effectiveness, and ‘best practice’) of different services (NHS acute hospital based; NHS community based; non-NHS community based) that provide support for PwMS, as perceived by the health professionals delivering the service?
- What are the experiences, expectations, perceptions of and needs for self-management reported by PwMS who receive services designed to provide support for self-management of MS?
- What are the essential components of a model of ‘best-practice’ for self-management of MS, based on the literature, the views of PwMS receiving self-management programmes, and the views of the health professionals providing self-management programmes to PwMS?

## 1.4 Summary

This chapter has introduced the concept of self-management and its relevance to PwMS. It has shown that people with long term conditions need to have certain coping strategies that might help them in controlling their condition. Some self-management models were introduced to help PwMS and people with different long-term conditions to manage their condition, including approaches that used CBT, and the importance of behavioural change when managing people with a long-term condition. The purpose of the work in the thesis has been stated, along with specific research questions. The next chapter will review the literature around self-management support for PwMS and other long-term neurological conditions.

# CHAPTER 2 – LITERATURE REVIEW

## 2.0 Introduction

This literature review provides an overview of self-management interventions for people with chronic conditions, in particular those with MS. Different types of study designs have been included in this review: randomised controlled trials, qualitative studies, systematic reviews, overviews, scoping reviews, books, and audits. Sources of data were obtained through a general search of different data bases, in addition to a manual search of reference lists. A scoping review included in the latter section of this chapter was informed by a systematic search strategy to identify self-management interventions for PwMS reported in the literature and experiences of PwMS in self-management interventions.

## 2.1 Self-management programmes in chronic illness

The concept of self-management in chronic illness was first introduced by Lorig et al. (1985), who reported outcomes of self-help education for people with arthritis. The literature mainly focused on self-management of arthritis as a chronic illness, involving its treatment, development, application and evaluation of self-management programmes (Kralik et al., 2002). The first chronic disease self-management programme began with an arthritis specific programme, which was developed by Kate Lorig (1993) at Stanford University, USA. The primary aim of the Arthritis Self-management Programme (ASMP) was to increase perceived self-efficacy for problem solving and decision making to manage the day-to-day health of people with arthritis (Hirsche et al., 2011). The ASMP draws on concepts of self-efficacy and behaviour change; it is taught in groups with a "train the trainer" approach, where master trainers coach new trainers that are less experienced in a particular topic or skill (Kralik et al., 2004). ASMP is a six-week course consisting of weekly two-hour sessions, managed by two instructors who are trained and who follow a detailed protocol; it is a community-based group programme that can also be led by lay individuals who experience arthritis (Newman et al., 2001). This programme teaches different skills that are intended to raise participants' self-efficacy to cope with their condition. What makes ASMP different in its approach, compared to other chronic self-management programmes, is that other programmes are led by health professionals only, in a hospital setting with service users who have the same diagnosis and have been selected through clinics. In contrast, the ASMP allows people with different types of arthritis to join the same group; this kind of intervention recognises some behaviour changes which are related to the person’s social world that take place outside of the clinical setting (Newman at al., 2001). Hence, the main aim of this intervention is to teach skills that individuals can integrate into their daily lives.

Some long-term neurological conditions have many characteristics that make self-management programmes particularly useful; because these conditions are longstanding, they put people with the condition at increased risk of secondary complications (Hirsche et al., 2011). The Chronic Disease Self-Management Programme (CDSMP) is another well explored self-management programme for long-term conditions (Hirsche et al., 2011). The CDSMP is based on experience of the ASMP (Lorig et al., 2001) and involves six sessions over a six-week period, each session lasting for two hours; it is delivered in community settings in the UK by two lay tutors experienced in course delivery (Barlow et al., 2009). The CDSMP comprises generic topics involving: an outline of self-management principles; exercise; management of pain; techniques used for relaxation; handling depression; nutrition; family and health professionals communication; and setting targets and aims (Barlow et al., 2009). The CDSMPs have been frequently used with individuals experiencing heart disease and diabetes, and people with such conditions are similar to those with stroke and spinal cord injury (SCI) in terms of requirements for long term management (Hirsche et al., 2011). However, PwMS face daily “up and downs” and related exacerbations or flare-ups similar to those experienced by individuals living with and managing arthritis (Hirsche et al., 2011). Therefore, the main aim of the CDSMP for conditions such as stroke, spinal cord injuries, and MS is to increase recognised self-efficacy to make decisions and solve problems to handle day-to-day health of those persons.

A before-after cohort study was conducted by Lorig at al. (2001) to evaluate outcomes (health status, health behaviours, perceived self-efficacy, and health service utilizations) of a long-term self-management programme for participants with one or more chronic diseases, in a "real-world" setting. The authors referred to the "real-world" due to the participant selection; as the participants were not recruited as "study-participants", neither were the intervention programmes given in a controlled study environment, suggesting that the outcomes can be obtained in a “real-world" health care setting. The CDSMP was offered in a total of 21 sites across the US. The classes were led by a pair of educators who had received 20 hours of training; the educators were health professionals and lay leaders. The study results revealed that the patient use of the CDSMP was related to better outcomes in all the study domains, but these results showed relatively small but statistically significant change in improvements of health behaviour, health status, self-efficacy, and fewer instances of using the emergency departments. In addition, the study results revealed substantially reduced health care costs after the implementation of the CDSMP.

"Bridges" is a well-developed self-management programme for long term neurological conditions, and specifically stroke, which was introduced in 2005, developed by Dr Fiona Jones (physiotherapist and stroke researcher) as an acknowledgment of the need to improve longer term support for stroke survivors. Bridges stroke self-management is located within the Faculty of Health and Social Care Sciences at Kingston University and St Georges, University of London, UK. The programme is made up of two components:

- Training workshops accredited by the UK Forum for Stroke Training (UKFST) for health related and social care workers who work with stroke survivors. The aim of these workshops is to teach health or social care practitioners working within the stroke pathway about self-management principles, and how to implement the Bridges programme on a one-to-one basis with individuals who survived stroke;

- An individualised workbook given to stroke survivors, or “clients”, through which practitioners work with their clients to help and guide their self-management. The workbook is composed of strategies and individual stories proposed by stroke survivors, as well as providing space for the participant to record his/her personal targets and succession.

In addition, the Bridges programme provides a carer’s booklet which is used to give information to family and friends of the clients using Bridges. The Bridges stroke self-management programme is regularly evaluated, and any suggestions and ideas from the evaluation feedback are always taken into consideration (Bridges, 2013).

Although the Bridges programme is considered to be thoroughly developed as a self-management programme for long term neurological conditions, it has only been introduced to people with stroke, brain injuries, and other long term conditions. There is currently no evidence demonstrating use of the programme with MS. It is unknown whether this particular self-management programme and its specified components can be applied effectively to PwMS.

## 2.2 Self-management programmes in long term neurological conditions and in MS in particular

An increased interest in self-management interventions for PwMS has been reported in the literature, particularly as PwMS live with a variety of symptoms that vary from day to day and over the course of years. Pain, fatigue, depression, and cognitive impairment often co-occur, and the effect of all may be greater than the sum of each individually; for example, depression can worsen fatigue, and cognitive impairment can worsen depression (Knaster at al., 2011).

Plow et al. (2011) conducted a scoping review to identify self-management tasks and skills that have been introduced and taught as components of self-management programmes for PwMS. The review aimed to describe and classify intervention strategies used in self-management education, and included 34 studies. The self-management interventions varied in content and approach. Intervention topics involved fatigue management, coping strategies, and stress, depression, and medication management. The authors used Lorig and Holman's (2003) self-management framework and Abraham and Michie's (2008) taxonomy of behaviour change techniques in order to classify and summarise self-management tasks and skills identified in the included studies. Plow et al. (2011) clarified that the Lorig and Holman framework directed the focus of the review towards intervention programmes that target the individual and change that person's point of view; i.e. interventions designed to raise their motivation level rather than interventions that focus on improving the health care system. The Abraham and Michie taxonomy was used to categorise intervention strategies, as it is the most comprehensive and validated classification system to describe strategies used in interventions to change behaviour. The results of the Plow et al. (2011) review showed that, whilst interventions varied in their delivery format and content, they aimed to improve the same outcomes. The main aim of all intervention strategies was to provide PwMS the opportunity to learn and engage in self-management tasks and skills. Additionally, most of the introduced interventions taught decision-making skills, problem-solving skills, and skills to change behaviour. Fewer interventions introduced skills for using resources, skills which can allow and enable PwMS to engage fully in their life roles.

It has been suggested that the use of self-initiated strategies give PwMS greater feelings of independence (O'Hara et al., 2000) and, hence, this is an empowerment strategy in the face of the disease of an unclear type. In addition, self-care strategies are chosen and developed by people with MS through experimentation. This concurs with Plow et al. (2011), defining the characteristic of self-management education as collaborative care, which implies that, although the professionals are experts about diseases, service users are experts about their own lives. Nevertheless, professional support is needed and this view is expressed by a lot of people with health needs engaged in self-help, and by PwMS in particular; yet, PwMS tend to discuss actions related to self-help with family, friends, and other individuals with MS, rather than discussing it with their physicians or health professionals (O'Hara et al., 2000).

The Plow et al. (2011) review included an experimentally tested fatigue management programme, which incorporates self-management education.

This programme (Packer et al., 1995) was a six-week energy conservation intervention which reportedly produced a decrease in the impact of fatigue for PwMS, which suggests it to be effective (Liepold & Mathiowelz, 2005). The programme highlights the importance of rest, communicating feelings of fatigue, the mechanics of the body, alterations to activity stations, prioritising activities and actions, budgeting energy, and balancing schedules (Liepold & Mathiewelz, 2005). Individuals participating in this programme have the opportunity to gain and become more proficient in skills such as decision making, problem solving, and using resources. Such fatigue intervention programmes that include self-management education are suggested to show improvement in quality of life and physical function in PwMS (Plow et al., 2011). Liepold and Mathiewelz (2005) determined the effects of the Packer et al. (1995) fatigue intervention programme by examining the test-retest reliability and the construct validity of the Self-Efficacy for Performing Energy Conservation Strategies Assessment (SEPECSA). The results of the study showed high test-retest reliability (ICC=0.77) and the construct validity was supported by the significant increase in SEPECSA score after applying the programme. Therefore, it can be concluded that fatigue management is an essential element of self-management for PwMS.

Management of a long-term condition, such as MS, is very different compared to the treatment of acute diseases, and requires good monitoring; from a clinical experience point of view, long term conditions require a multidisciplinary approach, with multifunctional health plans tailored to the patients' individual needs (Chaplin et al., 2012). Chaplin et al. (2012)

published an overview of the evidence for effectiveness of self-management programmes for people with long-term neurological conditions and described one model of an innovative self-management programme in Hertfordshire, UK.  This model delivered a new programme, the content of which was based on priorities from service user and carer perspectives. The programme comprised of three modules: the first module was based on priorities from both service user and carer aspects; the second module was based on service users only; the third module was based on condition-specific information for the service users only. Previous self-management programmes contained general knowledge or only information that was condition specific. This model was considered unique due to including customers (service users) and carers initially, proceeded by a generic module for customers, and ending with a separate condition-specific module for patients with long term conditions (MS). Chaplin et al. (2012) reported some feedback in the form of evaluation questionnaires from self-management groups; this general feedback highlighted that such groups were helpful, especially the peer support aspect. However, some people with early diagnosed MS found it difficult to mix with people who were more advanced in terms of disease deterioration, reporting that this mixing raised their anxiety levels and the level of fear of the future. Further, feedback from other groups suggested that the focus of the groups was around managing problems which, although realistic, again tended to focus attention on the negative aspects of the long-term condition.

Such feedback raises a crucial issue that health services should take into consideration; that is, how to manage people's sense of self-efficacy and expectations around their health and well-being, especially with a condition with an uncertain trajectory. It is vital to address ways in which people can maximise their own sense of control and feel enabled to manage their health through making their own choices to achieve positive outcomes.

Barlow et al. (2009) conducted an exploratory study which was nested in a randomised controlled trial (RCT). The aim of the RCT was to determine the effectiveness of the CDSMP when used by PwMS, in terms of self-management behaviours, self-efficacy, health status, and healthcare utilisation. The study was a two-group, randomised (n = 74), wait-list controlled (n = 64) trial with additional data collected from a group of informed non-attenders, who were aware of the research and the CDSMC, yet indicated that they did not want to attend (informed non-attenders). These participants formed a comparison group (CG) (n=74). Data were collected via questionnaires given at baseline, four months and 12 months follow up.

At the four-month follow-up, the study reported that most participants adopted techniques taught at the course, clarifying that relaxation and pacing were particularly useful for managing fatigue. The authors highlighted that energy conservation, pacing, and scheduling activity play a valuable role in avoiding over-exertion in periods of MS remission. They identified them as strategies to manage fatigue and to prevent later distress. In addition, participants’ self-efficacy and empowerment were enhanced by achieving small but realistic goals, which decreased the feelings of hopelessness, thus supporting the role of goal-setting in building patients' confidence.

Hirsche et al. (2011) explored the experiences of people with stroke, MS, and spinal cord injuries (SCI) who participated in the CDSMP by conducting semi-structured individual interviews with 22 participants. The CDSMP took place in Edmonton, Canada. The results of the study suggested that the timing of the CDSM intervention in cases of stroke and MS should be early in the process of recovery or shortly after diagnosis. Barlow et al. (2009) suggested that individuals with short term diseases are more likely to participate in a CDSMP, given that they will need less time to improve their self-management skills. In addition, Hirsche et al. (2011) reported different disease group reflections on the timing and readiness for the intervention programme; given that MS has the most unpredictable course, the MS group was less keen to agree about timing. In contrast, the stroke group agreed that the intervention workshop should be taken early. In contrast, the SCI group disagreed on the idea of participating in the CDSMP as early as after the injury; this might be due to young ages at onset of people with SCI, in addition to the long gradual period of recognition that SCI is a lifelong management process (Hirsche et al., 2011). This might reflect the difficulties and challenges regarding readiness for information when developing programmes for people with SCI (Hirsche et al., 2011).

The Motivational Model of Pain Self-management stresses the importance of a person's own beliefs and values in understanding health behaviours (Kartz et al., 2011). It is a unique model which relates to the clinically based motivational interviewing approach to understanding behaviour, and shows readiness, or motivation for a particular behaviour in terms of competing motivations, as a key element between patients' expectations and values and behavioural outcomes (Kartz et al., 2011). The data reported by Kartz et al. (2011) supported the Motivational Model of Pain Self-Management and clarified that readiness to change behaviour, which mediated the association of self-efficacy, anticipated importance of exercise, and persistence of task. In addition, this actual self-reported behaviour is predicted by readiness. Kartz et al. (2011) explained the way in which readiness to change was measured, by using the Multidimensional Pain Readiness to Change Questionnaire 2 (MPRCQ2); it effectively tests the suggested model and exercise and task persistence. It is suggested that MPRCQ2 helps in assessing readiness in order to change pain-related coping behaviours (Nielson et al., 2008). The validity of the MPRSCQ2 is supported by the positive association with adaptive pain-related coping, and the negative association with maladaptive coping (Nielson et al., 2008). In addition, it was suggested that MPRSCQ2 has the tendency to negatively associate with a measure of lack of readiness to self-manage pain (the PSOCQ Precontemplation scale) and associated positively with two measures of readiness to self-manage pain (the PSOCQ Action and Maintenance scales). Hence, Nielson et al. (2008) provided preliminary support for the validity and reliability of the MPRCQ2 scales. Acceptably high levels of internal reliability were obtained. However, the MPRCQ2 scales in Nielson et al. (2008) were conducted with participants recruited from an arthritis day programme, a Fibromyalgia Day Programme, as well as two survey samples with pain resulting from either a SCI or an amputation. This raises an important question about whether it is possible to validate the same questionnaire for PwMS. The study by Kartz et al. (2011) indicated that two subscales were taken from the MPRCQ2 to measure the readiness to begin using pain coping strategies, while the MPRCQ2 is considered to be relatively long and has multiple response options (Nielson et al., 2008). In addition, the Kartz et al. (2011) study was a cross-sectional design; this might limit the ability to draw a conclusion from the findings and hence to determine that self-efficacy and importance cause readiness, which then causes behaviour.

A systematic review of the effectiveness of self-management programmes for long-term neurological conditions, conducted by Rae-Grant et al. (2011), found limited but promising evidence supporting the value of programmes designed to promote self-management in MS and other neurological conditions. The review included 39 studies, the total number of PwMS from the included studies was not reported. The inclusion criteria for the studies were based on classification based on the criteria of the American Academy of Neurology (AAA) Quality Standards Subcommittee and Therapeutic and Technology Assessments Committees. The review included RCTs, cohort studies, and non-controlled studies. The Rae-Grant et al. (2011) review was designed to give evidence on the development of self-management interventions in MS, through exploring intervention programmes that focus on health promotion, prevention of falls, exercise, stress management, diet, and patient-directed self-care. Potential self-management interventions were suggested for the population with MS. The interventions that were reported to be effective for PwMS included: self-managed exercise programmes; motivational interviewing and goal setting; group and/or individual self-management sessions; self-management strategies based on the internet; strategies promoting telephone usage; lay-led self-management; and self-managed wellness programmes. However, the results of the review were liable to limitations; the review reported that the variety of self-management interventions made it difficult to compare the effectiveness of different treatment strategies. Nevertheless, the increased use of technologies, for example, the telephone and handheld tele-health devices, may provide additional opportunities for support and communication between individuals and their healthcare providers. Therefore, there is a crucial need for well-designed, condition-specific self-management programmes that cover a wide range of skills teaching using a multidisciplinary approach.

Hartley (2009) conducted a study to describe the development and components of a self-management and exercise model for PwMS; measures of gait, fatigue levels, quality of life, and mood were obtained at baseline and following programme completion, and the perceived benefits were recorded using a patient satisfaction questionnaire. The programme was developed and modified by a steering group composed of a physiotherapist, MS nurse specialist, one representative from the MS society, and two individuals who experienced MS. The programme was named ACTIVE, an acronym for

Advice, Coping Mechanisms, Training, Information, Value your health and Exercise, and was aimed at individuals with mild to moderate impairment; PwMS who could walk 100 meters without an aid or rest. It was a 14-week programme which comprised of combined information and exercise sessions held over a two-hour period, once a week, for six weeks in a hospital setting. In addition, the programme aimed to improve confidence to continue exercising and to find a suitable level of physical activity for each participant's needs, where exercise was continued in a leisure centre setting under the instruction of a health and fitness adviser for another eight weeks. One of the main components of the ACTIVE programme was the information sessions; these sessions were delivered by members of the multidisciplinary team and outside speakers with specific knowledge and expertise in particular areas. The information introduced in the programme aimed to give participants the chance to understand their condition in depth, how to manage some of their problems independently, and to identify to whom they can turn to when they need help and advice. The findings obtained from the ACTIVE programme suggested that PwMS that experience minimal to moderate disability showed improvement on several measured parameters. Additionally, significant improvements in walking speed and quality of life with no reported relapses were demonstrated. Furthermore, the satisfaction level of the participants was measured by a questionnaire and reported as high; individuals' responses were very positive, indicating possibilities of lasting benefits. However, there was no indication about the questionnaire's reliability and validity. Hartley (2009) stated the questionnaire was designed by a physiotherapist who was developing the service and the clinical effectiveness department in the acute trust who had experience in questionnaire development. Therefore, this might raise doubt as more information is needed to satisfy both reliability and validity of the questionnaire. Further outcome measures were collected at two time points: at the programme outset and after completing the 14-week programme. Hartley (2009) clarified the choice of the outcome measures, based on research by Petajan et al. (1996) suggesting that exercise programmes for PwMS may show improvement in the indicated areas, for example: quality of life, physical functioning, mood, and fatigue level. However, a control group study design would be more appropriate to ascertain whether the observed improvements may be attributed to the exercise sessions, the information component or the peer support of the group setting (Hartley, 2009).

Holman and Lorig (2004) explained that a person with a chronic condition should be continuously engaged in different health care practices for more effective treatment, and not a passive recipient of care who is only receiving information from the care provider. They also added, to obtain effectiveness and efficiency in treatment, the person with the long term condition should share knowledge and authority during the health care journey. This was emphasized by NICE guidelines published in 2012 regarding improving the experience of care for adults using the NHS. The guideline explained that, to enable a person with a condition/disease to be active in their health care, he/she should be involved in creating and managing their health strategy and use of services, in particularly for people with long-term condition (NICE, 2012).

## 2.3 Barriers to self-management

The barriers to chronic disease self-management can be classified into three broad categories: individual-based, relationship-based, and environmental barriers (Vallis, 2009). Vallis (2009) clarified the individual-based barriers in terms of individual motivational barriers and behavioural barriers. The motivational barrier is the difficulty for people living with long term conditions to engage in a self-management programme and to be motivated. Moreover, it is important to determine a person's readiness to begin changing his or her behaviour (Vallis, 2009). Furthermore, behavioural barriers may occur due to many people setting goals that they cannot achieve. The relationship-based barrier is about the relationship between the health provider and the person with a chronic disease; it is very important to have good communication between both sides to be able to openly discuss a subject that might help people with chronic illness to cope with their condition. Vallis (2009) also explained environmental barriers can be the society or culture influence on self-management. For example, it is very easy to choose an unhealthy diet in an urban society were life is too busy and can be too fast, in addition to multi-tasking behaviours, which can cause stress for people in general, and for a person with a chronic condition in particular.

Jerant et al. (2005) emphasized that many barriers to self-management could be defeated by self-efficacy enhancing interventions delivered in the home. The authors clarified this by giving an example of a person with low self-efficacy, due to his/her severe limitations and mobility, which disabled the person from participating in physical activities in a local community-setting. By contrast, such individuals may have a better chance to successfully participate in a home-delivered programme, which results in enhancement of self-efficacy.

## 2.4 Summary

This narrative literature review has introduced various types of studies and pieces of research about self-management in chronic disease conditions in general and MS in particular. People may differ in their responses to participate in an active self-management programme, and this is determined by many factors; the length of time since diagnosis, disease severity, age, and social help and support. Therefore, a structured self-management education programme may not particularly result in instant behaviour change.

Self-management is fundamental to understanding the change process. In addition, self-management in long term conditions has been considered as having components of both process and structure. Providing an individual with passive education can classify him/her into a passive learner or absorber, while the transitions process of self-management involve educating the individual how to respond to illness through daily life experiences and as a result of trial and error. A sense of responsibility and mastery towards the individuals’ responses to their illness may develop.

The diversity in content of self-management programmes in MS makes it difficult to identify which elements of the programmes are crucial to their success. Instead of evaluating whether self-management interventions work, a more beneficial question is to ask which components of self-management interventions do PwMS consider to be more likely to meet their needs; and which components of current self-management support for PwMS do experienced health professionals believe to be most effective, and part of best practice. In order to have a clear understanding, it is important to differentiate between self-management tasks and skills, and what is more effective and on what outcome variable. However, more attention needs to be directed to the content of the self-management programmes, how they are delivered, the type of study design and the attitudes and beliefs of the people participating in the intervention programme. A more structured approach to self-management studies in MS which compares different types of programmes will be helpful in targeting resources in the management of MS and will lead to more effective self-management interventions. Hence, a scoping literature review using a structured strategy search was conducted to help fill the gaps in knowledge and to identify the most appropriate approaches to self-management for PwMS.

## 2.5 Scoping literature review

### *2.5.1 Methods*

#### 2.5.1.1 Scoping review design

A scoping review is considered to be an ideal tool to identify the extent or scope of a body of literature, and to map the evidence available on a specific topic. In addition, a scoping review summarises key concepts in a specified research area or topic, in contrast to systematic reviews, where the quality of the evidence is assessed, and the results of the search are critically appraised and synthesized to inform practice or further research areas (Munn et al., 2018). Hence a scoping review was conducted. This scoping review adopted the proposed methodology or steps by Arksey and O’Malley (2005) that the researcher can follow while conducting a scoping review:

- identifying the research question/questions
- identifying relevant studies through a search strategy
- inclusion/exclusion criteria
- charting/ data
- collating, summarizing, and reporting results.

#### 2.5.1.2 Identifying research questions

The primary objective of this review was to identify the published self-management interventions / programmes for PwMS, and the strategies used to facilitate those interventions. Secondary objectives were to report in detail the content, mode of delivery, and patients' experiences of the different models or components of the self-management programmes.

*Search Question*

This literature review set out to answer the following questions:

1. What models of self-management for PwMS are reported in the literature?
2. What is the content of the self-management interventions for PwMS published in the literature?
3. What are the experiences reported by PwMS of self-management programmes?

#### 2.5.1.3 Identifying relevant studies

An initial search strategy was developed with support from the health librarian, who helped by explaining the use of databases by guiding selection of the relevant search terms.

Search terms of the study were as listed below, and combined using Boolean operators, using the databases CINHAL, Medline, AMED, Web of Science, Cochrane Library, PsycINFO, and ASSIA:

- Multiple Sclerosis or MS, MH "Multiple Sclerosis", Long term neurological condition
- Self-manag*, MH "Self-care", Individual* care, personalised care, person centred, person centred care
- Quality of Life or QoL
- Cop*, empower*, self-efficacy, self-esteem.

This initial strategy was piloted and discussed with the research supervisor and advisor. This helped the researcher to decide on the selected databases. This was followed by a full search of the selected databases using the same search terms. The search was refined by adding the year and the month of publication from January 1995 to January 2013 and selecting the English language option; the studies were screened for duplications across the databases and duplicates were removed. Following this, screening of the citations was undertaken in two steps: first, the titles and abstracts were screened for relevance, and non-relevant articles were excluded; then the full texts of the remaining articles were retrieved and screened for inclusion based on the specified inclusion and exclusion criteria. The search was subsequently updated to include publications up to April 2015. Screening of the articles was completed by the researcher and the research supervisor. Any uncertainty in the screening process was discussed by the researcher and the supervisor to obtain a more robust result. A flow chart was used to illustrate the research process (Figure 1).

#### 2.5.1.4 Inclusion/exclusion criteria

*Inclusion Criteria:*

The inclusion criteria were selected according to PICOS (Population, Intervention, Comparison, Outcome, Study type). PICOS criteria is known to have a high sensitivity to use across different databases and is recommended to identify the final included studies (Methley et al., 2014):

- Population: Adults with Multiple Sclerosis (MS)
- Intervention: studies should report a self-management approach

- Comparison: usual care or other intervention
- Outcomes: outcomes that reflect general well-being, ability to cope with the disease, quality of life, and other related outcomes
- Studies: all type of studies except for case studies, commentaries and reviews, published in English language between 1995-2015, with appropriate ethical approval.

*Exclusion Criteria:*

- Studies that included participants with other neurological conditions (not just MS)
- Studies that included more than a self-management intervention.

#### 2.5.1.5 Charting data

Relevant data from all included studies were extracted and tabulated to enable synthesis of findings, which were summarised in a narrative. The findings of the review are presented into two main parts, and data were extracted accordingly:

- Part 1: Content, mode of delivery and target groups in the studies.
- Part 2: Participants' experiences of the different models or components of the reported self-management programmes.

#### 2.5.1.6 Collating, summarizing, and reporting results

The search resulted in a total of 1124 citations from all the databases. A total of 456 duplicates were identified. Total number of citations after duplicates removal was 668. Screening from both title and abstract resulted in 106 citations. Screening from full text resulted in 29 citations. A total of 29 studies were reviewed. Figure 1 summarises the review process.

The review included 16 randomised controlled studies, one non-randomised controlled trials, two quasi-experimental studies, four pre-post studies, one questionnaire study, one observational cohort study, and four qualitative studies.

### *2.5.2 Results*

#### 2.5.2.1 Part 1: Reviewing the target groups, content and mode of delivery in the reported self-management programmes.

A total of 29 interventions were identified from the studies, 25 were non-qualitative studies, 16 of which were evaluated using a randomised controlled trial (RCT), whereas one trial used a controlled group but did not randomise participants. Eight other quantitative studies were also identified. All the included studies reported a positive outcome of the interventions used in the trials. The positive outcomes were mainly reported from interventions for fatigue management and well-being. A summary of the research design, number of participants and type of MS, intervention topics, and results of the study are provided in Table 1.

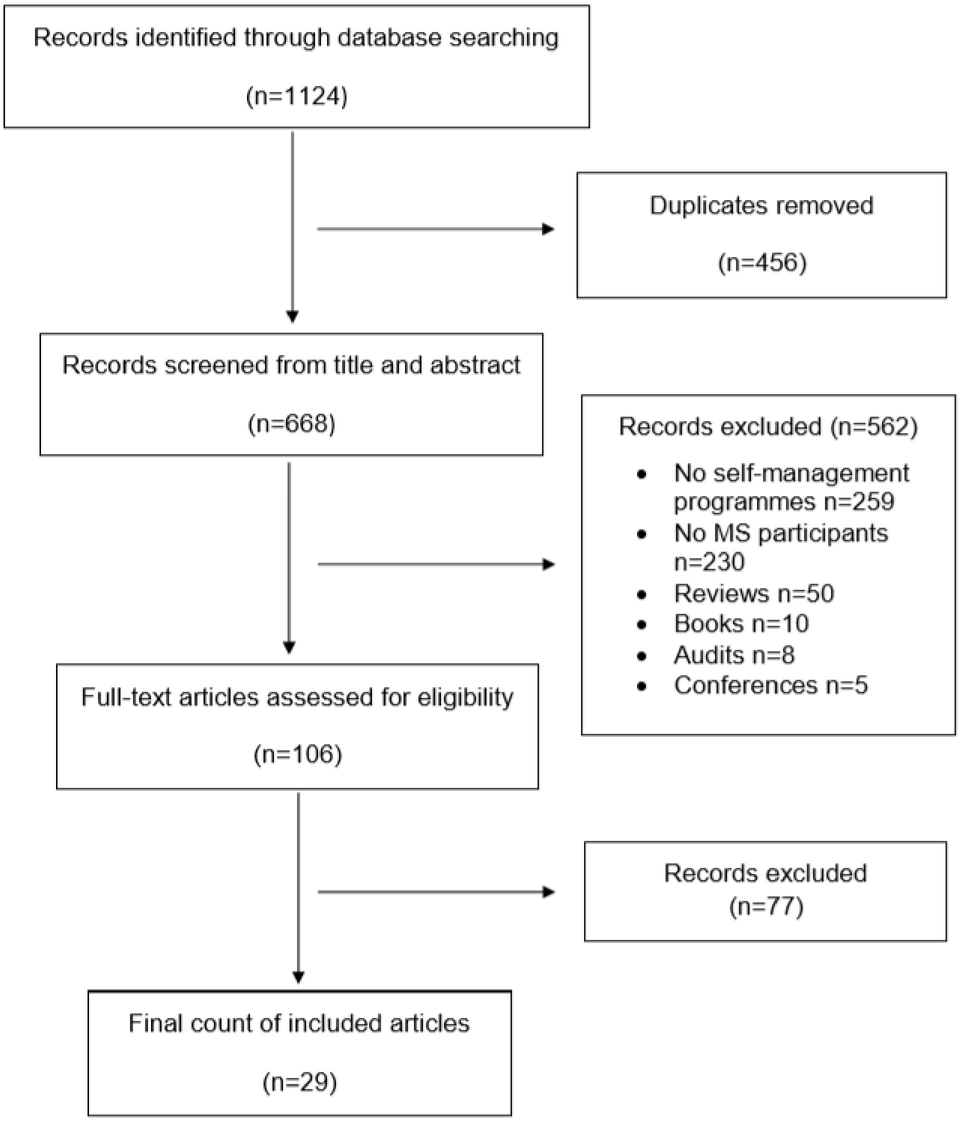

***Figure 1: Flow chart illustrating the results of the systematic search***

**Table 1: Summary of research design, participants, and description of interventions and findings of studies included in the review**

| Study | Design, purpose of the study, and delivery format | No. and type of PwMS | Intervention topics & length of intervention | Results / findings & author conclusions |
|---|---|---|---|---|
| Ng et al (2013) | A questionnaire study design to determine if an intensive wellness programme for PwMS can improve self-efficacy, QoL, and/or physical activity outcomes. Face to face group intervention | 98 PwMS returned the questionnaire after 1 month of the wellness program; 84 after 3months, 82 after 6 months. Types of PwMS not specified. | A 4-day educational wellness programme for PwMS which was composed of: Group-based individual assessment/ Group workshops/ Group lectures/ Group optional activities/ Individual consultations/ Individual optional consultations with different members of MDT. | The results indicated that a concentrated 4-day wellness programme for PwMS can improve self-efficacy and self-perceived health related outcome measures. However, the results showed no improvements in physical activity |
| Barlow et al (2009) | RCT design aimed to determine the effectiveness of the Chronic Disease Self-management course (CDSMC) for PwMS | Intervention group n=78, waiting list control group n= 64, control group n=74. Type of MS not revealed. | CDSMC which utilises the tenets of self-efficacy theory, providing mastery experience, role-modelling, persuasion and reinterpretation of physiological and affective states to assist PwMS making changes. | 170 participants responded at 4-month follow-up and 123 participants responded at 12-month follow-up. Results showed that the CDSMC had impact on PwMS in terms of self-efficacy and physical health status, with improvement on |

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| | | | Topics: self-management principles, exercises, pain and fatigue management, relaxation techniques, dealing with depression, nutrition, communication, problem solving, and goal setting.<br>6 sessions/week, each session lasted 2 hours. Questionnaires were sent to 261 participants at baseline. Participants responded after 4 and 12-month follow-up | depression and MS self-efficacy. In addition, CDSMC may play a role in PwMS experiencing mild to moderate anxiety and depression |
| Bombardier et al (2008) | RCT design to evaluate a motivational interviewing intervention using telephone based motivational interviewing using FRAMES model; which is acronym of 6 key elements: providing feedback, emphasizing | 130 MS participants. 70% relapsing-remitted, 10% secondary progressive, 5% primary progressive, 2% benign MS. 78% females & 22% males | Discussed topics were exercise, fatigue, anxiety, social support, and stress management. Over a period of 12 weeks. Conducted at weeks 1, 2, 4, 8, and 12. The initial telephone motivational interview duration was 60–90 mins. The other planned follow up calls were planned to be approximately 30 mins. | Increased health promoting behaviours in MS |

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| | freedom of choice and responsibility of change, giving advice, presenting PwMS with list of options regarding ways to change, expressing empathy, and enhancing self-efficacy and optimism to change. | | | |
| Feicke et al (2014) | Multi-centre, prospective, quasi-experimental study design to determine the impact of the self-management training programme (S.MS) for newly diagnosed PwMS | PwMS n=64,<br>IG n=31 (F=27), CG n=33 (F=23).<br>Types of MS: RRMS n=35, SPMS n=2, PPMS n=2, unknown type=23 | The CG received “S.MS” training programme aimed at improving self-management abilities especially for PwMS; consists of 7 modules: Living with MS, Epidemiology, Basic knowledge, Diagnostic, Therapy, Prognosis, Psychosocial aspects. Length of intervention not clear; either a whole day seminar or divided into five 90-min sessions. The CG received brochures | The results showed that IG who undertook the “S.MS” training programme showed a significant, sustained improvement of self-management abilities, anxiety and disease specific quality of life in comparison to the CG who read the brochures (usual care) |

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|  |  |  | which covered the same content at the S.MS training programme |  |
| Ghahari & Passmore (2010) | A three arm RCT study to evaluate an online fatigue self-management programme for people with chronic neurological diseases.<br>On-line delivery format | PwMS n=74<br>IG1 n=25, IG2 n=23, CG n=26.<br>RRMS n=39<br>Other unknown types n=20. | IG1 received a fatigue self-management on-line programme; a 7-week programme included activities and discussion on the importance of rest, communication, body mechanics, rearranging activity stations, setting priorities and standards and balancing a schedule, in addition to presentation of weekly information guided by self-management principles. IG2 an information-only group who received weekly general information about self-management via the internet for 6 weeks and had no access to the activities or interactive components of the programme. The CG had no intervention | The results showed no significant difference from both IGs or from the CG. In addition, a larger sample size is needed to evaluate the impact of the on-line programme on the fatigue, activity level and quality of life for people with chronic conditions. A face to face gold standard programme would be important to compare outcomes. |

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| Ghahari & Packer (2012) | Non-equivalent pre-test post-test control group study design to evaluate effectiveness of a face-to-face and an on-line fatigue self-management programmes and to compare these to 2 control groups.<br>Delivery format: face-to-face & on-line | PwMS n=70<br>IG1 n=10, IG2 n=19, CG1 n=18,<br>CG2 n=23.<br>Types of MS:<br>RRMS n=45,<br>unknown type n=24 | The IG1 received a face-to-face programme delivered using the 6-week published protocol outlines in Management Fatigue; each session included education, practice activities, discussions and a homework assignment. The sessions were based on the self-efficacy theory to increase confidence and ability to engage in specific behaviours. The IG2 received a 7-week online programme which included activities and discussion on the importance of rest, communication, body mechanics, rearranging activity stations, setting priorities and standards and balancing a schedule, in addition to presentation of weekly information guided by self-management. CG1 received weekly information-only programme on-line. CG2 received no intervention | The results of the study revealed that both the face-to-face and on-line versions of the fatigue management programmes effectively helped people with chronic neurological conditions to manage their fatigue. The on-line group helped participants to self-manage their depression and improve their self-efficacy in comparison to non-intervention group. |

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| Grossman et al (2010) | An RCT to examine a group intervention for enhancing Health Related Quality of Life (HRQOL) and alleviating symptoms of depression and fatigue among people with MS, examining post intervention and 6-month follow-up effects | PwMS n=150<br>IG n=76<br>CG n=74<br>Relapsing-remitting type n=65<br>Secondary-progressive n=85 | A mindfulness-based stress reduction intervention and included<br>1) a personal intake interview to define realistic goals of participants and establish personal rapport;<br>2) 8 weekly 2.5-hour classes in mindfulness practices (10–15 participants/group; exercises did not exceed participants' level of functioning)<br>3) one Saturday, 7-hour session at week six<br>4) homework assignments (approximately 40 minutes/day), emphasized as essential to success of the program<br>5) a post intervention interview to evaluate personal experiences, goal attainment, and future maintenance of acquired skills.<br>The CG group received regular care during the duration of the study, as | The findings emphasized the importance and potential success of interventions aimed toward psychosocial and existential distress of PwMS |

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| | | | provided by the neurology department of the hospital. This included one medical examination at pre-intervention and another at 6 months post intervention | |
| Hadgkiss et al (2015) | Pre-post study design to examine differences in patient-reported outcomes between people attending an Overcoming Multiple Sclerosis (OMS) programme retreat and those not. | PwMS n= 247<br>Type of MS not specified | A physician-led patient-centred risk modification programme, called the Overcoming Multiple Sclerosis (OMS) programme, aimed to educate PwMS to have more autonomy in decision making and taking control.<br>5-day live-in retreat day. Main focus was modifiable lifestyle factors that were suggested by a person with MS, with the help of health professional. | Results indicated significant reduction in fatigue, depression, and increased engagement of PwMS in decision making. |
| Hugos et al (2010) | RCT study to examine the efficacy of Fatigue: Take Control (FTC) programme. Face-to-face delivery format | PwMS n=30<br>G1 (FTC)=15<br>G2 controlled group (Wait List) n=15<br>Type of MS not specified. | The intervention group received Fatigue: Take Control (FTC) programme which is a novel comprehensive programme based on the Fatigue and Multiple Sclerosis guidelines. Groups of 6-9 participants met weekly for 6 weeks for 2 hours. FTC include DVD viewing, topic | The FTC intervention had a significant effect on the Modified Fatigue Impact Scale (MFIS) which indicated less fatigue in the FTC group, in addition to increase in self-efficacy. |

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| | | | focused group discussion, individual goal setting, and homework assignments. All participants received programme workbooks that include all of the information presented. | |
| Jalon et al (2012) | A pilot RCT to explore the feasibility and estimate the effectiveness of an energy conservation programme for the management of fatigue in MS in UK population. Group face-to-face format | PwMS n=23.<br>IG n=13,<br>CG n=10.<br>Types of MS:<br>RR n=5, PP n=3, SP n=13, unknown n=2. | The IG received an energy conservation programme. The CG received peer support consisting of education and discussion of common topics for people with MS as recommended by the MS Society, MS Trust and Action MS. Both interventions were 2-hours-long/week for 5 weeks. | The results revealed a trend towards an improvement in fatigue and patients valued the format and content of the programme |
| Kopke et al (2009) | RCT study to evaluate education programme on relapse management, using a booklet and face-to-face format. | 150 PwMS<br>IG n=77, CG n=73.<br>Relapsing-remitting type | The IG took part in a structured 4-hour education programme addressing an important field of decision making on relapse management in MS. The programme included the following topics: personal experiences, relapses, relapses | Physician-controlled therapies were reduced, and participants were more likely to refrain from CC therapy. Increased autonomous decision making. The reported number of relapses were higher in the CG. |

