

The experience of transitioning from relapsing remitting to secondary  
progressive Multiple Sclerosis

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## **ABSTRACT**

Multiple Sclerosis (MS) is a degenerative disease and a common cause of disability in adults. 85% of people with MS (pwMS) are initially diagnosed with relapsing remitting MS (RRMS), which involves discrete periods of relapses and remission of symptoms. Over time, most, but not all, pwMS transition to secondary progressive MS (SPMS), which is characterised by a gradual accumulation of disability. Little research to date has explored the experience of this transition. Nine pwMS and seven MS health professionals (HPs) were interviewed to explore pwMS' experiences, coping and needs during this transition. Four major themes were identified using Thematic Analysis (Braun & Clarke, 2006); 'is this really happening?', 'becoming a reality', 'a life of struggle', and 'brushing oneself off and moving on'. Findings suggest a process of moving from uncertainty towards confirmation of one's diagnostic label, the experience of which was influenced, in part, by the attitudes and approaches of HPs themselves. Understanding pwMS' experiences of the transition is essential if clinicians are to provide pwMS with appropriate support during the transition. Several possible implications for theory and practice were put forward.

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## **CHAPTER 1: INTRODUCTION**

### **Introduction to Multiple Sclerosis**

Multiple Sclerosis (MS) is a degenerative disease of the Central Nervous System, and a common cause of disability in adults (Coles, 2009).

Approximately 2.5 million people worldwide are affected by MS, with the majority diagnosed between the ages of 20-40 (Compston & Coles, 2008).

Symptoms vary across individuals, and may include fatigue, sensory loss, as well as difficulties with balance, walking, vision, bladder and bowel control, memory and concentration (Compston & Coles, 2008). There is no cure for MS, and the disease course is unpredictable and varies between individuals. As MS has a limited effect on life expectancy (Burgess, 2010), most people with MS (pwMS) will live with the condition for a long time and accumulate irreversible disability (Confavreux, 2008).

MS poses numerous challenges for both physical and psychological well-being, including unpleasant symptoms, treatment regimes and drug side-effects, as well as disruption to life goals, employment and relationships (Dennison, Moss-Morris & Chalder, 2009). Meta-analytic evidence indicates that pwMS have higher rates of depression than both the general population, and people with other chronic illnesses (Schubert & Foliart, 1993), as well as heightened anxiety (Zorzon et al., 2001), and low subjective well-being and quality of life (Benito-Leon, Morales, Rivera-Navarro & Mitchell, 2003). In spite of this, a substantial number of pwMS manage to adapt well to living with the illness (Antonak & Livneh, 1995).



For ease of classification, three standard clinical subtypes of MS have been described (Lubin & Reingold, 1996; NICE, 2003): primary progressive MS (PPMS); relapsing remitting MS (RRMS), and secondary progressive MS (SPMS). Whilst PPMS involves a gradual worsening of MS symptoms from the initial onset of MS, RRMS is characterised by periods where symptoms appear for at least 24 hours (i.e. a relapse), following which one recovers either partially or entirely, with a lack of disease progression between relapses (Lubin & Reingold, 1996). In contrast, SPMS is typically defined as deterioration independent of relapses for 6 months or more, which follows an initial RRMS course (Lublin & Reingold, 1996).

### **Transition from RRMS to SPMS**

85% of pwMS are initially diagnosed with RRMS (Lublin & Reingold, 1996). Although there is no cure, disease modifying drugs (DMDs) may reduce the number of relapses that pwMS experience, and the severity and duration of relapses may be managed via steroid treatment (NICE, 2003). Within approximately three decades of the onset of RRMS, 65-90% of pwMS will transition to SPMS (Compston & Coles, 2008; Trojano, Paolicelli, Bellacosa & Cataldo, 2003). Whilst many people with SPMS no longer experience relapses, some still experience them with little subsequent recovery, and undergo a gradual worsening of the baseline between relapses over time (Lubin & Reingold, 1996). DMDs are generally ineffective at slowing disease progression in SPMS (e.g. Panitch, Miller, Paty & Weinshenker, 2004; Cohen et al., 2002). As a result, guidelines from the Association of British

Neurologists (2007) recommend that DMDs are stopped in patients with SPMS who do not experience relapses, given their potential negative side-effects (Lonergan et al., 2009). Hence, the transition to SPMS may involve withdrawal of previous treatments, and a significant reduction in potential treatment options. Although this transition is common, it does not occur in all pwMS (Kalb, 2000). Furthermore, given the variability of the disease, diagnostic criteria for SPMS are not always easily applied in clinical practice, leading to delays in reclassifying patients with SPMS (Sand, Krieger, Farrell & Miller, 2014). SPMS is associated with poorer quality of life (e.g. McNulty, Livneth & Wilson, 2004), and heightened rates of depression and anxiety (Mohr et al., 1999) compared with other forms of MS.

Although research has examined the experiences of pwMS diagnosed with RRMS and of those living with established SPMS, little research has explored the experience of transitioning from RRMS to SPMS. This is a unique transition for a number of reasons. Firstly, it tends to be subtle, and is generally not a distinct phase in itself, often being confirmed in retrospect (Sand et al., 2014). Anecdotal evidence also suggests that the common, yet not inevitable, occurrence of the transition may lead pwMS to hope that they may escape it. This may result in a shattering of such hope on being reclassified (Kalb, 2000). Furthermore, this transition presents its own range of challenges given its inherent shift from a form of MS involving relapses interspersed with periods of wellness, to a progressive and irreversible form of the illness associated with a reduction in treatment options (Smith, 2009; Kalb, 2000). Anecdotal evidence suggests that the transition is associated

with a strong emotional reaction, which may include grief, anxiety, despair and anger (Kalb, 2000). In light of the above, there has been a recent call for research exploring the experiences and needs of pwMS as they transition to SPMS, to enable provision of adequate support for pwMS through this process (Wilson & Hartland, 2012).

Given a relative lack of research examining the experience of the transition to SPMS, this chapter will begin with an overview of existing qualitative literature examining the experience of living with MS, including the perceived needs, coping and adjustment associated with the following stages of the disease: (i) being diagnosed and living with RRMS; (ii) living with SPMS; (iii) living with MS across the disease trajectory. Given the in-depth insight into individuals' experiences provided by qualitative literature (Spencer, Ritchie, Lewis & Dillon, 2003), inclusion of these studies is aimed at enriching the reader's understanding of the experiences of pwMS. This is crucial, given the potential relevance of such findings for the transition to SPMS. Furthermore, this overview will highlight gaps in current knowledge regarding the experience of the transition. Following this, a model of psychological adjustment to MS will be outlined. Subsequently, an overview of the only study to date to have explored the experience of transitioning from RRMS to SPMS will be provided. Finally, a justification for adopting a qualitative approach for the current study will be presented, and the research aims will be outlined.

## **Experience of being diagnosed and living with RRMS**

Miller (1997) explored the experience of living with RRMS, including the receipt of a MS diagnosis, using hermeneutic phenomenology. Many participants described feeling relieved on receipt of their diagnosis due to discovering that their symptoms were not due to a fatal illness. Other themes included uncertainty due to the unpredictability of this stage of the disease, fear, loss, and concealment of one's disease given a lack of understanding within society about MS. Coping was facilitated through maintaining a sense of hope in relation to one's condition. Participants highlighted the value of receiving information about self-management, maintaining independence and accessing care. This study had a number of weaknesses including insufficient description of the methods of data collection and analysis. On the other hand, this study was strengthened by its inclusion of member checking<sup>1</sup> (Spencer et al., 2003), and the use of participants' quotations to support the findings.

Similarly, Koopman and Schweitzer (1999) found that receipt of diagnosis was associated with feelings of devastation and isolation. Relief was not described, however. These authors extended Miller's (1997) results by demonstrating that the pre-diagnostic phase where pwMS had been experiencing symptoms was associated with a heightened sense of confusion and worry about the meaning of one's symptoms. Similar to Miller, this study found that the post-diagnostic phase was characterised by a combination of uncertainty and hope. The quality of this phenomenological, qualitative study

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<sup>1</sup> Member checking refers to a process of verifying the accuracy of qualitative data analysis (e.g. codes, themes) with members of the group from whom the data were originally obtained (e.g. Spencer et al., 2003).

was enhanced by its use of both face-to-face and telephone interviews with each of the five participants, as well as through its illustration of the conclusions by a substantial amount of data (Mays & Pope, 1995).

Likewise, Johnson (2003) found that the pre-diagnostic period was one of anxiety due to uncertainty about the meaning of one's symptoms. Receipt of diagnosis was associated with shock and devastation, as well as isolation and abandonment, which was both due to the diagnosis itself as well as a sense of professionals withdrawing at this point due to little cause for immediate treatment. While the majority of participants described dissatisfaction with how this stage of their disease had been managed, a minority described satisfaction with their experience. As in Miller's (1997) study, a number of participants also described relief on receiving their diagnosis, and emphasised the value of receiving sufficient information and advice to support them through their adjustment. The quality of this study was strengthened by its inclusion of participants' quotes (Mays & Pope, 1995), and the use of member checking (Spencer et al., 2003), but was compromised by its reliance on participants' recall of their experiences which occurred up to 33 years previously, and its insufficient description of its methods of data analysis (Spencer et al., 2003).

Like Johnson (2003), Solari (2007) found varying degrees of satisfaction among pwMS regarding the experience of diagnosis communication. These ranged from acceptable to poor, with the period around the MS diagnosis being regarded as crucial in terms of how pwMS experienced their disease. All participants indicated that they would prefer their diagnosis to be

communicated to them unambiguously as soon as it was available. Solari and colleagues recommended improvements such as provision of an appropriate setting for diagnosis communication (e.g. private, sufficient time), tailoring of information for each individual, direction towards other sources of information (e.g. websites) and continuity of care. Recommendations regarding provision of adequate information are reminiscent of recommendations from previous studies (e.g. Miller, 1997; Johnson, 2003). This study was strengthened by its inclusion of participant quotes (Mays & Pope, 1995) and the use of member checking.

As in previous studies (e.g. Miller, 1997), Malcolmson, Lowe-Strong and Dunwoody (2008) found that receipt of diagnosis was commonly associated with relief. This study also described the experience of one individual who, in contrast to other studies, experienced no relief, but instead a sense of fear and lowered self-esteem, which suggests a range of potential responses to the receipt of a diagnosis across individuals. Findings also indicated that self-management techniques such as proactivity were found to be helpful in coping with this adjustment. This study used thematic analysis to analyse its results (n = 13). Although only one data collection method was used, the quality of this study was enhanced by the use of member checking, as well as substantial reporting of participant quotes throughout the article, supporting the credibility of the findings (Greenhalgh, 1997).

Using thematic content analysis, Edwards, Barlow and Turner (2008) found that the period between the onset of initial symptoms and receipt of a MS diagnosis was long and difficult for most of their participants, which was partly

due to difficulty in getting medical professionals to investigate their symptoms. Some participants were disbelieved by medical professionals, which left them feeling bitter and angry. Following this, many pwMs experienced dissatisfaction with the way in which their diagnosis was communicated to them, with some describing the manner in which this was carried out as 'unsympathetic' and 'casual'. As in other studies (e.g. Miller, 1997; Johnson, 2003), participants experienced both devastation and relief on receiving their diagnosis, which was often followed by uncertainty and anxiety about their future. Most participants indicated that they were not provided with sufficient information or advice about managing MS at the time of diagnosis. In contrast, a minority of participants reported being satisfied with the information and treatment that they had received, as in other studies (e.g. Johnson, 2003). Some participants felt that it is important for pwMS to accept that there are limited treatments available for MS. This study obtained its data via 24 semi-structured telephone interviews. Its limitations included its reliance on retrospective recall, with some participants having received their diagnosis up to 37 years previously, and insufficient description of the method of data analysis (Spencer et al., 2003). Furthermore, as the majority of participants were white females, confidence in the applicability of the results to men and other ethnicities is limited. The quality of this study was enhanced however through the inclusion of rich examples of raw data.

The findings of Dennison, Yardley, Devereux and Moss-Morris (2010) reflected those of previous studies (e.g. Miller, 1997; Johnson, 2003), in that the receipt of a MS diagnosis was often associated with feeling distressed and

overwhelmed, but it could be managed through maintaining positivity and the use of practical strategies (e.g. adapting one's activities) to maintain a sense of normality. This study used thematic analysis to examine the lived experience of adjusting to the early stages of MS, and recruited thirty participants in total. Results suggested that with time, many participants reached a point of acceptable quality of life and emotional well-being in spite of their MS. However, this seemingly positive adjustment was described as being under constant threat from MS, with many participants indicating that their successful adjustment was dependent on the absence of severe symptoms or relapses. While some participants found seeking support and advice from other pwMS to be helpful, others described avoiding this avenue in order to avoid reminders of the consequences of the possible worsening of their MS. This study had a number of limitations, including the use of only one data collection method, and its reliance on retrospective recall. The quality of this study was strengthened by its inclusion of substantial participant quotes.

In summary, the period between the onset of symptoms and the receipt of an initial MS diagnosis may be characterised by anxiety about the meaning of symptoms, and some individuals may struggle to have their symptoms considered seriously by health professionals. Such findings raise questions about the experiences of pwMS in the period leading up to a reclassification of SPMS, such as whether pwMS are aware of changes in their disease pattern, and what sense they make of this. Such questions are salient given the common, yet not inevitable nature of the transition, as well as the fact that



pwMS would have already have been living with MS for some time before being reclassified. The impact of such factors on pwMS' ability to detect changes in their disease pattern and the meaning that they attribute to such changes remains to be explored.

As demonstrated, receipt of the RRMS diagnosis may be associated with feelings of relief, shock, fear, uncertainty, and isolation. Given increased certainty regarding irreversible accrual of disability associated with SPMS, in contrast with the uncertainty associated with the fluctuating RRMS course (Kalb, 2000), how pwMS make sense of the reclassification merits exploration. Such investigation is also warranted in light of potential for the non-occurrence of the transition, which, according to anecdotal evidence, may lead pwMS to view the reclassification as bad luck (Kalb, 2000). The above findings also suggested that as time passes, some individuals may learn to cope and maintain an acceptable quality of life in RRMS, but that this may be dependent on the absence of severe symptoms. Given the trajectory of irreversible disability associated with SPMS, this result raises questions about how pwMS cope with the transition from RRMS to SPMS.

The studies above suggested a need for improved provision of high quality information tailored for each individual, and sufficient protected time for communication of the diagnosis. Ongoing professional support delivered by knowledgeable and empathic professionals, was identified as crucial for people with RRMS in order to support relapse management and to avoid feelings of abandonment. The extent to which such needs are met in relation to the transition to SPMS, and whether additional needs specific to this

transition exist, warrant investigation.