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|  |  |  | therapy, oral corticosteroid therapy (CC), options, reflections, and evaluation.<br>The CG did not receive any educational programmes. |  |
| Kos et al (2007) | RCT study to evaluate the short and long term efficacy of a multidisciplinary fatigue management programme (MFMP) in a face-to-face format | 51 PwMS<br>IG n=28, Placebo group n=23<br>Types of MS:<br>RR n=34, primary progressive n=5, chronic progressive=6, data not available n=6 | The IG received MFMP that consisted of 4 sessions of 2hours over 4 weeks. The MFMP provided information concerning possible strategies to manage fatigue and reduced energy levels (i.e. pharmacological treatment, diet, informing and involving the social environment, regular sleep, exercise, relaxation, cooling, assistive devices, adaptation of home/work environment and energy saving methods). The placebo group did not receive topics related to fatigue (i.e. car adaptations and driving abilities, communication skills, lift techniques for back protection and general information about MS) for the same duration as the IG. | The score on the Modified Fatigue Impact Scale showed no difference between the IG and the PG. A significant difference was found after 6 months follow up in response to the MFMP compared to PG. |

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| | | | Follow up after 6 months | |
| Lamb et al (2005) | This study presented the findings of a secondary analysis from a RCT study to determine whether there were any differences in the outcomes of PwMS who attended all 6 sessions of an energy conversation education programme compared with people who missed a session and received a self-study module.<br>Face-to-face group format | PwMS n=92<br>IG n=43<br>CG n=49<br>Type of MS: Progressive MS n=23, RR n=56, Unknown n=13 | IG attended all six sessions of energy conversation education groups based on the “Managing Fatigue” programme; the programme addresses the importance of rest, communication, body mechanics, organisation of activity stations, priorities and standards, balancing one’s schedule, and making future plans. Each session includes a warm-up activity, a review homework from the previous week, the introduction to new a material, discussion and application of that material, a homework assignment for the next session, and a conclusion. The CG who missed one session of the 6 sessions received a self-study module, consisted of a summary of the missed session, questions for the participant to reflect upon before the next session, and | The results of the study revealed that receiving a self-study module for missed sessions was just as effective as attending all sessions. In addition, the results suggested that participants who didn’t attend the session were still able to obtain information they needed in order to experience positive outcomes. |

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|  |  |  | ‘home work’ worksheets to complete to reinforce materials, |  |
| Mathiowetz et al (2001) | A repeated measures RCT design study to determine the efficacy of a 6-week energy conservation source on fatigue impact, self-efficacy, QOL, and energy conversation behavioural change in PwMS. Face-to-face group format | PwMS n=54<br>Type of MS;<br>chronic progressive n=12, RR n=20, exacerbating/remitting n=7, benign n=4, unknown n=12 | The experimental intervention group received energy conversation of 6 weekly 2-hour sessions, addressed the importance of rest throughout the day, positive and effective communication, proper body mechanics, ergonomic principles, modification of the environment, priority setting, activity analysis and modification, and a living balanced lifestyle. The course used lectures, discussions, long- and short-term goal setting, activity stations, and homework activities to teach participants into integrate the energy conservation principles into their performance of everyday tasks. The CG received 6 weekly 2-hour support sessions involving education on and discussion of topics commonly addressed in support groups | The study results revealed that a 6-week, community-based energy conversation course can be effective in reducing the impact of fatigue, increasing self-efficacy, and increasing some aspects of QoL in PwMS. However, these variables did not change significantly when experimental group was compared with the controlled group. |

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| | | | for individuals with MS and other chronic diseases. | |
| Maslakpak & Raiesi (2014) | A quasi-experimental study “pre-post-test study with control group” to investigate the effect of a self-management programme and regular follow-up on self-efficacy in PwMS.<br>Face-to-face group format and telephone follow up. | PwMS n=80<br>PwMS allocated to IG n=40 and CG n=40.<br>Types of MS:RR MS | The IG was divided into 4 small subgroups and attended 4 self-management training sessions, each session lasted for 2hrs/day. IG was provided with a self-management booklet including the content of the sessions. A total of 16 sessions were held. Contents of sessions included: discussion about basic information about MS, discussions on role management, discussions on emotional management, and a scenario session. CG received no intervention other their routine care.<br>Follow up after 2 months was undertaken for both groups | The results showed significant improvement in the mean of the self-efficacy score in the IG. Significant increase in the mean score of independence. Significant increase in the domain of control of worry, anxiety, and personal control which was reported in the follow up results. |
| Miller et al (2011) | RCT study to determine the effect of an internet-based self-management system | 206 PwMS randomised into two groups: G1 n=104 randomised to | A 12-month intervention that investigated the effectiveness of self-management using expanded secured web-based electronic messages in comparison to | No significant differences for the primary outcome measures |

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| | that utilized the use of electronic personal health records (e-PHRs) with PwMS. On-line format. | original system, G2 n=102 randomised to enhanced system. Type of PwMS not specified. | the original website. The expanded system permitted access to all features of the original system and also allowed participants to monitor MS-related symptoms, make decisions about seeking help for symptoms, and notify clinicians of issues to discuss at upcoming appointments. | |
| Mills & Allen (2000) | Pre-post evaluation. To examine the effectiveness of a short mindfulness of movement intervention to help with MS symptom management. Individual one-to-one format. | PwMS n=16<br>IG n=8, CG n=8.<br>All participants were secondary progressive MS. | The IG was allocated to 6 sessions of mindfulness of movement, posture, and breathing. Those sessions included: development of awareness of muscle tension, spinal alignment, posture, breathing, balance, shifting weight, and coordinated movement. Each participant was given written handouts, an audiotape, and a video tape. The CG were asked to continue with their current care and keep note of which of their own self-help measures were specifically | The results reported that the mindfulness of movement group showed a consistent and a significant pattern of improvements and less deterioration in comparison to the control group. |

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| | | | useful and to use these whenever appropriate. | |
| Mohr et al (2005) | Pre-post single group study design aimed to combine the efficacious ingredients of peer-support and skills management programmes using telephone administration, to manage emotional symptoms, problems in social roles, and symptom management in PwMS. Telephone contact delivery format. | A total of 16 PwMS. Type of MS not specified. | The intervention was telephone-administered peer support programme (TAPS). Eight-week programme; each session was 50 minutes long. The programme teaches a simple thought monitoring paradigm and attempts to increase pleasant activities. TAPS contains modules that target common MS-related difficulties, including fatigue management, management of cognitive problems and information on sexual dysfunction. | Results showed significant improvement across a broad range of outcomes for peer-support programmes in MS. In addition, results showed significant reductions in depression and improvements in QOL and wellbeing after PwMS participated as recipients of peer support. |
| Navipour et al (2006) | It is a pre-post study to evaluate the effect of a short term self-care programme on fatigue | 34 PwMS. Type not specified in the study. | The intervention course was 6 weeks long, the first two weeks consisted of seven sessions of 45–60 minutes long. Session 1 consisted of self-managed | Results showed significant improvement in fatigue scores after a 6 week self-managed graded |

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|  | and self-esteem in PwMS. Face-to-face delivery format in the first 2 weeks of the programme. |  | exercise programme and discussing diagnosis and treatment of MS, educational information packs were distributed to participants. Session 2-5 consisted of teaching different self-management techniques for different issues in MS. Session 6 and 7 consisted of practicing the taught self-management techniques by participants. | exercise programme, in addition to increased self-esteem |
| Sauter et al (2008) | A non-randomised controlled longitudinal study to evaluate the effect of an energy conservation course in reducing fatigue in PwMS. Face-to-face delivery format | 32 PwMS were recruited in the study, divided into 4 groups, each group consisting of 8 PwMS. 53% of PwMS were relapsing -remitting, 47% were progressive MS. | The intervention course consisted of six weekly sessions, 2hours per week, including practical activities and homework. Topics in the session included: importance of rest, communication and body mechanics, environmental adaptations, personal priorities and standards, time management and balancing self-care, work and recreational tasks. | The results showed reduced cognitive and physical fatigue in PwMS after participating in the fatigue management programme by using coping techniques taught in the course. |
| Stockl et al (2010) | Observational cohort study design to | There were 2 analysis populations, | The DTM programme is regular-intensity program, where consultations conducted | An MS DTM program focusing on medication management was |

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| | examine the effect of MS disease therapy management (DTM) to help PwMS manage their medication therapy. Face-to-face delivery format. | a claims data population (IG) and a patient-reported population PwMS enrolled in the DTM program who completed the month 0 and month 6 consultations. 2 CG who did not participate in the DTM programme. | intermittently at enrolment (month 0), month 1, month 4, and month 6. For the high-intensity program, consultations were conducted monthly throughout the 7-month program. The initial consultation typically lasted 40 to 60 minutes, and follow-up consultations lasted 20 to 30 minutes. During each consultation, the clinician examined PwMS' knowledge and health concerns and provided education on core topics. A personalized care plan that summarized and was sent it to the PwMS and to the prescriber of the injectable MS medication. | successful in improving adherence and persistence to injectable MS medications. The percentage of DTM patients reporting an MS relapse decreased by 33.6% from month 0 to month 6. |
| Rietberg et al (2014) | RCT to examine the effect of an individually tailored, multidisciplinary outpatient rehabilitation programme, compared to monodisciplinary | 48 PwMS were randomised into two groups; group 1 (intervention group) n=23 allocated to multidisciplinary treatment and group | Group 1 participants had a 12-week individualised exercise programme, consisting of 2 x 45-minute sessions/week of supervised aerobic training in circuit style, performed individually or in classes. Participants were also referred for 1-hour of | Results showed no significant difference between the two groups in the primary outcome measure and the two fatigue questionnaires. |

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|  | consultation by an MS nurse on chronic fatigue in MS. Face-to-face delivery format | 2 (control group) n=25 allocated to nurse consultation. Type of MS: primary progressive n=8, secondary progressive n=12, relapsing remitting n=28 | Occupational Therapy to set goals, time management, and fatigue management skills. In addition, the participants in the intervention group were referred to social work to address factors such as support from the environment, conflict at work, and coping with MS. The control group received consultation according to the Nursing Intervention Classification. The participants had a 1-hour session and evaluated in follow-up consultation every 3 weeks; the session included goal settings, planning of activities, priority setting, energy conservation, advice on nutrition and alcohol and drug intake, and homework assignments. A follow -up was made after 24 weeks for both groups. |  |
| Pilutti et al (2015) | RCT to examine the efficacy of behavioural internet intervention in increasing physical | 82 PwMS participants were included in the study. | The IG received the behavioural internet intervention included several components, namely a dedicated study website with information about becoming | Internet behavioural intervention showed positive effects on managing symptoms including fatigue, physical abilities, depression, and anxiety. |

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|  | activity and potentially increasing secondary outcome measures, i.e: fatigue, HQOL | IG n=41, CG n=41<br>Relapsing-remitting n=35, secondary progressive n=10, primary progressive n=7 | more physically active based on principles of Social Cognitive Theory (SCT), self-monitoring and goalsetting using a pedometer and activity logs, and one-one web-based video coaching sessions.<br>The CG was the waiting list group |  |
| Thomas et al (2012) | RCT to evaluate the effectiveness and cost-effectiveness of a six-session group-based programme for managing MS-fatigue (Fatigue: Applying Cognitive behavioural and Energy effectiveness Techniques to life Style (FACETS)) | 164 PwMS participants were included in the study and randomised in to IG n=84<br>CG n=80.<br>Benign n=6, relapsing-remitting n=75, secondary progressive n=39, primary progressive n=44, | IG received a group-based FACETS programme based on a conceptual framework integrating elements from cognitive behavioural, social-cognitive, energy effectiveness, self-management and self-efficacy theories. The intervention consists of six sessions (~90 min duration) held weekly and facilitated in groups of 6–12 by two health professionals with experience of working with PwMS.<br>CG received current local practice, including range of general advice and information provision about MS-fatigue to | Results showed that FACETS programme can effectively reduce fatigue in PwMS and can increase fatigue self-efficacy; in addition, results were only apparent at 4 months follow up post intervention. Changes in attitudes and lifestyle central to the programme are likely to take time to incorporate into daily routines. |

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|  |  |  | more detailed individualised management advice from a variety of health professionals. |  |
| Miller et al (2011) | RCT to assess an internet-based self-management system that utilized the electronic personal health records (e-PHRs) and determine its impact on self-assessed well-being, clinician-assessed well-being, and health care utilization in people with MS | 2 randomised groups:<br>enhanced system group n=84,<br>original system group n=83 | A 12-month intervention, where the enhanced group received an internet-based self-management system that utilized the e-PHR and determined its impact on self-assessed well-being, clinician-assessed well-being, and healthcare utilization in PwMS. Active intervention, which included secure messaging, self-monitoring, self-management of MS symptoms, and communication about upcoming clinic visits.<br>The original system group received the usual care which is a secure web-based messaging system. | Results showed no significant difference between the two groups. |
| Wassem & Dudley (2003) | RCT study design to evaluate an outpatient programme for PwMS | 27 PwMS participated in the study. Type of MS | The IG were assigned to a rehab MS programme; four 2-hour sessions with | The study results demonstrated decreases in fatigue and improved |

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| | to help improve their symptom management.<br>It was a face-to-face group delivery format | not specified in the study | group participants meeting once a week over 4 consecutive weeks.<br>Sessions included topics exercises, medication, communication, nutrition, sleeping. | sleep among the treatment participants. |

### *Type of delivery format/ mode*

The reported interventions were delivered in different formats or modes. Face-to-face group type interventions (n=17); on-line based self-management interventions, where PwMS required access to certain websites for the intervention (n=5); telephone-based delivery format targeting PwMS individually (n=2). Furthermore, two studies reported one-to-one, face-to-face delivery of their intervention, noticeably in interventions using mindfulness interventions and wellness one-to-one programmes of self-management.

### *Description of intervention topics provided for PwMS*

Fatigue self-management interventions were considered to be the most common amongst the other interventions identified in this review (n=9). The fatigue intervention topics encouraged physical activities, individual goal setting, prioritising, good communication between PwMS and health care providers, and thorough information and education about MS.

One of the fatigue management interventions aimed to reduce fatigue and decrease energy levels through a multidisciplinary fatigue approach; the intervention involved pharmacological treatment, nutrition, and allied health therapy, in addition to informing and involving the social environment (peers, carers and families) and to adopt energy saving techniques by prioritising and having regular sleep. This programme resulted in reducing fatigue after 6 months from commencing the intervention (Kos et al., 2007).

Fatigue Applying Cognitive behavioural and Energy Effectiveness Techniques to Life Style (FACETS) was one of the interventions used to manage fatigue and techniques to preserve energy; it is a programme based on combining elements from cognitive behavioural therapy (CBT), social cognitive theory (SCT), energy effectiveness, self-management and self-efficacy. The programme was delivered by health professionals who deliver care for PwMS. The intervention aimed to deliver management advice to PwMS. The study results showed effectiveness in terms of reduction in fatigue and increase in self-efficacy (Thomas et al., 2012).

Energy conservation interventions were also identified in the review of fatigue management programmes (n=4). Those interventions delivered educational courses which included topics around positive communication, body mechanics, priority setting, setting short- and long-term goals, time management, and recreational tasks. The results of the studies reported a decrease in fatigue levels, improvement in cognitive problems, promoted better QoL, and increase in self-efficacy (Jalon et al., 2012; Lamb et al., 2005; Mathiowetz et al., 2001; Sauter et al., 2008).

Other interventions were directly related to medical management, for example, disease therapy management (DTM). The intervention involved regular intensity programme consultations, education about MS, and setting a personalised care plan, in addition to an education programme about managing relapses in MS. It included PwMS expressing their own personal experiences about relapses in addition to shared decision with the consultants/physicians. Results of these studies reported an increase in autonomous decision making and decreased relapse in MS (Stock et al., 2010; Kopke et al., 2009).

Moreover, some of the interventions included self-management programmes that had shown successful results with other long-term conditions, and were hence suggested to be useful for PwMS. For example, the Chronic Disease Self-management programme/course (CDSMC) which promoted self-efficacy theory, self-management principles e.g. goal setting and problem solving, exercises, reinterpretation of the physiology of MS, and pain and fatigue management. The results showed that such programmes helped in controlling anxiety and reducing depression (Barlow et al., 2009), in addition to self-management programmes that promoted early self-management training for newly diagnosed PwMS. The training course included living with MS, epidemiology of the disease, basic knowledge about MS, prognosis of MS, and the psychological views of the disease. The results showed increased self-management abilities and better control of anxiety, and promoted a better QoL (Feicke et al., 2014).

Motivational interviews for self-management was one of the interventions identified in this review which emphasized freedom of choice and responsibility, ways to change, and promoted self-efficacy and adopted optimism behaviour change; the results showed improvement in health promoting behaviours in MS (Bombardier et al., 2008).

The review identified a mindfulness programme which aimed to enhance healthy related Quality of Life (QoL), decrease depression, and manage fatigue; it also encouraged PwMS to set realistic goals and aim towards psychosocial approach. The intervention included sessions related to the connection between movement, posture, and breathing, for example muscle tension, spinal alignment, posture, breathing, weight shifting, balance, and movement coordination. The results showed that mindfulness can help with movement coordination and reducing fatigue for PwMS (Mills & Aleen, 2000).

A wellness programme was also reported to improve self-efficacy, physical activities, and was also shown to improve management of secondary symptoms such as depression, stress, and anxiety. The intervention included individual assessment of the general health of a person with MS; this was composed of blood test, eye test, and physical fitness. Group workshops included cognition related topics, goal setting, and skill building; and group lectures included education about MS, sexual function, psychological aspects of MS, nutrition, exercise, stress management, complementary and alternative medicine, and goal setting (Ng et al., 2013).

One study conducted a tailored intervention aiming to compare effects of a fatigue management programme delivered by one member of the health care team (MS nurse) with an MDT approach for the individual person. The intervention group received an individual exercise programme (aerobic and circuit exercises), occupational therapy to deliver education about goal setting, time management, fatigue management and skills, and social support to support issues regarding employment and coping with MS. On the other hand, the control group received care from the MS nurse only, who discussed topics like activity planning, goal setting, and medical management. However, the results showed no significant differences between the two groups. Both groups showed positive results regarding fatigue management (Rietberg et al., 2014).

The review also reported an intervention aimed to promote healthy lifestyle behaviours through engagement in a physician-led patient-centred programme, the Overcoming Multiple Sclerosis (OMS) programme for PwMS. It was a 5-day live-in retreat which concentrated on factors to modify lifestyle, and empower PwMS to have more control over their own health. The programme was supported by resources, such as, books, websites, and social media; in addition, the programme specified an online platform for PwMS to share their experiences, commentary, and to contribute to a forum. The results showed that PwMS who undertook and engaged in the programme resources showed improvement in their mental and physical abilities, significant reduction in their fatigue and depression symptoms (Hadgkiss et al., 2015).

A peer-support and skills management programme using telephone administration to help PwMS manage their condition was identified in this review. The aim of the study was to pilot a telephone-administered peer support (TAPS) programme that provided skills training for PwMS to manage their emotional symptoms, social problems, and other symptoms, if applicable. TAPS was a programme based on a cognitive-behavioural approach, to help participants to cope with issues from the emotional and the social aspects of their lives. The intervention was an 8-week programme led by peer counsellors who met certain criteria (e.g. diagnosed with MS, no depression symptoms reported). The programme was delivered via a telephone call which lasted 50 minutes. The 50-minute session started with initial checking of the person’s mood, discuss any problems, set an action plan for specific tasks to help solve problems, and set up homework to be completed by the following session.  The results of the study suggested that self-management programmes with a specific structure can be delivered by peer counsellors over the telephone. In addition, such programmes can improve quality of life and well-being for PwMS (Mohr et al., 2005).

### *Summary of the findings*

Part 1 of the review aimed to identify and summarise self-management programmes reported in the literature, in addition to mode of delivery and content of those interventions. The intervention type, mode of delivery, and results of the selected studies were reported. The findings of Part 1 showed fatigue as the main symptom targeted by self-management programmes. Other interventions concentrated on improving secondary symptoms, such as depression and anxiety using self-management programmes related to a behavioural change / social cognitive theory approach, wellness, and mindfulness by increasing self-efficacy and sense of control in PwMS. Moreover, some self-management programmes in the studies were targeting the medical management of MS. The studies in the review showed that there were different modes of self-management delivery: group sessions,1:1 sessions, telephone, and internet/online sessions). Most of the studies showed positive outcome in their results in MS primary symptoms and secondary symptoms.

#### 2.5.2.2 Part 2: Reviewed participants’ experiences of the different models or components of the reported self-management programmes.

This part of the scoping review aimed to review the experiences of PwMS in using different models of self-management programmes. The review identified four qualitative studies. The identified studies were summarised and tabulated according to the purpose of the study, delivery format, number of participants, intervention topics, design of the study, themes, and conclusion. See Table 2 for details.

*Intervention topics*

Four different topics of self-management for PwMS were identified in this review: an intervention based on cognitive behavioural strategies, fatigue management, motivational interviews, and medical management programme. The cognitive behaviour intervention was called the “Mind over Matter” programme (Shevil & Finlayson, 2009) which was composed of a variety of content and structured components that enable participants to be in control of their cognitive changes. Participants were taught problem solving techniques to identify the cognitive challenges and how to apply cognitive management strategies to solve these problems. It was a community-based programme composed of five sessions that included:

- Session 1: cognitive symptom discussions and how those symptoms can affect daily activities for PwMS. Introducing cognitive management techniques through problem solving.
- Session 2: greater depth in explaining problem solving techniques to manage cognitive problems, and discussing case studies.
- Session 3: activity modifications and environmental modification (e.g. home adaptation)
- Session 4: discussing the emotional factors and the negative thoughts and their effect on cognition management. Explaining the benefit of communication and when to ask for help.
- Session 5: Setting future goals.

**Table 2: Summary of research design, description of intervention, themes and findings from qualitative studies**

| Study | Purpose of the study | Design of the study | No. of PwMS, gender, and type of MS | Intervention topics | Delivery format | Themes & findings | Author conclusions |
|---|---|---|---|---|---|---|---|
| Shevil & Finlaysion (2009) | 1. Increase knowledge of cognitive symptoms and their impact on daily functioning<br>2. Increase levels of self-efficacy in ability to self-mange cognitive symptoms.<br>3. Enhance ability to self- | 1. Focus groups<br>2. Program evaluation questionnaire<br>3. Facilitator reflection notes. | 35 PwMS. 26 females & 9 males. Mild-moderate cognitive impairment. Type of MS not specified. | Mind over matter learning to manage cognitive symptoms in MS. The activities included sessions to discuss cognitive MS symptoms, problem solving steps, environmental modifications, | Multiweek, group-based educational programme. 5 sessions, (2hrs /week) | 1. Problem solving<br>2. Goal setting delivery<br>3. Information about cognitive changes | People with mild to moderate symptoms of MS can benefit from a self-management programme to address cognitive changes in MS. Some essential structural elements as group format, homework, |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | manage cognitive symptoms through the use of cognitive solutions and strategies. | | | cognitive management strategies, and plan for the future by goal setting. | | | and between session calls enhances successful management of cognitive changes |
| Twomey & Robinson (2010) | To describe the subjective experiences of participating in a fatigue management programme for PwMS | Semi-structured interviews analysed by a phenomenological perspective | 8 PwMS (2 males & 6 females) relapsing remitting, secondary progressive, and benign MS | Fatigue management programme included: stress management, positive thinking, energy conservation, ergonomics, exercise and conditioning, supplements and medication, acupuncture, rights and | 8 week fatigue management programme (2hrs/session) | 1. Participant's experiences of ownership, active participation and empowerment<br>2. Experiences of legitimisation of fatigue and validation.<br>3. Experiences of support, having a shared voice | The findings revealed some benefits of the programme: empowerment, the experience of legitimisation and validation of fatigue, and the benefits from participating in a group programme. |

|  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|
|  |  |  |  | entitlement, education about fatigue, assertive communication and nutrition. |  | and shared experiences.<br>Further themes identified:<br>• lifestyle and occupational changes<br>• altered thinking about fatigue<br>• development of social supports |  |
| Mulligan et al (2013) | To outline the content and pragmatics of the Blue Prescription approach, to uncover what interactions are required to best deliver it, and to identify enhancements | Semi-structured interviews with participants, semi-structured interviews with the 2 physiotherapists, physiotherapists' clinical notes recorded during the trial, and meeting records | A total of 27 MS participants (23 female, 4 males). Type of MS varied between primary progressive, relapsing remitting, | Motivational interviewing with MS participants to discuss goals of their physical activity and to problem solve how a desired physical activity programme was to be achieved. | Blue prescription approach, using motivational interviewing with MS. Delivered by physiotherapist who visited PwMS on 1-3 occasions in the 1st & 2nd | • Satisfaction that the physiotherapist visits were at the participants' desired location and timing.<br>• Self-directed decision making. | Blue prescription approach could potentially be used with different chronic conditions due to its flexible approach in choosing the |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | to the approach. | from the advisory group | and secondary progressive | | week. At the end of the 3 months an exit visit from the physiotherapist was conducted. | • Respected preference and freedom of choices.<br>• Motivation to keep up with physical activity. | physical approach. |
| Keating & Ostby (1996) | Evaluation of a teaching programme for PwMS receiving interferon beta-1b therapy, and review of patients' perspectives of interferon therapy | Survey questionnaire containing 6 open-ended questions about patients' perceptions | A total of sixty PwMS (22 male & 38 female). Relapsing remitting type of MS | Teaching programme included: information on the multi-centre trial of interferon beta-1b therapy for MS, handout booklet and personal diary, and skills training to practice injection technique. | Teaching programme on interferon beta-1b therapy for MS. Participants were treated with interferon beta-1b therapy from 2-24 week. Length of the education programme unclear | • Self - confidence<br>• Positivity<br>• Psychosocial adaptation | Results revealed raised confidence in managing interferon beta-1b therapy, increased hope of controlling their disease, and professional nurses play an important role in patient education. |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | Participants were treated with interferon beta-1b therapy | | | |

Twomey and Robinson (2010) explored experiences of PwMS using a fatigue management programme. The programme included topics, such as, stress management, energy conservation, positive attitude/thinking, physical exercises, medication management, education about fatigue, nutrition, and topics of interest from the participants.

Motivational interviewing was used as a self-management programme based on the Blue Prescription approach. The authors of the study explained that the philosophy of the approach was to give freedom of choice for the person with a physical disability to choose their own physical activity and to provide ongoing support for this person; hence, motivating autonomy of choice (Mulligan et al., 2013). Motivational interviewing included topics such as physical activity, setting goals, and problem-solving techniques. The physical activities were chosen by the person with MS and ranged from home-based exercises to walking and recreational sports (Mulligan et al, 2013).

A medical management programme was also identified by this review. It aimed to explore experiences of PwMS following a teaching programme about interferon beta-1b therapy and the intervention programme included information on the beta-1b therapy for MS through use of an included information booklet and personal diary. The programme provided intensive training to practice injection techniques, and family involvement was essential. The participants were supplied with the manufacture’s kit and completed a check list of learning self-injection. The first dose of the medication was performed during the class. The training involved a tailored approach, taking into consideration participants with motor, sensory and visual disorders; hence, the carers and family had an important role to play in supporting this. The nurses delivering the programme also played an important role in enhancing self-management through motivation and educating PwMS about psychosocial adaptation to the long term disease (Keating & Ostby, 1996).

### *Themes Identified from experiences of PwMS involved in self-management programmes/models*

All of the experiences from the identified studies reported a positive outcome by PwMS who participated in the studies. Themes identified overlapped between the studies.

Decision making or shared decision was one of the common themes across the studies. PwMS reported that self-management programmes enabled them to be more involved in decision making regarding different aspects of their lives, for example, choosing their own exercises based on their level of activities. In addition, some of the interventions gave PwMS the choice of topics to be discussed as part of their cognitive behavioural therapy.

Problem solving was another theme identified by the reported studies; this was more specifically noted in the cognitive behaviour therapy programme, “Mind over Matter”, which promoted self-efficacy. This programme used a problem solving approach which enhanced cognitive management (Shevil & Finlaysion, 2009). The motivational interviewing programme also used problem solving techniques in their study and this increased motivation in PwMS in managing their disease (Mulligan, 2013).

Participants reported an increase in confidence after using self-management programmes, which subsequently increased the sense of empowerment. This was reported by participants in Twomey & Robinson (2010); the participants stated that positive thinking increased the sense of empowerment and control over managing their condition.

Goal setting was one of the skills encouraged in the reported self-management programmes identified from the qualitative studies included in this review. It was a theme identified by Shevil and Finlaysion (2009), and was reflected by the cognitive behaviour approach in promoting self-management. Figure 2 illustrates the identified themes from the qualitative studies.

In summary, the identified qualitative studies explored the experiences of PwMS using different self-management programmes. Those programmes included fatigue management, a behavioural change therapy approach, motivational interviewing, and medication management. Positive outcomes were reported by PwMS and themes such as problem solving, decision making, empowerment, behavioural change, and goal setting were identified.

*Figure 2: Identified themes and findings based on reported qualitative studies*

### *2.5.3 Discussion:*

This scoping review aimed to explore the various self-management interventions or programmes, published in the literature, to help PwMS manage their condition, in addition to exploring experiences of PwMS in using self-management programmes.

#### 2.5.3.1 Identified self-management programmes/models

The review identified several self-management programmes aimed to support PwMS in managing their condition, through medication management, MS symptom management, and MS secondary symptoms management.

*MS symptoms and secondary symptoms management programmes*

The majority of the identified studies in this review reported self-management programmes to support PwMS manage their fatigue symptom through non-pharmacological treatment/medication. It was reported that fatigue can be present in about 75-95% of PwMS and is known for being the most disabling symptom that affects the person with MS physically and emotionally (Hugos et al., 2010). Hence, the interventions in the review addressed management of the fatigue symptom by approaches including energy conservation, physical exercises, prioritising tasks, rest, and setting goals to meet PwMS. The NICE guidelines published in 2014 about MS management stated that stretching exercises, balance, and aerobic exercises can help with reducing fatigue in PwMS (NICE, 2014). The MS Society (2019) highlighted that the exercises should be tailored to meet the needs of PwMS; hence, choosing low energy exercises such as yoga can be an option to help PwMS reduce their fatigue symptoms. Energy conservative fatigue management programmes were introduced in this review. Thomas et al. (2012) used the Fatigue Applying Cognitive behavioural and Energy effectiveness Techniques to Life Style (FACETS) programme to manage fatigue symptoms for PwMS. The programme is based on cognitive behaviour change theory, which is a theory introduced by Bandura (1986), who explained that CBT is based on the interaction between cognition, emotion, and how we act or behave towards a certain situation. The NICE guideline (2014) report for MS management stated that often PwMS who have fatigue can have secondary related symptoms like anxiety or/and depression. Therefore, the guideline recommended using a cognitive behavioural approach therapy for treating fatigue or fatigue related symptoms. The energy conservation technique can help manage fatigue through communication, prioritising, and setting goals (short-term and long-term goals) (Jalon et al., 2012; Lamb et al., 2005; Thomas et al., 2012).

The review also explored the experiences PwMS using fatigue management programmes. It was identified that it increased their self-efficacy and therefore, made them more capable of decision making (Twomney & Robinson, 2010).

Mindfulness was also one of the self-management approaches introduced to help reduce fatigue and secondary symptoms due to fatigue as depression. Mindfulness can be an interaction between movement, breathing and posture. It makes the person aware of the muscle tension, spinal alignment, and works on balancing techniques with PwMS, therefore reducing their fatigue symptoms (Mills & Allen, 2000). It was also recommended by NICE (2014) to help in reducing fatigue in PwMS.

Psychological/behavioural management was the other management strategy highlighted in this review. The unpredictability of the MS disease, and the effect of MS in increasing physical disability, can lead PwMS to emotional distress and psychological challenges. Hence, it can result in mood changes, depression, and anxiety (MS Society, 2019). Therefore, the review identified some self-management programmes that can help control those symptoms.

The wellness programme which was introduced by Ng et al. (2013) was suggested to help increase self-efficacy, which can help in improving emotional or mental health problems related to the MS disease, leading to a better quality of life. The programme was an educational programme which was composed of a holistic approach to management for PwMS, including physical, emotional, behavioural, and physiological support. The programme of the educational course was composed of approaches towards decreasing stress, motivation, goal setting, and energy conservation strategies. This was reflected by the MS Society (2019) where it was defined as a long-term journey through life for PwMS, making them aware of their behaviour, and encouraging positive thinking or choices about their lives, for example, activities and lifestyle that can enable them to attain a better quality of life. The MS Society also reported that wellness is a holistic, multidimensional approach that includes physical, emotional, social, occupational, and medical dimensions.

The review identified other programmes that can promote well-being and health behaviours in MS; those programmes used the motivational interviewing approach. This approach encourages freedom of choice and responsibility of change by enhancing self-efficacy and optimism as a behavioural change technique (Bombardier et al., 2008; Mulligan et al., 2013). The Health Foundation (2011) emphasized that motivational interviewing can lead to behavioural change; this can increase their self-efficacy and support them in setting their own goals and setting strategies to move forward. It was reflected by PwMS, who participated in a motivational interviewing technique, that the programme increased their motivation and self-efficacy, and subsequently changed their behaviour towards decision making and freedom of choice (Mulligan et al., 2013).

Medical management was one of the approaches identified in the review. However, medical management for PwMS normally involves the individual’s GP, MS nurse specialist, and neurologist/neurology consultant, due to the reason for requiring medication to control the condition (MS Trust, 2017).
In this review, medical management involved mainly offering advice and information through educational courses, to clarify details about the MS disease course, its symptoms, and drug therapy.

Two of the reported studies involved medical treatment for PwMS aimed at promoting self-management of injectable MS medication (Keating and Ostby, 1996; Stockle et al., 2010). Both medical management programmes required intensive training and consultation. The injectable MS medications in the studies aimed to control relapses of the MS disease, involve PwMS in decision making regarding their medication intake through intensive educational courses and regular consultation points, and to support them to inject themselves independently. However, Keating & Ostby (1996) emphasized the importance of physical, cognitive, and visual ability for the PwMS to be able to demonstrate the technique. Hence, carers and family members were involved in the education course to support PwMS in learning the techniques. Both studies indicated the importance of PwMS being involved in decision making and influencing positive health behaviours. This was reflected by PwMS involved in Keating & Ostby (1996) indicating increased self-confidence, positivity, decision making, and psychosocial adaptation.

Ben-Zacharia et al. (2018) who conducted a narrative review exploring the impact of shared decision making on MS medication adherence. Ben-Zacharia et al. (2018) stated that MS medication such as disease modified drugs (DMD) prescription and administration should be combined with individual person’s preferences of choice, life style, MS disease course, level of physical and cognitive ability, and the safety and tolerance of the medication. Subsequently, interventions should aim to optimise medication adherence in PwMS by using a decision-making approach or model that takes into consideration preferences, involvement, and education of the person with MS (Ben-Zacharia et al., 2018).

### *Identified skills and techniques used by PwMS in self-management programmes*

The studies reported in the review identified common skills required by the person with MS to adopt or achieve in order to be able to self-manage. Therefore, most the interventions included certain techniques that PwMS have to learn to manage their disease course. Lorig & Holman (2003) explained the meaning of self-management and identified the tasks and skills of self-management for people with long term conditions. They reported that self-management programmes for long term condition should address three different tasks: medical/behavioural management, role management, and emotional management. In addition, self-management skills should include problem solving, decision making, utilisation of recourses, and the health professional–service user relationship. Some of these skills were used by PwMS in different self-management programmes. However, other skills or techniques were also identified in the review; for example, goal setting, pacing / prioritising, and positivity. The MS Trust (2014) produced a self-management guide called “MS and Me” identifying self-management techniques: knowledge, goal setting, and problem solving. All these techniques or skills were also identified from the literature included in this scoping review.

Education courses or information were provided by the intervention studies as part of their self-management programmes; those included education courses about relapse management, disease symptoms, and pharmacological treatment. NICE guidelines (2014) emphasized the importance of providing adequate information and education about the MS disease. This includes information at diagnosis and on-going information throughout the course of the disease; it includes educating PwMS about MS types, medication, social needs, and signpost PwMS to the required direction of therapy. This will encourage PwMS to monitor their symptoms and ask for help when required (MS Trust, 2014).

Goal setting was another technique addressed by the interventions in addition to being one of the themes from the qualitative studies. Each self-management programme addressed in the review included a topic regarding goal setting. Setting goals in a self-management programme is essential to enable PwMS to be more focused and have the sense of achieving a task (MS Trust, 2014). The MS Trust (2014) reported that those goals should be SMART goals, which means specific, measurable, achievable, realistic, and timed. However, in this review none of the included studies documented comments regarding SMART goals. In contrast to the MS Trust guidance, Jones et al. (2012) reported that setting SMART goals for people with long term neurological conditions, such as stroke, will not allow the person to be productive with problem solving and self-discovery, thereby, affecting their self-management philosophy.

The problem solving theme reflects the ability of PwMS to face their problems and think/analyse them to find a solution (MS Trust, 2014). This was reflected particularly in studies related to a behavioural change approach, where the interventions included cognitive behavioural therapy or were based on social cognitive behavioural therapy of change to increase self-efficacy, to enable PwMS to have more confidence in facing problems and solving them (Gahari & Packer, 2012; Maslakpak & Raiesi, 2014; Mathiowetz et al., 2001; Pilutti et al., 2015; Sauter et al., 2008; Thomas et al. 2012).

Decision making and shared decision were identified as being related to the relationship between the health professional and the person with MS. As some of the studies revealed, empowering PwMS with knowledge through the intensive education courses, and providing them with on-going information, helped them become more confident in making decisions or sharing decisions with their practitioner, and increased their decision-making behaviours (Keating & Ostby, 1996). This was particularly emphasized by Heesen et al. (2012), who explained that educating PwMS about their disease and providing them with evidence-based information could influence decision making processes and enhance self-management, thereby improving quality of life and well-being for PwMS. Extensive patient education, with a focus on evidence-based patient information, influences participation in the decision making process.

## 2.6 Summary

This review was conducted to answer the following questions:

- 1. What models of self-management for PwMS are reported in the literature?
- 2. What is the content of the self-management interventions for PwMS published in the literature?
- 3. What are the experiences reported by PwMS of self-management programmes?

Most self-management programmes for PwMS have focused on fatigue management. Cognitive behaviour/social cognitive behaviour approaches have been used to enhance behavioural change and self-efficacy. The limited insights into the perceptions and experiences of PwMS who have engaged with self-management suggest benefits of improved well-being, quality of life, general self-management skills, and confidence/empowerment. Themes identified from the included studies were problem solving, decision making, empowerment through self-efficacy and self-confidence, behavioural change, and symptom management.

This review has highlighted a gap in the literature and, therefore, further study is warranted to explore the experiences and perceived needs of PwMS for effective self-management, and health professionals’ perceptions of best-practice in supporting PwMS to self-manage. This new knowledge would be beneficial in informing a more comprehensive and service-user driven model for services providing support for PwMS to self-manage their condition. The next chapter will provide an overview of the aims of the work in this thesis, highlight the specific research objectives of the studies undertaken to achieve the aims, and provide information about the methodologies selected to underpin those studies. Details about ethical approval and other permissions for the studies subsequently reported in the thesis will also be included in this next chapter.

# CHAPTER 3: METHODOLOGY

## 3.0 Introduction

The aim of the study reported in this thesis was to develop a 'best practice' model of self-management for people with Multiple Sclerosis (PwMS), for use by PwMS and health professionals, based on: a) evidence from both a background and scoping review of the literature; b) opinions, perceptions and practice of health professionals experienced in delivering self-management programmes; and c) the views, experiences and perceptions of PwMS who have been supported in self-management.

Following on from the gaps identified in the background and scoping review of the literature, this chapter provides an overview of the objectives of the studies reported in this thesis, and details the ethical and other approvals that were required for appropriate governance of the research and methods.

## 3.1 Research aims

The research aims of the work in the thesis were addressed in two phases:

### *3.1.1 Phase 1: field study*

#### 3.1.1.1 Aims

The aim of Phase 1 was to characterise the self-management support provided by three different services delivering healthcare to PwMS in North Staffordshire and Cheshire: NHS acute hospital based; NHS community based; non-NHS community based.

### 3.1.1.2 Methodology

A field study method was used, involving:

- Focus group interviews with health professional staff involved in providing self-management support for PwMS in each of the three services, to explore and identify the underpinning philosophy, the perceived ‘uniqueness’ and effectiveness, aspects of perceived ‘best practice’, and the nature and extent of support for PwMS provided by those three services, and
- Observation of the three services in action to produce evidence to support the reported philosophy and aspects of best practice in self-management.

A field study is a flexible qualitative method to collect data, for example via face-to-face interviews, surveys, or direct observation (Bourgeault et al., 2010). The aim of a field study is to provide rich descriptive accounts of the incident/situation/subject being researched and explanations about someone’s behaviours. Therefore, the purpose of such is to view specific context as a production of interactions between people (Denzin and Lincoln, 2005).

Qualitative approaches are the most common approaches used in situations where little information is provided about the topic of the study, particularly when the questions under investigations are about understanding of the people’s interactions under certain circumstances, (Munhall, 2007). This was clearly the case in respect of the present study and therefore a qualitative approach was deemed the most suitable.

In this field study, two distinct phases were involved:

a) Focus group interviews with health professionals providing services to PwMS;

b) Structured and planned observations of the services in action with the collection of qualitative data from structured notes taken during the observation and on reflection after the observation sessions.

*Focus group interviews*

Frey and Fontana (1991) stated that a focus group interview can take place in a field setting, where the group can be stimulated by the researcher through a specific topic. The role of the interviewer is involved in asking people specific questions related to the topic of interest. The data generated can be objective and factual, or it can be subjective and qualitative. Researchers can use focus group interviews as a more efficient way to understand and interpret a social or behavioural event.

Therefore, a focus group interview was considered the most appropriate approach to be used in this study through asking health professionals specific questions about their services, to identify the underpinning philosophy, the perceived ‘uniqueness’ and effectiveness of the service, aspects of perceived ‘best practice’, and the nature and extent of support for PwMS.

### *Interviews*

Qualitative interviews involve the use of open-ended questions that can be asked directly to the research participant. Qualitative interviews can be either informal which involves an open conversation, semi-structured, open-ended, or a mix of all. This provides richness to the data for the researcher to analyse. This also helps collect triangulated data that can help explore the full spectrum of possible relationships between analytical themes within qualitative data; it can act be useful to link the data between categories/themes/codes within a qualitative analysis (Robinson, 2011)**.**

The presence of an interviewer is considered to be the main difference between interviews and any other methods of collating data. In interviews, due to the presence of the interviewer with the participant / interviewee, non-verbal data can be collected; in addition, any question can be clarified if the participants do not understand (Adams & Cox, 2008). Moreover, the interview method can result in a higher response rate, as many people might be more interested in talking to someone rather than writing their answers (Qu & Dumay, 2011).

The face-to-face interview offers many positive benefits; it can provide a holistic picture, analyses conversations spoken the participants through their own experiences, and enables participants to express their feelings and thoughts (Berg, 2007). Berg (2007) also emphasized that interviewing is a good tool to be adopted in a social research study, as it is considered to be an approach that can offer direct explanations when viewing participants' actions.

*Observation*

In addition to focus group interviews with staff delivering support for PwMS in the three services, observations of the three services in action were planned. Observation plays an important role in completing and supporting the information gained from interviews (Rodwell, 1998), which are limited because they only provide access to what people say they do, not what they actually do (Green & Thorogood, 2009). In contrast, observational methods allow the researcher to look into what people are actually doing (Green & Thorogood, 2009). Therefore, using observation in addition to interviews with participants is beneficial in obtaining a more in-depth and comprehensive understanding of the research topic.

Gold (1958) described four different roles for the researcher when conducting observation in field work: complete participant, participant as observer, observer as participant, and complete observer. One important factor determining the degree of a researcher's participation in an observational study is the nature of the setting. According to Gold (1958), there are important differences between the observer roles available to a researcher. The two extremes are the complete participant role, in which the researcher's identity and purpose of observing is not made obvious to research participants, and the complete observer role, in which the researcher observes from outside the setting and is not visible to participants who, therefore, do not know the researcher is observing them (e.g. using a hidden video camera or a mirror). On the other hand, the participant as observer role is where the researcher’s aims are known to participants, and both parties are aware of their relationship in the field work; however, the researcher is fully engaged with the participants’ activities. The final role is the observer as participant role, in which the purpose of the research is known to the participant, but the researcher’s role is only to observe participants’ activities without engaging with the participants (Gold, 1958).

The role of an observer as participant has been commonly used by many researchers in a variety of hospital and nursing contexts (Baker, 2006), and is considered to be the most appropriate and feasible to undertake, in order to further understand people’s actions, interactions and exchanges, rather than play a role of participant as observer and fully participate in their work or daily activities as a member of staff within the setting. Therefore, the role of observer as participant was chosen for this field study.

During observation, researchers in field studies observe participants in action and take notes on particular activities observed. Observation may be either direct, where the investigator is actually present during the task, or indirect, where the task is viewed by some other means like a video recorder set up in an office (Nielsen, 2002).

In direct observation, the data are collated via an observational method of people in a natural environment, where the behaviour of the participants is not interrupted or disturbed by the researcher. The advantage of a direct observation method is that provides data which is related to the context of what being observed; for example, interactions of participants, circumstances, and environmental surroundings (Kawulich, 2005). Hence, a direct observation method was chosen to collect data from the three services observed in action in the field study aiming to provide contextual data.

### *3.1.2 Phase 2: Individual semi-structured interviews*

The purpose of phase 2 was to explore the experiences, expectations, support and care needs of PwMS and how those needs were met, as reported by PwMS who have received support for self-management of MS from one or more of the three different services.

Individual semi-structured interviews were used to explore the experiences of PwMS, and their expectations and perceptions of self-management of their condition. A semi-structured interview was chosen because it is an in-depth interview where the respondents are posed with pre-set, open-ended questions that invite a detailed response, and thus are widely employed by different healthcare professionals in their research.

A semi-structured interview is based on an interview guide, which is a schematic presentation of questions or topics to be explored by the interviewer (DiCicco-Bloom & Crabtree, 2006). To achieve optimum use of interview time, interview guides serve the useful purpose of exploring many respondents more systematically and comprehensively as well as keeping the interview focused on the desired line of action. DiCicco-Bloom and Crabtree (2006) stated that questions in the interview guide should comprise the core question and many associated questions related to the central question. Hence, individual semi-structured interviews with PwMS were conducted in the three different services. See Appendix (9).

## 3.2 Analysis of qualitative data

### *3.2.1 Thematic analysis*

Thematic analysis is a method of identifying, analysing, and reporting patterns (themes) within qualitative data. It minimally organises and describes a data set in rich detail. However, it also often goes further than this, and interprets various aspects of the research topic (Boyatzis, 1998).

An inductive approach to analysis was used in the studies reported in this thesis, as the data were collected specifically for the research process of coding the data without trying to fill into a pre-existing coding frame (Braun & Clarke, 2006). The focus group interviews with health professionals and the individual interviews with PwMS resulted in qualitative data being collected, which were analysed using the thematic analysis approach adopted by Braun & Clarke (2006).

Digital recording data from phase 1 (focus group interviews) and phase 2 (individual semi-structured interviews) were transcribed verbatim, and transcripts were analysed through the six phases of thematic analysis outlined by Braun & Clarke (2006), summarised in Table 3. The data were read and re-read to establish familiarity with the content. Data were coded independently by two members of the research team, to identify themes from the data. Themes were developed through discussion with the wider research team, and sub-themes were identified.

**Table 3: Phases of thematic analysis adopted by Braun & Clarke (2006)**

| | |
|---|---|
| Phase 1 | Familiarising with the data, i.e: read and re-read data |
| Phase 2 | Generating initial codes |
| Phase 3 | Searching for themes |
| Phase 4 | Reviewing themes |
| Phase 5 | Defining and naming themes |
| Phase 6 | Producing the report |

### *3.2.2 Trustworthiness in Qualitative Research*

Trustworthiness is a way in which researchers can convince themselves and readers that their research results / findings are worthy of attention (Nowell et al., 2017). The concept of trustworthiness was refined by Lincoln and Guba (1985) who introduced trustworthiness criteria to ensure a trustworthy analysis in qualitative research.

In qualitative research, the process of data collection, data analysis, and report writing can occur concurrently throughout the research process

(Creswell, 2007). Therefore, it is important to know that the data analysis process might not be able to be distinguished from the actual data (Nowell et al., 2017). In addition, Nowell at al. (2017) reported that thematic analysis in particular can be an iterative and reflective process which can involve moving back and forward between phases. The phases of the thematic analysis that are reported by Nowell et al. (2017) are the same phases adopted by Braun and Clarke (2006) which reflect the trustworthiness of the analysis process.

#### 3.2.2.1 Means of establishing trustworthiness in the phases of thematic analysis

*Phase 1: Familiarising self with the data*

The different formats of qualitative data (e.g. digital recordings, transcriptions, documents, and field notes) can sometimes lack a consistent structure; however, all are considered to be useful and crucial for conducting a comprehensive analysis (Nowell et al., 2017). To be familiar with the data, the researcher should become immersed in the data; this involves repeated reading of the data in an active way searching for meanings and patterns (Braun & Clarke, 2006). In the studies in this thesis, the researcher read through the entire transcripts repeatedly prior to coding. This made the researcher immersed in the data and possible patterns started to be shaped. In addition, the research supervisor became familiar with the data collected from the interviews by checking the transcripts against the recordings and reading the transcripts at least once prior to generation of the initial codes.

### *Phase 2: Generating initial codes*

This phase involves the initial production of codes from the data, where the researcher keeps revisiting the data. This phase starts post being familiar with the data. It is a process of reflection of what the researcher can think of the data collected (Savage, 2000). During coding, important parts of the text should be identified and labels attached to index them as they might be related to specific themes (King, 2004).

In the two phases of the study, the initial generating of the codes was conducted independently by the researcher and the research supervisor. Codes were discussed in debrief meetings and team meetings, where thoughts about the codes were reflected and agreed codes were determined. Documentation of the team meetings were obtained in order for the researcher to revisit these documentations whilst thinking of possible themes. Those steps in phase 2 increase the means of trustworthiness in the thematic analysis (Nowell et al., 2017).

### *Phase 3: Searching for Themes*

This phase involves searching for possible themes after collating the generated codes of the data (Braun & Clarke, 2006). In these studies, an inductive approach was chosen, where themes were identified from raw data in relation to specifically asked questions (Boyatzis, 1998). In addition, diagramming of the codes was used to make sense of theme connections, and detailed notes about development and hierarchies of concepts and themes were kept.

### *Phase 4: Reviewing themes*

This involves refinement of the possible themes. Researchers review the coded data extracts for each theme to consider whether they appear to form a coherent pattern. The validity of individual themes is determined by checking whether the themes reflect the whole meaning of the data (Nowell et al., 2017).

In these phases, some themes were found to collapse into each other while other themes required to be broken down into subthemes. The selected themes were refined into more specific meaningful themes (Braun & Clarke, 2006). During this stage, themes and subthemes were reviewed by the researcher and the research supervisor, checking the developed themes against the raw data.

### *Phase 5: Defining and naming themes*

Braun and Clarke (2006) suggested that theme names need to catch the reader’s attention and give the reader a sense of what the theme is about. The data might generate multiple themes with some overlap between them (Pope, 2000). The researcher should take into account how each theme will fit into the whole story of the data reflecting back to the research question (Nowell et al., 2017). Hence, this phase of data analysis required meetings with the research supervisor, and consensus on theme names was achieved.

*Phase 6: Producing the report*

This is the final phase of the analysis, where the researcher has fully identified the themes and is ready to write up the report (Braun & Clarke, 2006). Braun and Clarke (2006) stated that the write-up of a thematic analysis should provide an incisive, logical, non-repetitive, and interesting account of the data within and across themes. In the studies reported in this thesis, some of the participants' quotations support the findings of the data. Themes and subthemes were also reported in forms of tables. In addition, thick description of the context was reported, and discussion of the findings was discussed with the research supervisor and the research advisor for more accuracy when reporting the data (Nowell et al., 2017). Therefore, conducting the thematic analysis through the above explained six phases played an important role in ensuring trustworthiness in the research reported in subsequent chapters of the thesis.

## 3.3 Research paradigm

This study adopted a phenomenological approach. Phenomenological approach in research is a qualitative approach used to identify a specific phenomenon through collating information and perception of people's lived experience. The qualitative methods used are usually inductive, gathering data through interviews, discussions, and participant observation (Groenewald, 2004)

Social constructionism emphasizes the interactions between people and the language used. Social constructionism in clinical practice reflects the person’s narratives through their social interaction (Burr, 2015). Self-reflexive is not the aim of social constructionism; its main aim is to explore more about the object under examination. Hence this research study adopted this paradigm to reflect and explore participants’ interactions and experiences.

## 3.4 Research ethics and governance permissions

In preparation for each of the studies, and prior to the start of either study, appropriate and relevant ethics and governance approval and permissions from service managers were obtained.

NHS ethics approval was obtained for phase 1 and 2 (see Appendix 1), with permission for recruitment from all three sites provided by the Tayside Medical Science Centre (East of Scotland Research Ethics Service) (EoSRES) committee. In addition, since one of the sites was a non-NHS community-based service, which has their own ethics committee, further ethics approval and permission was provided by the charity that provides the service (Appendix 2). Letters of permission to approach the teams involved in providing support for PwMS were also obtained from the Research and Development Office for the acute NHS hospital service (Appendix 3) and the NHS community-based service (Appendix 4).

### *3.4.1 Reflection:*

The journey of obtaining the above-mentioned ethics approvals was not easy. The amount of time and effort spent in completing the required application forms was tremendous. I had to complete several draft copies and several supervisory meetings prior reaching the final copy. The total time waiting for approvals was approximately 5-6 months. The waiting patiently for the approvals to arrive was nerve wracking. However, on a positive note, I gained a new skill in completing such forms and this gave me a greater depth of insight into the methodology used in my research. Using the Integrated Research Application System (IRAS) enabled me to input information about my project to ensure the data I collected was appropriate to the type of my research study. It also helped me to meet the regulatory and governance requirements to conduct my study. This detailed process was part of my in-depth planning for my project; every detail was considered carefully. Hence the recruiting of participants and data collecting ran smoothly.

### 3.5 Chapter summary

The methodologies and study designs included:

- A field study which consisted of focus group interviews and observation of three services providing self-management support for PwMS
- Individual semi-structured interviews to explore the experiences, expectations and perceptions of PwMS around self-management of the condition.

Qualitative data were collected to explore:

- a) views and beliefs of health professionals experienced in delivering self-management programmes (phase 1); and

- b) the views, experiences and perceptions of PwMS receiving support to self-manage (phase 2).

A more detailed account of the methods used in each study is presented in chapter 4 (phase 1) and chapter 5 (phase 2) along with the findings and a discussion of those findings for each study.

# CHAPTER 4: PHASE 1 - FIELD STUDY INVOLVING FOCUS GROUP INTERVIEWS WITH HEALTH PROFESSIONALS PROVIDING SUPPORT FOR SELF-MANAGEMENT, AND OBSERVATION OF THE SERVICES IN ACTION

## 4.0 Introduction

In this chapter, the detail of the methods used in the field study will presented, in addition to data from the field study involving three different services: an NHS Acute Trust MS service; an NHS Community service; and a non-NHS Community Service (not-for-profit registered charity). The field study included a focus group interview with team members from each of the three services who were involved in providing support for self-management, and an observation study of each of the three services in action.

## 4.1 Methods

### *4.1.1 Aims of the study*

The aim of the study was to characterise the self-management support provided by three different services delivering healthcare to PwMS.

A field study method was used, involving: focus group interviews with health professional staff involved in providing self-management support for PwMS in each of the three services, to explore and identify the underpinning philosophy, the perceived ‘uniqueness’ and effectiveness, aspects of perceived ‘best practice’, and the nature and extent of support for PwMS provided by those three services; and observation of the three services in action in order to produce evidence to support the reported philosophy and aspects of best practice

### *4.1.2 Inclusion/Exclusion Criteria*

#### 4.1.2.1 Inclusion criteria

Members of teams of rehabilitation health professionals providing support for PwMS to self-manage the condition in the service were included in the focus group interviews and observation of the services in action.

In addition, PwMS with an age of 18+ years and at any stage of MS receiving services to support self-management of the condition, and who would be observed indirectly alongside the health professionals, were considered to be participants in the observation component of the field study.

#### 4.1.2.2 Exclusion criteria

Members of teams of health professionals who did not consent to being involved in either the focus group interviews or the observation sessions were excluded.

People diagnosed with other long-term conditions were not included in the observation sessions, and observation was not undertaken if the session included PwMS with severe cognitive dysfunction that impacts on capacity or the ability to provide informed consent.

### *4.1.3 Recruitment*

#### 4.1.3.1 Recruitment of rehabilitation health professionals

The team leaders of the three identified services were approached by email inviting their team to participate in the focus group interviews and observation of sessions provided for PwMS to support them in self-management. A meeting was arranged with the research team to discuss the study in detail with the rehabilitation team members. This provided an opportunity for the teams to ask questions and discuss any concerns they might have, and for the research team to provide reassurance and a full explanation of the purpose of the study.

*Informed consent*

Information sheets about the research study aims, objectives, and phases were sent out to the participants (health care professionals and PwMS), in addition to a consent form (see Appendix 5 and Appendix 6). Written informed consent was gained for each individual participating in the focus group interviews. For the observation sessions, the nature and purpose of the observations was made clear and informed consent obtained from those likely to be observed.

### *4.1.4 Focus Group interviews – procedures*

The purpose of the focus group interviews in this field study was to explore and identify the underpinning philosophy of the services, the perceived ‘uniqueness’ and effects of the service provided, aspects of perceived ‘best practice', and the nature and extent of self-management support provided by those three services for PwMS.

The conduct of the focus groups was based on guidelines suggested by Krueger et al. (2000), who highlighted the characteristics of the focus group interviews: participants, environment, moderator, analysis, and reporting. The participants in the group should be selected carefully; the environment should be comfortable with suitable seating, and the discussion audio recorded; the moderator should have good communication skills to conduct a group interview and use pre-determined questions; the analysis and the reporting of the data collected from the interviews should be systematic, with appropriate reporting. Therefore, this study adopted similar guidelines for the conduct of the focus group interviews.

#### 4.1.4.1 Development of the focus group interview schedule

Initially, the larger research question of the study was written, and outlined the broad areas of knowledge that would be relevant to answering these questions. Questions were developed within each of these major areas, shaping them to fit particular kinds of respondents. The goal was to tap into the health professionals' experiences and expertise in providing care for PwMS in general, and self-management. Focus group Interview schedule topics were developed and discussed with the research supervisor.

Consensus was obtained on the following topics/proposed questions:

- Qualifications and total year of experience of the health professionals

- Understanding or definition of self-management
- Nature or content of self-management programme or support provided for PwMS
- Unique aspect of the service
- Average frequency of contacts and duration of a self-management programme
- Perceived essential components of self-management support for PwMS
- Perceived effectiveness and individual components of services in meeting the aims and supporting PwMS to self-manage the condition
- Perceived outcomes of the service
- Perceived best-practice in providing support for self-management of MS
- Outcome measures used to evaluate the service
- Experiences of delivering the programme, including any difficulties or ease experienced and implementation
- Perceived improvements that could be made to their self-management programme.
- Barriers and enablers to improving or developing their self-management programme.

Frey and Fontana (1991) reported that focus group interviews can be used for interpretation of questions being prepared for survey or a specific event/topic. Hence the focus group interview schedule was piloted with a sample of four lecturers from the School of Health and Rehabilitation at Keele University, to check if the questions stimulated discussion of the topic appropriately, and that the questions were asked in an appropriate sequence and were not repetitive. The pilot focus group interview lasted approximately one hour. Positive feedback was given by the group of lecturers; no changes were required to the schedule. A final draft of the questions was completed and discussed with the research supervisor. Consequently, a final version of the focus group interview schedule was developed (See Appendix 7).

#### 4.1.4.2 Data collection

Interviews were led by the researcher. All focus group interviews took place at the group’s usual work base. Audio-taping captured the qualitative data which was subsequently transcribed verbatim and anonymised during the process of transcription. The transcripts were checked against the audio file for accuracy by two members of the research team independently and corrections were made. Field notes were recorded in writing by the interviewer immediately after completion of the interview.

#### 4.1.4.3 Data Analysis

The focus group interviews resulted in qualitative data being collected. The thematic analysis method was used to analyse data collated from the focus group interviews, using the thematic analysis approach adopted by Braun & Clarke (2006), as described in chapter 3. See Table 3 for details.

After listening and re-reading the transcripts several times, the transcribed data were coded independently by the researcher and by the research supervisor. Codes were discussed and compared before preliminary themes and sub-themes were identified. These were subsequently discussed by the research team and further refined until the final themes were agreed.

### *4.1.5 Observation study – procedures*

The observation of the service in action was part of the field study. It aimed to observe aspects of the services such as group sessions, education events and workshops, which were observed by the researcher to gain further insight into the service provided.

With the researcher as an observer as participant, periods of observation were carried out in three local services for PwMS delivered in three different settings: NHS acute hospital – MS service; NHS community service; non-NHS community service.

The main purposes of the observations were to achieve:

- Active observation of interactions and careful listening to conversations: who talks to whom, whose opinions are respected, how decisions were made; in order to better understand how decisions were actually made and to what extent health professionals involved PwMS in decision-making in everyday healthcare encounters
- Detailed note-taking of the frequency and use of nonverbal expressions; use and types of gestures, language and terminology; use of strategies and motivational methods; frequency and opportunity for questions and discussion

- Detailed note-taking of the style and mode of content delivery; perceived attitudes of service providers; methods of communication; and other significant features observed in the sessions.

Field observations included observing different types of care provided for PwMS. The detailed note-taking of the activities of the three observed services was documented in a structured observational tool (appendix 8). Field notes of observations and perceptions were developed, revisited and refined following each period of observation through an iterative process (Charmaz & Mitchell, 2001). See observation methodology section in chapter three for details, and Tables 8, 9 and10 in this chapter for illustration of the observed sessions.

The observations took place during the day, arranged and planned in advance with each service. Service users at each service were informed in advance that a researcher might be attending the service on certain days during a specific period to observe some of the centre activities. Information sheets were given to health professionals delivering the session and PwMS attending the session on the same day of observing the service in action.

PwMS and health professionals who agreed to the researcher observing them were given consent forms and their signature was obtained. In order to reduce the possibility that the researcher’s presence while observing the different sessions might affect participants’ behaviours, a number of strategies were adopted, for example:

- The researcher explained to the participants that her presence was as a ‘student’ doing research, and she was in no way ‘monitoring’ their performance (Fox, 1998; Stoddart, 1986);
- The researcher positioned herself as unobtrusively as possible during observational periods, e.g. sitting in a corner of the room, or in between participants without participating in the activity. In addition, the researcher reassured PwMS who were observed that the main interest was only to observe care provided by the service in action.

#### 4.1.5.1 Data collection:

The detailed note-taking of the activities of the three observed services was documented in a structured observational tool (Appendix 8). This tool was developed accordingly to meet the researcher aims of the observed session. This included the type of session, the interaction between the participants, the gesture and language used, and summary of the findings. Bowling (2002) reported that a framework or structured tool is warranted to avoid risk or bias and to keep the researcher on track. Hence the tool was developed.

*Analysis of observational data*

Field notes of observations and perceptions were developed, revisited and refined following each period of observation through an iterative process. According to Rodwell (1998), in constructivist inquiry, the data from observations are generally not entered into the raw data that will be coded and categorised for analysis, as is the case with the interview data. Rather they should be used as ‘background’ to increase depth and scope in the process of generating findings and developing interpretations and understandings. This approach was adopted in the current study. The main intention within the analysis was to look for themes, patterns or relationships that were related to whose opinions were respected, and how decisions were made, in order to better understand how decisions were actually made and to what extent health professionals involved PwMS in decision-making in everyday health care encounters. Coding incident-by-incident is more appropriate for observational data than word-by-word or line-by-line coding partly because the field notes already comprise the researcher's own words and interpretations (Charmaz & Mitchell, 2001). In the present study, field notes were analysed through incident-by-incident coding or coding the whole events or scenarios. Codes generated are described in Table 5.

## 4.2 Findings

This section begins by presenting the demographics of the participants, with a brief description of their respective services, before presenting the inductively derived themes from the analysed transcripts from the focus group interviews and summarised findings of the observation sessions.

### *4.2.1 Characteristics of group participants and their services*

All three services covered a wide geographical region providing care for PwMS living in North Midlands and Cheshire areas, including both an acute MS regional service, and two community-based services some distance apart. Both community services were linked to the regional acute NHS service. Table 4 summarises the characteristics of the health professionals who were involved in the three interviews from the three centres. The total number of health professionals who participated in the focus group interviews across the three services was 17.

#### 4.2.1.1 NHS Acute Hospital, Regional MS Service

The acute NHS MS service was set up in 1998, when a modifiable disease clinic was started on the basis of providing Interferon treatment for PwMS. Interferon is a pen injection that can reduce the inflammation that damages nerves in MS (MS Society, 2019). The service continued to develop to provide support and care for PwMS. The modifiable disease clinics are managed by neurology consultants and MS nurse specialists. The MS service also provides psychological support for PwMS.

**Table 4: Summary of characteristics of the focus group participants according to service**

| **Participant characteristics** | | **Total (n)** | **NHS Acute (n)** | **NHS Community (n)** | **Charity Community (n)** |
|---|---|---|---|---|---|
| **Gender** | Male : Female | 4 : 13 | 0 : 3 | 0 : 5 | 4 : 5 |
| **Profession** | Physiotherapist | 4 | 0 | 1 | 3 |
| | Occupational Therapist | 3 | 0 | 3 | 0 |
| | MS Nurse Specialist | 3 | 2 | 1 | 0 |
| | Psychologist | 1 | 1 | 0 | 0 |
| | Counsellor | 1 | 0 | 0 | 1 |
| | Sports Therapist | 1 | 0 | 0 | 1 |
| | Employment Advisor | 2 | 0 | 0 | 2 |
| | Operation Manager | 1 | 0 | 0 | 1 |
| | Centre Manager | 1 | 0 | 0 | 1 |
| **Number of years qualified** | 1-2 years | 1 | 0 | 0 | 1 |
| | 3-10 years | 5 | 1 | 2 | 2 |
| | >10 | 11 | 2 | 5 | 4 |

The focus group interview, which lasted for 44 minutes, involved MS Nurse Specialists (n=2) and a Psychologist (n=1).  All three were female. The interviewed health professionals were not the only representatives of the service; the MS service involves neurology consultants, and rehab team in a different hospital and community settings. However, not all of the MS service team members were able to be present in the interview. The three health professionals interviewed were employed by the MS service in the NHS acute hospital.

The time since qualification for the MS Nurse Specialists ranged from six and a half years to 30 years. They started their nursing careers working as nurses on neurology or neuro-surgery wards, and then joined the MS service in the hospital. The psychologist had 15 years of experience of supporting people with long term neurological conditions. She worked between two different sites, one in the community and the other in the acute NHS Trust.

#### 4.2.1.2 NHS community service

The NHS community service had been in place for approximately 12 years. It is a neurorehabilitation service that provides therapy for people with progressive neurological conditions. More specifically, the service provides diverse care for PwMS; this includes physiotherapy, occupational therapy, psychological support, and an MS nurse specialist who provides medical advice when required. The focus group interview, which lasted for 1:10 hrs, involved Occupational Therapists (n=3), a physiotherapist (n=1), and an MS

Nurse Specialist (n=1). All were female. Their work experience varied from fifteen to thirty-two years, and all had at least 10 years of experience working with PwMS.

#### 4.2.1.3 Non-NHS community neurotherapy Centre (not-for-profit, registered charity)

The community neurotherapy service started 30 years ago, and was set up to provide wide diversity in therapy for people with long term neurological conditions, but specifically for PwMS. The focus group interview, which lasted for 1:15 hrs, involved physiotherapists (n=3; two were female), a counsellor (n=1, female), sports therapist (n=1, female), employment managers (n=2, both male), operation manager (n=1, male), and the centre manager (n=1, female), who was also a physiotherapist by profession. Their work experience varied from 1 – 30 years. The sports therapist was newly qualified, with just one year of experience at the centre. The rest of the team had at least 7 years of experience in treating or supporting people with long-term neurological conditions.

### *4.2.2 Findings from the focus group interviews*

Themes identified from the analysis were related to two main categories: the service, and self-management, which will now be presented.

#### 4.2.2.1 The service

Three themes were identified that related to the service: diversity, accessibility, and best practice. For each theme, subthemes were also identified, as summarised in Table 5.

**Table 5: summary of themes and subthemes relating to the service**

| **Theme** | **Subthemes** |
|---|---|
| Diversity | Skill mix |
| | The specialist with expertise |
| | Mode of delivery of care |
| Accessibility | Flexibility of referrals |
| | Open access |
| | Region covered |
| | Continuity of support |
| Best practice | Philosophy of care |
| | Quality of life focussed care |
| | Holistic approach |

*Theme: Diversity*

Health professionals interviewed in the three services highlighted that providing diverse care opportunities increased choices for PwMS receiving support. Managing physical comorbidity and multimorbidity were seen as key goals for treating PwMS. Whilst supporting the management of clearly defined MS symptoms and advising on and providing MS specialist medication were viewed as important functions of specialist care services, non-MS symptoms and a more holistic approach to wellbeing were also considered important in supporting PwMS' candidacy for these three services.

Within this theme of diversity, three subthemes were identified: skill mix, the specialist with expertise, and mode of delivery of care

*Subtheme: Skill Mix*

Across the three services, there was a wide-ranging skill mix of health professionals involved in providing care to PwMS including neurologists, physiotherapists, occupational therapists, MS nurse specialists, speech and language therapists, sports therapists, psychologists, counsellors, employment advisors, operation managers, complementary therapists, podiatrists, and service managers. Each professional had an essential role in helping PwMS manage their symptoms physically, medically, mentally, functionally, and symptom-specifically. However, not all three services included the same range of professions or job roles. The acute NHS hospital (Regional MS Centre) mainly involved disease modifying clinics and psychosocial group meetings; the NHS community service provided physiotherapy sessions, OT sessions, and fatigue management groups; the non-NHS community service provided physiotherapy sessions, counselling, psycho-social group therapy, employment advice, speech and language therapy, and complementary therapies.

Within physiotherapy sessions, there was a range of services offered, some of which reflected traditional physiotherapy practice, and some of which were more diverse, and involved other professionals:

> *"And also adding to physio, we've got various other things at the centre, like the Hyperbaric O2 chamber, and also we have a physio fitness suite, and we have Tai Chi, aerobics, and we also have counselling help" (Physiotherapist, non-NHS community service)*

*Subtheme: The specialist with expertise*

All of the health professionals had experience in supporting and caring for people with long term neurological conditions in general and MS in particular. In addition to the interprofessional ideology of all three services, professions from both health and social care worked closely together to deliver collaborative practice for providing client or patient centred health care. This interdisciplinary approach meant that professional boundaries and roles were sometimes blurred:

> *"I think because we are an inter-disciplinary team and we're not a multi-disciplinary team, we don't work in our own professional silos, so there's a lot of merging and blurring of roles" (Occupational Therapist, NHS community service)*

Occupational therapy included some specialist services, reflecting the experience and expertise of the professionals delivering the services:

> *"From an OT perspective, we do everything from splinting, vocational rehab, cognitive assessment, stress management, psychological support, equipment provision and specialist equipment provision and therapy"*
> *(Occupational Therapist, NHS community service)*

The inclusion of MS Nurse Specialists in the teams contributed to the specialist care that PwMS received, in conjunction with medical doctors, at various stages of the disease, to support treatment and management of symptoms:

> *"We've got a treatment clinic, so those who need to go onto disease modifying therapies that would be myself with Dr [name]. Then there's the clinic where people who are already on treatment, so it's about monitoring the condition, managing the symptoms, and referring on if necessary; and then we've got a symptom management clinic, so those who possibly, a lot of them are more progressive with their MS and they're not eligible for treatments, it's about managing their symptoms" (MS Nurse specialist, NHS acute service)*

Similarly, specialist psychologist support was available:

> *"I am a psychological therapist and I specialise in working with people who've got MS" (Psychologist, NHS acute service)*

*Subtheme: Mode of delivery*

Sessions were delivered to PwMS in three different modes: face-to-face group therapy; one-to-one individual intervention or contact; and telephone contact (see Table 6). The NHS acute hospital service involved one-to-one sessions and included disease modifying therapy clinics with MS nurse specialists and consultant neurologists, group psychosocial sessions delivered by psychologists in conjunction with MS nurse specialists, and telephone contact for advice. Both the NHS community service and the non-NHS community service provided all three modes of delivery of support sessions. The group therapy sessions in the non-NHS community service involved physiotherapy, gym exercise, psychosocial support, counselling, complementary therapy, and social events.  One-to-one sessions included physiotherapy, counselling, occupational therapy, and employment/financial advice. The NHS community service provided group sessions in physiotherapy, weight control/fitness, and fatigue management sessions. Their one-to one sessions included physiotherapy, occupational therapy, and MS specialist nurse advice sessions when required. The two community services also had telephone contact facility for advice/special appointments.

**Table 6: illustration of the various modes of delivery of sessions in the three services**

| Mode of session delivery | Acute NHS hospital | NHS community | Non-NHS community |
|---|---|---|---|
| **One to one** | √ | √ | √ |
| **Group sessions** | √ | √ | √ |
| **Telephone contact support/advice** | √ | √ | √ |

Participants explained that the mode of delivery depended on the service user needs and type of MS. Different types of care delivery were provided to ensure that individuals living with MS were supported through proactive conversations with their clinician or health and care professionals. These conversations focus on what matters most to that individual and the support they need to manage their health and wellbeing. It is a process of sharing information, identifying medical and non-medical support needs, discussing options, contingency planning, setting goals, and monitoring progress through regular review.

However, it did seem, at times, that the decision about the mode of delivering support was made by the health professional, and not specifically by the PwMS, although there was some accounting for individual preference:

> *"Initially we do a physiotherapy assessment and then we decide what they need, either a one-to-one sort of physio or*

> *group physio, so we just decide whichever suits them.”*
> *(Physiotherapist, non-NHS community service)*

> *“From the physio perspective, the patient gets referred to us or they can be self-referred as well; and then initially we do a physio assessment and then we decide what they need.”*
> *(Physiotherapist, non-NHS community service)*

*Reflection:*

I approached three different services in my research study. The first was an acute NHS service, which was also a regional MS service, that delivers diagnostic clinics for suspected MS and related conditions. It had a good reputation as an MS Centre of Excellence. It was mainly medically focused, staffed by neurological consultants and MS nurse specialists. I noticed the absence of allied health professionals, for example, physiotherapists and occupational therapists. Hence the diversity of the care provided to PwMS was limited.

The NHS community service was a specialist community-based neurological rehabilitation service. The service provided good diversity of care and skill mix of staff, which I considered to be particularly helpful for PwMS. This was also reflected by the non-NHS community-based regional service, which was set up and provided by a charity.

Each service provided care and support for PwMS on different levels. I can understand the lack of service diversity and skill mix in the acute NHS setting due to the fast pace of the service; however, I do believe that having a skill mix of different health care professionals can optimise treatment plans and support PwMS to manage their condition holistically.

### *Theme: Accessibility*

Accessibility is the second theme identified and included four subthemes: flexibility of referrals; open access of the service; regional cover of the service; and the continuity of care or PwMS. Participants acknowledged that PwMS generally require comprehensive lifelong health care to support and maintain their health, social function, and well-being across the life span:

> *"We see people from diagnosis right through the process, through to palliative [care]. So, we're with the patient throughout that journey" (Physiotherapist, NHS community service)*

Hence, accessing and using health-care services is important for the continuum of the health care delivery system to PwMS. This theme therefore reflects the accessibility of facilities and services for PwMS.

#### *Subtheme: Flexibility of referrals*

Participants explained the different referral methods used for referring PwMS to the targeted services. Each team clarified how PwMS were referred to them; they explained that PwMS are usually referred by their own doctor (general practitioner; GP), consultant neurologist, social services, and sometimes by carers:

> *“They can be referred by anyone from social services, consultant, GP, and we even get carers referring in, but we always get the permission from the GP.” (Physiotherapist, Non-NHS community service)*

In the acute setting, PwMS can be referred via A&E to the MS services. Employment advisors emphasized that PwMS are referred to them by the service itself or by any local NHS service to help with any employment advice:

> *“Somebody gets referred to us from this centre or from any local sort of NHS centre and we would meet people for what we call initial interview to get some background into the person and their family and maybe how long they’ve had the condition.” (Employment Advisor, non-NHS community service)*

Health professionals in these services also ensured a close relationship between all levels of the healthcare system and helped to ensure PwMS received the best possible care by directing them to be assessed by each profession:

> *‘We look at the referral and we decide who is the most appropriate professional to perhaps do that initial visit but, most times, most people will see and be assessed by each profession at some point in the community.”*
> *(Physiotherapist, non-NHS community service).*

*Subtheme: Open access of the service*

Health professionals emphasized the importance of flexibility for people accessing their services and approaching health professionals. In addition, they reported how they can provide care by either the person with MS visiting the centre itself or by health professionals visiting service users/PwMS in their own home. They also highlighted the importance of allowing patients/clients to self-refer when they judge advice is needed, rather than them relying on appointments fixed by the service.

The access to community and specialist care was reported by the two community services, who reported the easy access to the services and their ability to ensure open access to their clients for advice or further information:

> *“We are open access as well. We open episodes of care now and we end episodes of care but the patient, if they need input again in the future, they can just call us. They don’t need to go through a referral pathway to re-access the service.” (Occupational Therapist, NHS community service)*

Access was perceived as being closely linked to responsiveness as, to be a responsive service, professionals had to ensure that access was as fast as possible, whilst ensuring appropriate support. To that end, PwMS were not actually discharged from services, which enabled them to self-manage their needs by re-accessing services as required:

> *"We've got over 2500 patients on our case load haven't we, we see and we never really discharge anybody, so at any time we can have these patients contacting us." (MS Nurse Specialist, Acute NHS Hospital)*

*Subtheme: Regional cover of the service*

This configuration of services enable PwMS to access care and support within their own geographical area/region. The health professionals stated that covering a wide region makes the process of diagnosis and treatment of PwMS quicker by accessing the closest MS centre. They explained that home visits to PwMS can include East Staffordshire, South Derbyshire, North Midlands, and some parts of Chester. This helped PwMS who struggle physically to get out of their own homes due to physical disability or cognitive decline.

However, participants also reported that whilst some local hospitals across the region are not regional centres with disease modifying treatments, the MS nurse specialist based in a local community service can see PwMS in the community to review new symptoms, and liaise with the individual's GP for a prescription of oral steroids if required until a referral back to the consultant neurologist at the regional centre can be made. This can help relieve patients' symptoms and speed up the referral process:

> *"I think the wider thing is I link in, because our local hospital is not a Regional Centre with disease modifying treatment so, very often, they're quite a long way from a regional unit which could be up to 30- 35 miles away, and so we're talking about Nottingham, Birmingham, Stoke and Derby which is a little bit nearer. They all have different consultants and they all have different MS Nurses geared around the drugs. So very often, if they have a change in symptoms, I very often will see them to see if it is a relapse and see if it's anything else that's not a relapse but just causing the symptoms, and then I will liaise with that centre if it's appropriate." (MS Nurse Specialist, NHS community service)*

> *"We do have the facilities, if it's appropriate, to give steroids in the community. It is usually oral steroids now. At the moment, that has to have a GP to prescribe." (MS Nurse Specialist, NHS community service)*

*Subtheme: Continuity of care*

Ensuring continuity of care was considered to be an essential aspect of the service by all participants. Continuity of care between a person with a long-term neurological condition and one health care professional over a long period of time allowed professionals to gain knowledge of participants' functioning. Indeed, one physiotherapist from the non-NHS community service reported that they had a patient "*who had been coming for the past 30 years".* Continuity of support subsequently made it easier to identify when optimum health and wellbeing was not being maintained and to identify areas for intervention. In effect, continuity of care allowed professionals to judge criteria for candidacy of care at an individual level:

> *"I think it's because of the constant contact, you're not there for 10 minutes and you're off. We don't discharge patients" (Physiotherapist, non-NHS community service)*

Continuity of care facilitated a positive professional-patient relationship, ensuring trust and that PwMS felt listened to, which was perceived as improving their experiences of care. Gaining trust was viewed as central for the honest discussion of sensitive issues, and health care professionals reported service users were more likely to bring up sensitive issues with a professional who had earned their trust, over a prolonged period of time in some cases:

> *"The thing about the centre as well, it's the relationship they do build up with the staff, and if they feel confident to be able to disclose things at times, that you point them in areas like the counselling" (Counsellor, non-NHS community service)*

However, disclosure of highly sensitive or personal issues and concerns was made not only to counsellors. Other members of the healthcare team, who had built up a relationship with their service users, were able to offer the support as and when it was most needed:

> *"And I think because we've got the constant contact with people they're quite happy to tell us about anything, whether it is family issues - they come with all sort of things - and we've had sessions where we've only sat with a box of tissues even between a physio session where they have a melt down completely." (Physiotherapist, Non-NHS community service)*

By using this longitudinal collaborative approach, professionals aimed to ensure that goals and services were relevant to person-centred care and patient-chosen goals, and therefore had a higher likelihood of being adhered to. Getting to know and trust one professional also enabled discussion of sensitive issues that could be physical or psychological in nature.