### **Experience of living with SPMS**

Two qualitative studies to date have examined the experiences of living with established SPMS. The first of these, Olsson, Lexell and Soderberg (2008), used phenomenological hermeneutic interpretation to explore the experience of ten women living with SPMS. The two themes which emerged were 'living with an unrecognisable body' (Olsson et al., 2008, p. 424), including loss of control over one's body and feeling directed by one's MS, and 'trying to maintain power' (Olsson et al., 2008, p. 424), such as by seeking information to reduce the unpredictability of their disease, and striving to maintain one's work role. This study was strengthened by its inclusion of rich examples of raw data, although its inclusion of only female participants may compromise the applicability of the results to men with SPMS.

Following this, Olsson, Skar and Soderberg (2010) explored the meaning of feeling well in women with SPMS. They found that in spite of living with the challenging consequences of SPMS, participants reported being able to feel well through finding a pace for their daily life where they could perform ordinary tasks, and through feeling needed and understood by others, so that their MS was not their dominant experience. Additionally, participants described the cultivation of an inner strength and resolve to feel well in spite of their disease as helpful. Similar to Dennison et al. (2010), wellness was strongly related to the severity of one's symptoms and their impact on one's

degree of disability on a given day. This study used the same methodology and was subject to the same strengths and limitations as the previous study (i.e. Olsson et al., 2008).

Given the focus of these studies on living with established disability, the value of exploring pwMS' prior adjustment from RRMS is highlighted. For instance, it remains unclear how pwMS reach such a point of coping with established disability, and whether adjustment to one's condition begins prior to, during, or following the transition from RRMS. This is salient given that, in advance of the transition, pwMS would have already been living with MS, albeit in a different form. Furthermore, given the loss of control over one's body described in relation to living with established SPMS, it remains unclear how pwMS make sense of, and respond to, the changes in their disease pattern prior to being reclassified.

### **Experiences, coping and needs across the disease trajectory**

Whilst the previously reviewed studies focused on the experiences of living with specific stages of MS, a number of studies have explored experiences of MS in general, by including participants at various stages of the disease trajectory. Many of these findings echoed the results of studies in relation to RRMS and SPMS, reviewed above. For instance, similar to Olsson et al. (2010), Kirkpatrick-Pinson, Ottens and Fisher (2009) examined successful coping with MS by interviewing ten women who self-reported as coping well with the disease in spite of its associated challenges. As in Olsson's study,

successful coping was facilitated by provision of information about MS, as well as the availability of good support systems, including support groups in the progressive phase of the disease. This study was strengthened by inclusion of participant quotes, but weakened by a lack of member checking (Mays & Pope, 1995).

Also echoing the results of previously reviewed studies (Olsson et al., 2010; Dennison et al., 2010), Fleming-Courts, Buchanan and Werstlein (2004) found that while living with MS presented a range of challenges for all ten participants, they demonstrated a capacity to meet such challenges through refocusing their priorities, and careful planning of their activities. As in previous studies regarding RRMS and SPMS (e.g. Solari et al., 2007; Olsson et al., 2008), participants emphasised the value of being listened to, and provision of information about their condition. The quality of this study was compromised a lack of member checking of the data (Mays & Pope, 1995). Theme validation was increased, however, through investigator triangulation of themes<sup>2</sup> (Green & Thorogood, 2004).

Similarly, in their exploration of the experiences of pwMS across the disease trajectory, Wollin, Yates and Kristjanson (2006) identified four themes which reflected many of the findings reported previously. Receipt of the MS diagnosis was associated with disbelief and devastation, echoing the findings of Edwards (2008) and Dennison et al. (2010), discussed above. The next theme of losses and forced life choices reflected the findings of other studies

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<sup>2</sup> Investigator triangulation involves using multiple investigators to review the findings, which can provide a check on selective interpretation and illuminate blind spots in analysis.

(e.g. Reynolds & Prior, 2003; Fleming-Courts et al., 2004), as did the third theme of difficulty in accessing services and information (e.g. Johnson, 2003). The final theme was that of cycles of grief, accommodating change, following which relief is found. This theme was somewhat reflective of the findings of Reynolds and Prior (2003), who described acknowledgement of one's difficulties as an important stage in the process of adjustment and coping. This study was weakened by its reliance on retrospective recall from many years earlier.

As demonstrated, many of the findings in relation to living with MS across the disease trajectory echoed those regarding living with RRMS and SPMS. However, a number of studies exploring MS across the disease trajectory built upon previously reviewed findings regarding RRMS and SPMS. For instance, Reynolds and Prior (2003) interviewed twenty-seven women at various stages of MS, and used an interpretative phenomenological approach to explore their strategies for living with MS. Living with MS was described as a continuous process of negotiation between negative and positive forces. As in previously reviewed studies (e.g. Olsson et al., 2010), coping was facilitated through looking after one's health, maintaining positive relationships, engaging in meaningful occupations, and adapting tasks to meet one's current level of functioning where necessary. This study built on the previous findings, however, by identifying additional means of coping, such as through actively valuing positive life experiences, clarifying one's values, and finding benefit in adversity. For some, MS was viewed as an opportunity for personal growth. Acknowledgement of one's difficulties, at least to oneself, was reported as an

important turning point for many participants, following which they were able to move forward with their lives. Although helpful, it was acknowledged that such coping strategies did not eliminate the impact of MS on participants' lives, which has been reported by other studies (e.g. Koopman & Schweitzer, 1999). This was a high quality study with well-described analysis methods (Mays & Pope, 1995), and inclusion of participants' quotations, providing evidence for the researchers' interpretations (Greenhalg, 1997).

Whilst previous studies gathered data from pwMS alone, two studies incorporated the insights of multiple stakeholders (e.g. carers, health professionals) into their investigation of the experiences of pwMS. For instance, Edmonds et al. (2007) included the perspectives of both pwMS and carers in exploring the issues for people severely affected by MS. Their results suggested that pwMS are concerned with losses and changes stemming from their MS, particularly in relation to declining independence and physical functioning, and changes in personal relationships. This theme of losses has been reported by previously reviewed studies (e.g. Wollin et al., 2006). The experience of loss and change emerged as continuous and evolving right across the disease trajectory. Although there was an insufficient description of the qualitative analytic method and a lack of member checking of the data, the study was strengthened by its inclusion of participant quotes.

Similarly, Golla, Galushko, Pfaff and Voltz (2012) explored healthcare professionals' (HPs) perceptions of the unmet needs of pwMS using content analysis. Results indicated that unmet needs included support for family and friends, with some participants highlighting the need for relatives and friends

of pwMS to be provided with psychological support and information about the disease course. Other unmet needs stemmed from deficits in communication among HPs, resulting in pwMS sometimes not being provided with adequate individualised information and advice. Challenges with managing everyday life, and maintaining continuity of one's roles in life were also reported. This study built further on previous studies, by highlighting a number of challenges faced by HPs (e.g. time pressure), which inhibited their ability to meet the needs of pwMS. These results also indicated that many HPs felt insufficiently equipped when breaking bad news to pwMS. The quality of this study was compromised by its insufficient description of its analytic method, but strengthened by its inclusion of a heterogeneous sample of HPs, which may have enhanced the generalizability of the findings.