This continuity of care approach between the health professional and the service user made it easier for the health professional to clarify which individuals required a constant follow-up or closer monitoring, in comparison to an individual who could be seen over longer scheduled timeframes. Consequently, this reflects back to the open access facility in the services which provides continuous care and support to help PwMS in their daily living activities and improve their quality of life:

> *"So, some of the clients we've got…have been on the books now for nearly 30 years. They're not seen all the time but seen when they need to be seen." (Occupational Therapist, NHS community service)*

The varied experiences of professionals suggest that the responsiveness needs of every person with MS may be different, depending on how they view their status as an 'expert patient', and services may need to be flexibly tailored around individual preferences.

### *Theme: Best Practice*

The health professionals suggested that the best practice in providing support for PwMS was to have a clear philosophy of care that is focused on improving quality of life for PwMS by using a holistic approach to empower them to manage their own condition and symptoms. These became the sub-themes for this section. Outcome measures are used in the three services to improve the service quality and practice.

### *Subtheme: Philosophy of care*

Participants expressed individual opinions and different philosophies of care about what they considered to be best practice in supporting PwMS They emphasized the importance of supporting service users throughout their treatment journey and how each treatment is different from one person to another:

> *"Because with MS, everybody is different and, although it's the same condition, it affects people differently; so you can't rule out and say this is the only treatment that's working for a particular person." (Physiotherapist, non-NHS community service)*

They also highlighted that services should enable PwMS to choose their own treatment plan and to encourage them in doing things they can achieve:

> *"I think, as well, to enable people to know what their choices are and to make sure that they're well-informed, so they can make choices themselves." (Occupational Therapist, NHS community service)*

They also highlighted that best practice is for the service to be person-centred. The course of MS as a disease is known to be unpredictable and to fluctuate on a daily basis:

> *"I think for best practice, as you report, is it's person centred. With certain conditions, such as MS, is that your life can fluctuate on a daily basis or half daily basis, how you feel, how you're affected etc. - so it's got to be person centred." (Employment advisor, non-NHS community service).*

Hence, the services need to be centred around individual needs. These health professionals emphasised that rapid response of the service on receipt of a referral helps PwMS to gain quicker access for their initial assessments, to make sure they receive the agreed therapy/medical treatment as soon as possible.

In addition, the needs of PwMS were re-evaluated constantly in the services, physically, psychologically, and socially:

> *"You've got to constantly re-evaluate, the social situation and physical situation, and see where we can help and what we can do is actually modifying things for them as well, because we do get people who are very, very capable, doing Pilates, and we've got people in electric wheelchairs who can't walk; so we modify everything for them, it's more tailor-made, adapted." (Physiotherapist, non-NHS community service)*

The key element of the constant re-evaluation is to work together in partnership so treatment can be tailored to meet individual requirements:

> *"It's also based on a good initial assessment and constant re-evaluation to make sure that you and the patient are going the right way and working together in partnership." (Physiotherapist, NHS community service)*

Furthermore, a positive attitude was also considered to be an important aspect within the philosophy of care, and considered to be a key element of best practice. Participants highlighted that MS is a long-term condition where an individual with MS can go through relapses and a decline in physical function of the body hence, having a positive attitude and keeping PwMS in a better positive mood can encourage them to adapt to the new situation and to achieve realistic goals:

> *“I think positivity as well. The one thing that I notice when I’m going around is we…do have a very, very positive attitude, don’t we? We try to encourage that. It’s a long-term condition and we can’t do anything about it really and we can’t know how the medical side is going to go but actually, as far as deconditioning, we have a massive input into that because we know, certainly with MS, there are two parallel lines of deterioration, don’t we? De-conditioning can actually be more disabling than the MS process itself. I think all of us are about trying to intervene in that de-conditioning process and educate people and with that positive input, keep people at as high a level as possible.” (Occupational Therapist, NHS community service)*

*Subtheme: Quality of life focused care*

Improving individual quality of life was highlighted by participants as a key element of best practice. They stated that, due to the chronic nature of the disease and the psychological and physical symptoms resulting from the disease, PwMS require good support and encouragement to help them achieve the best quality of life. This is achieved by helping them become more independent, by educating them with the right skills to cope with the condition. In addition, it was repeated that quality of life is enhanced when people can participate fully in decisions that affect their lives and take responsibility for themselves. This means having the right information, skills, opportunities and a supportive context that recognises diversity in all its forms:

> *“We like to have the philosophy that they are a person with a long-term condition and we’re here to support them, live the best possible life that they can, get the best quality out of it and being as independent as they can; and our role is to empower them and give them the skills.”  (Occupational Therapist, NHS community service)*

Participants stated that the quality of life of a person with MS is closely linked to that of their family. Both sides experience health, emotional, social and financial impacts of their own, which are usually under-recognised and poorly addressed in public policy and services. Hence it is crucial to involve the person with MS, their employer (where appropriate), and family in a care plan, which should also address employment and financial problems resulting as impact of the disease. The employment advisor highlighted that best practice can be reflected by a service linking closely with other organisations to help overcome financial/employment barriers to achieving a better quality of life:

> *"It's about linking up those services and identifying how all those services link together to sort of support the person and their family in trying to maintain some quality of life. It's important from our point of view as, doing employment advice, in talking to an employer and the person with the condition as well as the family. It's about showing them that there is a full service there that's available." (Employment advisor, non-NHS community service)*

Quality of life was reflected in ensuring PwMS can get an early diagnosis, appropriate treatment, regular monitoring to reduce disease activity and delay disease progression. In addition, engaging with appropriate employment services that will enable and empower people living with MS to gain or retain employment, is considered to be important in the early stages of the disease, and whilst PwMS are still able to maintain their employment.

*Subtheme: Holistic approach*

All participants referred to the importance of providing holistic care, addressing the needs of the whole person and all their interrelated social, psychological and physical needs, instead of simply treating one medical aspect of a person's condition. From this perspective, PwMS should be viewed as candidates for care due to their additional physical and social needs**:**

> *“So, it’s like trying various other treatments as well, and again with the holistic therapies, even with the MS Society, they say not just physio; even the other allied therapies can help with the condition.” (Physiotherapist, non-NHS community service)*

The participants emphasized that the holistic approach plays a crucial part in decision making; PwMS have the choice to decide the type of treatment and type of sessions they want to be involved in. In addition, they can decide whether they need to continue with a specific treatment or if they want to stop a certain task / therapy for a while, due to physical or psychological factors. This reflects the service flexibility and empowerment of the service users in taking decisions:

> *“We do give them the choice to decide what works for them, what they’re happy about doing so there’s no hard and fast rule that you have to go this way or that way.” (Physiotherapist, non-NHS community service)*

It was noticed across the three services that the holistic approach is reflected by the joint working between the different health professionals / health services. This included medical practitioners, allied health professionals, and social workers. MS nurses have direct connection with the community intervention team or district nurses in situations where an individual with MS has a relapse. The intervention team can provide service users with intravenous steroids in the community; they can visit PwMS at their own home when unable to attend the Relapse Clinic. In addition, they do joint working with the continence team in the community, where a joint assessment between the MS nurse specialist and the continence team can take place. They also identify any extra support needs, financial and social difficulties:

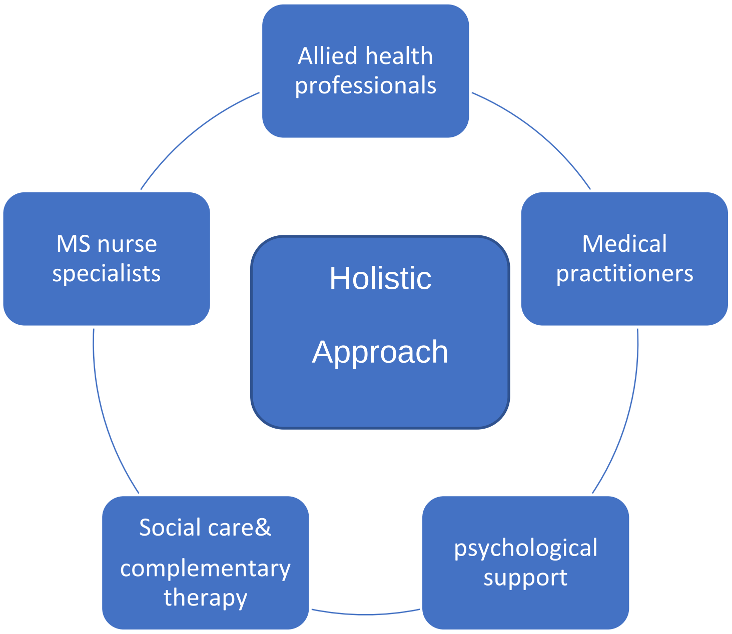
> *"In our area, and I know because I do work in two areas – the joint working with the Continence Team – we can meet up, do an assessment together and then I will then maybe follow that on, and ensure that that client is managing their treatment plan; and I suppose, signposting to other services and organising district nurses and training of maybe carers, for example, bowel irrigation system, self- catheterisation."*
> *(MS Nurse Specialist, NHS community service)*

All three services reported that they adopt a holistic approach by supporting PwMS to adapt to the new change and life style, such as exploring leisure and hobbies:

> *"Looking into hobbies and leisure, so I more recently went to a Driving Centre for someone that wasn't able to drive anymore." (Occupational Therapist, NHS community service)*

> *"Lifestyle and shopping. We've taken quite a few people shopping that have had issues there, so it's whatever area that person identifies that they've got a difficulty."*
> *(Occupational Therapist, NHS community service)*

***Figure 3: A summary of the holistic approach described by the participants to deliver care for PwMS.***



#### 4.2.2.2 Self-management

Self-management was the second category identified from the focus group interviews in the three services. Two major themes were identified from the coding process:

- Self-management essentials
- Self-management barriers.

For each theme, sub-themes were also identified, which are summarised in Table 7.

**Table 7: Summary of themes and subthemes around self-management**

| **Theme** | **Subthemes** |
|---|---|
| Self-management essentials | Empowerment |
| | Education / information |
| | Self-management courses and programmes |
| Self-management barriers | Time |
| | Accepting the change |
| | Memory and cognition |
| | Costs / funds |

*Theme: Self-management essentials*

Participants reported that Multiple Sclerosis as a disease takes an unpredictable course, and a self-management approach can help PwMS to cope with their condition. They emphasized that self-management can empower PwMS in making decisions to control their treatment plan to manage their symptoms. Empowerment, education and information, and self-management courses are subthemes that have been identified in this self-management essentials theme.

*Subtheme: Empowerment*

Participants acknowledged that empowering PwMS is an essential component of self-management. It involves the power of self-confidence and self-belief, which is referred to as self-efficacy, and participants considered promoting self-efficacy to be part of their role, in addition to or instead of conventional therapy or support:

> *"So, empowering people and giving them the belief that they can do it as well, rather than the traditional patient/healthcare professional role." (Occupational Therapist, NHS community service)*

They explained that self-belief and confidence empower PwMS to make decisions about their healthcare. In addition, the rapport between the service users and health professionals plays an important role in increasing their confidence to make such decisions:

> *"From the very beginning, for them to have the confidence to self-manage themselves. For me, to begin that therapeutic relationship really early on and to get a really solid therapeutic relationship which then gives them the*

> *confidence to self-manage." (Occupational Therapist, NHS community service)*

The health professionals interviewed highlighted that a person with a long-term condition is not a "patient" and explained that the word "patient" reflects a passive recipient of care; hence, it is a term unlikely to be used in their services, or more specifically not in the community services:

> *"We certainly are very picky about the word "patient" because, in our minds, patient is a passive recipient of care. These are people with a long-term condition, but people first." (Occupational Therapist, NHS community service)*

Self-management is about informed choices and for PwMS to be in control. Participants reflected on the collaboration between the person with the condition and the health professional / service, once again highlighting the importance of establishing trust between them, which enables PwMS to have more control in making a decision:

> *"So it's very important to make sure that we build up good trust because they're more likely to have the confidence to self-manage and have belief that the well-informed information you're giving is well-informed information, so they can make those choices." (Occupational Therapist, NHS community service)*

Furthermore, they considered this collaborative approach to be of help to PwMS in accepting a diagnosis about their condition, by being honest about the course of disease, as some PwMS can be in denial.

> *"Accepting the condition and the change can be difficult, they're just in denial. You've got to get to an honesty stage with the client." (Employment advisor, non-NHS community advisor)*

The MS nurse specialists make sure to give PwMS informed choices about their medication/drugs, hence the person with MS can make their own informed decision regarding medication based on what is available to them. However, the acute NHS team emphasized that, initially, when a person is diagnosed with MS, he/she might feel out of control and unable to make decisions due to the lack of information of relevant medications and their effects/side effects:

> *"I think control is a key word actually for the clients, because I think, when they first present with the issues regarding MS, they feel out of control and they feel that the MS is controlling them; and I think that's where psychology plays a big part in helping them to look at how they can begin to think how they can manage this condition and make choices to keep them in control."  (Psychologist, NHS acute hospital)*

Making choices was also reflected in choosing the type of exercise and type of session to attend, for example, whether a group session or a one-to-one (1:1) session, or even sometimes to skip the exercise therapy session. It is important that PwMS make these choices themselves about managing their symptoms, to help overcome the consequences of the physical/psychological problems secondary to the condition. The health professionals explained that some of the newly diagnosed PwMS try to avoid group sessions, to avoid seeing other service users for whom the disease is more advanced. Hence, some PwMS prefer to choose the 1:1 sessions, and to attend during different appointment times, sometimes out of hours, rather than when the group sessions are being run:

> *"Because we do have a lot of newly diagnosed people in their twenties, so what we have done is, because they have this tunnel vision where they don't want to see other people having problems, because they're going to be in the same situation down the line. What we've usually done is we give them appointments out of hours so that they're not here when lots of people are around in the building; so we see them first thing in the morning before the centre starts picking up on numbers, so they come into individual therapy."  (Physiotherapist, non-NHS community service)*

People who are happy to be involved in group sessions can also support their peers and help them in making choices through their shared experience. It was noted that observing people with a similar condition in a group setting can increase PwMS's confidence to cope with their condition:

> *"I think meeting other people with similar types of MS and in that similar pathway and that journey through their MS, they know they're not on their own." (MS nurse specialist, NHS acute Hospital)*

It was noted that partners and family members of the PwMS can also take part in decision making by being involved in the treatment session; they exchange ideas in the session to get familiar with exercises given, so that they can adapt them to their home environment:

> *"The patients are having treatments here, their partners or carers…obviously they're talking to each other, and they exchange how they deal with their condition or their partner's condition." (Physiotherapist, non-NHS community service)*

### *Subtheme: Education and Information*

Health professionals emphasized the importance of education in supporting PwMS to self-manage their condition. They explained that education programmes focusing on self-care skills can enhance patients' independence, and their ability to cope with problems related to MS, and accordingly, improve their adaptability skills. They can be taught the tools of self-management or attend training events to help them recognise their sense of responsibility, and avoid having things being done for them; the self-management tools should be used effectively, appropriately and in a timely manner.  Hence, PwMS should be given appropriate and effective support and guidance to access information related to MS, to enable them to cope with the condition:

> *"We're not there to do things for them. It's actually giving them the responsibility and the motivation to go forward with whatever advice or management tools that we give them." (Physiotherapist, NHS community service)*

> *"We try to point them to the right direction." (MS Nurse Specialist, NHS community service)*

Two main educational options were identified: psychological education, and general education about the condition.

*Psychological education*

Health professionals stated that psychological education can raise self-awareness in PwMS, by attending 1:1 counselling sessions or psychosocial groups to give them the appropriate tools to adapt to the new condition. It is important to understand the behaviour patterns of the person with MS to acknowledge their individual needs, and equip them psychologically to manage their difficulties:

> *“It’s about self-awareness but also that psycho education, giving them the tools to be able to apply them when they’re not in counselling and they’re not round the centre to kind of challenge their way of thinking really.” (Counsellor, non-NHS community service)*

The psychologists explained that psycho-social group sessions are patient-centred, highlighting that they are service user led, hence no prepared agenda is required. Psychological issues are usually discussed, such as stress, anxiety, and depression. PwMS can learn from their peers’ experiences, and they can share their own experience of certain situations, or a certain coping method that can help other service users to cope in similar situations. Group members build up a friendly relationship between themselves, which was considered to be peer support:

> *“The MS group…is person centred, very humanistic in the way it’s run, it’s client led and although I facilitate with [name], it’s very much looking at what the clients bring per week, so we don’t have a set agenda.” (Psychologist, NHS acute Hospital)*

Some service users might fear the 1:1 counselling session and feel they are not ready for an intense conversation; therefore, they would favour attending the group sessions where they can build up their relationship with their peers and the psychologist; after they gain more confidence they might approach the psychologist for a 1:1 session to discuss personal issues or certain difficulties. It was reflected that PwMS have the feeling of belonging when participating in a group setting; they feel free in expressing their real feelings. They can discuss a variety of issues, such as relationships, practical issues such as transport, and holidays. This gives PwMS the opportunity to share their experiences and choose the right coping methods to manage their symptom:

> *"It's a confidential space that we have for people to come in and they talk about…whether it's feelings, relationships, sometimes it's practical, things around motor vehicles, holidays; share with each other. I mean what one gentleman said to me was 'the first time I've felt as I belong because it was for people who understood'; he didn't have to explain when he said 'when I have a conversation and I can't find the word the word just won't come out' and everybody else in the group is nodding because they understand him."*
> *(Counsellor, non-NHS community service)*

#### *General information: education / introduction to MS*

Participants explained that newly diagnosed PwMS can join educational groups to educate them about the disease, symptoms, treatment, and management. These sessions are usually delivered by MS nurse specialists or consultant neurologists. On some occasions, other health professionals deliver part of the education sessions, for example, a pain management consultant, or a rehabilitation consultant. These educational sessions can help in directing or signposting newly diagnosed PwMS to service options or information points. Participants stated that educating PwMS about their disease can promote self-management thinking, which enhances decision making:

> *"Patient education is very important and here we have The Info Point, which gives information about their condition and also help to manage their symptoms and it's like how to manage all the symptoms of MS. So, directing them to the right areas and educating the patient." (Physiotherapist, NHS community service)*

> *"I always look at what clients can do and not what they can't, so it's all about self-management and promoting the education side of it so that they're able to make these choices." (Psychologist, NHS acute Hospital)*

Participants highlighted the importance of educating service users about timing; educating them to be aware of any triggers for needing support, such as relapses, fatigue, or psychological problems, in order to choose the right time to approach the service for further support, advice or treatment. This helps service users to avoid using the facility unnecessarily, and consequently helps in decision making.

*Subtheme: Self-management courses / programmes*

Participants explained that a self-management approach underpins most of the intervention programmes provided to MS clients. This includes exercise sessions, psychoeducational sessions, and complimentary therapies. However, they considered that fatigue management was one of the most essential programmes provided to promote self-management.

*Exercise sessions*

In exercise sessions, whether 1:1 or group sessions, exercises can be tailored to suit each individual. Exercise empowers PwMS to self-manage in their own environment, for example, by doing exercises to increase posture and muscle strength. In addition, PwMS with higher level exercise abilities can have access to community leisure centres/gymnasia to continue to maintain or increase their exercise tolerance. This allows PwMS to manage their own exercise programme and increase their confidence level in approaching community gyms without relying on the service therapists:

> *"We also do higher level exercise groups as well, in a little gym in the clinic. We then, hopefully, will get them to access something in the community at a leisure centre, or a gym, or whatever they want to do." (Physiotherapist, NHS community service)*

Moreover, weight management programmes were also highlighted by the participants. They are delivered by physical instructors who can encourage those high exercise tolerant PwMS to work harder in a protected place provided in the service, and then help them to move on to fitness clubs/gym in the community:

> *"We provide a protective environment, but our role is to facilitate them, so that they move on from that and access stuff in the community." (Occupational Therapist, NHS community service)*

### *Fatigue Management*

The NHS community service provides fatigue management programmes for PwMS. These programmes are based on Fatigue Applying Cognitive Behavioural and Energy Effectiveness Techniques (FACET) principles (Thomas et al., 2015). A qualified member of staff should complete a training course facilitated by the MS Society in order to deliver these programmes to PwMS. These programmes empower PwMS with the tools to help make changes to their new life style after being diagnosed with MS, and help in building up relationships through peer group meetings. This approach also helps through shared experiences, friendships, and general wellbeing; as fatigue can lead to mental and physical tiredness, therefore affecting wellbeing of PwMS

Participants emphasized that fatigue is the most common symptom in MS and yet it is considered to be an invisible symptom. Hence, providing group fatigue management sessions can help PwMS to be less reliant on the healthcare professionals and empower them to manage their fatigue by using self-management tools suggested in the group meetings. These tools might include planning, prioritising /delegating, energy effectiveness strategies, and pacing activities. In such groups, PwMS are made to feel that they have permission to be fatigued, as it is a shared experience in the group. People in the group can also share coping strategies to help manage their fatigue symptoms:

> *“People often feel that they’re lazy and one of the things that the groups do is give them permission to have fatigue because we describe what it is. It’s a unique physiological factor for people with MS and that fatigue isn’t experienced by anybody else with any other condition quite like that.”*
>
> *(Occupational Therapist, NHS community service)*

MS nurse specialists offer advice on specific medication that can help with fatigue management, or low mood can be discussed in these groups. However, not all of the teams interviewed provide fatigue management groups and some participants reported it to be under-utilised in some areas. The NHS community service was the only service that provided a fatigue management group.

*Theme: Self-management barriers*

Participants reported that delivering self-management programmes or implementing self-management in their services provided some challenges, which were sometimes considered to be barriers to supporting self-management. Those barriers included time and other resources such as funding, accepting the change, and memory / cognition.

*Subtheme: Time*

Participants stated that there were two types of time barrier: the time barrier from the health professional’s point of view, and the time barrier that the person with MS might experience. They explained that health professionals find that they sometimes have insufficient time due to work overload and other such pressures.

The preferred mode of delivering support can be a factor that creates a barrier due to time: some service users might require one-to-one support, and are not ready to interact with group therapy, and, as such, this can be time consuming. Participants also reflected that if time was not an issue, they would be able to support PwMS in gradually self-managing all aspects of their life. However, it is difficult to dedicate all that time to one person only.

Moreover, in acute NHS organisations, it might take up to 18 weeks to be seen by an MS Nurse Specialist or MS Counsellor. Consequently, PwMS are likely to be referred first to a general counsellor via their GP, and this might not be as useful as the counselling sessions provided by MS specialists. Furthermore, the waiting list for social services referrals regarding home aids or adjustments might take up to 18 months, therefore limiting independence and self-management:

> *“I know someone with MS who is actually showering outside, they’ve put a shower outside because she can’t get in the bathroom. I referred to social services and rang up to chase it for an urgent stair lift and they said it would be 18 months wait and this person can’t go upstairs.” (MS nurse specialist, NHS acute Hospital)*

On the other hand, some PwMS might not have the time to manage their own conditions due to family or work commitments. Participants clarified that, due to the busy lives or routines that PwMS might have, normal office working hours might not be suitable for them, and this was another potential factor that could delay intervention programmes that might encourage self-management strategies:

> *“It is just where they are in life, MS affects people within families so all those things become more important than the condition; quite often they don’t have the time to manage their condition because they’re changing nappies or worrying about the mortgage instead.” (Physiotherapist, NHS community service)*

### *Subtheme: Funding*

Participants reflected on costs, and the difficulties they experience in providing some equipment due to tight budgets. They also reported that some of the clients have high expectations, which the health service or health professionals might not be able to meet. To overcome this barrier, the participants like to be realistic with their clients and not give them false hopes in providing equipment:

> *"Cost - just as in we all have to be quite mindful now with what's available equipment-wise. The expectations - sometimes, patients have high expectations and we can't always meet that. We also have a responsibility for the public purse as well, so there's only X amount of money out there and it's got to be shared equally." (Occupational Therapist, NHS community service)*

*Subtheme: Accepting the change to lifestyle*

Some PwMS stay in denial of their new condition initially and are reluctant to accept the change in their new life style. Participants acknowledged this problem and were willing to participate in providing support and interventions that are considered to be essential to enable PwMS adapt to and cope with their condition. They also emphasized the importance of family support, and the notion that it is essential for families to accept adapting to the new challenge, and to support the person with MS, and to try to engage in the goals set by those PwMS and help them achieve those goals:

> *"You need a family there to try and understand. We do goals and we also try write goals and the patients get a copy of this and they're engaging in that goal; it might be that it's a goal for the patient and they've got to achieve that by a certain*

> *date. So that's one way of trying to keep them supported by their families." (Occupational Therapist, NHS community service)*

*Subtheme: Memory and cognition*

Memory loss and cognitive impairment can result from MS. Therefore, one of the challenges identified by the participants was that PwMS might frequently require reminding about appointments to avoid missing them, or miss plans or goal setting from previous sessions. Sometimes, this meant that some sessions needed to be repeated:

> *"Memory and cognition is a barrier, if they've forgotten what we've said, they're invited to come and do it all over again." (Physiotherapist, NHS community service)*

Hence, keeping relatives or friends engaged was a strategy used to overcome this barrier, and using different ways of delivering information is a potential way of engaging PwMS with the treatment strategy:

> *"That's when we bring them in with their relatives and carers, you've got to look at other ways of passing over information." (Occupational Therapist, NHS community service)*

Similarly, involving partners or family members in finding out the source of specific problems was considered to be important for finding out information in cases where the person with MS had problems remembering an event that might have impacted on their functional ability:

> *“Patients with memory problems might forget that they had a fall in previous week, so we go to ask the partner what was wrong.” (Physiotherapist, non-NHS community service)*

### *4.2.3 Findings from observation of the services in action*

This section presents the characteristics of the treatments provided for PwMS and the number of observed sessions across the three service, in addition to reporting the results of the collected data from the observed sessions across the three services. Characteristics of the treatment provided in the NHS acute hospital (MS regional service), NHS community service, and non-NHS community service are presented in Tables 8, 9, and 10.

**Table 8: Summary of support provided in the NHS acute hospital (MS regional service) and the number of sessions observed**

| **Classes/Treatment provided to PwMS** | **No. of sessions observed** |
|---|---|
| 1:1 Modified Disease Therapy clinics | 4 |
| Psycho-educational group sessions | 3 |

**Table 9: Summary of support provided in the NHS community service and the number of sessions observed**

| Classes / treatment provided for PwMS | No. of sessions observed |
|---|---|
| Physiotherapy group sessions | 2 |
| Cognitive Behaviour Therapy for Fatigue management (group sessions) | 2 |

**Table 10: Summary of support provided in the non-NHS community service and the number of sessions observed**

| Classes/treatments provided for PwMS | No. of sessions observed |
|---|---|
| 1:1 physiotherapy session | 2 |
| Group Pilates based sessions | 2 |
| Standing physiotherapy group session | 1 |
| 1:1 Counselling session | 1 |
| Tai Chi session | 1 |
| Yoga group session | 1 |
| Gab n' Go session | 1 |
| Podiatry session | 1 |

In each session observed, detailed field notes were documented in a note book the researcher assigned only for collecting observation data; the data collected was guided by the observation tool (see Appendix 8). After each observed session the researcher documented a brief summary of what has been observed prior to attending the next session. Following collecting the observed sessions on the day, the researcher documented / recorded the collected data in the structured observational tool.

When all the data collection was completed from all the observational sessions observed in the three services, the researcher read and re-read the completed forms of the structured observation tool to get familiar with the data collected. The completed forms were also sent to the research supervisor to read the collated data. The next stage was coding the data documented in each form. The codes created were revised, meetings with the research supervisor and advisor in the coding stage were conducted to ensure rigor in the coding phase. Finally four themes and sub-themes were developed. See Table 11 for details.

#### 4.2.3.1 Diversity of care

The three services provided variety of care for PwMS. It was noticed that care provided for PwMS in the community services was more diverse and had a larger group of Multidisciplinary Team (MDT) members on site in comparison to the Acute NHS hospital, were the sessions observed included DMT sessions and psychosocial group support.

The non-NHS community service provided a variety of therapy options that PwMS had the opportunity to choose from, for example, complementary therapies. However, no particular fatigue management programme was introduced in the either the NHS acute hospital or the non-NHS community service.

It was observed that PwMS had the option to choose between 1:1 therapy or group therapy. However, health care professionals could influence the choice by explaining the benefits from either session.

#### 4.2.3.2 Physical activities

The physical activity sessions delivered in the non-NHS community service and the NHS Community Service showed the normal routine activities that can be delivered in any physical activity class setting to people with long term conditions. This was clearly observed in the 1:1 physiotherapy sessions, group physiotherapy sessions, Tai-Chi session, and Yoga sessions. However, it was noticed in the acute hospital setting that no physical activity sessions or classes were delivered or assigned to PwMS. PwMS with different types of MS had limited physical activity/activities according to the type of MS and the level of their physical disability; this affected their daily life performances, hence exercises or physical activities were tailored to meet their needs. The majority of PwMS across the different services explained that fatigue was one of the main issues that was limiting their daily activities. One person stated to the therapist the new adaptation to her home environment was made to allow her cope with the new transition.

**Table 11. Main Themes and sub-themes generated from observational data analysis:**

| **Themes** | **Sub-themes** |
|---|---|
| **Diversity of care** | • Medical management<br>• Physical management<br>• Psycho-social support<br>• Complementary therapy<br>• Counselling |
| **Physical activities** | • Limitations in activities<br>• Meaning of activities after MS<br>• Performance of daily activities<br>• Invisible physical disabilities |
| **Interaction with others** | • Relationship between PwMS & Health professionals<br>• Relationship between service users (PwMS in particular)<br>• Receiving or asking help of others |
| **Self-management** | • Medical management<br>• Fatigue management<br>• Decision making<br>• Emotional management<br>• Goals and wishes for the future |

#### 4.2.3.3 Interaction with others

The interactions between different health professionals and PwMS showed that a good rapport had been developed, allowing PwMS to speak freely about their feelings and ask for help if required. It was observed in the gestures and the language used, particularly in the non-NHS community service, as most of PwMS were regular clients of the service and had been attending for many years. This was obvious in the interactions between PwMS themselves, between PwMS and service users with other long-term conditions, and PwMS with health professionals, for example, PwMS talking about their partners or family member to the therapist in a relaxed way, in addition to laughing during the session. Another example was, during an interaction between PwMS themselves, one of the participants asked about plans for the weekend. The participants from both sides seemed to be relaxed in the session due to the long duration and on-going nature of the relationship.

#### 4.2.3.4 Self-management

The essential point of observing the services in action was to look for self-management strategies/elements in the sessions delivered to the service users/PwMS. The routine physiotherapy sessions and other physical activity sessions did not implement any self-management skills in their approach.

During observations of the Disease Modified Treatment (DMT) clinics in the acute NHS hospital, it was noticed that PwMS were involved in making choices about the medicines provided for them in the clinic. The MS nurse specialist played an important role in explaining the types of medication that can help controlling the symptoms of the different types of MS. Leaflets about different types of medication were given to PwMS for details and information of the medication provided.

Psychosocial educational group sessions, counselling sessions, and Gab n' Go group sessions played an essential role in emotional management and support for the PwMS, providing opportunity for them to express their feelings openly about their condition, in addition to allowing them to engage with their peers, learn from others' experiences, and support new members of the groups. A number of the different group members expressed their first sense of shock after being diagnosed with MS, and reported how they came to terms with their diagnosis and how frightened they were. The sessions were led by a psychologist who asked brief general questions such as "How are you feeling today? Is there anything in particular you would like to talk about?". PwMS were mainly the key people to direct and to be in control of the sessions. The psychologist suggested possible management strategies to overcome a specific circumstance or situation. However, PwMS were involved in making the decision / choosing the right strategy to manage.

The CBT fatigue management groups mainly discussed the idea of fatigue management in PwMS by using a tool as a coping strategy. The tool included: situation; unhelpful thoughts; emotions; alternative thoughts; scoring point section for rating unhelpful thoughts and emotions. The fatigue management sessions embedded the skills and strategies of self-management, which involves decision making, self-tailoring, goal setting, self-monitoring, and self-efficacy (de Silva, 2011). The session was led by an Occupational Therapist (OT) and an MS nurse specialist assisted in the session. All PwMS in the sessions were interacting in the session. PwMS discussed their workload, social commitments, reflected on goals achieved during the week and goals yet to be achieved. The OT role was essential in terms of directing questions to the participants which lead to conversations.

In summary, the observation sessions added to the data reflecting the care provided for PwMS, whether it was medical, physical, psychological, or social support. It allowed the researcher to observe the interaction between PwMS and the care providers/health care professionals, in addition to the interaction between service users themselves.

### 4.3 Reflection:

The observation process was interesting, a new experience that I had not experienced before. It gave me great insight into the variety of different support that the services provided to PwMS. It also granted me the opportunity to see the interaction between PwMS and health professionals, and interaction between PwMS amongst each other. The psychosocial groups were the most interesting sessions to observe; listening to the stories of PwMS made me emotional at times, and it was hard to hold back my tears at some stories. On the other hand, some stories were delightful to hear. I was amazed how PwMS supported their peers, even if it was just a little encouragement or advice. They felt they are not alone living with this condition. Observation was an interesting method to see the service in action, and reflect on what was reported by the health professionals in the focus group interviews.

## 4.4 Discussion

### *4.4.1 Providing care for PwMS*

Health services are experiencing significant change to meet the rising challenge of providing care for people with chronic conditions that can challenge professional expertise (Russell et al., 2009). The service category was one of the categories identified from the focus group interviews. It explored the care provided for PwMS and the importance of accessibility of care, health care professional expertise, and how to provide best practice services. In addition, the diversity of care and the skill mix/experiences health professional were also noticed in the observation sessions.

#### 4.4.1.1 Diversity of care

Diversity in healthcare teams in the three services enabled a broad range of opinions and talents to be used and shared in a collective manner, which benefits service user care. This was reflected by the skill mix in the services; skill and experience of staff gave the service users the opportunity to increase their knowledge and the freedom of choice between care provided. The three services provided different care mixes delivered by MS specialist nurses, specialist physiotherapists, specialist occupational therapists (OT), psychologists, neurologists, and complementary therapies. In the hospital-based MS service, the MS nurse specialists and neurologists worked closely together and shared the Modified Drug Disease clinics; disease modifying drugs (DMDs) are a group of treatments for people with relapsing multiple sclerosis. They reduce the number of relapses PwMS experience as well as reducing the severity of any relapses (MS Trust, 2018).

All health professionals explained the importance of diversity of care and the need for multidisciplinary support to help PwMS deal with the range of symptoms and to help them manage their condition as independently as possible. This is in agreement with the NHS England Multidisciplinary Handbook published in 2015 which reported that a Multidisciplinary Team (MDT) consists of healthcare and possibly social care professionals from different disciplines who use their combined knowledge, skills and experience to understand the needs of people with MS. In addition to collaborative working and regular meetings to define, develop and review MS service provision, they will use their expertise and understanding of the course of the disease to develop pathways and / or protocols that underpin the delivery of high quality and effective care to PwMS.

The mode of therapy delivery varied between one to one sessions and group sessions. Health professionals emphasized the importance of both modes and explained the freedom for clients to choose between them. It was emphasized by health professionals that, in group therapy, PwMS often have fewer reservations about discussing their issues with others because they can identify with the members of the group. In addition, group members can develop their communication abilities, social skills, and results in individuals being able to learn to accept criticism from others. Lincoln et al. (2011) reported that group therapy has some advantages for PwMS; it can provide the opportunity for PwMS to create a sense of belonging, and within a group setting there are similar mental and social issues that can be addressed. Lincoln et al. (2011) also explained that, within a group therapy session, there is more sympathy and less judgment because there is a greater understanding of the thinking cycles and behavioural choices. Furthermore, group sessions can help to develop healthy coping skills, making it easier for a person to discover which coping mechanisms can work well for them (Lincoln et al., 2011). Most of the PwMS involved in the study emphasized the importance of being involved in group therapy sessions, they highlighted that it is a friendly atmosphere where different ideas can be discussed, for example, different coping mechanisms suggested by different members of the group, in addition to motivation during group physical exercises.

A one to one mode of delivery of treatment sessions was another choice of receiving therapy. This mode of delivery was mainly required for modified drug therapy sessions, physiotherapy sessions, and counselling sessions. It was clarified by health professionals that some PwMS can feel uncomfortable in group therapy sessions, hence a one to one session might be a better option. In addition, some PwMS may feel like they are not receiving an adequate level of attention, which would create feelings of rejection. One-to-one sessions have been found to be highly effective in the treatment of a wide range of mental health conditions such as depression, anxiety and stress, eating disorders, a broad range of addictions (addiction counselling is only for adults), and for young people who are struggling with a mental health problem (Harvey & Gumport, 2015).

#### 4.4.1.2 Accessibility

Health professionals explained the importance of flexible access to professionals and how it can contribute in securing the continuity of care. Kielmann et al. (2010) emphasized that the desire for flexible access to the services is fundamental in ensuring confidence with self-care. In addition, the relationship between health professionals and PwMS is very important to increase trust, confidence, and mutual respect and, consequently, can help in shared decision making and increasing communication skills (Thompson, 2007). This reflects the findings of the current study where easy access to the service, health professionals, and continuity of care are crucial in involving PwMS in decision making. However, it also reflected the important role of health professionals to identify when optimum health and wellbeing is not being maintained, and to identify area of intervention required. In addition, PwMS who have advanced cognition impairment might not able to maintain optimum health, hence, a health professional is required to advise and suggest a suitable intervention. This implies that a self-management approach/programme should also be flexible and individualised to meet PwMS needs. In other words, needing a flexible service and continuity of care does not mean that it will not fit into a self-management model of care; in fact, it might enhance shared decision making.

#### 4.4.1.3 Best practice

The data from the health professional focus group interviews highlighted the importance of every service strategy of care to support PwMS throughout their disease journey. This can optimize the quality of life for the service users by involving them in decision making and enhancing a positive attitude throughout their journey with MS. This is supported by the MS International Federation (2018) which highlighted that access to comprehensive and effective treatments, and care for changing physical and mental health needs during life with MS, can improve quality of life for PwMS. Moreover, it emphasized that a positive attitude can increase their quality of life if it was embedded in the service policy.

A crucial point of the best practice was the holistic approach provided by the services, which involved medical, physical, psychological, social and complementary care. This was reflected in the observation sessions, and by the health professionals' focus group interviews. Barnes and Campbell (2010) explained that a holistic approach should involve life style changes and a team approach to management, where PwMS are part of the team. The findings of this study highlighted that the service should support PwMS throughout the whole disease journey, offer initial assessment, regular review and monitoring, offer support and information when required, and aim to empower and encourage self-management to maximise potential and minimise disability.

### *4.4.2 Self-management*

Self-management was the second category identified from the focus group interview data and a theme from the observation data. The health professionals discussed what they considered to be self-management essentials and self-management barriers. Current evidence suggests that service users with effective self-management skills make better use of available health services (Lawn et al., 2009). The World Health Organization (WHO) has identified several competencies required by health professionals and services to deliver optimum care to people with long term conditions, including patient-centred care, partnering and adopting a public health perspective. This is in addition to empowering people with chronic conditions towards adopting self-management strategies (WHO, 2005).

#### 4.4.2.1 Empowerment

Health professionals highlighted the importance of empowering PwMS to help them manage their condition. They explained the importance of not thinking that a person with a long-term condition is a passive recipient of care. This is in agreement with Kielmann (2010) who emphasized that the concept of self-care is to divert from PwMS being passive recipients to being active partners who can share responsibilities for their care. In addition, health professionals indicated that their role is to encourage self-confidence to support PwMS to have more control of their condition and their lives. This involves discussing potential risks and benefits associated with different treatment options which will help PwMS make choices and have confidence in their care plans. The NHS (2019) recommended that health professionals should involve patients in making decisions about their own care and treatment.

Shared decision making is a process in which the person with the condition, health care professionals, and carers work together and collaborate to choose appropriate diagnostic tests, treatment, and disease management strategies based on clinical evidence and the values and preferences of patients (Ben-Zacharia et al., 2018). This was reflected by the health professionals' interviews where they reported that the collaboration between PwMS and the health professional enables PwMS to have more control in decision making. This does not indicate that a person with MS is solely responsible for identifying his/her needs. This can be in partnership with an experienced health professional who has insight into the options and potential modifying activities/interventions and so the person with MS can make the most of the services that are available to them. Therefore, a self-management model should provide a good service-user–health-professional relationship for building up trust and continuity of care from a health professional who "knows" the person with MS and can make suggestions about care that this person might not even have considered. Hence, shared decision making is required to enhance empowerment for PwMS.

The MS nurse specialist acts as an expert in the relationship, keeping up to date on advances in MS, the latest treatments, and the implications of these treatments for PwMS (Chrysovitsanou et al., 2012). This was observed in the services and was also reported by the health professionals who highlighted the importance of the MS nurse’s role in giving informed choices to PwMS regarding medication/ care plans.