In summary, studies exploring the experience of living with MS across the disease trajectory echoed many of the previously reviewed studies in relation to RRMS and SPMS. However, some of these studies built upon previously reviewed findings, by suggesting that some pwMS may learn to cope with their illness through finding benefit and meaning in everyday life, and by viewing living with MS as an opportunity for personal growth. Such findings also indicated the potential value of acknowledging one's difficulties in being able to move forward with one's life. Provision of support for pwMS' friends and family emerged as a need that had not been reported previously. These findings also indicated a number of challenges faced by HPs in providing adequate support for pwMS. Whilst such findings highlighted difficulties faced by pwMS across the disease trajectory, it remains unclear to what extent such

findings apply to the specific experience of transitioning from RRMS to SPMS.

### **Coping and Adjustment in MS**

Given the range of challenges posed to pwMS' well-being, and variability in how they cope with such challenges described above, the coping and adjustment of pwMS has captured the attention of numerous researchers.

Dennison, Moss-Morris and Chalder (2009) carried out a systematic review of 72 studies examining psychological factors associated with adjustment in MS.

Adjustment outcomes, in the context of this review, included psychological and emotional well-being, quality of life, and the subjective impact of MS on life domains. They subsequently proposed a model of psychological adjustment to MS, based on this review. In accordance with the cognitive behavioural model (Beck, 1976), Dennison et al.'s model suggests that early life experiences and an individual's personality provide the basis for beliefs about oneself and others. Such beliefs, in turn, influence one's values, goals and behaviour. According to this model, changes such as the receipt of a MS diagnosis, experiencing a relapse, or disease progression, lead to disruption of one's emotional equilibrium and quality of life. Emotional distress arising from such disruption is expected at this point, according to the model. This reflects the qualitative findings outlined above regarding pwMS' experience of the initial diagnosis of MS (e.g. Koopman and Schweitzer, 1999; Johnson, 2003; Dennison et al., 2010). This model suggests that if prolonged, such disruption and distress lead to adjustment difficulties. In line with Lazarus and Folkman's (1984) influential stress-coping model, Dennison et al.'s model



posits that appraisal of one's MS is associated with adjustment outcome.

Appraisals of MS as stressful and threatening, rather than controllable or a challenge, is linked with worse adjustment according to this model. Given the inevitable deterioration and frequent withdrawal of DMDs associated with SPMS, exploration of pwMS' appraisal of the transition is warranted.

Also in accordance with Lazarus and Folkman (1984), Dennison et al. (2009) propose that one's choice of coping strategies is linked with adjustment outcome. Their model differentiates between a variety coping strategies associated with successful and unsuccessful coping. Coping strategies, in this context, are regarded as conscious efforts that individuals make to manage stressors. Coping through emotion-focused strategies such as wishful thinking or avoidance, and experiencing uncertainty about one's MS emerged as having a strong evidence base for their link with poor adjustment. Other factors such as the presence of dysfunctional cognitions and cognitive errors, unhelpful illness representations, unhelpful beliefs about pain, helplessness, and perceived barriers to health behaviours emerged as having a modest evidence base for their link with unsuccessful adjustment, according to their review.

In line with Lazarus and Folkman's (1984) model, Dennison et al. (2009) proposed that coping through the use of positive reappraisal and problem-focused strategies (i.e. strategies aimed at altering the source of one's stress) were strongly associated with better adjustment in MS. This echoes the qualitative findings reviewed above in relation to coping with RRMS through proactivity (e.g. Malcolmson et al., 2008), as well as the reported usefulness

of information to support self-management in RRMS (e.g. Miller, 1997). Better adjustment was also strongly linked with perceived social support, and coping through seeking social support. This is somewhat reflective of the above qualitative findings in relation to coping with SPMS (Olsson et al., 2010), and MS across the disease trajectory (Kirkpatrick-Pinson et al., 2009). According to Dennison et al.'s (2009) review, perceived control and self-efficacy in relation to one's MS and life more generally, maintaining optimism, hope, benefit-finding, and acceptance of one's illness were modestly associated with better adjustment. Several of these factors are reflected in the qualitative literature reviewed above, including coping through benefit-finding (Reynolds & Prior, 2003), acceptance of one's MS (Edwards et al., 2008; Wollin et al., 2006), and maintaining a sense of hope (Miller, 1997; Koopman and Schweitzer, 1999). Limitations of Dennison et al.'s review include the inclusion of methodologically weak studies, and a potential for bias of the results due to the exclusion of studies which were not published in peer-reviewed journals. Such factors may have compromised the validity of the model described above. However, Dennison, Moss-Morris, Silber, Galea and Chalder (2010) found support for this model in relation to the early stages of MS. In particular, they found that cognitive and behavioural factors (e.g. unhelpful appraisals, degree of acceptance of MS, catastrophising, coping through avoidance) accounted for 37.1% ( $p < .001$ ) of variance in distress. In contrast, illness severity only accounted for 2.2% of the variance in distress. These authors acknowledged that experimental and longitudinal research is required to explore causality.

Dennison et al. (2009) argued that the extent to which the above psychological factors are linked to disease exacerbation or progression requires investigation. Hence, the extent to which this model applies to the transition from RRMS to SPMS remains to be explored. Such investigation is crucial, given research indicating that psychological factors often better predict individual variation in adjustment compared to illness factors (Dennison et al., 2010; Thomas et al., 2006). Furthermore, unlike illness factors, psychological factors may be modified through psychological intervention (Dennison et al., 2009). Hence, insight into the coping and adjustment of pwMS in relation to the transition may enable identification of potential avenues for psychological intervention aimed at enhancing their psychological well-being at this stage.

### **Transitioning from RRMS to SPMS**

No published research to date has examined the experience of transitioning from RRMS to SPMS. An unpublished Masters of Science (MSc) dissertation (Hourihan, 2013) is the only study to have explored this topic to date. This study used Interpretative Phenomenological Analysis (IPA) to analyse its data. Similar to studies exploring the experience of receiving a diagnosis of RRMS (e.g. Edwards et al., 2008), Hourihan found that pwMS were aware of a change in their condition before receiving a reclassification of SPMS. In spite of this, the re-classification was unexpected, and associated with fear and a sense of abandonment by professionals, reminiscent of the experiences of being diagnosed with RRMS (e.g. Johnson, 2003). However, Hourihan argued

that feelings of abandonment may be further exacerbated at the onset of SPMS due to declining frequency of doctors' appointments, which may stem from feelings of powerlessness among HPs to make a positive difference in the progressive stages of the illness. Hourihan also indicated a lack of knowledge among pwMS about the disease trajectory, which may have contributed to their shock on being reclassified with SPMS.

As in previously reviewed studies (e.g. Miller, 1997), Hourihan's study suggested that pwMS value psychological support and provision of sufficient and accessible information by professionals to support them in coping with this adjustment. Hourihan also found that there was a lack of information available to pwMS on being reclassified with SPMS. Furthermore, the process of gaining information about disability benefits was described as arduous. MS peer support was described as helpful at this stage of the disease trajectory, as was coping through positive relationships with family and friends, where available.

This was a small study, with only five participants, and there is no published research to verify the findings. Although Hourihan identified a number of unmet needs of pwMS during the transition it did not explore barriers to meeting such needs. Additionally there was little investigation of pwMS' coping and adjustment in response to the transition, aside from seeking social support. Finally, although Hourihan found that all participants had noticed changes in their disease pattern prior to being reclassified, this study did not explore how pwMS responded to, or made sense of such changes.