Health care professionals in the focus group interviews stated that making a choice or decision in the care plan can vary according to the type of treatment, length of treatment session, and the mode of delivery. They reported this included choosing the type of exercise and whether to be involved in 1:1 sessions or group sessions. In addition, the observation session reflected that PwMS who participated in group sessions had good peer support and learned from their shared experiences, which consequently impacted on their decision making. Mazaheri et al. (2011) explained that group counselling is a crucial method in physical and mental rehabilitation for PwMS. It can allow PwMS to share their own personal experiences, consequently understanding the affective aspect of the problem and discovering coping strategies.

#### 4.3.2.2 Education and information

Health professionals interviewed in the three services emphasized that education about the MS disease course is essential to help PwMS manage their condition. Self-management education aims to maintain a good quality of life and increase self-efficacy (Magharei et al., 2019). Embrey (2005) emphasized that educational programmes can increase self-confidence in PwMS, and enable them to identify coping strategies that allow them to make positive changes, which help them to deal with the unpredictable course of the disease.

Health care professionals emphasized the importance of psychological education or psychosocial education. It was highlighted that counselling sessions, whether 1:1 or group sessions, can help in understanding the behaviour pattern of PwMS. This is supported by a Cochrane review conducted by Thomas et al. (2006), who reported that cognitive behavioural approaches can be beneficial in the treatment of depression, and in helping PwMS cope with MS.

#### 4.3.2.3 Self-management barriers

Common self-management barriers were identified from the health professionals' focus group interviews. These included time, funding/cost, accepting the change, and cognition/memory barriers.

Insufficient time due to work overload was a common subtheme reported by health professionals interviewed. They reported that some PwMS might require one to one support during the therapy session, hence this might be time consuming. Health care professionals in the acute NHS hospital emphasized that seeing an MS nurse specialist or MS counsellor might take a long time because of time slot availability. This might raise a question whether PwMS have been receiving equal care from the services, and whether health professionals have alternative plans to resolve this problem. More specifically, the NHS acute hospital MS regional centre has a reputation of for excellent care; however, it is unclear whether this excellent approach was only fulfilled from the medical management side, with and the other essential therapies side being neglected. Taking into consideration the NICE guideline which published recommendations about MS management (NICE, 2014), the importance of co-ordination of care between health professionals in providing a holistic approach of care to meet the needs of PwMS, and included different team members of the staff including psychologists and MS nurses, should be emphasised.

Jerant et al. (2005) reported that cost can be a barrier for self-management especially for PwMS who would struggle to afford certain activities like going to the gym. In addition, it might be costly joining a self-management programme if it was not offered free of cost. Health care professionals highlighted that cost barriers can limit provision of equipment which might be useful for PwMS. Hence, health professionals should be realistic with their clients to avoid false hope. However, it was identified from the focus group interviews that the MS Society provide different classes for free or for a small fee to encourage PwMS to exercise. This raises another question, whether PwMS are being signposted to these offers on a regular basis, and whether there is someone in the service specifically making time to network with the MS Trust or MS Society to provide enough information to PwMS regarding provision from those sectors. The NICE guidelines (2014) did not identify or provide any recommendation regarding free resources for PwMS to use to encourage physical exercises and activity. Such guidelines need to reflect on free access to exercises and physical fitness outside the MS services to encourage PwMS to have opportunities to improve / maintain their physical fitness.

#### 4.4.2.4 Accepting the change

Health professionals in the focus group interviews highlighted the “self-denial stage” where PwMS were not ready to accept the new transition in their life. Knaster et al. (2011) stated that motivation for self-management programmes can help in accepting the change and to encourage coping with the condition. This is by using coping skills which help in managing the condition. In addition, health professionals highlighted that support from family and friends is very important for PwMS to accept the new changes in their life.

#### 4.4.2.5 Memory and cognition

Loss of memory is one of the important symptoms that PwMS might struggle with. Hence, it might be a reason for missing an appointment or forgetting to set goals, consequently hindering effective management of their condition. The MS Trust (June, 2019) reported that problems with recall are common in MS and can affect many aspects of everyday life. Health professionals in the focus group interviews stated that keeping relatives and friends engaged in the person’s life can help them to overcome this barrier. They also suggested involving carers or families in treatments sessions in order to remind them of new exercises or coping strategies. This was reflected in the observation sessions, where families and carers were involved in some of the interventions provided for PwMS.

A focus group study by Knaster et al. (2011) suggested coping strategies that might be helpful in overcoming some of these barriers. Such strategies included changing behaviours: PwMS who participated in their study reported that regular exercising helped them to perform activities, including walking, yoga, swimming, and lifting weights, which enabled them to be more effective in managing their condition. Another strategy suggested was increasing social support; many participants described peer support systems, such as MS support groups and exercise classes for PwMS, which improved their ability to cope with MS, in addition to accessing information about MS and utilizing medical treatment.

#### 4.4.2.6 Physical activities

The majority of participants in studies of self-management support for people with long term conditions are reported to be interested, feel able and are committed to developing self-management skills. Therefore, engagement in selecting the physical activity is more likely to occur when interventions are tailored to the needs of individual patients (Panagioti et al., 2014). The physical activity sessions delivered in the NHS and non-NHS community services showed the normal routine activities that can be delivered in any physical activity class setting to people with long term condition. This was clearly observed in the 1:1 physiotherapy sessions, group physiotherapy sessions, Tai-Chi session, and Yoga sessions. However, it was noticed in the acute hospital setting that no physical activity sessions/classes were delivered or assigned to PwMS. It was also noticed that PwMS with different types of MS had limited physical activity / activities; hence, this affected their daily life performances which subsequently made their choice of exercises limited to low energy exercises, for example, yoga and Tai Chi. The majority of PwMS across the different services explained that fatigue was one of the main issues that was limiting their daily activities. One person stated to the therapist that the new adaptation to her home environment was made to allow her cope with the new transition. This reflects the coping strategy suggested by Gibson and Frank (2003); environmental manipulation can play an important role to minimal physical effort in PwMS.

#### 4.4.2.7 Interaction with others

The interaction between different health professionals and PwMS showed a good rapport had been developed, allowing PwMS to speak freely about their feelings and ask for help if required. It was observed in the gestures and the language used, which was noticed particularly in the non-NHS community service, as most of PwMS were regular clients of the centre and had been attending for many years. For example, they talked about plans over the weekend and reported some family stories. This was obvious in the interactions between PwMS themselves, between PwMS and service users with other long-term conditions, and between PwMS and health professionals. This is supported by a practical guide published by the Health Foundation (2015) to support self-management in people with long term conditions. The guide highlighted the importance of the relationship between health professionals and the person with the long-term condition, and the peer support relationship. Hence, clinician and service user should work together to co-produce health improvements (The King’s Fund, 2011).

## 4.5 Chapter summary

The data collected from the three focus group interviews, presented in this chapter, were embodied by two main categories: The Service, and Self-management. The main themes identified from the service category included diversity, accessibility, and best practice. The main themes identified from the self-management category were self-management essentials and self-management barriers. In addition, the data collected from the observation sessions identified four main themes: diversity of care, physical activities, interaction with others, and self-management

The perceived central role of health professionals in providing care and support for PwMS was managing comorbidities, providing support for emotional and physical needs and coordinating care services. Person-centred care was viewed as essential when managing an unpredictable and variable condition, and was achieved through providing holistic care that managed all of the social, psychological and physical factors experienced by PwMS. A strong professional–service-user relationship developed through a long-term continuity of care was central to providing ongoing person-centred care to PwMS.

Empowering PwMS, providing adequate information about MS, and psychosocial education are essential components of educating a person with MS to enable them to cope with their condition. Health professionals can face barriers in providing care and support for self-management for PwMS, and PwMS need to go through the process of accepting their condition and be able to engage in their treatment plan to overcome any obstacle that may stop them from managing their own condition.

The observation data was an essential part of the field study. It reflected what care was available for PwMS in the three services. In addition, it confirmed that a self-management approach was presented in the care provided by the three services.

Chapter five will report the results of individual semi-structured interviews that were used to explore experiences of PwMS, their expectations and perceptions of self-management of the condition.

# CHAPTER 5: PHASE 2 – EXPERIENCES, EXPECTATIONS AND PERCEPTIONS OF THE SELF-MANAGEMENT AND SUPPORT NEEDS OF PEOPLE WITH MS

## 5.0 Introduction

This chapter reports on the second phase of the PhD. It explores the experiences, expectations, and support and care needs of PwMS who have received support for self-management from one or more of the services (NHS acute Hospital, NHS community service, non-NHS community service).

## 5.1 Methodology

### *5.1.1 Purpose and objectives*

The purpose of the second phase was to explore the experiences, expectations, support and care needs of PwMS and how those needs were met, as reported by PwMS who have received support for self-management of MS from one or more of the three different services.

### *5.1.2 Design*

Individual semi-structured interviews were used to explore the experiences, expectations and perceptions of PwMS related to self-management of the condition. A semi-structured interview methodology was chosen because it is an in-depth interview where the interviewees are asked open-ended questions. This methodology is widely employed by different healthcare professionals in their research (Braun & Clarke, 2006).

The interview questions and topics were chosen by the researcher and discussed with the research supervisor for further advice. Subsequently the interview questions were developed and the final interview schedule was finalised (see Appendix 9).

### *5.1.3 Population and sample*

Purposive sampling was used to recruit eight participants. The services approached were able to identify four people with relapsing-remitting MS and four with progressive MS. The aim of this phase was to explore the lived experience of PwMS in relation to self-management. Finlay (2011) explained that a phenomenology study is a study which explores lived experience of a phenomenon, where data saturation is not required. What is more important is the quality of the descriptions/analysis rather than data saturation in this case (Finlay, 2011).

#### 5.1.3.1 Inclusion and exclusion criteria

*Inclusion criteria*

PwMS who were:

- aged 18+
- at any stage of MS
- receiving self-management support from any of the three included services, e.g. Acute NHS hospital UHNS MS service, NHS community service, or Non-NHS Community service.
- able to provide informed consent

- able to communicate clearly either verbally, or in writing, or using a communication aid or other appropriate communication support strategy.

*Exclusion criteria*

PwMS who:

- were living with other long-term conditions e.g. Chronic Obstructive Pulmonary Disease (COPD), Rheumatoid Arthritis (RA), and Osteoarthritis (OA), that might influence their support needs
- demonstrated severe cognitive dysfunction that would impact on their ability to participate in an interview
- PwMS who were unable to provide informed consent

### *5.1.4 Recruitment*

Participants were recruited through each of the services by asking each service to forward to all their clients with MS an invitation to volunteer to participate in the study, and an information sheet explaining the study (see Appendix 10). PwMS who were interested in participating in these individual interviews were asked to contact the researcher directly.

The researcher arranged to visit those individuals who expressed an interest in finding out more about the study, at a mutually convenient location, and provided more detailed information about the study and answered any questions. After that, the interested participants were asked to provide informed consent, undergo screening for eligibility (according to inclusion and exclusion criteria) and subsequently were recruited, before arranging the interviews.

### *5.1.5 Ethical Issues*

Participants were free to withdraw from the interview at any stage. See chapter 3 section 3.4 for details about ethics approval. It was recognized that participants might experience anxiety about discussing topics such as the circumstances of the MS and its consequences, and their experiences of managing their condition, which might be painful and possibly distressing. However, they were free to choose not to respond to any questions and also free to stop the interview or the recorder at any time and it was carefully explained that if they chose to do so that this would not affect the care or treatment they were receiving.

### *5.1.6 Procedures*

#### 5.1.6.1 Development of the interview schedule

The interview schedule was developed and discussed in detail within the research team prior to conducting the interviews. The interview questions are reported in appendix 9. Interview topics were:

- Experiences of “self-management” and how is self-management being supported by the rehabilitation team.
- What is particularly helpful in a self-management programme.
- Are PwMS needs being met with the self-management programme they receive.

- Do PwMS value a self-management programme as part of the services they receive.
- Self-management programme to be led by a lay person or a health professional.

The interviews were scheduled to last no more than one hour and were conducted by the researcher. It was intended that the data from this phase would inform a ‘best practice’ model of self-management, which might help in supporting PwMS in the future.

#### 5.1.6.2 Data collection

The information sheets were given to participants via each service (Appendix 10). Those interested in participating in the interviews contacted the service to set a day and time that suited him/her. A telephone call from the service confirming the day and the time of the interview was received by the researcher. The interviews were held at the same location the participants attend for their treatment. This meant the PwMS participants were familiar with the place/surroundings. They had no extra time commitment to make. Before the start of the interview, the aim of the interview was restated and written consent was obtained (Appendix 11). The researcher ensured that the room in which the interview was carried out was quiet room, with no interruptions, and the interviewee was assured that no-one else could overhear the discussion, to assure confidence and anonymity. The researcher made sure that the participants had a comfortable chair to sit in, and they were offered comfort/toilet breaks. The researcher sat in a comfortable chair facing the participant. Digital recording captured the qualitative data. Field notes were recorded in writing by the interviewer immediately after completion of the interview.

#### 5.1.6.3 Data Analysis

The digital recording data were subsequently transcribed verbatim and anonymised during the process of transcription by the researcher. The transcripts were checked against the audio file for accuracy by two members of the research team. Transcribed data were coded independently by the researcher and by a research supervisor researcher. See chapter 3 section 3.3.2 for a detailed description of the data analysis approach. Thematic Analysis was chosen in this study to identify patterns of meaning across the whole dataset, to identify the experiences, expectations, support and care needs of PwMS, and to discover if those needs were met, as reported by PwMS who have received support for self-management of MS from three different services. Codes were discussed and compared before preliminary themes and sub-themes were identified. These were subsequently discussed by the research team and further refined until the final themes were agreed.

## 5.2 Findings

A total of eight PwMS were interviewed from the three different services: NHS acute Hospital n=2, NHS community service n=2, non-NHS community service n=4. The sample included four participants with relapsing MS, and four with secondary progressive MS. See Table 12 for a summary of participant demographics and characteristics. The duration of the interviews ranged from 32:37 to 53:36 minutes.

### *5.2.1 Themes*

Three main themes were identified from the data analysis: the MS journey, MS services, and self-management. Each theme included subthemes, as summarised in Table 13.

#### 5.2.1.1 Theme: The MS journey

All participants included in the study described their journey with MS. They highlighted how they had been diagnosed with MS, the relapses during the course of the disease, and how it affected their life physically, psychologically, and professionally. This theme was identified from two subthemes, the MS disease course, and life transition, as described below.

**Table 12: Summary of participant characteristics and demographics**

| **Pseudonyms** | **Ant** | **Amy** | **Mike** | **Jill** | **Phillipa** | **Sandra** | **Rebecca** | **Silvia** |
|---|---|---|---|---|---|---|---|---|
| **Age (years)** | 54 | 56 | 50 | 44 | 40 | 64 | 27 | 60 |
| **Gender** | M | F | M | F | F | F | F | F |
| **Type of MS** | Secondary progressive | Secondary progressive | Relapsing remitting | Relapsing remitting | Relapsing remitting | Secondary progressive | Relapsing remitting | Secondary progressive |
| **Time since diagnosis (years)** | 20 | 32 | 15 | 15 | 23 | 26 | 4 | 28 |
| **Service** | Non-NHS Community | Non-NHS community | Non-NHS community | Non-NHS community | NHS community | NHS community | Acute NHS hospital | Acute NHS hospital |

**Table 13: Summary of themes and subthemes relating to the service**

| **Theme** | **Subthemes** |
|---|---|
| MS Journey | MS disease course |
| | Life transition |
| MS Services | Mode of delivery |
| | Disease modifying drugs clinics |
| | Therapies provided by the service |
| Self-management | Self-management strategies |
| | Qualified vs. lay person delivering self-management |

*Subtheme: MS disease course*

PwMS explained their journey during the course of the disease, from day one of diagnosis until the present day. Their time of diagnosis ranged from 5 years to 20 years+. Some of the most common early symptoms reported included vision impairments, ‘pins and needles’ in their lower limbs, fatigue and mobility difficulties/impairments:

> *“It started with sort of mild sensory symptoms and that was it, I didn’t have any motor symptoms. Then I had another relapse, I didn’t work for quite a long time. Walked with a stick for two years, and then eventually got myself sorted out and went back to work” (Jill)*

> *“I started having immense pains in my head. We’re talking pains that I’ve never experienced before; absolute agony. I didn’t go to bed for probably three months. I had to sleep in sort of a sun chair that you lift the arms and lean back” (Sandra)*

Participants described the MS diagnostic journey, which started from visits to their own General Practitioner (GP), who then referred participants to neurologists for further investigations. An MRI scan was the main method of investigation to detect an active MS lesion. In addition, some participants received a lumbar puncture as an additional diagnostic method. These methods helped in the early diagnosis of MS:

> *"I was in the hospital for six days. I had a spinal tap. When they discharged me, one of the neurologists was really good. He took my mum and my partner into a room and he showed them the MRI images and he explained what it was. But he said "I hope that you're one of these people that doesn't affect you for another seven years." (Rebecca)*

> *"They first investigated me for Transient Ischemic Attacks (TIAs). I was sent to Birmingham to have an MRI. I went there and I almost think that, although the Dr didn't say it, I almost thought perhaps he thought it was something like a tumour or something like that, but they found nothing, that was in 1991. In 2004, I'd had quite a lot of trouble again, so my doctor sent me to visit a neurologist and he sent me for another MRI scan and discovered that I had got MS." (Sandra)*

Participants reported that, when initially diagnosed with MS, the specific type of MS was not immediately identifiable. They had to monitor progression of their symptoms and to be aware of any further relapses. Some participants believed that their MS was due to a shock they had in their life or a stressful event that might have led to MS:

> *“My mother died in 91’, whether it was the shock of that, I don’t know but later on that year, I started having immense pains in my head.” (Sandra)*

> *“We’d been living in Australia and then we’d come back but I don’t know, I kind of linked it to stress of moving back across the world. We moved back when my daughter was two and shortly after getting back this had happened.” (Jill)*

A sense of uncertainty was reflected in some of the conversations about the course of the disease, more specifically when they were initially diagnosed. Some participants stated that MS did not significantly affect their life, and their relapses were manageable so far; others highlighted that they had never experienced a relapse but instead had experienced continuous progression of the symptoms throughout the years, which is typical of progressive MS:

> *“I thought I was going to get relapses, like double vision again and get better, but my legs have gone and the past five years, it seems to have gone from gradual decline to be accelerating a bit.” (Ant)*

*Subtheme: Life transition*

The MS disease course can be life changing. Due to the chronicity of the disease, PwMS need to adjust to the transitions of new situations in employment or work, home adaptation, and family or peer support. Some participants had to change their working hours from full-time to part-time to help them adapt to this transition. Some participants had to resign from their jobs, or found alternative styles of working, or hobbies, such as working from home if able:

> *"I was working full time and I dropped a day to sort of concentrate on coming here, it's better for me not to work full-time too." (Jill)*

> *"I stopped work, I think it was September last year. At the time I was having to use a walking stick, so that kind of made me…I felt useless. I felt like I was in the way I think, because I couldn't move. I worked in a garden centre, and because I couldn't move any of the stock, or be involved in anything that meant lifting. So, basically, I was left stood at the till, and that's not me" (Phillipa)*

Some participants highlighted that new home adjustments were required to manage the transition in their lives. One participant stated that she moved to a bungalow so that everything could be on one level to preserve energy. Others also emphasized the importance of having their own exercise machines or equipment at home to help them maintain physical fitness. Occupational Therapists were also involved at times to help participants with the new home adjustments and to fit any required equipment:

> *"Moved to a bungalow last year, that's helped a lot, I was struggling on the stairs, so that helped. Obviously, I've seen Occupational Therapy, they've come out to me a few times and given me few tips." (Phillipa)*

> *"I have an electric Thera-trainer at home, which I go on for an hour a day, it keeps my legs moving because when I first go on it my legs are like rods, they really don't want to move, but because it's an electric machine my legs do move." (Amy)*

Three out of the four participants with secondary progressive MS were wheelchair users. They explained how their physical mobility had gradually declined and, hence, they had to use new mobility aids such as a wheelchair or a mobility scooter to help them transfer from one place to another, or had to have adaptations added to their car so that they could go out:

> *"I use the wheelchair now when I go out which is great and my car is a left foot adaptation which is better and I can drive safely." (Ant)*

One of the participants emphasized how their lives had changed tremendously due to the condition, and highlighted the importance of making sure that facilities for people with disabilities were available in the places they planned to attend:

> *"All my mates will organise a party somewhere and I'll say to them have they got a disabled loo, or have they got steps?" (Amy)*

Participants reflected on the importance of the family and carer support in their life transition. However, some stated that they did not like being completely reliant on their partners and families. They try to achieve as much independence as possible:

> *"Certain things I try to avoid, when I know I'm going to struggle, my husband helps with things like shopping and family helps as well." (Phillipa)*

> *"My husband keeps saying 'Oh I'll give up work and I'll look after you full time' and I'm thinking no, don't do that, and it also gives him space away, but I need my space as well, we all need space." (Amy)*

### 5.2.1.2 Theme: MS Service

Each MS service played an important role in helping PwMS in managing their condition and improving their quality of life in different ways. The MS Service theme was identified from subthemes of mode of delivery, disease modifying drugs clinics, and therapies provided for PwMS.

*Subtheme: Mode of delivery*

The mode of delivering services in each location was described in chapter four. Participants across the three services confirmed that they could choose to be in either a one-to-one therapy session or a group session and/or both. Their preference was dependant on the care required. Two participants, one with relapsing-remitting type MS (NHS community service) and the other with secondary progressive MS (non-NHS community service) were reluctant to join group-based care. One justified this by not having sufficient time to join the sessions and clarified that, due to her own profession, she might end up being in a group attended by her own patients. The other stated that some psycho-educational groups can sometimes reflect negative energy as some people attending these groups took the opportunity to “moan”, which was not welcomed by all those attending:

> *“I would go to these groups if I had the time, I mean if I wasn’t working full time” (Jill)*

> "No, don't stick me in a group of people that want to moan about their illness, because they should be doing something about it and that's maybe very wrong of me to say." (Amy)

However, some of the participants emphasized the importance of having the group sessions to help them interact socially with other PwMS, and this social contact increased their confidence to keep going*:*

> *"Being in a group, I've been some friends. I've obviously heard more stories and certainly on my side. A lot of people in the group are in a worse state than I am, so I feel for them. When you're in a group you can see how differently MS can affect each person, and you learn from these stories" (Phillipa)*

*Subtheme: Disease Modifying Drugs*

The disease modifying drugs (DMD) are a type of treatment that PwMS undertake to reduce the severity of any relapses they might experience due to their MS disease course (MS Society, 2019). This subtheme explains the importance of the DMD for management of relapses for the relapsing-remitting type of MS. PwMS who are prescribed these drugs attend the DMD clinics for their treatment, mainly in acute hospital settings. Appointments are normally made with the MS Nurse Specialist to advise and give information about the drugs/infusions. Participants normally attend a 1:1 session with the

MS Nurse Specialists and decisions regarding the medication are made at that appointment.

Participants who take these medications highlighted the importance of the MS Nurse Specialists and the support provided by them:

> *"The MS nurses are brilliant, they're fantastic. You know, you just ring up and if you've got any problems, or something that's new, a new symptom. They're brilliant at getting back to you." (Phillipa)*

> *"In September when I saw the MS nurse, she explained that I've got relapsing remitting and she did give us some information about the disease modifying drugs." (Rebecca)*

However, not all of the participants felt that way at the beginning of their disease course. One stated that she had experienced difficulties in the past accessing someone, such as a nurse specialist, during the weekend following a relapse. The only option she had was to attend the local A&E department for advice, but no medication could be prescribed to help in symptom management:

> *"I've gone into, my leg is gone again, I can't walk. It's really stressful, it was a weekend. Ended up going to A&E and they*

> *can't give you steroids. They can't get in touch with you later. It's that lack of some fast-tracking support." (Jill)*

Some of the participants highlighted that DMDs have progressed throughout the years. They stated that new DMDs are now available to help with relapsing-remitting MS symptom management. In addition, the MS Society is giving out information regarding classes for newly diagnosed MS patients. These classes are led by MS Nurse Specialists in different areas within the UK. One participant explained that in the past they were limited in DMD decision making. Currently more DMD options are available to choose from:

> *"At the time, the only thing that was sort of available was Beta Interferon, so I went on that, but after few years, that wasn't suiting me. Few years later other things have come out, so I ended being put on Mitoxantrone and on Copaxone." (Mike)*

*Subtheme: Therapies*

There were a variety of therapies mentioned by the interviewees across the three services. These therapies provided care and helped in improving the health of PwMS, physically and mentally. The main therapies highlighted were exercise sessions, Occupational Therapy, and counselling/psycho-social care.

*Exercise Sessions*

Participants emphasized the importance of the exercise sessions provided by the service. These exercises included 1:1 physiotherapy sessions, Pilates group exercises, and gym exercises. These sessions were only delivered in the two community services. PwMS who were recruited from the NHS acute hospital were not provided with any exercise sessions in the acute setting. However, they were signposted to exercise therapy sessions, for example Pilates sessions, held in community settings, such as a public gym. Participants who were interviewed in the community services all had 1:1 physiotherapy sessions. They highlighted the importance of these sessions and emphasized that it helped increasing their exercise tolerance, improved posture, and gait:

> *“I have one to one with the physio, and it’s six weeks on and six weeks off and it is absolutely invaluable. The physio keeps right on top of you. Exercises help you move your body, actually move your muscle. You’re responsible for yourself and you should move.” (Amy)*

> *“I suppose some of the things that the physio told me to do, I remember to do, like sitting up, you know the sitting up straight and shoulder down. And I found she’d asked me to push through my left foot ‘cause I don’t. And sometimes I’ve found when I’ve been out and about that can help me walk better.” (Jill)*

One of the PwMS interviewed from the NHS acute hospital was signposted to local group exercises classes. Those classes included Pilates with a neurological physiotherapist, in which some of the exercises can be completed sitting down, since some of the PwMS in the group lack balance control when standing.

Other participants reported the importance of tailoring the exercises according to their needs at home. They highlighted the importance of continuity of physical activities for their bodies to maintain their functional level. In addition, some of the participants were able to afford a private Pilates trainer in their own home:

> *"I have a bar that you can hold onto when you're walking along, it is at the height of my right arm, because my right arm is permanently like that, so I jam this arm into the bar, like that, and then I move the chair away, so that way I'm getting my arm exercises." (Amy)*

### *Occupational Therapy*

The role of occupational therapy was highlighted by the PwMS interviewed who reported that it helped in terms of hand support and dexterity. Neuropathic pain in the extremities, more specifically in the upper extremities, was reported as a big problem, as it affects upper limp functional activities. Hence, the role of the Occupational Therapists was considered to be crucial in improving sensation and upper limb strengthening. In addition, the need for splinting to avoid contractures in the hands was recognised:

> *"The OT made me a splint for my hand because my right hand clamps up, so I put my hand into a resting splint."*
> *(Silvia)*

*Psychological Support*

Participants expressed how the MS affected them psychologically. They emphasized the importance of the psychological support from the beginning of the MS journey. Some of the participants highlighted that they were left feeling unsupported after being diagnosed, and they stated if the psychological support was provided from the start it was would help with managing their mood and energy:

> *"I got quite ignored really, and it probably does for a lot of patients, there's no psychological support. It is a massive shock, and you know sort of massive trauma. I don't remember being offered anything to help me cope with that. At the time it was just get myself out of the hospital, go home and try and get my life together. So I think at that point, that support would've been helpful." (Jill)*

All three services provided psychological support for PwMS as reported by the health professionals (see chapter 4). However, one of the PwMS interviewed at the acute NHS hospital had not received information regarding the psycho-social group support that was offered to PwMS receiving care from the hospital. Some participants were reluctant to join a psycho-educational support in a group setting, as they might see the progression of the course of disease in other group members, which might affect them negatively:

> *"I know it sounds awful but with people that have got MS, that may have the progressive type, and you see them in a wheelchair, I've got to admit that I can't help but let it play on my mind that, 'will it be me one day?'. That is the only thing that puts me off." (Phillipa)*

In contrast, some participants stated the importance of attending these groups. They highlighted the importance of peer group support in lifting the spirits up to help manage their condition:

> *"I find these groups really good. You don't feel on your own. There's somebody always there to talk to and share ideas to manage my MS." (Silvia)*

#### 5.2.1.3 Theme: Self-management

Self-management was the third theme identified, with subthemes of self-management strategies, and qualified health professional vs lay person self-management programmes. This theme encompasses participants' perceptions of self-management and strategies they had experienced and found to be useful to help them cope with their condition by managing their symptoms physically, psychologically, and socially.

*Subtheme: Self-management strategies*

PwMS reported their thoughts on self-management and their understanding of the term. Hence, the following strategies were identified based on the interviewer's interpretation.

*Positive attitude*

Most of the PwMS interviewed emphasized the importance of having a positive attitude towards MS to help them manage their symptoms or condition. This was reflected in their determination to attend therapy sessions and accept the change to their lifestyle. Furthermore, they recognised that interaction with positive people can help them in managing their MS. They reflected that a positive attitude can be obtained through socialising, peer and family support, and support from health professionals:

> *"On a psychological level, it's that positivity just…thinking I am doing the best I can, and I am sort of recovering from that initial relapse." (Phillipa)*

> *"They are very positive here, the majority are very positive in the exercise classes, which keeps you going." (Sandra)*

One of the participants referred to Cognitive Behavioural Therapy and how it helped him to engender a positive attitude towards his condition by controlling his worry and anxiety. These sessions were delivered to him via 1:1 sessions at the non-NHS community service. These sessions were covered over a period of a few weeks and influenced attitudinal change and learning to put things into perspective:

> *“I have done Cognitive Behavioural Therapy (CBT), it was really helpful, helpful to get things into perspective in your life and stop worrying about things. Instead of thinking about the negative things, think about positive things.” (Mike)*

### *Fatigue Management*

Fatigue was the main symptom highlighted by the PwMS who were interviewed. They explained that it is a difficult symptom to manage but, by adopting the right strategies, it can be controlled. Controlling fatigue was reflected by pacing, delegating, and setting realistic goals.

Some of these management strategies were delivered through the group psycho-educational sessions or through a fatigue management course. However, some of management strategies were developed from their own experiences during the course of the disease, where some of them learnt to listen to their own body and know when to stop and pace themselves whilst doing tasks:

> *“When I feel I am starting to struggle, I stop, like restart switch by stopping from doing what I’m doing, then I can keep going again. I suppose it’s the pacing isn’t it?” (Jill)*

> *“I think with these fatigue management classes, it’s been a change of a mindset if you want. It’s firstly recognising what causes your fatigue and then, kind of…if you can pinpoint it and then manage it. So breaking down your normal daily routine and making the tasks more manageable and then realising that, just a short break between that and the next task will greatly improve things.” (Phillipa)*

It was also suggested that family support and carer support helps in managing the fatigue symptoms. Hence, delegating to family members or friends to help with completing daily tasks can result in good fatigue management techniques:

> *“I always have the carer when I’ve been to the centre, because I will know that my legs will be knackered. So when I’m home I have my dinner and I will know that I will just switch off and I will be just out of it.” (Amy)*

### *Diet and MS*

Three of the MS participants highlighted that a healthy diet can help in maintaining energy levels. In addition to having specific food requirements to help with food digestion, one of the participants in the non-NHS community service stated it would be useful to have a dietitian to give more information on an appropriate diet:

> *“I don’t eat any dairy, but I have the most fantastic diet, I eat a lot of rice, I eat brown, wholemeal, organic rice. I have fruits to maintain a healthy diet” (Amy)*

> *“It would be useful to have a dietitian to help us maintain our energy levels.” (Jill)*

### *Decision Making*

Participants reported that they were empowered to make decisions about all the treatments or therapy offered to them, and to choose their preferred mode of delivery, such as 1:1 sessions or group sessions. They also highlighted that some decisions are shared between the health professional and the person affected by MS. It is about taking the responsibility and not being a passive recipient:

> *“We always have that sort of joint-decision making. For example I am going to see the occupational therapist today*

> *to look at seating and that’s come about from discussion with the physiotherapist.” (Silvia)*

*Subtheme: qualified health professional vs. lay person delivered self-management programmes*

One of the questions in the interviews asked whether participants would prefer a self-management programme to be led by a health professional or a lay person. Participants’ preferences varied. Some PwMS thought it was better for such programmes to be led by a health professional, as they would be more knowledgeable and would know the answers to questions. However, most of the PwMS preferred having a programme led by a person with MS in conjunction with a qualified health professional. They explained that the lay person would have been living the same or similar experiences and would, therefore, be able to reflect on those experiences and bring their experiences to the programme to offer peer support; but a health professional would be able to offer a medical or therapy point of view to help PwMS manage their condition. In conclusion, having an MS self-management programme led by both might be more effective.

> *“I think it’s a combination isn’t it. I think having somebody with the condition does help because they understand what the patients experience, and it is more objective from health professional viewpoint. So I think having the combination instead of just one person in necessarily” (Jill)*

## 5.3 Discussion

The purpose of this phase was to explore the experiences, expectations, support and care needs of PwMS, and how those needs were met, as reported by PwMS who have received support for self-management of MS from one or more of the three different services.

### *5.3.1 The MS journey and disease course*

The theme of the MS journey was identified from discussion about the MS disease course and life transitions. Each interviewee described their journey with MS since the day of diagnosis and how much it affected their lives consequently leading to a new transition.

MS is a disease of various types, with a complex and unpredictable course. It can include many different symptoms which interfere with the physical, cognitive, and psychological abilities of PwMS (MS Society, 2019). Due to the unpredictability of the disease course, PwMS can be anxious about what might happen next, which instils in them a sense of uncertainty. Participants reported their journey with diagnosis from their first visit to the General Practitioner (GP) to being referred to the MS Neurologist specialist. Some PwMS reported the initial misdiagnosis of MS, as the diagnosis might initially be misled by the potential for other neurological diseases, at least until further investigations confirm the MS disease. PwMS with the relapsing remitting type described the attacks and flare ups of MS, while PwMS with secondary progressive type explained the gradual deterioration of the disease. Some participants highlighted the lack of support after the initial diagnosis of their MS, explaining the importance of initial support after revealing the official diagnosis. PwMS emphasized that it would be easier to have the psychological support from the beginning of the journey rather than later. A Cochrane review by Thomas et al. (2006) reflected the importance of psychological support/intervention to support PwMS in their MS journey. The review reported that psychological interventions improved both the psychological and physical well-being of PwMS. This can be achieved by managing their mood, anxiety and depression. The review emphasized the role of psychological interventions by increasing self-management, self-efficacy, and reducing stress. This resonated with the findings of the focus group interviews where it highlighted the role of the counsellor and psychologist in behavioural change and managing depression and stress.

### *5.3.2 Life transition*

PwMS who participated in the study explained how MS changed their lives in different aspects, physically, socially, emotionally, and psychologically. This made them adapt to the new life style and try to cope with their condition as much as possible. Coping or adapting to MS sometimes can be limited in terms of choices, for example, changing their work or decreasing their working hours. This can play a role in PwMS facing financial challenges as well as emotional challenges.

MS progression can bring emotional changes, starting with the moment of diagnosis. Common emotions that PwMS might experience include grief and sadness, worry, fear, moodiness, and irritability; and, in more severe cases, or during progression, PwMS may feel anxiety or depression (Multiple Sclerosis Trust, 2019). Therefore, involving family and friends from the start might make it easier for PwMS to cope with the new change in their lives. PwMS explained that new home adjustments and physical mobility aids helped in coping with their physical changes.

Some of the participants discussed the changes they had experienced in their jobs and lifestyle, but it was surprising that the concept of loss did not emerge as a theme or subtheme from the data. Campbell (2015) stated that one of the greatest challenges of living with a long term condition is to accept loss; for example, losing one’s job and friends or family due to the new condition in one’s life. Campbell (2015) further explained that the sense of loss can lead to grieving, which is associated with the relapse of symptoms. The participants in this study were not open about experiences of their own losses during the interviews, and it might have been of interest to have explored this through sensitive questioning in the interviews. However, exploring loss specifically was not the aim of the individual interviews with PwMS in this study.

The National MS Society the MS Trust in the United Kingdom highlighted the new transition after diagnosis and living with MS as a long-term adjustment. They emphasized the importance of changing life style including exercise, diet, stress, mental health, work, and sleep. Adopting a healthy life style, sharing experiences, and taking control, can help PwMS in managing their condition (MS Trust, 2019).

This was reflected by the findings of the literature, field study, and the individual interviews. The data indicated the importance of adapting to the new life style due to the course disease. Hence a person with MS might benefit from an early education to provide PwMS with the variety of task and skill they will need to adopt to cope with the new transition. The tasks might be as medical, physical, emotional/cognitive, and psychological management. In addition to obtaining certain skills to help PwMS take control of their condition; problem solving, self-efficacy, decision making, and goal setting.

### *5.3.3 Support available from the three services*

Experiences of the support that was available from the three services were varied in terms of treatment and therapy. However, there were also some similarities across all three services.

All three services delivered their care in 1:1 sessions or group sessions. This was dependant on the type of therapy and the choices available to PwMS receiving support. It was noticed that some of participants who were considerably new to diagnosis preferred the 1:1 sessions as they feared facing the reality of seeing other PwMS with more progressive disease course.

However, most of the participants enjoyed the psycho-social educational groups and felt they were more confident in managing their MS; they did not feel they were the only people struggling with disease and such groups were a good platform for shared experiences. Mazaheri et al. (2011) reported that group counselling is one of the most important methods in somatic and psychological rehabilitation of PwMS. Knowing the experiences, feelings, beliefs and emotions of other PwMS, based on learning from other group members, is necessary to indicate the importance of group discussion on quality of life of PwMS. In addition, peer support programs have become a common method of providing support for people living with chronic illness. Utilizing peers as resources has been proposed as an effective means for coping with a stressful life experience and for gaining support from others who share a common factor, although data are somewhat mixed on the efficacy of peer support (Uccelli et al., 2004). However, a 1:1 treatment will be needed for PwMS who require disease modifying drugs that are usually conducted by the MS nurse specialist. This was mainly explained by PwMS who attended the NHS acute service.

### *5.3.4 Therapies*

Different therapies provided by the three services helped PwMS physically, emotionally, socially, and psychologically. However, it was noticed that the community services had a lot more care options in comparison to the NHS acute hospital. One of participants from the NHS acute hospital reported that she was not aware of the psychosocial group session. Dingley et al. (2008) reported that there is a possibility in the acute care setting for communication failure to occur. This might affect the service user and the resource use. In addition. Some care providers often have their own view of what the service user wants, hence, miscommunication might occur between the MDT. However, the focus group interview data reflected on the crucial role of a teamwork and effective communication within the team, regional teams, and service users.

It was reflected by the interview data that exercises were essential in terms of managing their physical activities; increasing their muscle strength, increasing their joint mobility, posture, and improving balance.  They also reported that exercises can be in form of physiotherapy sessions, yoga, and Pilates exercises. The MS society (2019) emphasized that an exercise programme should be tailored to meet a person with MS needs, and physical trainer should adjust or initiate an exercise programme for PwMS according to their limitations and capabilities. This can be reflected by the triangulation of the collected data, as the data revealed that exercises in the services were meeting the needs of each person with MS. Some of these service users were wheelchair reliant, hence, seated exercises were selected. In contrast, other PwMS with more capable physical fitness were able to join the standing physiotherapy sessions. However, this was only seen in the NHS community and the non-NHS community services. The NHS acute hospital lacked provision of exercises sessions. However, it was reported by the MS nurses that they had connection with another regional rehab hospital that PwMS can be referred to for commencing rehab.

In addition, PwMS who joined the yoga and Tai Chi group exercises found the sessions relaxing and met their physical needs. This was also reflected by the MS Society (2019) who stated that yoga and Tai Chi exercises represent low energy exercise level, and can help with decreasing the level of stress. Therefore, an exercise programme should be tailored according to PwMS needs, with consideration of the type of MS and individual energy levels.

Occupational Therapy is one of the essential therapies provided to PwMS. It was reported by participants in the interviews that the occupational therapist (OT) helped them in new home adjustments, in terms of equipment and other facilities. In addition, some PwMS required specific hand therapy / upper limb therapy to improve functioning. It was noticed from the field study that the occupational therapy played an important role in delivering the fatigue management programme (FACET). The programme was led by an OT. In addition, this was also revealed from the findings of the review, as some of the fatigue programmes were OT led. Hence, OT has an important role to play in helping PwMS manage their condition by provision of certain equipment at home that can provide a better coping environmental style, or/and delivering fatigue management programmes to help them manage their fatigue symptoms.

Psychological support was one of the main essential therapies provided by the three services. Taking into account the change of life style, mood, and emotional well-being post diagnosis, the support provided by psychological intervention can help with decreasing levels of depression, low mood, and increase level of physical activities (Thomas et al., 2010). Whether the support comes in the form of 1:1 or group sessions, the PwMS in the study highlighted its benefits in helping coping with MS. Some PwMS enjoyed the group therapy sessions, whilst some other participants preferred the 1:1 counselling sessions. Psychological support was also recommended as part of the coordination of care which is recommended by NICE guidelines as part of their MS management (NICE, 2014). The guidelines highlighted the secondary related symptoms in MS, such as cognition, fatigue, or physical limitations, which might lead to depression, anxiety, and stress. Psychological approaches identified from the literature included cognitive behavioural therapy (CBT), energy conservation education, mindfulness, and educational counselling. The NICE guidelines recommended embedding CBT and mindfulness for fatigue management which can reduce fatigue related symptoms such as depression and anxiety. It was noticed from the interview data collected that group therapy sessions like psychosocial groups helped PwMS to engage and enhance the feeling of belonging to a group of people who shared the similar feelings/symptoms. This was reflected by McGuire et al. (2015) who emphasized that psychoeducational support groups can enhance active coping, social support, and improve quality of life in PwMS. In addition, it triangulates with the data which was identified in the scoping review indicating that an educational wellness programme which is composed of topics including motivation, goal setting, and self-management was able to increase self-efficacy in PwMS and improve their mental health problems (Ng et al., 2013). Therefore, based on the scoping review, NICE guidelines, focus group interviews, and the individual interviews, PwMS would best be supported by having a psychoeducational therapy available in their services, to help them engage with their peers, improve their self-efficacy, and health related outcome measure. Subsequently improving their physical activity and reduce fatigue.

### *5.3.5 Self-management*

Self-management is one of the important themes that was identified from the individual PwMS interviews. It explored self-management strategies that can play a crucial role in helping PwMS managing their own condition. It was highlighted that having a positive attitude helped PwMS manage their symptoms. This attitude can be obtained by socialising, family and peer support, and health professional support.

Cognitive behavioural therapy (CBT) effectively reduces fatigue directly following treatment in patients with MS. CBT can improve fatigue perceptions, increased physical activity, less sleepiness, less helplessness, and improve physical functioning, consequently enhancing a positive attitude (Akker et al., 2018). This comes into agreement with one of the participants who reported CBT made him think positively.

Fatigue is the most common symptom in MS. Fatigue intensifies other symptoms of MS, such as difficulty with walking, incontinence, spasticity, pain, visual deficits, and lack of concentration. Fatigue, therefore, makes everyday life more challenging for PwMS (MacAllister & Krupp, 2005). Fatigue management was reported several times by PwMS interviewed. Management strategies are delivered by the psycho-social educational groups delivered by psychologists and fatigue management course delivered by Occupational Therapists. PwMS found these therapy sessions useful in controlling fatigue by pacing, delegating, and setting goals.

Fatigue management programmes can result in behaviour change to manage fatigue through developing and integrating the self-management skills of problem solving, decision making, taking action, and self-tailoring (Mulligan et al., 2016).

Decision making was part of self-management techniques/skills reported by PwMS during the interviews. They highlighted they had the power in decision making with regards to treatment and mode of treatment delivery. Shared decision making and support for self-management are among a range of approaches that have been developed over the last 20 years to help change the relationship between health professionals and patients. Through good communication and relationship between health professionals and PwMS, self-efficacy can be enhanced, subsequently increasing decision making in PwMS (Lewis-Barned, 2016).

### *5.3.6 Qualified health professionals versus lay person in delivering self-management programmes*

Most of the PwMS interviewed preferred having a health care professional delivering a self-management programme, due to the level of knowledge a health care professional might have. However, other participants thought it would be a good idea for a lay person and a health professional to work together in order to deliver a self-management programme.

One of the questions that was raised by the researcher in the interview was whether PwMS prefer a self-management programme to be delivered by a lay person with MS or by a health professional. This question was asked to explore their views on their preferences. Most of the answers indicated the preference of a health professional. However, some of the participants highlighted the importance of a professional experience in delivering care and some of them stated a joint session would be ideal. However, this raises the question of whether a joint session with a lay person and a health professional is ideal, and whether the framework of the session would be different if it was delivered by a lay person in terms of preferences in the content due to a specific coping strategy the lay person might prefer; or there might be the need for educational courses about self-management programmes for both health professionals and the lay person. Mohr et al. (2005) conducted a study of delivering a skills management programme related to emotional symptoms, social problems, and symptom management by a lay person using telephone. The lay person attended an educational course about the programme prior to commencing the intervention. Results of the study showed significant improvement in depression and QoL.

The MS Trust (2018) reported that the Expert Patient programme is a self-management programme which enhances self-confidence for PwMS to manage their condition. It is a six-week course which is delivered by lay people who are diagnosed with long term conditions. The course objectives are to increase participants' confidence and, more specifically, encouraging participants to be more active. This was another example of a programme which showed that lay people could also deliver self-management programmes. However, the purpose of this study (phase 2) was to explore the experiences and thoughts of self-management from the perspective of PwMS. Hence, the involvement of lay people in delivering self-management programmes might be a topic to explore in further research to expand the evidence base.

### 5.4 Chapter summary

The data presented in this chapter related to three themes: the MS journey, the MS service, and self-management.

To cope with the unpredictable course of MS as a disease, participants utilised a variety of self-management strategies to proactively manage their condition where possible. This required varying levels of support from health and social care professionals. Participants reported the need for increased support at the beginning of the diagnosis in the acute and community settings.

Self-management should include shared decision making between the health professionals and PwMS. In addition, utilising the health professional's competency and knowledge alongside the experiences of PwMS was considered to be important in helping PwMS effectively manage a self-management programme.

Chapter six will discuss what appear to be the emerging components of best practice in providing support for PwMS to self-manage their condition, based on a) evidence from the literature, b) the views, experiences and perceptions of health professionals experienced in delivering self-management programmes, supported by observation of services in action, and c) the views, experiences and perceptions of PwMS. Thus, a model of ‘best practice’ for use by PwMS and health professionals will be proposed.

# CHAPTER SIX: DISCUSSION

## 6.0 Introduction

The main aim of this PhD study was to propose a self-management model of "best practice" to support PwMS, based on evidence from the literature, the views, experiences and perceptions of PwMS and those of health professionals experienced in delivering self-management programmes.

The primary research objective was to explore how PwMS can be best supported to self-manage their condition. Specific research questions addressed in the thesis were:

- What self-management programmes for PwMS have been reported in the literature, and what is the content of those programmes, and what are the experiences of PwMS who have received these programmes?
- What are the characteristics (such as the underpinning philosophy, the nature and extent of support provided, the 'uniqueness', the effectiveness, and 'best practice') of different services (NHS acute hospital based; NHS community based; non-NHS community based) that provide support for PwMS, as perceived by the health professionals delivering the service?
- What are the experiences, expectations, perceptions of and needs for self-management reported by PwMS who receive services designed to provide support for self-management of MS?
- What are the essential components of a model of 'best-practice' for self-management of MS, based on the literature, the views of PwMS receiving

self-management programmes, and the views of the health professionals providing self-management programmes to PwMS?

The thesis objective and research questions have been answered through the literature review, including the scoping review, the field study involving both focus group interviews with health professional teams and observation of those teams in action, and semi-structured interviews with PwMS.

This chapter will synthesise the findings from the literature review, field study, and the interviews with PwMS who have been supported in self-management, as reported and discussed in chapters two, four, and five, to propose a novel and comprehensive model of self-management support for PwMS based on best practice identified in those findings. The researcher’s personal thoughts and reflections from undertaking the research will also be presented, along with the strengths and limitations of the work presented in the thesis, and recommendations for further research and clinical practice.

Self-management was an important category identified in the interview data from both the health professionals (focus group interviews) and PwMS (individual interviews). Barker et al. (2018) reported that self-management has long been recognised as an essential part of any model of care for people living with a long-term condition. In addition, self-management has been identified as an essential tool in reducing demand for services (Barker et al., 2018). However, the precise nature of self-management and its key elements, as they apply to PwMS, has not been formally articulated until now. Hence, the search for a model of best practice in self-management as outlined in this thesis was warranted. Therefore, exploring the literature, knowing the underpinning philosophy of the services, and gaining insights into the experiences of health professionals and PwMS, can all contribute to proposing a self-management model of best practice that can help PwMS manage their condition, and guide services that aspire to providing a comprehensive service to meet the needs of service users and their carers.

The three services who participated in the field study had a reputation for providing excellent care for their service users. The MS regional centre in the NHS acute hospital is known as a centre of excellence delivering diagnostic clinics for suspected MS and related conditions in addition to specialised clinics and treatment facilities for PwMS. The NHS community service is led by therapists who have a wealth of experience of supporting people with long-term neurological conditions and their philosophy is renowned in the region for supporting self-management. Furthermore, the non-NHS community service has a reputation for being client-centred and providing what the clients ‘request’, and the fact that it is very well attended from a relatively large geographical area suggests that it is meeting the needs of PwMS.

## 6.1 The policy and practice context for self-management in MS

A report published by NHS England (2019a) highlighted the new shift in the NHS towards a more personalised approach to health and care to encourage and equip people with long term disease to manage their symptoms. This can help maintain independence and quality of life over longer periods of time, and to have control over their mental and physical health. Hence, approaches to managing chronic illness are shifting from the traditional provider-patient relationship to a paradigm in which individuals with chronic conditions play a key role in guiding their own care, in partnership with health care providers (Grady & Gough, 2014).

NICE guidelines (2015) reported that MS is a potentially highly disabling long term disease with considerable personal, social and economic consequences for the person living with it. MS can progressively impact the ability of a person with MS to work, more specifically if this person is diagnosed with the progressive type of MS, in addition to the PwMS who face relapses of the disease. Hence, a diagnosis of MS can cause an adverse effect on quality of life of the PwMS and that of their families. Subsequently, this can affect the self-esteem, self-efficacy, and mood of PwMS. Therefore, the MS Trust (2014) explained that self-management can help build and maintain self-esteem and a sense of positivity by being more involved, realistic, having good family and friend support, and using exercises to improve physical fitness; this should consequently increase the sense of wellbeing and lift mood.

NHS England (2019b) proposed a model for personalised care as a long-term goal to achieve in their 2023/2024 vision. The Comprehensive Model for Personalised Care has been co-produced with people with long term conditions taking account of their lived experience, and with a wide range of stakeholders. The key components of the model are: shared decision making between health care professionals and people with the long-term condition; personalised care and support planning; enabling choice making; having social and community-based support; self-management support; personal health finance and integrated personal budget. This model is still to be evaluated. However, this is a general model and not specific to one particular long-term disease. It was noticed that the MS Trust reported a guide to self-management for PwMS clarifying self-management techniques and actions which in some way overlap with some components of the Comprehensive Model for Personalised Care (MS Trust, 2014). The guide stated that self-management techniques for PwMS should include increasing knowledge about MS, goal setting, and problem solving. The guide also clarified that the actions required by PwMS to achieve self-management in MS is to recognise when a relapse of the condition is present, manage those symptoms, make informed treatment choices, utilising resources, and share decision making with health professionals. In addition, the guide reported that being physically active and exercising, and making the right choices in eating and drinking healthily, can lead to a better life style, consequently increasing quality of life for a person living with MS.

A surveillance of management in Multiple Sclerosis in adults was proposed by the NICE guidelines (2018), updating information regarding pharmacological management, non-pharmacological management, and new research recommendations. The non-pharmacological management update recommends that mindfulness-based training, cognitive behavioural therapy

(CBT) or fatigue management should be considered for treating MS-related fatigue symptoms, therefore suggesting these interventions can reduce fatigue in PwMS. The Mental Health Organisation in the UK (2019) defined mindfulness as the interaction between thoughts, feelings and the body. It is also considered to be a preventative approach for people who suffered with recurrent depression. The MS Trust (2018) reported that mindfulness is considered to be an alternative / complementary therapy that can be an active part of self-management for PwMS along with other medical treatment. The MS Trust further reported that some studies showed that mindfulness can decrease pain, stress, anxiety, and depression. Subsequently people who were receiving mindfulness training showed a better sleeping pattern after the training in comparison to before mindfulness training. The NHS (2016) stated that CBT is an approach based on thoughts, feelings, physical sensations and actions. It aims to deal with overwhelming problems positively, and break down the problems into smaller parts to be more manageable. In addition, it can help PwMS manage their fatigue. Hence some fatigue management interventions are based on CBT (NHS, 2016). This PhD study has also considered the guidelines and policies mentioned in this section regarding self-management for PwMS as a guide to propose a self-management model for PwMS.

## 6.2 Proposing an integrated best practice model across the illness trajectory - the key elements

This section will discuss the key elements of a proposed best practice self-management model for PwMS based on the findings of the literature review, field study, and the semi-structured individual interviews. It will discuss the early support and information given to PwMS and how this might help PwMS cope with their condition, the access to diverse support in community and acute settings, and introduce self-management tasks that might help PwMS manage their condition, in addition to discussing the barriers to self-management, and finally proposing what the researcher thinks might be a best practice self-management model for MS by reflecting back the findings of the work in the thesis.

### *6.2.1 Early support and information*

Health professionals and PwMS who participated in the studies reported in this thesis described the MS journey as variable and unpredictable, with constantly changing needs over the course of a lifetime. Each service described their philosophy of care towards PwMS in terms of care provided, and it was noticed in particular that early support and information, diversity of services provided and the skill mix of health professionals, accessibility of the MS service, and continuity of support were considered to be essential components in supporting PwMS.

Early support for people receiving a diagnosis of MS was an essential point highlighted by health professionals as well as PwMS in this thesis. The NICE MS Guideline number “CG186” (NICE, 2014) stated the importance of early support at the time of diagnosis, and information at the time of diagnosis; this is normally given by the neurologist consultant who diagnosed the condition. The guideline also suggested that a follow-up appointment should be within 6 weeks of diagnosis, and this can be with any health care professional who is an MS specialist. In addition, the person with MS requires a single point of contact for ongoing information and support; this is mainly the MS nurse. This was a guideline to improve quality of care for PwMS at early diagnosis. However, this was not truly reflected in the experiences of three PwMS who participated in the individual interviews in this thesis, in which they expressed the feeling of being left alone directly after diagnosis and stated that they would have appreciated more support at the beginning of their MS journey. However, the other PwMS interviewed did not mention this. They highlighted the importance of early psychological support, or even simply receiving more information / education about the disease, in helping them adapt to the new condition. This is in contrast with Dennison et al. (2018), who reported that information, advice and support for people in the early stages of MS might be overwhelming and the information might be too sensitive. This might increase anxiety for PwMS and result in alienating those who are newly diagnosed from contacting the MS services. Dennison et al. (2018) clarified that talking about the possibility of needing a future mobility aid or new adaptations with newly diagnosed PwMS might be seen as a future threat or overwhelming for PwMS. This might raise a question about whether the overwhelming feeling at the point of the diagnosis leaves the person with MS in denial. This was reflected by the health professionals in the focus group interviews where they emphasized that the newly diagnosed PwMS might be reluctant to accept the change to the new life style post-diagnosis and clarified that this can be considered as one of the barriers to engaging with early support for self-management.

In contrast, a Cochrane study conducted by Kopke et al. (2018) reported that information provision for PwMS can help in increasing their knowledge of MS and may have a positive impact on quality of life and decision making. In addition, the review reported no negative side effects from providing information to PwMS at the early diagnosis stage. Healthcare professionals from the field study in this thesis also emphasized the importance of delivering comprehensive information about the condition, treatment, local support groups and services, employment and social care information to PwMS at early stage of diagnosis, to help the person with MS to manage their condition and make informed choices. This is in agreement with Funnell and Anderson (2004), who explained the crucial role of education and appropriate information sharing in order to encourage and empower people with long term conditions to effectively enable self-care management throughout their disease journey.

Therefore, it can be concluded that early support and information provision is considered to be a good practice in agreement with guidelines for MS, experiences of PwMS, and experiences of health professionals providing care for MS. However, this might be dependent on whether the person with MS is ready to receive this information, and the timing of delivery should be done in accordance with the service-user’s choices. In addition, a point of contact could be any health care professional with appropriate experience of MS, for example, physiotherapist, occupational therapist, MS nurse, or psychologist, who is able to provide accurate information regarding the course of the disease. However, this might require health professionals to undertake training on how to deliver information to support PwMS post diagnosis; it would be particularly valuable for such training to include techniques in delivering such sensitive information.

### *6.2.2 Access to diverse support*

In each of the three services involved in the focus group interviews, the diversity of care provided and the skill mix of the health professionals was considered to play an important role in helping PwMS manage their condition and control associated symptoms, whether the problems experienced by PwMS were psychological, physical, medical, or social. This was also interpreted as a holistic approach in providing support for PwMS. This is in agreement with the NICE guideline (NICE, 2014) which states the importance of a multidisciplinary team of health professionals who can provide/co-ordinate care for PwMS; these include the neurologist, MS nurse specialist, physiotherapist and occupational therapist, speech and language therapist, psychologist, dietitian, continence specialist, and providers of social care. However, data collated from this study showed greater diversity in providing care for PwMS, more specifically in the non-NHS community service. It included direct access to complementary therapy, an employment advisor, and personal trainers. This diversity of skill mix equipped PwMS to cope with their condition from different points; for example, attending yoga classes or Tai Chi classes helped PwMS to relax and maintain their anxiety under control, and helped PwMS to exercise despite the low energy / fatigue symptoms. This might suggest that NICE guidelines do not yet include the full range of support for PwMS and health professionals that PwMS perceive to be beneficial, such as yoga, Pilates, and Tai Chi. The absence of these more complementary therapies from national guidelines might suggest that there is a need for more robust research to explore the effectiveness of such therapies so that they might be included in future guidelines, subject to the findings of that research.

It was noticed from the observed sessions that the yoga, Pilates and Tai Chi classes included people with different types of MS, for example, PwMS who use a wheel chair were welcomed to join the session. Each session was tailored to an individual’s own physical ability. It was also noticed that these types of classes teach specific movements which can be connected to feelings and sensation through listening to specific types of music while performing the activity. The MS Trust (2017) reported that gentle approaches like yoga, Pilates, and Tai Chi are considered to be low energy exercises which can help PwMS focus on balance and flexibility. In addition, the MS Trust highlighted that other complementary therapies such as meditation and mindfulness can help with stress, anxiety, and / or depression, and NICE (2018) reported that mindfulness therapy can reduce fatigue in PwMS. However, mindfulness sessions were not offered by any of the services involved in this study, and PwMS did not mention mindfulness as an option available to them.

The health professionals interviewed also emphasized the accessibility of the service as being important and something that should be included in the service philosophy of care. This is considered to be a component of good practice, as reflected in the data from both the service users and the health professionals, as well as in the published literature. The MS Trust reported a consensus view for the future of MS services, which was published in 2016, and which stated that, due to the unpredictability of the MS disease, PwMS will require good care coordination with access to a multidisciplinary team that can help them manage their MS symptoms (MS Trust, 2016). Hence, an on-going open access service that PwMS could access whenever they felt the need for additional support could be considered to be an essential component of best practice.

### *6.2.3 Self-management tasks*

This section will provide discussion on self-management elements identified in the findings of this study. The findings identified these elements as self-management tasks that can help PwMS to cope and take control of their condition. Therefore, medical management, fatigue management, stress and emotion management, empowerment and decision making, and knowledge and understanding are proposed to be components of a best practice self-management model.

#### 6.2.3.1 Medical management

The reported self-management tasks included medical management, which identified the importance of the role of the neurologists and the MS nurse specialist in shared decision making when choosing medications, for example, Disease Modified Therapy (DMT). This was also clarified thoroughly by the MS nurse specialists participating in the focus group interviews. Ben-Zacharia et al. (2018) emphasized the importance of shared decision-making for optimising medication adherence in PwMS. Shared decision-making should focus on the preferences of the person with MS, their level of education, and their engagement with the process. Ben-Zacharia et al. (2018) also reported that a better understanding of the characteristics of the person with MS, and other factors contributing to disease modifying drug non-adherence, could improve clinical outcomes. Hence, full education about the different disease modifying drug therapies is essential.

NICE guideline number CG76 (NICE, 2009) recommends involving PwMS in decisions about prescribed medicines and supporting adherence. The guideline explained that involving PwMS in decisions about medicines requires good communication between health professionals and the PwMS; healthcare professionals should adjust their consultation style to meet the needs of PwMS, so all PwMS have the chance to be involved in decision making about their medication at the level they wish for. In addition, the guideline clarified that the healthcare professional’s role should help PwMS to make decisions about their treatment based on an understanding of the benefits and risks rather than misunderstanding or misinterpretation. Moreover, the guideline stated that assessing adherence to medication aims to find out whether PwMS require more information and support rather than monitoring.

In this PhD the researcher spent time observing the DMT clinics at the NHS acute hospital as reported in chapter four, in the observation section. It was noticed that the MS nurse specialist played an important role in clarifying the risks and benefits from proposed medicines and the person with MS had the choice in deciding whether to take that medicine or not. However, PwMS were given the leaflet about the medicine at the time of the session, and risks and benefits were also explained in the same time slot; this raises the question whether all this information in one session might be too overwhelming for the person with MS. Another question is to what extent the person with MS feels under pressure to make a decision about their medication, because of the time pressures associated with being in an acute setting such as a busy out-patient clinic, where time with the consultant is limited.

Medical management is, therefore, an essential self-management task that PwMS need to learn as part of managing their condition. In addition, good communication between the health professionals and PwMS is required; this can be achieved by giving PwMS sufficient time to understand the proposed risks and benefits of the medicine in order to make sure the information has been accurately understood by the person with MS.

#### 6.2.3.2 Fatigue management

Fatigue in MS can be considered to be a multidimensional symptom; therefore, it should be treated with a multidimensional approach targeting behaviours of PwMS as well as their emotional and mental attitude towards fatigue (Angela et al., 2019). Fatigue can be correlated with anxiety, depression, difficulty in sleeping, and any potential medical problems such as anaemia or thyroid disease. The NICE guideline (NICE, 2014) recommends a fatigue management programme for treating MS-related fatigue; such programmes can include assessment and treatment for this secondary fatigue, educational interventions, behaviour change interventions, relaxation therapy, and energy conservation management. The effectiveness of the fatigue programmes was reflected in the findings of the scoping review, in addition to the experiences of the PwMS and staff in the NHS community service reporting its perceived effectiveness.

The MS Society (2019) reported that fatigue management programmes are often based on strategies such as rest, prioritising tasks, improving posture, organising living and work, healthy eating, and exercise. Such programmes can contribute to making changes to behaviour, habits, and routines for PwMS. Fatigue management programmes can be conducted in group settings, and sometimes individually. In addition, the MS Society (2019) explained that such programmes can involve family members, friends, and carer. This was supported by PwMS who participated in this study, who emphasized the importance of peer and family support during their MS journey.

PwMS in this study highlighted the importance of being in control of the fatigue symptoms they might experience during the disease course. Some of the service users attended a fatigue management programme which helped them coping with fatigue symptoms; this included pacing, goal setting, and delegating. The fatigue management course was a programme based on Fatigue Cognitive behavioural and Energy Effectiveness Techniques (FACET) principles (Thomas et al., 2015), which is a cognitive behavioural approach that was delivered by the Occupational Therapist in the NHS community service, and which was observed as part of the research in this thesis.

Thomas et al. (2015) explored strategies used following a group-based FACETS programme via the Fatigue Management Strategies Questionnaire (FMSQ). The programme is a six-week programme consisting of six sessions about MS-related fatigue, rest, sleep, activity, setting SMART goals, stress management, recapping and taking the programme forward. Participants in that study found the intervention effective in helping them manage their fatigue using strategies like pacing, delegating, grading tasks, and using positive attitudes towards themselves, and the authors concluded that the intervention is effective at helping people manage their fatigue. These strategies of the FACETS programme and the topics discussed were the same strategies and topics delivered to PwMS who participated in this study and who were being supported by the NHS community service.

Another fatigue self-management programme for PwMS was introduced by Paker et al. (1995) in New Zealand; the Managing Fatigue programme (MF). It is a six-week course for energy conservation. The sessions discussed the importance of rest, communication, activity stations, priorities and standards, balancing schedules, course review and future plans. It is a course delivered by occupational therapists and, lately, the Swedish guidelines for MS rated the MF programme and aerobic and strength training as having stronger scientific evidence than medication in managing fatigue (Lexell et al., 2019).

It was noted from the field study (phase 1 in this thesis) that the FACET programme had been introduced only in the NHS community service. Hence, only the health professionals in the NHS community service reported on the importance of this programme and how much it can help PwMS manage their fatigue symptoms. This might be due to the Occupational Therapist (OT) delivering the programme being based in this NHS community service. In comparison, the NHS acute service and the non-NHS community service only referred PwMS to OT if they required home environment adjustments or splints for upper limbs. Therefore, it can be concluded that individual therapists' experiences and expertise might be unique to different services. This might indicate the training need for OTs in other services if they are to deliver this or a similar fatigue management programme.

Cognitive Behavioural Therapy (CBT) is also an approach recommended by NICE Guidelines (2014) for fatigue management. A recent systematic review and meta-analysis conducted by Phyo et al. (2018) in Australia reported that CBT was significantly effective in reducing fatigue levels in PwMS in comparison to other psychological interventions such as relaxation and mindfulness.

It can be concluded from the findings of this study based on the literature review, guidelines, field study, and individual interviews with PwMS that a successful fatigue management programme should include a CBT approach and conservative energy techniques that can help PwMS control and reduce their fatigue symptoms. However, this approach can be personalised to meet each individual's needs, as this approach is based on the concept of one's thoughts, feelings, physical sensations and actions being interconnected (Hind et al., 2014). Each person with MS has different goals, priorities and pacing techniques which can be used. Moreover, PwMS highlighted the importance of peer support and family support in helping PwMS to manage their fatigue. Hence, involving carers, friends, and family members to undertake fatigue management programmes along with PwMS to enable them cope with their fatigue symptom would be useful. In addition, it might be worth offering occupational therapists and other health professionals who deliver care and support to PwMS the opportunity for training in delivering and supporting fatigue management to help PwMS who use different MS services to manage their fatigue.

#### 6.2.3.3 Psychological well being

Emotional well-being is considered to be the most important component of overall wellbeing (Kidd et al., 2017). PwMS can struggle with depression, stress, and anxiety due to the chronicity of the disease and the unpredictably of the disease course (The National MS Society, accessed June 2019).

This PhD study highlighted the importance of psychological support whether it is delivered in a one to one setting as counselling sessions or in a group session which is signposted as psychosocial support groups. From observation of these sessions in the three services, it was noticed that these sessions were mainly driven by PwMS.

One of the PwMS participants highlighted the importance of positive thinking to improve their well-being. Negative emotional reactions to the diagnosis of a chronic illness may result in behavioural changes, for example, the sense of denial and unwillingness to get treatment. Therefore, positive psychology is a comprehensive approach towards mental health that aims to enhance optimal functioning and increase the idea of accepting the reality (Schrank et al., 2014). However, health care professionals did not mention the positive attitude or the positive psychology approach in enhancing positive thinking and increasing emotional well-being. On the other hand, they mentioned that some of PwMS can be in a state of denial of the disease and clarified that this difficulty of acceptance can be a barrier to self-management.

It was noticed from the study that group psychosocial sessions could enhance positive thinking by having the feeling of belonging to a group of people who might share similarities. PwMS were more open to suggestions and ideas about coping with MS through their peer group. Hence, most of the PwMS reflected that they were able to make friends out of these groups who they felt were like family. This was also emphasized by the health professionals in the services, who also reported the importance of psycho-social groups in sharing skills or approaches to cope with MS, in addition to the feeling of belonging which can be experienced by the PwMS attending these sessions.

It was also observed that some PwMS required one to one psychological support from the counsellor or the psychologist in the service to discuss sensitive subjects, for example, a misunderstanding/argument between the person with MS and their partner / spouse, which can be too personal to share amongst a group. Both the group psychology and one to one support were mainly controlled by PwMS and suggestions to solving the problem / situation were suggested by PwMS in both settings. The psychologist / counsellor was there to organise the solution ideas suggested by PwMS and help with problem solving skills, for example, encouraging PwMS to be open about their feelings with their partners, to learn to say no when tasks are going to be hard to complete on that day, and to try to focus on some activities that the person with MS enjoys doing. Such strategies could be incorporated into CBT sessions, if available, where overwhelming tasks or thoughts can be broken down into smaller tasks by using behaviour changing techniques (NHS, 2019).

Hind et al. (2014) reported that CBT can be used to treat depression by using skills to identify negative thoughts affecting feelings and behaviours. In addition, CBT techniques can involve more problem-solving coping styles, which can decrease depression and therefore improve wellbeing of PwMS. CBT techniques can include: setting life goals after the diagnosis of MS that are realistic; management of negative emotions related to MS; positive, negative, and illusory thinking related to the disease; effective communication; and the ability to ask for help (Grazianlo et al., 2014).

In summary, CBT is an essential approach in reducing depression and improving well-being; this was reflected by NICE guideline (2014) and other evidence reported in the literature. In addition, the FACETS programme delivered by the NHS community service in this study was a programme with a CBT approach. It would be useful for a CBT programme to be introduced from the early stages of diagnosis as it can help in reducing anxiety or stress management for PwMS when they receive such depressing news of diagnosis. This was also reflected by the PwMS who were interviewed, who felt that psychological support from the early stages of diagnosis was missing.

#### 6.2.3.4 Empowerment and decision making

Self-management skills highlighted in the literature were decision making, problem solving, goal setting, coping strategies, and self-tailoring exercises or management. Mishra et al. (2015) reported a process to enhance decision making for PwMS. The process starts with resolving the uncertainty: this includes gathering information, evaluating and weighing information, and making the best choice. To continue enhancing decision making, PwMS should prioritise values and expectations, being consistent in setting realistic goals, and aim to reach goals by taking small steps, establishing a routine, and enhancing skills and maintaining hope.

The use of problem-based learning / problem solving approaches have shown that they can help PwMS identify and understand the important elements of the situation, develop an understanding of the relationship between elements, and facilitate improved decision-making, communication, and collaboration. This is mainly obtained through PwMS engaging with these approaches, being provided with relevant and timely knowledge and information, gaining confidence, and being committed to making new health adjustments (Schaffler et al., 2018). Health professionals in this study highlighted that goals for PwMS should not just be medically-related, and MS services should recognise the importance of overall health and well-being; this is in agreement with the consensus view reported by the MS Trust in 2016 (MS Trust, 2016).

Health professionals in the three different services reported self-management essentials that might help PwMS manage their condition. Empowerment was one of the essential subthemes identified as a crucial element of self-management. Empowerment can overlap with the skills identified by the literature in terms of the power of decision making and self-belief in taking control, and self-efficacy. Empowerment is both a process and an outcome; it is a process to raise one’s ability to think in a critical way and to react autonomously, but it is also considered to be an outcome when an enhanced self-efficacy occurs as the result of the process. Hence, when PwMS actively engage, they will be more likely to increase their understanding of their MS and will have a better relationship with their health professional, consequently having a better outcome (Hadgikss et al., 2014).

Empowering PwMS to manage their condition can enable them in making informed decisions about their health and improve their psychological well-being (Kidd et al., 2017).

Health care professionals who participated in the study reported that PwMS can experience a lack of control due to the unpredictably of the MS disease course, coping with the uncertain and degenerative progression of MS, and dealing with the resulting psychological burden. Therefore, empowering PwMS by increasing their self-efficacy, taking action, and shared decision making should help them to cope with the transition in their lives. Health professionals who were interviewed also highlighted that education is an essential component to empower PwMS; examples given were that education can be provided regarding fatigue management, and psychological support to empower PwMS to understand and ultimately be more involved in managing their own symptoms of fatigue and changes in mood.

Bandura (1997) stated that Social Cognitive Theory (SCT) is a theory which embeds a certain / unique way that the person can acquire to maintain a behaviour; it takes into account the individual past experiences, that can influence reinforcements, expectations of whether a person will engage in a certain behaviour and why. Bandura (2006) distinguished self-efficacy from other conceptual elements such as self-esteem, being in control, and outcome anticipation. He emphasized that perceived self-efficacy is a judgment of how much the person in capable of doing something, whereas self-esteem is a judgment of self-respect (Bandura, 2006).

The self-management programme for stroke survivors demonstrated the impact of stroke survivors in engaging / participating in activity, change of mood and self-efficacy after stroke. The Bridges workbook has been an essential part of their support package since 2008 and promotes self-efficacy through motivating mastery experiences and modelling through case studies related to stroke survivors. The tool contains their approach to self-management and creates a structure for a new way of working for health professionals (Bridges, 2007). In addition, research about Bridges self-management has shown that health professionals who underwent the Bridges training have changed their attitudes, ideas, beliefs and practice towards utilising a self-management approach in their practice. Their research also highlighted that stroke pathways in both hospital and community services have showed consistent improvement in how self-management has merged with rehabilitation. In addition, the use of the Bridges self-management programme showed valuable changes in the use of self-efficacy principles, goal setting, and increased self-confidence which continued to progress after discharge from rehabilitation (Bridges, 2019). However, despite the fact that Bridges is a well-established self-management programme for stoke survivors, and they recently have developed a self-management programme for people with brain injuries, this however, might not be adaptable for PwMS.

This PhD study data showed that no specific model of self-management has been used, such as the Bridges self-management programme, in the three services to help PwMS manage and take control of their condition. The data collected reflected that PwMS had the power to take control of their exercise programmes, medication, and psychological support through shared decision making. However, empowering PwMS was not taught through specific programmes but was integrated through the different sessions they received from the three services. Hence, a proposed self-management programme which can help PwMS set their own goals, increase shared decision making, and self-efficacy is required to be introduced in the three different settings. Training for health professionals will be required to deliver such a programme to PwMS.

#### 6.2.3.5 Knowledge and understanding

According to Ellis et al. (2017), a good self-manager is a person who has good morals, good knowledge, and is active as a person. Activation is used to describe a person’s knowledge, skill, and confidence in managing their condition. These proposed attributes are also reflected in the findings of the studies in this thesis, in which knowledge / education / information were reported to be essential, along with the importance of being an active person by taking control of the condition, getting involved in decision making, and utilising resources to self-manage MS.

It was noticed from the interviews with PwMS that not all participants had equal opportunity to receive enough information / education about managing their condition. This was more specifically in the acute setting. On the other hand, most of the PwMS interviewed in the community services had greater access to educational courses, physical activities, complementary therapy, and counselling / psychological support. However, this study did not aim to make comparisons between the three services. The main aim was to propose a model of best practice for self-management to support PwMS in coping with their condition.

Healthcare professionals are trained in a traditional approach to education that does not always prove to be effective (Brackenridge, 1999). The act of instructing a person with a long-term condition about what to do, merely based on their clinical understanding of the disease, cannot be expected to meet the unique challenges posed by that chronic disease (Brackenridge, 1999). Certainly, evidence suggests that those healthcare professionals who are able to understand their service user’s health beliefs should be in a better position to suggest treatments that are more suited to their personal circumstances and requirements (Funnell & Anderson, 2010). In addition, despite the fact that the health professionals involved in the study were trying to dispense with the classical “patient” term, they were still using it during their interviews to refer to their service users. Hence, self-management requires a change of mind set, or a change of the traditional perception or relationship between the health professional and the person with MS, and equip PwMS with adequate knowledge and understanding of MS to enable them manage their condition.

### *6.2.4 A tailored approach*

Referring back to the literature, the field study, and the perception of self-management held by PwMS, it was perceived that there is no one-size-fits-all model. Every person with MS is different from all perspectives; from the type of MS, time of diagnosis, age of disease onset, symptoms associated with MS, social life, psychological and physical perspective.

Foot et al. (2014) observed that many people with a long-term chronic condition do not necessarily see a role for themselves in managing their own health, or they appear to be ineffective in self -management, due to the lack of confidence or deficiency of skills. They also recognise that a ‘tailored’ approach to support for individuals and care delivery is likely to maximise patient outcomes.

Each person is different and has different characteristics, which might modify the effectiveness of a standardised self-management intervention (Bos-Touwen et al., 2015). Hence, more tailored approaches will be needed. In a tailored approach, the treatment exposure is dynamic instead of being more fixed; a customized approach based on the unique characteristics of that person. Customization refers to the personalized treatment in relation to variation of content (topics), behaviour change techniques, mode of delivery, and dose. Most often, Bandura’s social cognitive theory can be used to underpin such an approach, as it emphasizes how cognitive, behavioural, personal, and environmental factors interact to determine motivation and behaviour, particularly aiming at increasing service users' self-efficacy in a tailored self-management programme (Bos-Touwen et al., 2015).

Therefore**,** in order for there to be an effective relationship between healthcare professionals and PwMS, and for self-management to be embraced successfully, it is crucial that any self-management model is sufficiently flexible that it can take into account individual differences and needs; a flexible self-management model of collaboration, in which communication, joint problem solving and shared decision making are possible, should be considered (Heisler et al., 2002).

### *6.2.5 Barriers to achieving self-management*

Potential barriers to self-management were suggested by the health professional participants, who explained that acceptance of the condition / diagnosis of MS might, to some PwMS, become a dilemma and potential barrier to PwMS engaging with a self-management approach and support available to them, as some PwMS can be in a state of denial, more specifically at the beginning of their journey. The health professionals also highlighted cognitive dysfunction and insufficient resources as potential barriers to effective tailored self-management for PwMS. For a person with MS to engage with a self-management programme and take responsibility for managing medication and symptoms requires a certain level of cognitive ability. Consequently, PwMS who experience significant cognitive dysfunction, such as memory loss, the ability to process and retain complex information about symptom management, or the ability to make an informed decision about their care, is likely to find self-management to be more challenging than those who have intact cognition. These individuals are potentially going to need more support from the health professional teams. Yet, time, funding and staffing resources in the acute hospital service and community may be insufficient to enable those teams to deliver tailored self-management programmes to PwMS effectively, coupled with a heavy workload that has to be met in a limited time. Alternative ways of delivering tailored support for PwMS to self-manage should be considered by services, for example, involving ‘expert patients’ and lay people or carers with experience of MS, who could provide unique support in both acute and community settings for PwMS at all stages of the disease. Training could be provided for them to be skilled in specific aspects of support, enhancing the service provided by health professionals.

### *6.2.6 Description of the proposed self-management model*

The proposed self-management model was developed post the findings of the scoping review, field study, and the interviews with PwMS. The findings suggested in order to obtain self-management support for PwMS, the MS service should obtain certain provision and characteristics.

Steps taken in developing the model of best practice post findings and analysis included:

- A meeting with the research supervisor to discuss and map the essential elements of the model. Hence a preliminary map of the model was introduced (see Appendix 12).

- The MS service provision and characteristics were identified, based on the findings of the whole thesis and the discussion of the studies. See Figure 4.
- A service model of self-management for PwMS was developed. See Figure 5.

#### 6.2.6.1 Characteristics of the service

Based on the findings and the discussion of the study the essential components of the model were identified. The MS service, with both a regional centre and community-based service, is proposed to have certain characteristics to promote self-management support. Some of the characteristic may apply to regional services and not apply to community services and vise-versa, and some might overlap.