## **The current study**

This study aimed to build on Hourihan's (2013) work through gaining a more thorough understanding of the experiences of pwMS throughout the transition to SPMS, from when they first noticed changes in their disease pattern to the period following the reclassification of SPMS where people made sense of this news. It aimed to explore the coping and needs of pwMS throughout the transition, and to identify barriers to meeting such needs in order to illuminate ways forward. It was hoped that this would be achieved through interviewing a slightly larger number of pwMS, as well as by incorporating the perspectives of specialist MS health professionals (HPs). A growing body of qualitative literature in healthcare has explored the perspectives of HPs in combination with those of patients in examining the issues faced by patients and healthcare services (e.g. Pooley et al., 2001; Lester et al., 2005; Pinnock et al., 2011; Golla et al., 2012; Brown et al., 2013). These studies revealed high levels of agreement between patients and HPs, as well as highlighting tensions between what patients want and what services are able to provide. Golla et al. (2012) argued that inclusion of HPs may contribute towards identification of barriers to meeting patients' needs, illuminating ways forward. Golla et al. (2012) also highlighted the value of including specialist HPs' perspectives on the experiences of pwMS given their substantial direct contact with pwMS. They argued that including multiple stakeholder perspectives is essential for gaining a holistic view of patient experiences. Their findings revealed that HPs not only displayed excellent insight into the experiences of pwMS, but that HPs identified a broader range of relevant issues than pwMS themselves, such as in relation to patients' unmet needs.

Hence, it was hoped that inclusion of HPs in the current study would lead to generation of a wider range of themes related to pwMS' experiences than by interviewing pwMS alone. It was also hoped that inclusion of HPs would contribute to identification of unmet needs of pwMS during this transition, and the barriers to meeting such needs.

### **Rationale for Adopting a Qualitative Approach**

There is now a significant body of literature on the use of qualitative methodologies in healthcare research, particularly in the study of chronic illness (e.g. Barbour, 1999; Charles & Walters, 1998; Williams, 1999, 2000). Qualitative methodologies aim to explore phenomena from the perspective of those being studied, and strive to provide an in-depth understanding of people's experiences (Spencer et al., 2003). This is in contrast to quantitative methodologies which do not fully embrace the participant's viewpoint, due to their inherent imposing of the researcher's assumptive framework (Macran et al., 1999). The use of qualitative methodologies is helpful in areas where there has been little previous research, and where quantitative methodologies may prematurely limit the breadth of one's exploration (Lyons & Coyle, 2007). Given that this study aimed to explore the experiences of people who had transitioned from RRMS to SPMS, and in light of the limited amount of previous research in this specific area, a qualitative approach was deemed more appropriate.

## **Research Questions**

The current study aimed to investigate the following questions. This was achieved by interviewing both pwMS and HPs:

- 1) How do pwMS experience transitioning from RRMS to SPMS?
- 2) How do pwMS cope with this transition?
- 3) What are the needs of pwMS during this transition, and the barriers to these?

## **CHAPTER 2: METHODOLOGY**

### **SAMPLE SIZE**

The sample consisted of 16 participants, comprising nine people with MS (pwMS), and seven health professionals (HPs) (see Tables 1 and 2). All participants were recruited from a neurological and neurosurgical hospital in London. There is currently a lack of consensus regarding sample size for Thematic Analysis (TA). The sample size of 16 was within the range of sample sizes in published qualitative studies that used TA to explore the experiences of pwMS (Malcomson et al., 2008; Edwards et al., 2008; Dennison et al., 2010). The sample size was also comparable to studies that used TA as outlined by Braun and Clarke (2006) (e.g. Brown, Whittingham, Sofronoff, & Boyd, 2013; Fielden, Sillence, & Little, 2011). Guest, Bunce and Johnson (2006) found that six to twelve participants is sufficient to reach a point of data saturation when using TA. Given that the current study aimed to reach a point of data saturation within the time constraints of the project, the sample size of 16 was regarded as sufficient for achieving this aim.

### **INCLUSION CRITERIA/ EXCLUSION CRITERIA**

#### **People with MS**

##### *Awareness of reclassification of SPMS*

Participant awareness of a confirmed reclassification of SPMS following a previous diagnosis of RRMS was required. Such information was recorded in participants' medical notes. Participant awareness of their reclassification was required to eliminate any risk of distress caused by the researcher inadvertently revealing a diagnosis that they may not have been aware of.



#### *Up to 24 months post-reclassification*

Initial inclusion criteria required that participants would be interviewed within twelve months of their reclassification of SPMS in order to minimize the effects of recall bias. However, due to difficulties with recruiting sufficient numbers, this criterion was later extended to 24 months post-reclassification.

#### *Fluent in English*

Given the reliance of qualitative approaches such as TA on participants' expression through language, it was decided that participants would need to speak English fluently.

#### *Not experiencing onset of a new comorbid condition*

PwMS experiencing onset of a new comorbid condition were excluded in order to avoid interference of the impact of the additional condition on their recall of the experience of transitioning from RRMS to SPMS.

### **Health Professionals**

#### *MS Specialist Health Professionals*

A range of MS specialist HPs (three MS Specialist Consultants, one Consultant Neurologist, two MS Specialist nurses, and one MS Specialist Physiotherapist) who had worked with pwMS who transitioned from RRMS to SPMS were recruited given their substantial contact with pwMS and insight into their experiences.

**Table 1: Participant demographics – pwMS**

<b>Participant</b>	<b>Time since onset of MS symptoms</b>	<b>Time since MS diagnosis</b>	<b>Time since last relapse</b>	<b>Severity of last relapse</b>	<b>Time since reclassification of SPMS</b>	<b>Indoor mobility</b>
1	10 years	5 years	48 months	Severe	12 months	Walks unaided
2	30 years	30 years	33 months	Moderate	5 months	Walks using stick/frame, or holds onto furniture/somebody
3	11 years	11 years	24 months	Severe	1 month	Walks using stick/frame, or holds onto furniture/somebody
4	18 years	8 years	24 months	Moderate	12 months	Walk unaided
5	4 years	2 years	24 months	Mild	1 month	Walks using stick/frame, or holds onto furniture/somebody
6	29 years	10 years	12 months	Mild	3 months	Walks using stick/frame, or holds onto furniture/somebody
7	25 years	25 years	2 months	Severe	24 months	Walks using stick/frame, or holds onto furniture/somebody
8	22 years	9 years	20 years	Severe	21 months	Walks using stick/frame, or holds onto furniture/somebody
9	20 years	17 years	24 months	Moderate	6 months	Walks using stick/frame, or holds onto furniture/somebody

**Table 1: Participant demographics – pwMS (continued)**

<b>Participant</b>	<b>Gender</b>	<b>Age</b>	<b>Ethnicity</b>	<b>Marital status</b>	<b>Number of dependents</b>	<b>Education level</b>	<b>Employment status</b>	<b>Occupation</b>	<b>Interview duration (minutes)</b>
1	Male	49	Indian	Married	0	Degree	Full-time employed	Test Analyst	22
2	Female	58	White	Married	0	Degree	Part-time work	Community Matron	42
3	Female	44	White	Divorced	1	Diploma	Retired	Nursery school teacher	26
4	Female	52	White	Married	3	Degree	Part-time work	Researcher	44
5	Female	51	White	Divorced	0	Diploma	Permanently sick/disabled	Salesperson	65
6	Female	43	White	Cohabiting	1	Higher National Diploma	Permanently sick/disabled	HR coordinator	62
7	Female	44	White	Married	0	Degree	Permanently sick/disabled	Social worker	81
8	Male	68	White	Married	0	Higher National Diploma	Retired	Electrical engineer	21
9	Female	50	White	Single	0	Degree	Retired	Therapist	36