*Figure 4: Mapping the essentials of an MS service for self-management for PwMS*

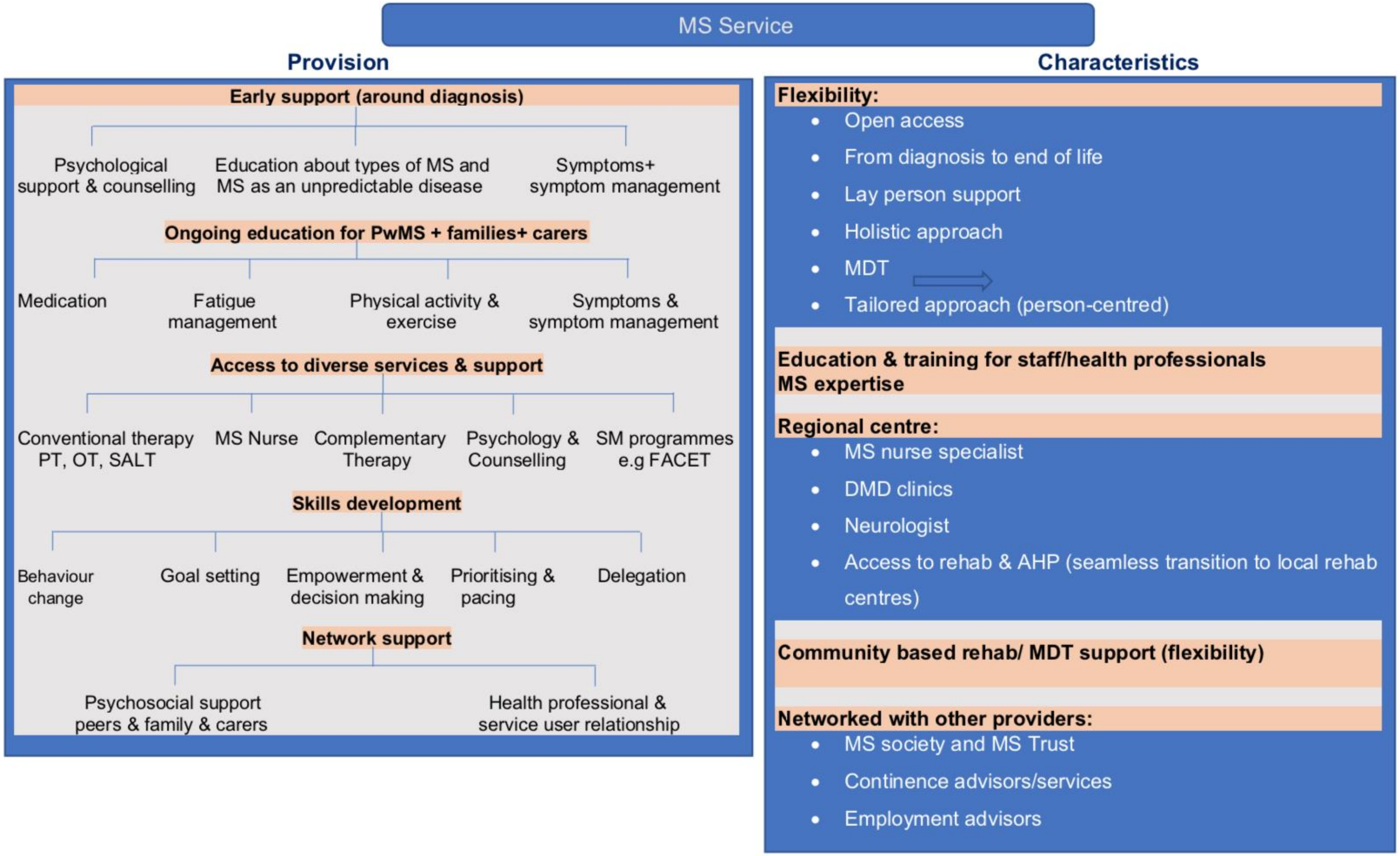
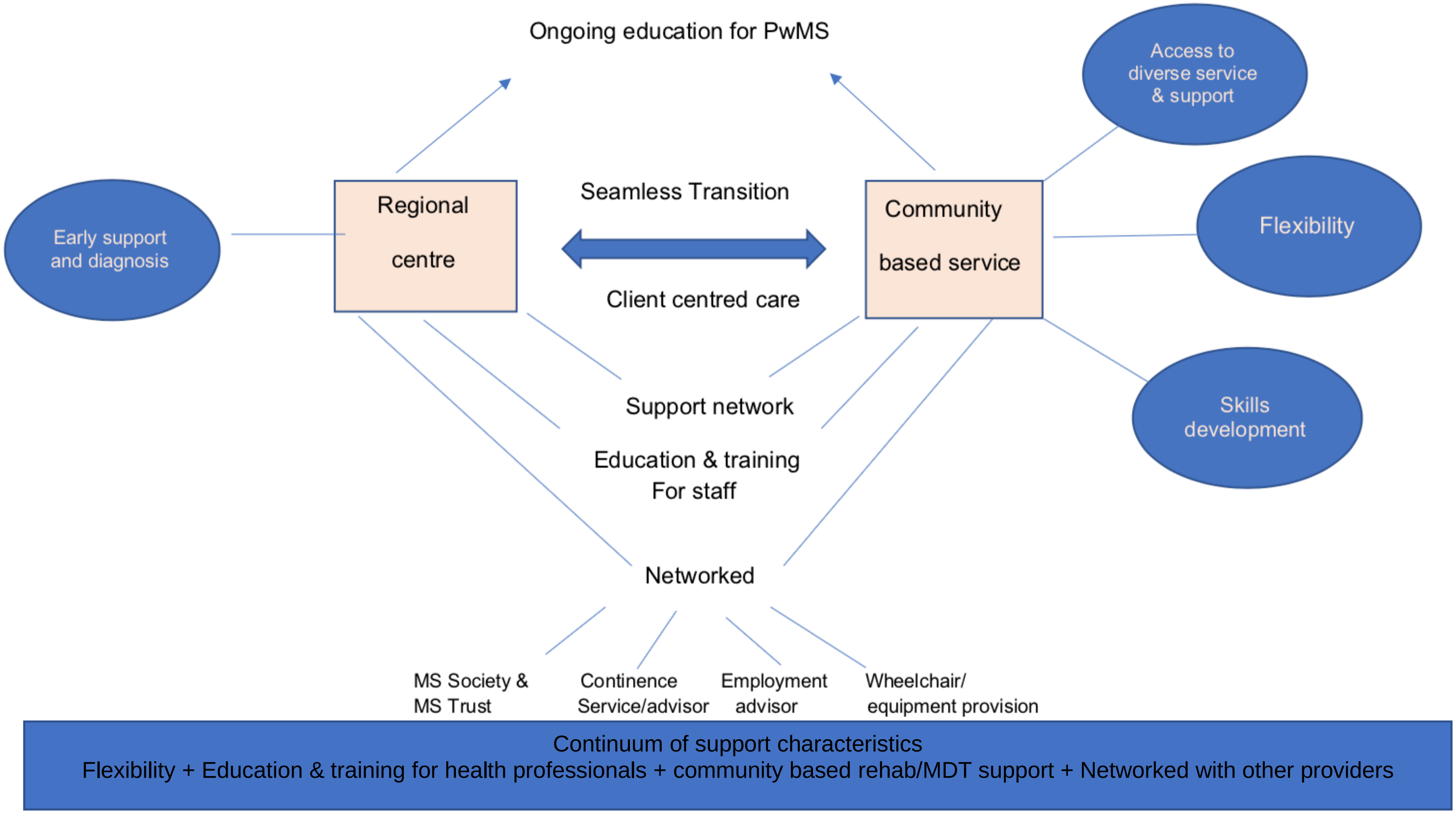


***Figure 5: Service self-management model for PwMS***



*Flexibility*

An MS community service should be an open access service for PwMS from the day of diagnosis to the end of life journey. The holistic approach is an essential element to be embedded in the service; this requires an MDT from a range of different specialties who are all aware of each service user’s needs.

For ensuring optimal MS care and self-management, the regional center should also have diversity of care available from different specialties, for example, MS nurse specialist, Disease Modified Treatment (DMT) clinics, neurologist, access to specialist rehabilitation and allied health professionals, and seamless transition to local rehabilitation centers.

*Education and training for health professionals*

Access to ongoing and specialist education for all healthy professionals and lay people involved in providing support for PwMS in the service is important to increase MS expertise and specialist support, for example, investing time in training staff in self-management strategies for PwMS in particular. Training can be fulfilled by allocating time for workshops and educational courses about self-management. This characteristic can support the regional service and the community based service to ensure good education for all members of health professionals in all sites.

*Networked with other providers*

Healthcare services supporting PwMS to self-manage need to be networked with other providers who can deliver particularly specialist care and information /

education for more individual needs, so that PwMS have seamless access to these services as well, as required. The MS society and MS Trust play an important role for PwMS, and provide an informative point of contact and care provision as highlighted in the findings of this study; hence a good link between these charities and the community and the regional services would be essential. In addition, access to other specialist services, such as continence advisors / services, is needed to support those PwMS who require support to control or manage specific and less general symptoms. The role of an employment advisor cannot be underestimated in supporting the journey of PwMS of working age, due to the unpredictability of the disease and the diagnosis of the disease from a young age. Furthermore, PwMS might require equipment aids which will encourage independency and to be less reliant on others. Hence, having a good point of contact with and timely access to wheelchair providers and other providers of specialist equipment, such as specialist seating and other specialised aids and adaptations, could be considered to be essential to promote self-management and independent living.

#### 6.2.6.2 Provision of the service

The importance of early support for PwMS was highlighted in several sections of the thesis. The early support should start form around diagnosis time and it is proposed to include psychological education and counselling for PwMS who are newly diagnosed, to support them mentally and emotionally, through education about the unpredictability of the disease course and its types, and education about the expected symptoms and symptom management. Hence, this educational support should continue throughout the course disease and should also be available for family members and carers as well as service users / PwMS. The education should include advice, options and information about medication management, fatigue management, physical activity and exercise, and specific symptom management (e.g incontinence, memory problems, dietary issues).

The service should provide access to diversity of care and support; for example, conventional therapy such as physiotherapy, occupational therapy, and speech and language therapy (SALT), complementary therapy, psychological support, and provide self-management programmes of those adopting the CBT/SCT approach (e.g FACET programme).

In addition, the skills of self-management should be developed by the MS service. This include encouraging goal setting for PwMS, coping skills, empowerment and shared decision making, prioritising tasks or jobs by delegating to peers, carers, family members, and enhancing behaviour change to increase self-efficacy. Furthermore, good communication a network between health professionals and PwMS is warranted to encourage a good rapport between them. The psychosocial support is also essential and this is to build up the relationship between PwMS and their families/peers.

### *6.2.7 Strengths and limitations of the model*

The proposed model hypothesizes the mechanism by which self-management support leads to self-management for PwMS. It is proposed that a service with the above essential characteristics and provision can deliver self-management support for PwMS that meets their needs and supports them in learning to cope with the disease, through empowerment, to developing decision making skills, and enhanced self-efficacy. A strength of the model is that it is novel, having been informed by findings from the literature, including evidence-based guidelines, a field study of three different but highly respected clinical services providing support for PwMS to self-manage that are renowned for providing excellent care, and the experiences of PwMS. Consequently, this model is more comprehensive and reflective of the preferences and holistic needs of PwMS than service guidelines that have previously been published (for example, NICE guidelines and MS Trust guidelines for self-management support).

However, all the services and participants involved in the studies reported in this thesis, whose perceptions and experiences have informed the model, have all been located in the Midlands region. Consequently, the findings and therefore the model may not be transferable to other regions or other services. Furthermore, this proposed self-management model is still to be refined, its feasibility and acceptability to be explored, and its effectiveness in supporting PwMS to self-manage is still to be determined. A robust programme of intervention development, refinement and co-production involving services users, carers, health professionals and stakeholders in other regions is being planned as the next stage of the research.

## 6.3. Ensuring rigour in the study, and strengths and limitations

### *6.3.1 Purposive sampling*

A purposive sampling approach was used as a method to recruit PwMS and health professionals to the study. This method is largely used in qualitative research, to identify and select participants that are especially knowledgeable about or experienced in a phenomenon of interest (Palinkas et al., 2015). Bernard (2002) stated that participants selected should have the availability and willingness to be involved in the study.

However, the individuals were also selected from a relatively small geographic region which represented the population from that region only. It is also important to recognise that limitations cannot necessarily be corrected by the researcher and maybe an increased and wider cross section of participants might be difficult to manage. This may in turn have produced further limitations in terms of time and labour resource issues.

### *6.3.2 Triangulation of data sources*

Data triangulation was achieved through a field study with health professionals and semi-structured individual interviews with PwMS as explained in chapter four and chapter five. Data triangulation is known to increase the credibility of the study (Thurmond, 2001). However, one of the primary disadvantages of triangulation is that it can be time-consuming. Collecting more data requires greater planning and organization, hence observing the services in action, focus group interviews with health professionals, and semi-structured individual interviews with PwMS, were time consuming especially as the researcher targeted three different services in different areas across the Midlands region.

For more rigorous research and trustworthy findings, a triangulation investigator method was used, which involved the researcher and supervisory team checking recordings, transcripts, and developing themes from the collected data (Thurmond, 2001).

### *6.3.3 Reflexivity and use of reflective journals*

Mortari (2015) explained the value of reflection and, more specifically in research, stated that reflection is an essential mental activity, both in private and professional life. He also added that reflexivity is largely practiced in qualitative research, where it is used to legitimate and validate research procedures.

Choosing this study in particular was reflected on a personal level. A family member who was diagnosed with MS made me think seriously about the approaches towards self-management to support PwMS. This is due to the difficulties and lack of knowledge in self-management this family member was experiencing, in addition to the lack of self-confidence and self-belief in managing his condition. This made me consider investigating self-management as a support for PwMS.

I reflected throughout the entire duration of this study. I have also questioned myself many times as to which role or part I had to play in order to receive the information I required. Silverman (2011) reinforces the importance of constant reflexivity, which is necessary due to the fact that the researcher becomes intrinsically involved in the world they are studying and there is, therefore, a need to question the way in which observations are drawn and interpreted. I made sure to be as objective as I could during data collection to avoid any biased way of obtaining data through observations/interviews. In addition, the rigorous way of analysing the data through having regular meetings with the supervisory team and identifying codes and themes independently, enhanced trustworthiness of the study.

My personal connection to MS gave me a better understanding of the topics identified by the participants, and greater insight into the challenges faced by PwMS. This encouraged me to continue filling the gaps about my view of MS.

I completed written reflective pieces after each observation session during the field study when I was observing the three MS services in action; returning to these pieces made me realise how much I was paying attention to every single detail in the observed session, which reflects the rich data obtained from that aspect of the field study. In addition, it was interesting that, while listening to the recordings of the focus group interviews with health professionals, and the individual interviews with PwMS, and subsequently transcribing the recordings, my memory took me back to the setting of the interviews and the faces of the interviewees.

In addition, I kept a reflective journal throughout my study. It helped me to remember all the decisions I took and the interpretations I made, as well as reminding myself of my own role in the research, my impact on the research and its impact to me. It also helped me to provide an audit trail when I was writing up my research.

Conducting this PhD study was a long journey which started in 2014. It was like a roller coaster journey which had both happy moments and ‘bumpy’ moments. Every stage of the study was challenging in its own way. Obtaining data through interviews was the first challenge, especially since that was my first experience of collecting research data through interviews. I can reflect back on my first health professional focus group interview, where I struggled at times to stop interviewees from diverting away from the specific point/question asked. My interview skills definitely improved throughout the other interviews, more specifically after reflecting back and debriefing with my supervisor, and considering tips suggested by her.

Moreover, taking into consideration that English is my second language, I initially encountered some difficulties transcribing the digital recordings, more specifically where participants had broad accents or dialects and used ‘slang’ language; hence, it was important that a second assessor (the research supervisor) checked the accuracy of the transcripts of the recordings to ensure accuracy, enhancing rigour and trustworthiness of the data.

There were times throughout this research that I questioned my role as a researcher, and as a healthcare professional asking myself; what I was doing, what have I taken on? During the time I spent with the participants, I was aware that I was carrying out research, I asked questions gathering information whilst picking up on cues from the participants. I reflected on my role as a health practitioner where I strive to provide an excellent service to the people I treat. I also reflected on how, as a practitioner, I kept using the word patient, and how I needed to change terminology used in my practice as a physiotherapist. However, I work in an acute hospital environment, which makes it difficult to not address people who are admitted to the hospital as patients. This research study definitely changed my clinical practice on the professional level, by the way I am approaching service users, getting them more involved in their treatment plan, and in goal setting.

## 6.4 Strengths and limitations of the thesis

The aim of the work in the thesis was to propose a self-management model for PwMS based on and informed by perceived and reported best practice by exploring the literature, identifying the characteristics and philosophy of care of the services providing care for PwMS, and experiences and perceptions of PwMS and those of health professionals experienced in delivering self-management programmes. Hence the studies reported in the thesis were undertaken. The findings of the study answered the research questions proposed in the study and a therefore, a proposed self-management model for PwMS was identified.

The work reported in this thesis offers original insights into the understanding of self-management by health professionals involved in supporting PwMS to self-manage, and by PwMS themselves who are being supported to self-manage their condition.

Healthcare professionals should be aware of the psychological status of PwMS in order that appropriate skills may be adopted, enabling PwMS to be able to come to terms with and feel empowered to manage their condition. Hence it is crucial that any self-management model is sufficiently flexible that it can take into account individual differences and needs.

This study did not explore the skill mix or the other care provided by other services in the regions. Hence, further insight to different skill mix and provision around the UK might be required in future studies.

## 6.5 Conclusion: clinical applications and recommendations

Considering findings from exploring the literature, no extensive evidence on the most effective self-management support programs for PwMS was identified. It was concluded from the literature that it is challenging to have a fixed model which can support all PwMS in general. Every individual is different in terms of onset of MS, type of MS, MS symptoms. There are common symptoms that PwMS can relate to from all types of MS, for example, fatigue, loss of memory, and impaired physical activities, all of which can vary from one person to another.

Despite the fact that many self-management programmes reported in the literature for different long-term conditions like stroke, diabetes, and chronic obstructive pulmonary disorder were referred to as successful programmes to help a person with a chronic disease to control his/her condition, this does not necessarily mean that it can be successful for PwMS. This was reflected in the findings of the scoping review, field study and the semi-structured interviews used to clarify what can be done to help PwMS manage their condition. Hence, a novel, comprehensive and holistic model of self-management support for PwMS was created. It was also drawn from the findings that the philosophy of care in a service impacts on the success of self-management support. Hence the characteristics and provision of the service were identified and proposed in the model.

## 6.6 Recommendations for further research

Further research is needed to progress to a stage of co-production / co-design of a refined model of self-management, by taking the proposed model and building on it in conjunction with a group of PwMS, carers, and health professionals. The Medical Research Council (MRC) framework for evaluating complex interventions (Craig et al., 2008) suggested different stages prior to evaluation of a certain intervention/model:

- development of the model, and this has been explained comprehensively in this thesis;

- test for feasibility by visiting different self-management centres/ services and introduce the model to health professionals and PwMS, and see what their views are about the model, in addition to stakeholders
- evaluating the model by assessing its effectiveness by conducting a questionnaire and exploring PwMS and health professionals about the model
- implementation of the model by co-production with stakeholders

Having developed a model, the next step is to secure funding to achieve phase 2 of this work, refining the model in conjunction with stakeholders, and explore its feasibility and acceptability in different regions, prior to evaluating and investigating its effectiveness in supporting PwMS to manage their condition. Ultimately, the intended impact of the research is to improve support for PwMS from the point of diagnosis up to end of life, so that PwMS feel empowered and in control of their symptoms and their lives.

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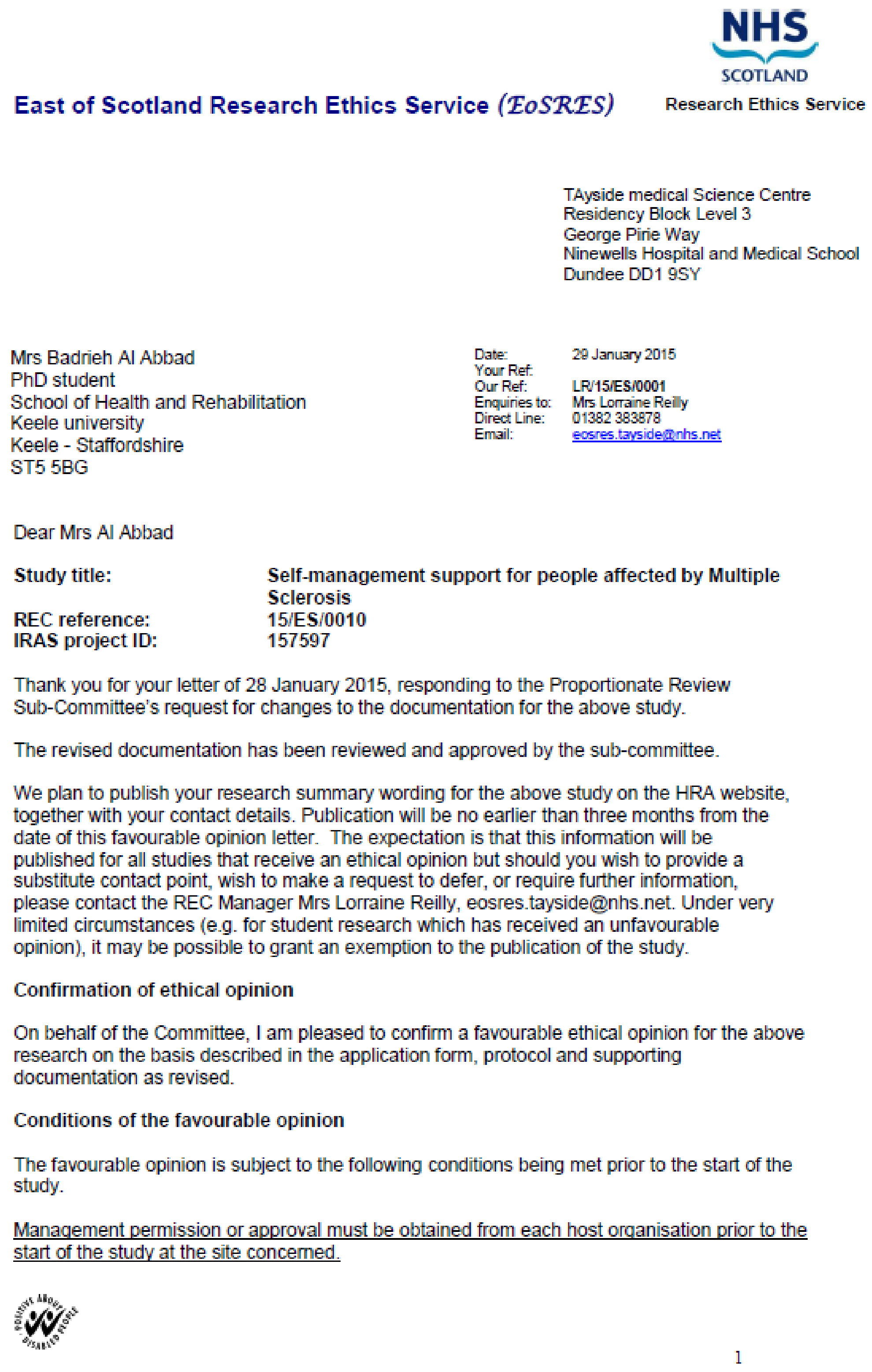
# Appendix 1: NHS ethics approval letter for phase 1 and 2



NHS
SCOTLAND
East of Scotland Research Ethics Service (*EoSRES*)
Research Ethics Service

TAyside medical Science Centre
Residency Block Level 3
George Pirie Way
Ninewells Hospital and Medical School
Dundee DD1 9SY

Mrs Badrieh Al Abbad
PhD student
School of Health and Rehabilitation
Keele university
Keele - Staffordshire
ST5 5BG

Date: 29 January 2015
Your Ref:
Our Ref: **LR/15/ES/0001**
Enquiries to: Mrs Lorraine Reilly
Direct Line: 01382 383878
Email: eosres.tayside@nhs.net

Dear Mrs Al Abbad

| | |
|---|---|
| **Study title:** | **Self-management support for people affected by Multiple Sclerosis** |
| **REC reference:** | **15/ES/0010** |
| **IRAS project ID:** | **157597** |

Thank you for your letter of 28 January 2015, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Mrs Lorraine Reilly, eosres.tayside@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

**Confirmation of ethical opinion**

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

**Conditions of the favourable opinion**

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

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

1

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

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

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

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

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

### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.
There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

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

### Ethical review of research sites

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

### Approved documents

The documents reviewed and approved by the Committee are:

| Document | Version | Date |
|---|---|---|
| Copies of advertisement materials for research participants [Flier (PaMS Phase 2)] | 1 | 19 December 2014 |
| Copies of advertisement materials for research participants [Flier (Health Professionals, Phase 3)] | 1 | 19 December 2014 |
| Copies of advertisement materials for research participants [Flier (PaMS Phase 3)] | 1 | 19 December 2014 |

|  |  |  |
|---|---|---|
| Covering letter on headed paper [Cover letter to the East of Scotland Research Ethics (REC1)] |  | 26 January 2015 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Keele Insurance Letter] |  | 28 July 2014 |
| Interview schedules or topic guides for participants [The interview schedule for Health Professionals (Phase 1)] | 1 | 20 December 2014 |
| Interview schedules or topic guides for participants [The interview schedule for PaMS (Phase 2)] | 1 | 19 December 2014 |
| IRAS Checklist XML [Checklist_28012015] |  | 28 January 2015 |
| Participant consent form [Participant Consent Form(PaMS, Phase 1)] | 1 | 19 December 2014 |
| Participant consent form [Participant Consent Form (Phase 3)] | 1 | 19 December 2014 |
| Participant consent form [Participant Consent Form(HP,Phase1)] | 2 | 26 January 2015 |
| Participant consent form [Participant Consent Form (Phase 2)] |  |  |
| Participant information sheet (PIS) [Participant Information Sheet (HP, Phase 1)] | 2 | 26 January 2015 |
| Participant information sheet (PIS) [Participant Information Sheet(PaMS, Phase 1)] | 2 | 26 January 2015 |
| Participant information sheet (PIS) [Participant Information Sheet (Phase 2)] | 2 | 26 January 2015 |
| Participant information sheet (PIS) [Participant information sheet (Phase 3)] | 2 | 26 January 2015 |
| REC Application Form [REC_Form_05012015] |  | 05 January 2015 |
| Referee's report or other scientific critique report [Independent Peer Review Committee Outcome Letter] |  | 20 October 2014 |
| Research protocol or project proposal [Research Protocol] | 1 | 19 December 2014 |
| Summary CV for Chief Investigator (CI) [CV Badrieh Al Abbad] |  | 19 December 2014 |
| Summary CV for supervisor (student research) [CV Sue Hunter] |  | 11 December 2014 |

**Statement of compliance**

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

**After ethical review**

Reporting requirements

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

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

☐ Notifying the end of the study

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

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

**15/ES/0010 Please quote this number on all correspondence**

Yours sincerely

L Reilly

pp
**Dr Carol Macmillan**
**Chair**

Email: eosres.tayside@nhs.net

| | |
|---|---|
| Enclosures: | "After ethical review – guidance for researchers" |
| Copy to: | Mrs Emma Skinner<br>Dr Darren Clement, University hospital of the North Midlands |

## Appendix 2: Ethics approval and permission from the non-NHS community based service

neuro
therapy centre
supporting those affected by neurological conditions

16/03/15

Dear Badrieh,

Further to your recent approach for participation in your research work, I am happy to report that the Research and Ethics Committee has now met to consider your request and is happy to recommend your work.

Thank you for attending the Centre this afternoon with your supervisor, Sue Hunter, we greatly appreciated your time and the opportunity to show you both around the Centre, and give you more information about the services we offer.

Having had the chance to ask further questions about your research we are happy to endorse your work, and will assist you in finding suitable candidates for inclusion, and inform our staff and partners of the work you will be doing.

We are grateful of the opportunity to strengthen our links with Keele University and look forward to being part of this work which we are sure will help to define what a good self-management program should look like for people affected by MS (PaMS), which could be of significant value when approaching commissioners and charitable trusts for potential funding.

Please do not hesitate to contact myself or Claire should you require any further information.

Yours sincerely,

Jane Johnston-Cree MCSP
Centre Manager

Neuro Therapy Centre, Unit C1- C4 Brymau Estate 1,
River Lane, Saltney, Flintshire, CH4 8RG

Tel: 01244 678619 email:- claire@neurotherapycentre.org
Reg. Charity Number 700904 Company Number 2269526
Website - www.neurotherapycentre.org

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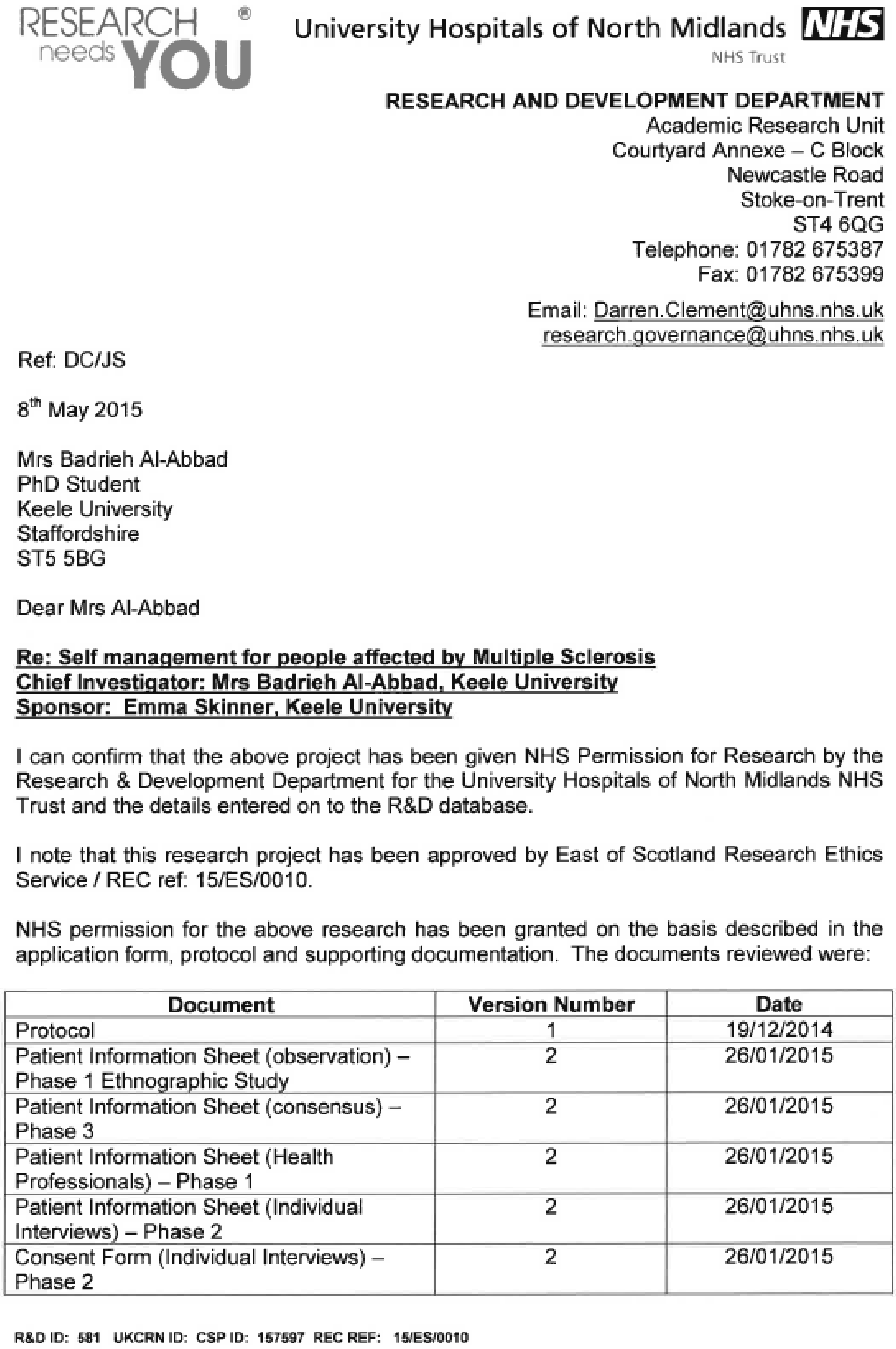
LOTTERY FUNDED

# Appendix 3: Permission letter from NHS acute hospital Trust Research and Development department



RESEARCH needs YOU®
University Hospitals of North Midlands NHS
NHS Trust

**RESEARCH AND DEVELOPMENT DEPARTMENT**
Academic Research Unit
Courtyard Annexe – C Block
Newcastle Road
Stoke-on-Trent
ST4 6QG
Telephone: 01782 675387
Fax: 01782 675399

Email: Darren.Clement@uhns.nhs.uk
research.governance@uhns.nhs.uk

Ref: DC/JS

8th May 2015

Mrs Badrieh Al-Abbad
PhD Student
Keele University
Staffordshire
ST5 5BG

Dear Mrs Al-Abbad

**Re: Self management for people affected by Multiple Sclerosis**
**Chief Investigator: Mrs Badrieh Al-Abbad, Keele University**
**Sponsor: Emma Skinner, Keele University**

I can confirm that the above project has been given NHS Permission for Research by the Research & Development Department for the University Hospitals of North Midlands NHS Trust and the details entered on to the R&D database.

I note that this research project has been approved by East of Scotland Research Ethics Service / REC ref: 15/ES/0010.

NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

| Document | Version Number | Date |
|---|---|---|
| Protocol | 1 | 19/12/2014 |
| Patient Information Sheet (observation) – Phase 1 Ethnographic Study | 2 | 26/01/2015 |
| Patient Information Sheet (consensus) – Phase 3 | 2 | 26/01/2015 |
| Patient Information Sheet (Health Professionals) – Phase 1 | 2 | 26/01/2015 |
| Patient Information Sheet (Individual Interviews) – Phase 2 | 2 | 26/01/2015 |
| Consent Form (Individual Interviews) – Phase 2 | 2 | 26/01/2015 |

| | | |
|---|---|---|
| Consent Form (Ethnographic Study) – Phase 1 | 2 | 26/01/2015 |
| Consent Form (Consensus) – Phase 3 | 1 | 19/12/2014 |
| Flier (Health Professionals – Phase 3) | 1 | 19/12/2014 |
| Flier (PaMS – Phase 2) | 1 | 19/12/2014 |
| Flier (PaMS – Phase 3) | 1 | 19/12/2014 |

The research sponsor or the Chief Investigator, or the local Principal Investigator at a research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The R&D office should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The R&D office should be notified within the same time frame of notifying the REC and any other regulatory bodies.

Approval by the R&D Dept therefore assumes that you have read, understand and agree to comply with the:

- Research Governance Framework (www.doh.gov.uk/research)
- Data Protection Act
- Health and Safety Act
- ICH Guidelines on good clinical practice
- All applicable Trust policies & procedures

In line with these requirements may I draw your attention to the need for you to provide the following documentation/notifications to the R&D Department throughout the course of the study and that all amendments (including changes to the local research team) need to be submitted to R&D in accordance with guidance in IRAS:-

- Annual Progress Report Form (sent to you by this department)
- End of Study Declaration Form (available on IRAS website)
- Changes to study start and end dates
- Changes in study personnel

Please note that the NHS organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This will be achieved by random audit by our department.

I would like to take this opportunity to wish you well with your research. If you need any further advice or guidance please do not hesitate to contact us.

Yours sincerely

Dr Darren Clement
R&D Manager – University Hospitals of North Midlands NHS Trust

Cc Chief Investigator – Mrs Badrieh Al-Abbad, Keele University
Sponsor Representative - Emma Skinner, Keele University

Dr Indira Natarajan, Clinical Director of Neurosciences, UHNM
Jill Stacey – Professional Head for Research Nursing, UHNM
Helen Grocott – Information Governance Manager, UHNM
Laura Longshaw – R&D Auditor & Monitor, UHNM

# Appendix 4: Permission letter from NHS community-based Trust Research and Development department

Better Together

Staffordshire and NHS
Stoke on Trent Partnership
NHS Trust

Badrieh Al Abbad
School of Health and Rehabilitation
McKay Building
Keele University
Keele
Staffs
ST5 5BG

2nd Floor Morston House
The Midway
Newcastle-under-Lyme
Staffordshire
ST5 1QG

Tel: 0845 602 6772 x 1629
Fax: 01782 663 778
www.staffordshireandstokeontrent.nhs.uk

6th May 2015

Dear Badrieh,

**NHS PERMISSION FOR RESEARCH**

**Study title;** Self-management support for people affected by Multiple Sclerosis (PaMS)
**Acronym:**
**Rec Reference;** 15/ES/0010
**IRAS project number:** 157597
**Chief Investigator**: Dr Sue Hunter
**Sponsor;** Keele University
**Research site/Participant Identification Centre:** Staffordshire and Stoke on Trent Partnership NHS Trust

We can confirm that the above project has been given NHS Permission for Research by the Research Development Unit for the Staffordshire and Stoke on Trent Partnership NHS Trust and the details entered on to the R&D database.

We note that this research project has been approved by the East of Scotland Research Ethics Service on 29/1/15.

NHS Permission for the above research has been granted on the basis described in the application form, Protocol and supporting documentation.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, ICH GCP, any other relevant legislation such as the Data Protection Act and NHS Trust policies and procedures.

Chief Executive: Stuart Poynor    Chair: Dr Nigel Ratcliffe
Staffordshire and Stoke on Trent Partnership NHS Trust is responsible for providing NHS services in Staffordshire and Stoke-on-Trent

**Conditions of NHS Permission**
It is now a national initiative that the Trust is expected to recruit the first patient into a new study within 30 days. Please inform this office if you anticipate problems in achieving this for your study. The research Sponsor, Chief Investigator or the local Principal Investigator at the research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.

The R&D Office should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action.

The R&D Office should be notified within the same time frame of notifying the REC and any other regulatory bodies.

**After NHS permission**
All amendments including changes to the local research team need to be submitted in accordance with guidance in IRAS.

For further information regarding how to notify us of any amendments to the study please refer to the Amendments Guidance for Researchers found on the following web link:
http://www.crncc.nihr.ac.uk/researchers/amendments/

Please note that the NHS organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This will be achieved by random audit by our department.

We would like to take this opportunity to wish you well with your research. If you need any further advice or guidance please do not hesitate to contact us.

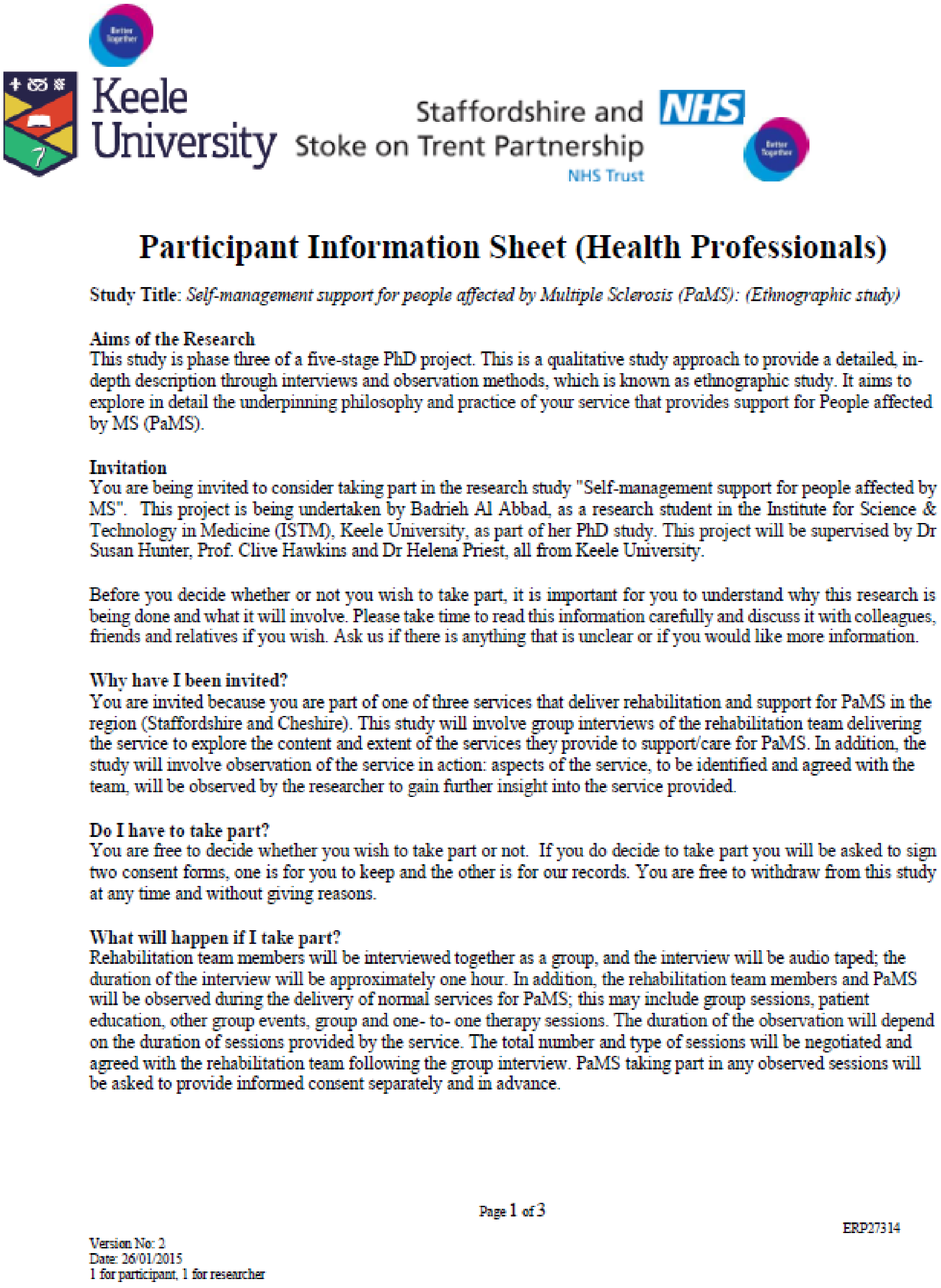
Yours sincerely

Dr John C Packham
Associate Medical Director

6/5/15
Date of NHS Permission

cc:
Chief Investigator
Sponsor

## Appendix 5: Participant Information Sheet for phase1 (field study)



Keele University

Staffordshire and Stoke on Trent Partnership NHS Trust

# Participant Information Sheet (Health Professionals)

**Study Title:** *Self-management support for people affected by Multiple Sclerosis (PaMS): (Ethnographic study)*

**Aims of the Research**
This study is phase three of a five-stage PhD project. This is a qualitative study approach to provide a detailed, in-depth description through interviews and observation methods, which is known as ethnographic study. It aims to explore in detail the underpinning philosophy and practice of your service that provides support for People affected by MS (PaMS).