**Table 2: Participant demographics – HPs**

Participant	Gender	Age	Ethnicity	Occupation	Time working with pwMS	Number of patients they had worked with who had transitioned from RRMS to SPMS	Interview duration (minutes)
1	Female	35	Other Asian	MS Specialist Consultant	9 years	>50	36
2	Female	29	White	MS Specialist Nurse	15 months	11-50	26
3	Male	58	White	Consultant Neurologist	30 years	>50	18
4	Female	40	White	MS Specialist Nurse	7 years	>50	48
5	Male	43	White	MS Specialist Consultant	15 years	>50	30
6	Female	42	White	MS Specialist Physiotherapist	15 years	>50	30
7	Male	41	Indian	MS Specialist Consultant	14 years	>50	20

## **RECRUITMENT**

All participants were recruited from a neurological and neurosurgical hospital in London. Participants were recruited via purposive sampling, whereby they were sought out deliberately according to specific inclusion criteria relevant to the objectives of this study. This approach is consistent with the findings of Guest et al. (2006), whose investigation regarding the minimum number of participants required for data saturation in TA, discussed above, was based on the use of purposive sampling.

### **Recruitment of pwMS**

Over approximately 5 months, MS clinic staff (MS consultants and MS nurses) identified pwMS who met the inclusion and exclusion criteria. Participants who met these criteria were invited to take part by their clinician during routine clinic appointments. They were provided with a Participant Invitation Letter (Appendix A), Information Sheet (Appendix C), and a pre-paid return envelope. Interested participants had the option of contacting the researcher via telephone using the contact details provided on the Information Sheet. Alternatively, if they preferred the researcher to telephone them, participants could complete a tear off slip at the end of the Information Sheet, which was posted to the researcher's university department using the pre-paid envelope. When speaking to the primary researcher, candidates were given the opportunity to ask any questions, and if they agree to be interviewed, a time and place was arranged. All pwMS who responded decided to take part.

## **Recruitment of HPs**

HPs were recruited at a service-wide meeting, during which the researcher carried out a presentation about the study. Participant Invitation Letters (Appendix B), Information Sheets (Appendix D), and pre-paid envelope were distributed following the presentation. Participants indicated their interest in participating either in person following the meeting, or contacted the researcher via the contact details provided on the Information Sheet. Once again, when speaking to the primary researcher, candidates were given the opportunity to ask any questions, and if they agree to be interviewed, a time and place was arranged.

## **INTRODUCTION TO THEMATIC ANALYSIS**

Thematic Analysis (TA) is a method for identifying and analysing patterns of meaning within data (Braun & Clarke, 2006). Although previously described as a poorly defined, yet widely employed qualitative method (Boyatzis, 1998; Braun & Clarke, 2006), TA has recently received recognition as a method in its own right (Braun & Clarke, 2006). As indicated by Braun and Clarke, many of the past criticisms of TA stem from a lack of clear guidelines for how to employ this method. These authors served to remedy this lack of clarity by establishing a series of clearly defined phases through which researchers must pass in order to carry out TA. These are discussed in detail below (see 'Data Analysis').

TA stems from the much older tradition of content analysis (CA), with which it shares many of its procedures and principles. CA is an approach for determining the frequency of particular categories within data, such as specific words or images. CA has received criticism for its often exclusive reliance on frequency outcomes, as well as its removal of codes from their context, hence reducing their meaning (Silverman, 1993). TA was developed, in part, to move beyond CA's focus on solely observable material, towards consideration of implicit and latent structures within data (Merton, 1975). Hence, this method is capable of illuminating both the manifest and latent factors contributing to an issue. It is used not only to minimally organise and describe data, but also often includes an interpretation of aspects of the research topic (Boyatzis, 1998).

TA is a flexible approach, in that it can adopt an inductive or 'bottom up' approach (e.g. Frith & Gleeson, 2004), or a deductive, 'top down' approach (e.g. Boyatzis, 1998). Its flexibility also means that it is not tied to any pre-existing theories or epistemological assumptions. TA can be an essentialist or 'naïve' realist method, which assumes that data is a simple and direct representation of reality, although Braun and Clarke (2006) indicated that they themselves do not subscribe to such a position. TA is also capable of adopting perspectives at the other end of the continuum, namely constructionist or relativist standpoints, which assume that meaning and experience are constructed through language as opposed to being inherent. Finally, TA can also adopt positions which fall in between these two poles, by adopting phenomenological or critical realist perspectives (e.g. Willig, 2013).

Whilst the former is concerned with the quality of subjective experience, the latter assumes that data is not a direct mirror of reality, but requires interpretation in order to further our understanding of phenomena. According to Braun and Clarke (2006), whichever position is adopted, it is important that researchers make their assumptions explicit.

### **ADOPTING AN INDUCTIVE APPROACH**

As stated above, the flexibility of TA enables researchers to adopt either an inductive or deductive approach. The former is a data-driven approach which involves analysing the data without trying to fit it into pre-existing coding frames or pre-conceptions. Hence the researcher is guided by the data itself, from which themes are derived. Deductive approaches tend to be driven by the researcher's theoretical interests rather than the data itself, and therefore are not as capable of generating rich descriptions of the overall data as inductive approaches (Braun & Clarke, 2006). In light of a lack of research exploring the transition to SPMS, as well as the aims of this study, an inductive approach was chosen, as it was regarded as a more suitable means of gaining an in-depth and thorough understanding of people's experiences. Inductive TA is commonly used in studies exploring the experiences and meanings of individuals (e.g. Brown et al., 2013; Frith & Gleeson, 2004).

### **EPISTEMOLOGICAL POSITION**

The current study adopted a critical realist approach (Willig, 2013), which sits firmly between the opposing poles of essentialism or realism and constructionism or relativism. This approach assumes that although data are



capable of revealing the nature of reality, it is not a direct, 'mirror-like' reflection of such reality. Instead, interpretation is required in order to further one's understanding of the underlying influences that impact on the phenomena of interest. Such influences include social, physiological, and psychological processes, which may be outside participants' awareness. This choice of epistemological position reflected a desire to incorporate the experiences and insights of participants, the meanings attached to the experiences of pwMS, as well as acknowledging the impact of their wider context on these meanings. It was felt that this position acknowledged both the reality of MS symptoms, as well as the influence that broader socio-cultural factors have on the experiences of pwMS. This position was in line with the reasoning behind the inclusion of HPs, given their potential to offer broader insights onto the factors impacting on patients' experiences than patients themselves (Golla et al., 2012). Although TA has been described as a flexible position in terms of choice of epistemological position, it has been suggested that this approach is suited to adopting a critical realist position (Harper, 2011).

### **RATIONALE FOR CHOOSING THEMATIC ANALYSIS**

TA was chosen as the most appropriate method of analysis given the lack of research specifically addressing the unique transition from RRMS to SPMS. In light of this, it was decided that an approach which identified themes within participants' understanding would provide scope for further investigation in the future.