**Invitation**
You are being invited to consider taking part in the research study "Self-management support for people affected by MS". This project is being undertaken by Badrieh Al Abbad, as a research student in the Institute for Science & Technology in Medicine (ISTM), Keele University, as part of her PhD study. This project will be supervised by Dr Susan Hunter, Prof. Clive Hawkins and Dr Helena Priest, all from Keele University.

Before you decide whether or not you wish to take part, it is important for you to understand why this research is being done and what it will involve. Please take time to read this information carefully and discuss it with colleagues, friends and relatives if you wish. Ask us if there is anything that is unclear or if you would like more information.

**Why have I been invited?**
You are invited because you are part of one of three services that deliver rehabilitation and support for PaMS in the region (Staffordshire and Cheshire). This study will involve group interviews of the rehabilitation team delivering the service to explore the content and extent of the services they provide to support/care for PaMS. In addition, the study will involve observation of the service in action: aspects of the service, to be identified and agreed with the team, will be observed by the researcher to gain further insight into the service provided.

**Do I have to take part?**
You are free to decide whether you wish to take part or not. If you do decide to take part you will be asked to sign two consent forms, one is for you to keep and the other is for our records. You are free to withdraw from this study at any time and without giving reasons.

**What will happen if I take part?**
Rehabilitation team members will be interviewed together as a group, and the interview will be audio taped; the duration of the interview will be approximately one hour. In addition, the rehabilitation team members and PaMS will be observed during the delivery of normal services for PaMS; this may include group sessions, patient education, other group events, group and one- to- one therapy sessions. The duration of the observation will depend on the duration of sessions provided by the service. The total number and type of sessions will be negotiated and agreed with the rehabilitation team following the group interview. PaMS taking part in any observed sessions will be asked to provide informed consent separately and in advance.

Page 1 of 3

ERP27314

Version No: 2
Date: 26/01/2015
1 for participant, 1 for researcher

### What are the benefits (if any) of taking part?

There will be no personal benefits to you by volunteering your time for this study. However, your participation will contribute to the exploration of the content and extent of rehabilitation services and support for PaMS. This information will help to inform a model of "best practice" in the final phase of the PhD study.

### What are the risks (if any) of taking part?

It is not anticipated that any participants will be harmed or subject to any distress if they take part in this study.

### How will information about me be used?

If you agree to take part in this study, no personal identity information about you will be collected or used; however, demographic details of the skill mix, experience e.g: time since qualification of team members, and geographic location of the service will be collected, along with information about how long the service has been in place. After the data have been collected, pseudonyms, or fictitious names, will be used in the interview transcript and observation notes to maintain anonymity and confidentiality; no information such as full name, address, or date of birth, of the participants involved in the observation will be obtained or recorded.

All data will be stored in accordance with the Data Protection Act (1998). Data will be stored securely on a password protected computer to which only the researcher and the supervisor will have access to maintain confidentiality. If any information about the PaMS being observed is required, which the individual PaMS are unable to provide, such as age, time since diagnosis, type of MS, etc., the researcher will ask the rehabilitation team for this with the appropriate consent from the PaMS.

### Who will have access to information about me?

Only the researcher and the supervisors will have access to information. All data will be kept in a secured, password protected PC and locked in a secure office. Pseudonyms will be used. The data will be stored in line with the sponsor's (Keele University) guidelines; the data will be retained by the chief investigator for five years at Keele University.

### What if there is a problem?

If you have a concern about any aspect of this study, you may wish to speak to the researcher (Badrieh Al Abbad) who will answer your questions.

<u>Researcher</u>
Badrieh Al Abbad
School of Health and Rehabilitation
McKay Building
Keele University
ST5 5BG
Contact: 01782 734250 (office)
Email: b.k.n.al.abbad@keele.ac.uk

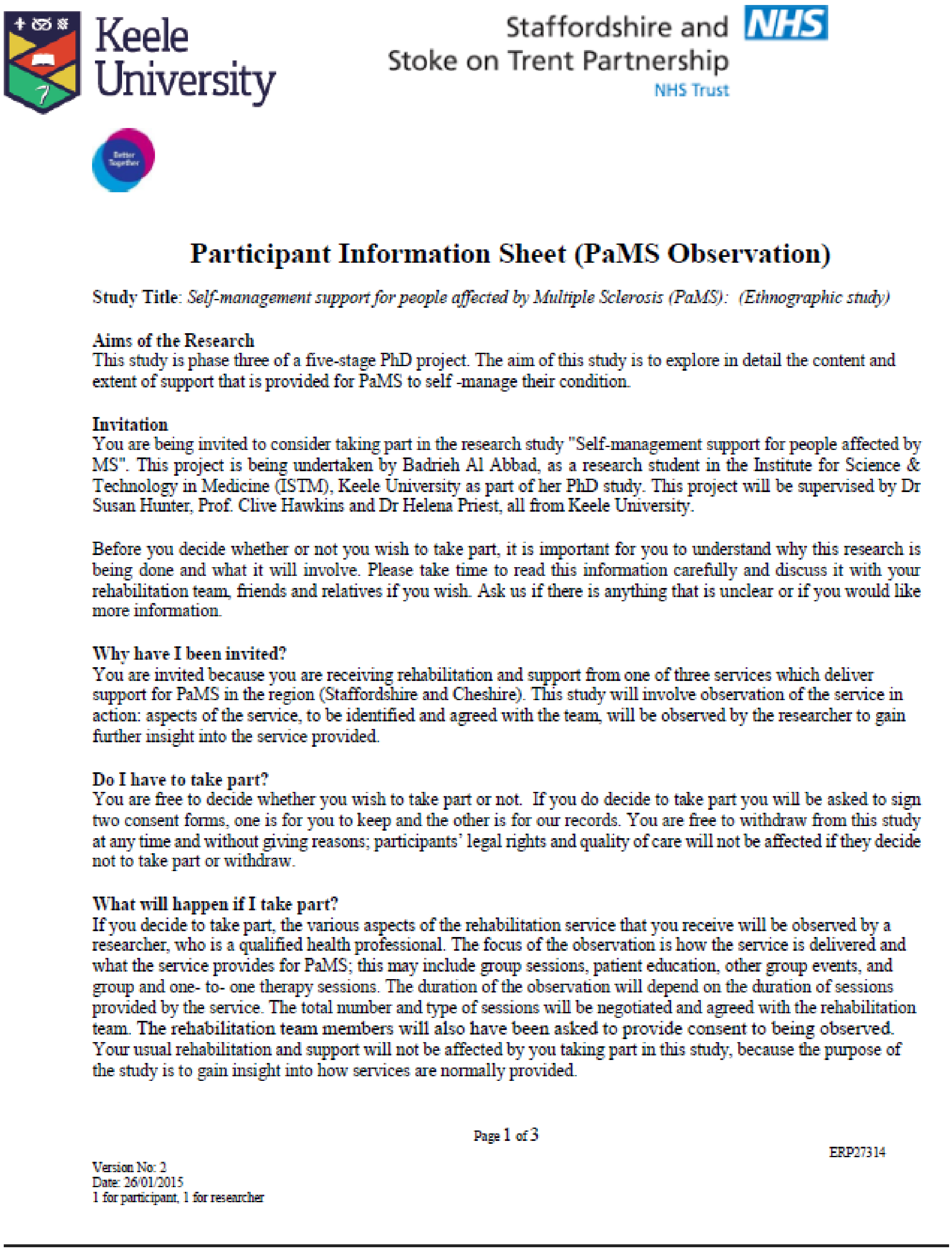
Alternatively, if you do not wish to contact the researcher you may contact her supervisor Dr Susan Hunter at the following address:

<u>Supervisor</u>
Dr Susan Hunter
School of Health and Rehabilitation
McKay Building
Keele University
ST5 5BG

Contact: 01782 733809
Email: s.m.hunter@keele.ac.uk

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please write to Emma Skinner who is the University's contact for complaints regarding clinical trials research at the following address:-

Emma Skinner
Clinical Trials Governance Officer
Research & Enterprise Services
IC1
Keele University
ST5 5BG
E-mail: e.skinner@keele.ac.uk
Tel: 01782 733374



Keele University

Staffordshire and Stoke on Trent Partnership NHS Trust

# Participant Information Sheet (PaMS Observation)

**Study Title**: *Self-management support for people affected by Multiple Sclerosis (PaMS): (Ethnographic study)*

**Aims of the Research**
This study is phase three of a five-stage PhD project. The aim of this study is to explore in detail the content and extent of support that is provided for PaMS to self -manage their condition.

**Invitation**
You are being invited to consider taking part in the research study "Self-management support for people affected by MS". This project is being undertaken by Badrieh Al Abbad, as a research student in the Institute for Science & Technology in Medicine (ISTM), Keele University as part of her PhD study. This project will be supervised by Dr Susan Hunter, Prof. Clive Hawkins and Dr Helena Priest, all from Keele University.

Before you decide whether or not you wish to take part, it is important for you to understand why this research is being done and what it will involve. Please take time to read this information carefully and discuss it with your rehabilitation team, friends and relatives if you wish. Ask us if there is anything that is unclear or if you would like more information.

**Why have I been invited?**
You are invited because you are receiving rehabilitation and support from one of three services which deliver support for PaMS in the region (Staffordshire and Cheshire). This study will involve observation of the service in action: aspects of the service, to be identified and agreed with the team, will be observed by the researcher to gain further insight into the service provided.

**Do I have to take part?**
You are free to decide whether you wish to take part or not. If you do decide to take part you will be asked to sign two consent forms, one is for you to keep and the other is for our records. You are free to withdraw from this study at any time and without giving reasons; participants' legal rights and quality of care will not be affected if they decide not to take part or withdraw.

**What will happen if I take part?**
If you decide to take part, the various aspects of the rehabilitation service that you receive will be observed by a researcher, who is a qualified health professional. The focus of the observation is how the service is delivered and what the service provides for PaMS; this may include group sessions, patient education, other group events, and group and one- to- one therapy sessions. The duration of the observation will depend on the duration of sessions provided by the service. The total number and type of sessions will be negotiated and agreed with the rehabilitation team. The rehabilitation team members will also have been asked to provide consent to being observed. Your usual rehabilitation and support will not be affected by you taking part in this study, because the purpose of the study is to gain insight into how services are normally provided.

Version No: 2
Date: 26/01/2015
1 for participant, 1 for researcher

**What are the benefits (if any) of taking part?**
There will be no personal benefits to you by volunteering your time for this study. However, agreeing to be observed will contribute to the exploration of the content and extent of rehabilitation services and support for PaMS. This information will help to inform a model of "best practice" in the final phase of the PhD study.

**What are the risks (if any) of taking part?**
It is not anticipated that any participants will be harmed or subject to any distress if they take part in this study.

**How will information about me be used?**
If you agree to take part in this study, no personal information about you, such as your full name, date of birth, or contact details, will be recorded. Any other information relating to your support needs that may be noted during the observation, will be anonymised and your participation in this study will remain confidential. You and your health professional will be given a fictitious name, or pseudonym, in any written report resulting from the study.

**Who will have access to information about me?**
All data will be stored in accordance with the Data Protection Act (1998). Only the researcher and the supervisors will have access to information. All data will be kept in a secured, password protected PC and locked in a secure office. The data will be stored in line with the sponsor's (Keele University) guidelines; the data will be retained by the chief investigator for five years at Keele University.

**What if there is a problem?**
If you have a concern about any aspect of this study, you may wish to speak to the researcher (Badrieh Al Abbad) who will answer your questions.

Researcher
Badrieh Al Abbad
School of Health and Rehabilitation
McKay Building
Keele University
ST5 5BG
Contact: 01782 734250 (office)
Email: b.k.n.al.abbad@keele.ac.uk

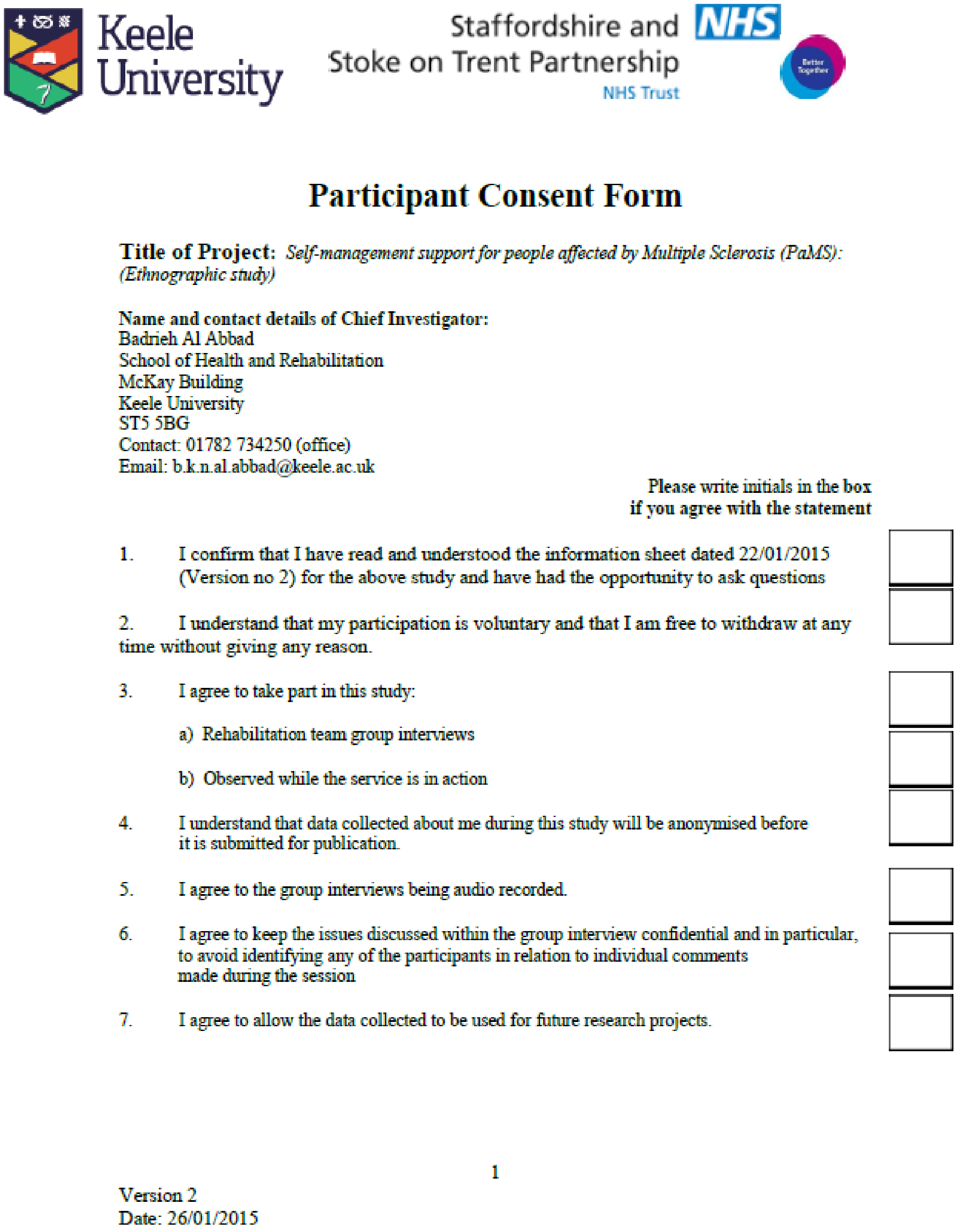
Alternatively, if you do not wish to contact the researcher you may contact her supervisor Dr Susan Hunter at the following address:

Supervisor
Dr Susan Hunter
School of Health and Rehabilitation
McKay Building
Keele University
ST5 5BG
Contact: 01782 733809
Email: s.m.hunter@keele.ac.uk

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please write to Emma Skinner who is the University's contact for complaints regarding clinical trials research at the following address:-

Emma Skinner
Clinical Trials Governance Officer
Research & Enterprise Services
IC1
Keele University
ST5 5BG
E-mail: e.skinner@keele.ac.uk
Tel: 01782 733374

## Appendix 6: Participant consent form for phase 1 (field study)



Keele University

Staffordshire and Stoke on Trent Partnership NHS Trust

# Participant Consent Form

**Title of Project:** *Self-management support for people affected by Multiple Sclerosis (PaMS): (Ethnographic study)*

**Name and contact details of Chief Investigator:**
Badrieh Al Abbad
School of Health and Rehabilitation
McKay Building
Keele University
ST5 5BG
Contact: 01782 734250 (office)
Email: b.k.n.al.abbad@keele.ac.uk

**Please write initials in the box if you agree with the statement**

1. I confirm that I have read and understood the information sheet dated 22/01/2015 (Version no 2) for the above study and have had the opportunity to ask questions ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐

3. I agree to take part in this study: ☐

   a) Rehabilitation team group interviews ☐

   b) Observed while the service is in action

4. I understand that data collected about me during this study will be anonymised before it is submitted for publication. ☐

5. I agree to the group interviews being audio recorded. ☐

6. I agree to keep the issues discussed within the group interview confidential and in particular, to avoid identifying any of the participants in relation to individual comments made during the session ☐

7. I agree to allow the data collected to be used for future research projects. ☐

1

Version 2
Date: 26/01/2015

| | | |
|---|---|---|
| Signature | Date | Name of participant |
| Signature | Date | Researcher |

Version 2
Date: 26/01/2015

Keele
University

# Participant Consent Form

## (for use of anonymised quotes)

**Title of Project:** *Self-management support for people affected by Multiple Sclerosis (PaMS): (Ethnographic study)*

Name and contact details of Chief Investigator:

Badrieh Al Abbad
School of Health and Rehabilitation
McKay Building
Keele University
ST5 5BG
Contact: 01782 734250 (office)
Email: b.k.n.al.abbad@keele.ac.uk

**Please write initials in the relevant box according to your agreement**

1. I agree for my anonymised quotes to be used ☐

2. I do not agree for my anonymised quotes to be used ☐

| | | |
|---|---|---|
| Signature | Date | Name of participant |
| Signature | Date | Researcher |

Keele University

Staffordshire and NHS
Stoke on Trent Partnership
NHS Trust

# Participants Consent Form

**Title of Project:** *Self-management support for people affected by Multiple Sclerosis (PaMS): (Ethnographic study)*

**Name and contact details of Chief Investigator:**
Badrieh Al Abbad
School of Health and Rehabilitation
McKay Building
Keele University
ST5 5BG
Contact: 01782 734250 (office)
Email: b.k.n.al.abbad@keele.ac.uk

**Please write your initials in the box if you agree with the statement**

1. I confirm that I have read and understood the information sheet dated 19/12/2014 (version no 1) for the above study and have had the opportunity to ask questions ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my medical care or legal rights being affected. ☐
3. I agree to take part in this study. ☐
4. I understand that data collected about me during this study will be anonymised before it is submitted for publication. ☐
5. I agree to allow the dataset collected to be used for future research projects* ☐

| | | |
|---|---|---|
| Signature | Date | Name of participant |
| Signature | Date | Researcher |

## Appendix 7: Focus group interview questions (field study)

**Title: Focus Group Interview at (Service name)**
**Date:**
**Introduction:**

I would like to thank you for taking the time to take part in this interview. My name is Badrieh, a PhD student at Keele University. I am a physiotherapist by background and this interview is part of my PhD study. I would like to remind you that you are here for a focus group interview because you are part of the rehab team in your service which provides support and care for PwMS. The purpose of this interview is to explore the content and extent of the services you provide to support/care for PwMS. The interview question list includes around 14 questions. This interview will last for approximately an hour and will be audiotaped.

Pseudonyms will be used in the interview transcript instead of your real names for anonymity purposes. Please bear in mind that the conversation within this room will remain confidential including confidentiality of participants. you can withdraw at any time, but the previously recorded data will still be used since we cannot differentiate individual voices on the recording of the focus group.

Does anybody have any questions before we proceed to the interview?

The digital recording will start now.

Can you please introduce yourself?

What is your profession and how long have you been in this profession?

How long have you worked in this service?

I- Overview of the service

1. How long has the service been in place?
2. Can you give me an overview of how you go about providing support and care for PwMS?
3. Can you summarise the content and extent of the services you provide for PwMS?
4. What do you consider “best practice” in providing support for PwMS?

II- Understanding of Self-management:

1. What do you understand from the term self-management of long-term conditions?
2. What do you think the essential components of self-management support for PwMS can be?

III- How their service delivers Self-management support:

1. Do you consider your service delivers support for Self-management for PwMS?
2. What is the nature or content of self-management or support provided by your service for PwMS?

3. How often do you deliver self-management in the rehab programme you offer to PwMS and for how long do you keep supporting PwMS to self-manage?
4. How do you measure your service in supporting PwMS to self-manage their condition?
5. What are the experiences of delivering the self-management programme? Any difficulties in implementation?
6. Any improvements that could be me made to self-management programmes for PwMS?
7. What do you think the barriers of self-management programmes for PwMS are?
8. Do you think the term “Self-management” is a good term to use?

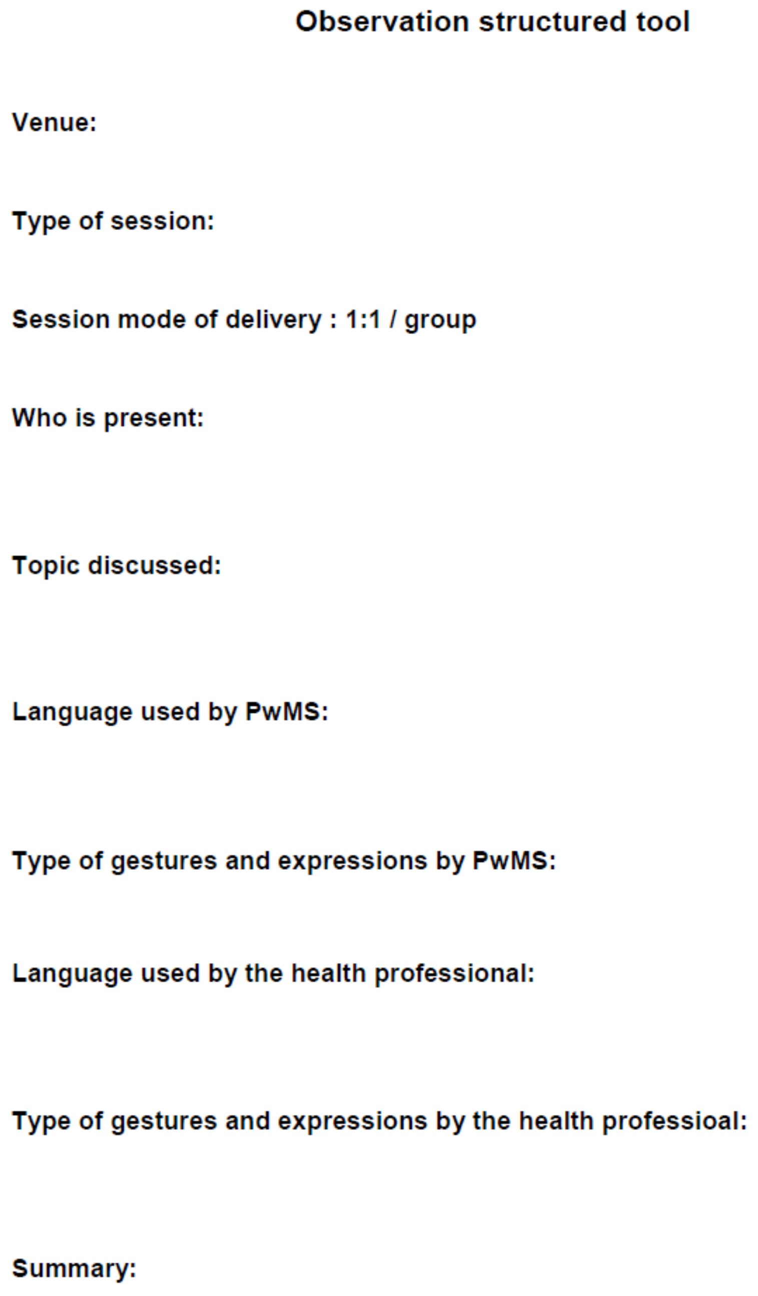
Do you have anything else you would like to add before we end the interview?

Summary of the main points

Audiotape will be stopped now

Thank you for your time to take part in my study.

## Appendix 8: Structured observational tool (field study)



### Observation structured tool

**Venue:**

**Type of session:**

**Session mode of delivery : 1:1 / group**

**Who is present:**

**Topic discussed:**

**Language used by PwMS:**

**Type of gestures and expressions by PwMS:**

**Language used by the health professional:**

**Type of gestures and expressions by the health professioal:**

**Summary:**

## Appendix 9: Semi-structured interview questions (Phase 2)

**Title: Individual PwMS Interview at (Service name)**
**Date:**
**Name of PwMS:**
**Type of MS:**

**Introduction**

I would like to thank you for taking the time to take part in this interview.

My name is Badrieh, a PhD student at Keele University. I am a physiotherapist by background and this interview is part of my PhD study. I would like to remind you that you are here for an interview because you use this service as part of your MS management plan. The interview question list includes around 9 questions around your experiences, expectations, support and care needs from the service.  This interview will last for approximately an hour and will be audiotaped.

Pseudonyms will be used in the interview transcript instead of your real name for anonymity purposes. Please bear in mind that the conversation within this room will remain confidential including confidentiality of participants. you can withdraw at any time. If you felt uncomfortable in your chair, please let me know.

Do you have any questions before we proceed to the interview?

The digital recording will start now

**Questions:**

1- What is your name, age, and how long you have been diagnosed with MS? What type of MS you are diagnosed with?

2- Would you like to tell me a little bit about yourself?

3- How long have you been coming to the service?

4- What do you think is a helpful in your current therapy?

5- Do you feel you are getting what you need from your therapy programme?

6- How do you manage your condition?

  - Describe a situation when you had to use a skill to manage your condition
  - What was the outcome?

7- Is there an element/skill in your rehab programme which helps you control your condition?

8- What do you think are the difficulties you face when managing your condition?

9- What does self-management mean to you?

10- Do you think self-management is being supported by the rehabilitation team in your service?

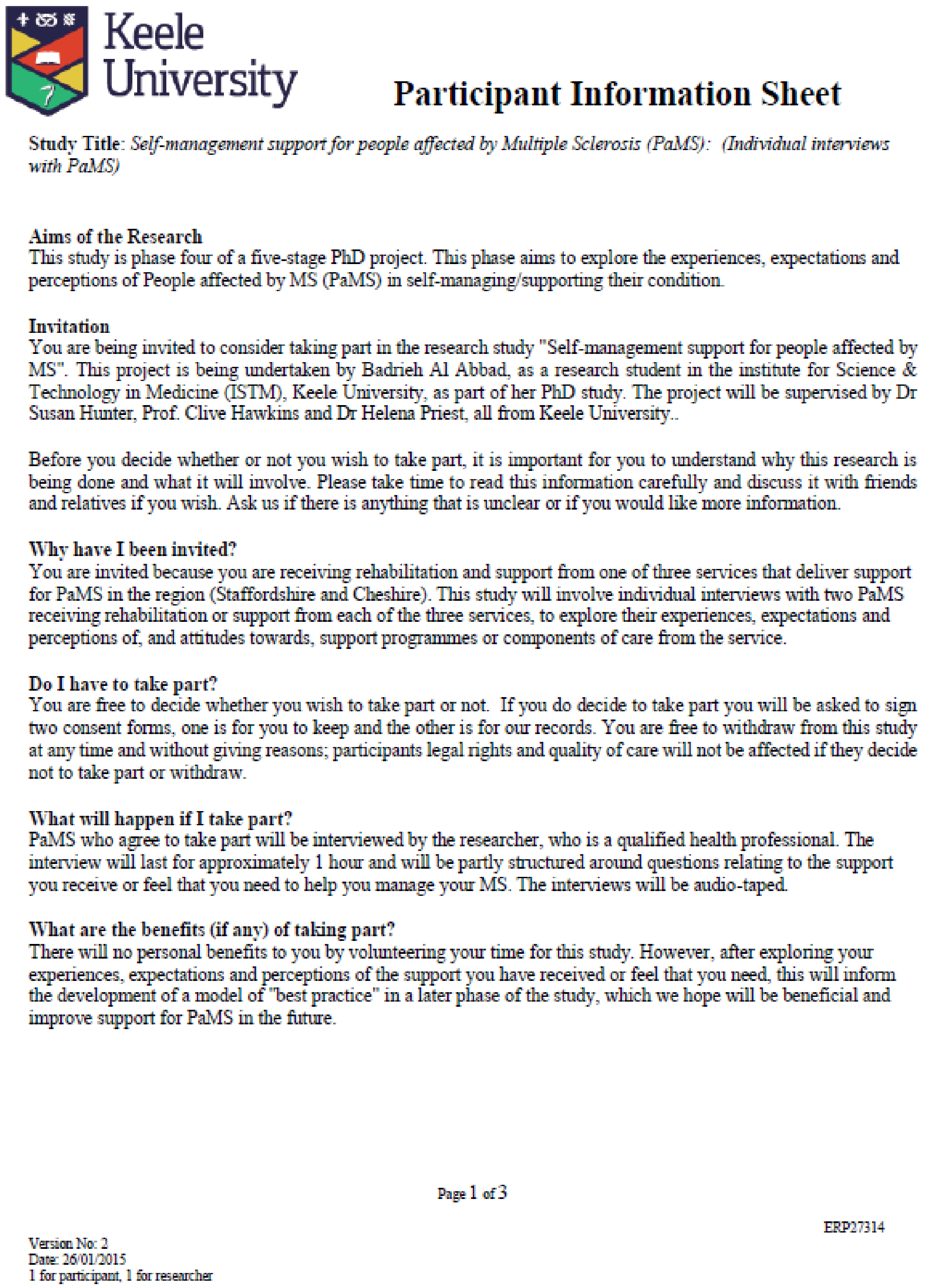
11- Do you want a self-management programme as part of the service you receive?

12- Do you think it is important that your self-management programme led by a lay person or a health professional?

13- Do you have anything else you would like to add?

- Summary of the main points
- The audiotape will be stopped now
- Thank you for your time

# Appendix 10: Participant Information Sheet (phase 2)



Keele University

## Participant Information Sheet

**Study Title**: *Self-management support for people affected by Multiple Sclerosis (PaMS): (Individual interviews with PaMS)*

### Aims of the Research

This study is phase four of a five-stage PhD project. This phase aims to explore the experiences, expectations and perceptions of People affected by MS (PaMS) in self-managing/supporting their condition.

### Invitation

You are being invited to consider taking part in the research study "Self-management support for people affected by MS". This project is being undertaken by Badrieh Al Abbad, as a research student in the institute for Science & Technology in Medicine (ISTM), Keele University, as part of her PhD study. The project will be supervised by Dr Susan Hunter, Prof. Clive Hawkins and Dr Helena Priest, all from Keele University..

Before you decide whether or not you wish to take part, it is important for you to understand why this research is being done and what it will involve. Please take time to read this information carefully and discuss it with friends and relatives if you wish. Ask us if there is anything that is unclear or if you would like more information.

### Why have I been invited?

You are invited because you are receiving rehabilitation and support from one of three services that deliver support for PaMS in the region (Staffordshire and Cheshire). This study will involve individual interviews with two PaMS receiving rehabilitation or support from each of the three services, to explore their experiences, expectations and perceptions of, and attitudes towards, support programmes or components of care from the service.

### Do I have to take part?

You are free to decide whether you wish to take part or not. If you do decide to take part you will be asked to sign two consent forms, one is for you to keep and the other is for our records. You are free to withdraw from this study at any time and without giving reasons; participants legal rights and quality of care will not be affected if they decide not to take part or withdraw.

### What will happen if I take part?

PaMS who agree to take part will be interviewed by the researcher, who is a qualified health professional. The interview will last for approximately 1 hour and will be partly structured around questions relating to the support you receive or feel that you need to help you manage your MS. The interviews will be audio-taped.

### What are the benefits (if any) of taking part?

There will no personal benefits to you by volunteering your time for this study. However, after exploring your experiences, expectations and perceptions of the support you have received or feel that you need, this will inform the development of a model of "best practice" in a later phase of the study, which we hope will be beneficial and improve support for PaMS in the future.

Page 1 of 3

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Version No: 2
Date: 26/01/2015
1 for participant, 1 for researcher

**What are the risks (if any) of taking part?**
It is not anticipated that you will be exposed to any risk. However, in the event that the interview causes you any feelings of distress, the interview will be paused or stopped if that is your wish, and the rehabilitation team in the service will be informed so that they can provide you with any additional support you may need.

**How will information about me be used?**
If you agree to take part in this study, no personal identity information about you, such as full name, date of birth, or address, will be collected or used. Information about your experiences, expectations and perceptions of and attitudes towards support programmes or components of support programmes reported by you will be collected; after the data have been collected and the interview is transcribed, or written up, you will be given a fictitious name, or pseudonym, to maintain anonymity and confidentiality of you taking part. The information that you provide will be analysed by the research team and used to contribute to a model of 'best practice' of providing self-management support for PaMS.

**Who will have access to information about me?**
All data will be stored securely on a password protected computer, in accordance with the Data Protection Act (1998), to which only the researcher and the supervisor will have access, to maintain confidentiality. If you are unable to provide information about your MS, such as length of time since your diagnosis, or the type of MS you experience, the researcher will ask the rehabilitation team/service to provide this information, with your approval and agreement. The data will be stored in line with the sponsor's (Keele University) guidelines in which the data will be retained by the principal investigator for at least five years at Keele University.

**What if there is a problem?**
If you have a concern about any aspect of this study, you may wish to speak to the researcher (Badrieh Al Abbad) who will answer your questions.

**Researcher**
Badrieh Al Abbad
School of Health and Rehabilitation
McKay Building
Keele University
ST5 5BG
Contact: 01782 734250 (office)
Email: b.k.n.al.abbad@keele.ac.uk

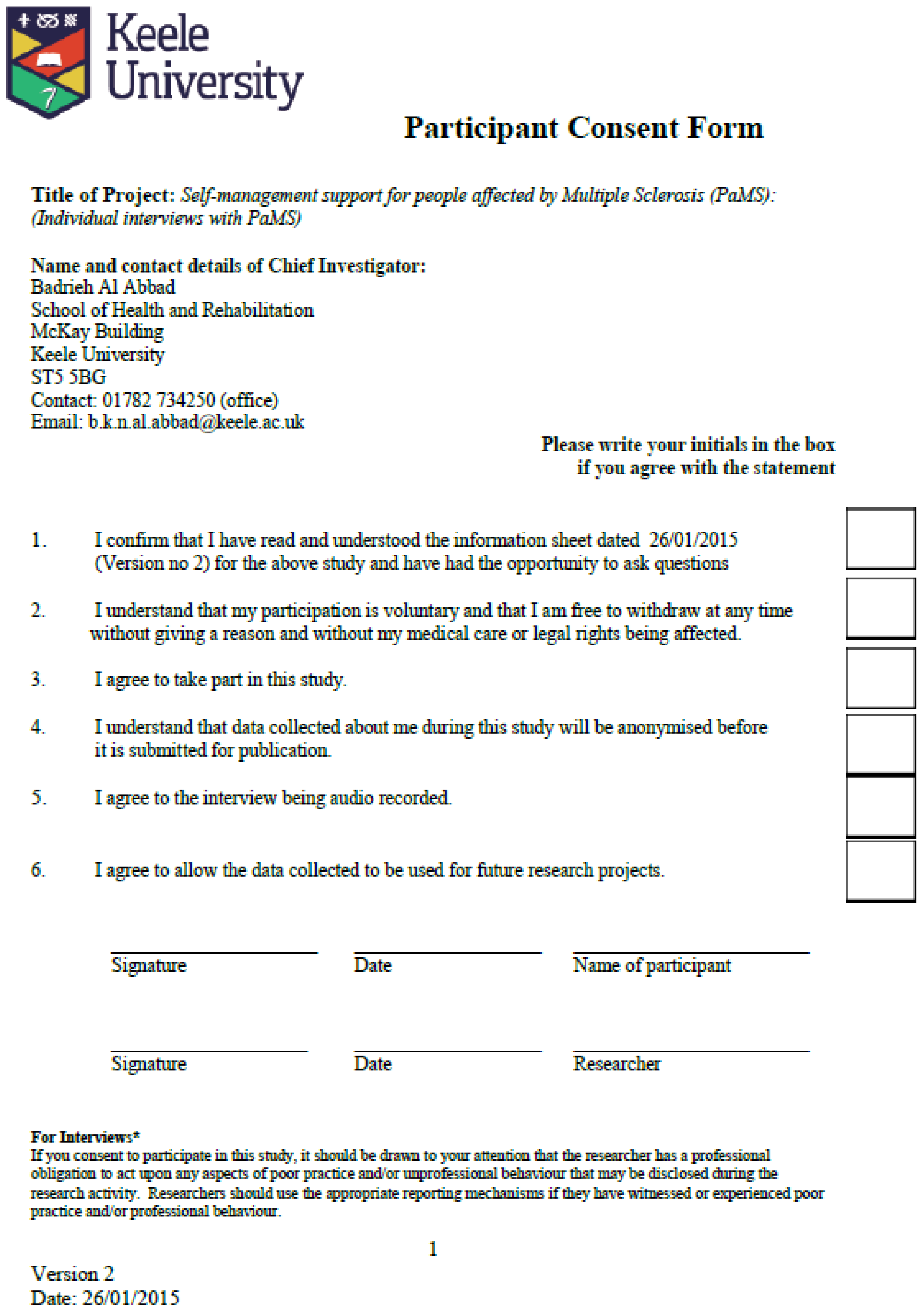
Alternatively, if you do not wish to contact the researcher you may contact her supervisor Dr Susan Hunter at the following address:

**Supervisor**
Dr Susan Hunter
School of Health and Rehabilitation
McKay Building
Keele University
ST5 5BG
Contact: 01782 733809
Email: s.m.hunter@keele.ac.uk

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please write to Emma Skinner who is the University's contact for complaints regarding clinical trials research at the following address:-

Emma Skinner
Clinical Trials Governance Officer
Research & Enterprise Services
IC1
Keele University
ST5 5BG
E-mail: e.skinner@keele.ac.uk
Tel: 01782 733374

## Appendix 11: Participant consent form (phase 2)



Keele University

# Participant Consent Form

**Title of Project:** *Self-management support for people affected by Multiple Sclerosis (PaMS): (Individual interviews with PaMS)*

**Name and contact details of Chief Investigator:**
Badrieh Al Abbad
School of Health and Rehabilitation
McKay Building
Keele University
ST5 5BG
Contact: 01782 734250 (office)
Email: b.k.n.al.abbad@keele.ac.uk

**Please write your initials in the box if you agree with the statement**

1. I confirm that I have read and understood the information sheet dated 26/01/2015 (Version no 2) for the above study and have had the opportunity to ask questions ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my medical care or legal rights being affected. ☐
3. I agree to take part in this study. ☐
4. I understand that data collected about me during this study will be anonymised before it is submitted for publication. ☐
5. I agree to the interview being audio recorded. ☐
6. I agree to allow the data collected to be used for future research projects. ☐

Signature ____________ Date ____________ Name of participant ____________

Signature ____________ Date ____________ Researcher ____________

**For Interviews***
If you consent to participate in this study, it should be drawn to your attention that the researcher has a professional obligation to act upon any aspects of poor practice and/or unprofessional behaviour that may be disclosed during the research activity. Researchers should use the appropriate reporting mechanisms if they have witnessed or experienced poor practice and/or professional behaviour.

1

Version 2
Date: 26/01/2015

Keele University

# Participants Consent Form
## (for use of anonymised quotes)

**Title of Project:** *Self-management support for people affected by Multiple Sclerosis (PaMS): Phase 4 (Individual interviews with PaMS)*

**Name and contact details of Chief Investigator:**
Badrieh Al Abbad
School of Health and Rehabilitation
McKay Building
Keele University
ST5 5BG
Contact: 01782 734250 (office)
Email: b.k.n.al.abbad@keele.ac.uk

**Please write your initials in the appropriate box according to your agreement**

1. I agree for my anonymised quotes to be used ☐

2. I do not agree for my anonymised quotes to be used ☐

Signature Date Name of participant

Signature Date Researcher

## Appendix 12: Preliminary map of the model of best practice for self-management support