TA was also chosen due to its flexibility regarding its epistemological and theoretical stance, enabling the adoption of a critical realist perspective, as discussed above. Furthermore, the inherent flexibility of this approach means that it is suited to studies which gather and integrate data from multiple stakeholders (e.g. Wong et al., 2014; Brown et al., 2013; Jarrett et al., 1999).

TA is commonly used as a method for exploring people's experiences (e.g. Brown et al., 2013; Fielden et al., 2011; Dennison et al., 2010), as it capable of providing rich, detailed and complex accounts of data (Braun & Clarke, 2006).

Adopting TA also enabled the researcher to explore process related questions, such as how pwMS experienced the transition from RRMS to SPMS. Given the time constraints of a DClinPsych, this would not have been possible using longitudinal or quantitative methods.

Finally, previous qualitative research within the area of MS has employed TA (e.g. Dennison et al., 2010), specific guidelines on how to carry out this method were available, and the researcher had access to supervision and training in TA.

### **THEMATIC ANALYSIS COMPARED TO OTHER METHODS**

TA was chosen as the analytic method after careful consideration of how the research question could be best answered. A number of other methods were considered, but deemed less appropriate than TA for the requirements of this study.

Discursive approaches (DA) overlap with TA in that they involve a search for patterns or themes across an entire data set. However, DA place significant emphasis on the construction of social phenomena through language (Willig, 2008), as well as the performance aspects of speech. As a result, there is less emphasis on gaining an understanding of the 'true' nature of peoples' experiences. Although the current study acknowledged the impact of linguistic, socio-cultural and historical factors on peoples' experiences, it did not regard approaches which viewed participants as merely discursive agents as in line with the research aims.

Like DA, Foucauldian Discourse Analysis (FDA) does not seek to understand the true nature of phenomena, but rather how particular versions of such phenomena are constructed through language (Willig, 2013). This particular approach focuses on how power and culture contribute to the construction of dominant discourses, and explores how these discourses relate to peoples' feelings and behaviour (Willig, 2008). It could have been interesting to have focused primarily on the discourses that exist around the transition from RRMS to SPMS. This was decided against however, given that this study aimed to understand the experiences of pwMS, and to identify ways to inform intervention in the real world (Willig, 1999).

Grounded Theory (GT) was also considered as a potential approach. This method focuses on peoples' responses to social situations, and how their behaviour, in turn, influences social processes. Although GT has recently been applied to experiential questions, its overall aim is to identify the social processes which underlie and account for such experiences, and to develop

theories of such processes (Charmaz, 2006). The generation of a theoretical model of social processes was not the focus of this research, given its primary aim of understanding people's experiences of transitioning from RRMS to SPMS.

Interpretative Phenomenological Analysis (IPA) is another approach that was considered, given that it is used for exploring participants' subjective experiences in substantial detail (McLeod, 2001). The primary focus of phenomenological research, including IPA, is to gain a better understanding of *how* participants experience the world, often without furthering our understanding of the broader factors which shape such experiences, or how they relate to external reality (Willig, 2013). Through adopting a critical realist approach, TA offered an avenue not just for exploring the reality of pwMS' experiences, but also enabled incorporation of the broader socio-cultural factors which contribute to these experiences. IPA involves relatively small sample sizes and emphasises idiography rather than generalizability (Smith et al., 2009). Given that this study aimed for its results to form the basis of interventions for pwMS, an approach such as TA, which involved larger sample sizes than IPA, was regarded as more appropriate as it was more likely to lead to a point of data saturation (Guest et al., 2006). Furthermore, as IPA requires a relatively homogenous sample of participants who are 'experts' in the experience being investigated, TA was regarded as more appropriate given this study's inclusion of HPs.

## **ETHICAL CONSIDERATIONS**

The study received full ethical approval from the Nottingham 2 – East Midlands research ethics committee (Appendix E) and the Psychology Department, Royal Holloway, University of London (Appendix F). The NHS Research and Development department at the site of recruitment also granted approval for the research to take place (Appendix G). A substantial amendment was later agreed to in order to better facilitate recruitment (Appendix H).

### **Informed Consent**

All participants were over 18 years old and deemed to have capacity. By providing suitable candidates with an invitation letter and information sheet, participants were able to decide in their own time about whether to participate, and only if interested did they make themselves known to the researcher.

The information sheet outlined the purpose of the research, what participation would involve, the risks and benefits of participating, that it was voluntary, the right to withdraw, and how confidentiality and anonymity would be applied. In the case of pwMS, candidates were informed that their decision regarding participation would not have any impact on their receipt of medical care.

Informed consent was gained for participation, as well as for recording of the interview and the possibility that verbatim extracts could be included in the final report. Participants completed a consent form (Appendices I and J), which was countersigned by the researcher. Participants were offered a signed copy, and a copy was placed in their medical record.

## **Confidentiality**

The information sheet explained how confidentiality would be applied. This was reiterated to participants when gaining informed consent before each interview. Participants were informed of the limits of confidentiality, such that disclosure of risk could result in confidentiality being broken. In the case of pwMS, participants were informed that their GPs would be notified of their participation via letter (Appendix K). Before participating, they were asked to give written consent for this to happen when completing the consent form.

Participants were assigned an identification number to ensure anonymity. All identifying information was removed when transcribing the data. All data was stored securely in a locked cabinet, and electronic data was stored on an encrypted USB memory stick which adhered to NHS confidentiality standards.

## **Risks**

It was hoped that participants would benefit from having an opportunity to speak openly about their experiences during the interview. Given that pwMS were recruited from routine MS clinics where their needs would have already been thoroughly assessed, it was not expected that further discussion of the reclassification of SPMS would be any more distressing than discussing their condition at a clinical interview. However it was acknowledged that the interview process had the potential to raise issues that were sensitive and distressing for both pwMS and HPs. Potential distress was minimised in several ways. Firstly, service user involvement in the development of the interview schedule helped to ensure that its wording and structure was

sufficiently sensitive and conducive towards the development of rapport between researcher and participant. Secondly, participants were informed of their right not to answer any question that they wished, and to withdraw their participation at any time. Thirdly, the researcher employed their therapeutic skills to respond to any participant distress in a sensitive and empathetic manner. All interviews were conducted in a private setting in order that participants felt comfortable when discussing potentially sensitive issues.

Participants were provided with an opportunity for verbal debriefing at the end of each interview. They were provided with a debriefing sheet following their participation which included an overview of the purpose of the study, the researcher's contact details and, in the case of pwMS, contact details of support agencies (Appendices L and M). In the event that further support was necessary, it was agreed that the researcher would either notify the participant's MS team, or discuss with the participant alternative sources of support. No participants required this follow-up.

## **DATA COLLECTION**

Data was gathered via individual face to face, semi-structured interviews, as is common in TA (Wilkinson et al., 2004). Given the nature of the research question, this was regarded as the most appropriate method of data collection as it allowed participants to generate rich and detailed data. Interviews with HPs occurred at their place of work, while interviews with pwMS took place at their homes. Given that many pwMS experience difficulty with mobility, this

form of data collection enabled pwMS to participate in this study within the comfort of their own homes.

The interview schedules (Appendices N and O) were developed using published guidance (Willig, 2013), based on relevant literature, and further developed through discussions with research supervisors, fellow qualitative researchers, and service users (see Service User Involvement). Each of the questions in the interview schedule for HPs mirrored those for pwMS, in that they asked HPs about the experiences of pwMS. For instance, whilst pwMS were asked 'How did you deal with the impact of this reclassification?', HPs were asked 'How do you think pwMS deal with the impact of this reclassification?'. The interview schedule was used in a flexible manner, enabling the researcher to ask follow-up questions regarding interesting and unanticipated issues that were brought up. Many of the initial questions were open and exploratory (e.g. 'Can you tell me what it was like to receive a reclassification of SPMS?'), which allowed participants to provide detailed accounts of what was important to them. Interviews lasted between 22 and 81 minutes for pwMS, and 18 to 48 minutes for HPs. Interviews were audio recorded and subsequently transcribed verbatim by the researcher who removed all identifying information.

In order to contextualise the interview, a demographic questionnaire was administered for both pwMS (Appendix P) and HPs (Appendix Q). As with the interview schedule, this questionnaire was based on relevant literature and developed further through discussions with research supervisors and peers.



## **SERVICE USER INVOLVEMENT**

Two patients with MS who were receiving treatment at the hospital where the research was based were asked by their clinician to provide feedback on the information sheet and interview schedule. Feedback was integrated into the development of these items prior to their use in the study.

## **DATA ANALYSIS**

The data was analysed using TA as outlined by Braun and Clarke (2006), and guided by supervision from a Senior Lecturer in Health Psychology experienced in qualitative research. Qualitative software (NVivo 10) was used to assist the researcher in managing and organising the data. The stages of analysis were as follows.

*Familiarising oneself with the data:* All interviews were transcribed by the researcher. Transcribing is regarded as an excellent way for researchers to begin familiarising themselves with qualitative data (Riessman, 1993). Some researchers argue that the process of transcribing is an important phase of data analysis in itself, through which the researcher may develop a thorough understanding of the data, and through which meanings can be generated (Bird, 2005; Lapadat & Lindsay, 1999). After the data was transcribed, the researcher further immersed themselves in the data by reading the entire dataset a number of times so that patterns of meaning could begin to emerge. The recordings were also listened to several times to ensure the accuracy of the transcription. During this phase the researcher took notes and marked ideas for coding which they returned to in later phases of the analysis.

*Generating initial codes:* Once the researcher had sufficiently familiarised themselves with the data, initial codes were generated. Codes are defined as ‘the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon’ (Boyatzis, 1998, p. 63). In light of the inductive approach adopted, coding was aimed at simply capturing the meaning contained within data segments, as opposed to approaching the data with any pre-existing coding frame. This process involved giving equal attention to the entire dataset, to identify features of the data that were of interest, including both semantic and latent content. Initial coding revealed substantial overlap between data for pwMS and HPs. Following review and discussion with the research supervisor it was therefore decided to code the data for pwMS and HPs together as a whole, as in other similar studies (e.g. Brown et al., 2013). Given the time constraints of this project, separate coding of HP and pwMS data would not have enabled reaching a point of data saturation (Guest et al., 2006). Data extracts reflecting each code were collated, ensuring that enough of the surrounding data was retained in order to retain context (Bryman, 2001). Data extracts were coded as many times as was necessary to ensure that each code contained all relevant extracts.

*Searching for themes:* Once the entire dataset had been coded, similar or related codes were then organised into potential themes. All initial codes relevant to the research questions were combined into themes. Braun and Clarke (2006) also recommend the development of thematic maps to facilitate

the generation of themes. These enabled the researcher to consider relationships between themes (Appendix R).

*Reviewing themes:* Candidate themes were then reviewed and refined. This involved considering whether the collated extracts formed a coherent pattern within each theme. If not, the theme was revised. This was done either by renaming the theme, combining overlapping themes, creating a new theme in the case of diverse themes, relocating extracts that did not fit into another existing theme, or discarding them from the analysis. This process was repeated until all the candidate themes formed a coherent pattern. Following this, the validity of each theme was assessed in relation to the entire dataset. This process also allowed for coding of any additional data within themes that had been missed in previous coding stages. This process of reviewing and refining codes was repeated until a satisfactory thematic map had been developed that adequately reflected the dataset (Appendix R).

*Defining and naming themes:* Collated data extracts within each theme were then reviewed in order to identify what particular aspect of the data they captured. Themes, including both overarching themes and sub-themes, were then defined and named accordingly. Where possible, participants' own words were used as theme labels. Care was taken to ensure that theme definitions and names sufficiently captured the essence of each theme, and adequately distinguished them from the other themes. Consideration was also made in terms of how each theme related to the overall story that was evident in the data. In addition, care was taken to develop short but punchy names that captured the essence of each theme.

*Producing the report:* The final stage of report production involved selecting examples of transcript to illustrate elements of the themes. These extracts clearly identified issues within each theme, and presented a clear example of each point that was made.

### **QUALITY IN THEMATIC ANALYSIS**

Qualitative researchers have for some time been engaged in discussions regarding how to assess validity and quality in their research. While the criteria used to judge the scientific value of quantitative research are not meaningful when applied to qualitative research, evaluating the quality of qualitative research is still essential in order that it can make claims and be clinically applicable (Yardley, 2008).

Generic criteria for conducting good qualitative research have been drawn up (e.g. Henwood & Pidgeon, 1992; Elliott et al., 1999; Parker, 2004; Yardley, 2000; 2008), which can be applied to TA (Braun & Clarke, 2006). For instance, according to Yardley (2000), qualitative research should demonstrate the following:

#### *Sensitivity to Context*

Attention was paid to existing research and theory in the generation of the research aims, and considered throughout the analysis. The involvement of service-users in the development of the research, and inclusion of verbatim extracts helped to ensure sensitivity to the perspectives and socio-cultural context of participants. The researcher strove to maintain an awareness of

their own characteristics and assumptions throughout the research process (see Researcher As a Person-In-Context), and reflected on these in their discussions with the research supervisor about analysis and writing up.

### *Commitment and Rigour*

To facilitate in-depth engagement with the research topic, the researcher observed a specialist MS clinic at the research site which was dedicated to supporting pwMS through the transition phase. This enabled the researcher to develop a detailed and real-world insight into the context of such clinics, including management of the transition phase. To ensure rigour, the researcher attended lectures on TA, and consulted published literature to develop their knowledge and skills. The rationale for choosing TA and the characteristics of the sample are outlined above, which aim to highlight the appropriateness of the sample and technique.

### *Transparency and Coherence*

To ensure transparency, a clear and detailed account of the sample, design, procedures and analysis have been discussed above. In order to allow readers to follow how the analysis process took place, details of initial coding have been included for a section of a transcript (Appendix S). Regular consultation with both supervisors took place, one of whom has expertise in the area of MS and one in qualitative analysis. Peer supervision was used throughout the research process in which sections of the transcripts were co-analysed to enable the researcher to gain multiple perspectives and facilitate cross validation. To provide a credibility check (Elliott et al., 1999) an entire

individual transcript was analysed by a fellow qualitative researcher (Appendix T), which enabled discussion and agreement of themes. Candidate names for themes were also discussed in peer supervision and with the supervisor in order that they could be checked for 'fit' with the quotes assigned to them. Like Braun and Clarke (2006), Yardley (2000) emphasised the importance of providing a clear and convincing argument for how the research was carried out, which has been discussed in previous sections.

### *Impact and Importance*

This aspect highlights the importance of contributing to existing theory and understanding regarding the research topic. The aims and unique contribution of this research were discussed in the Introduction. The Results and Discussion sections will attend to how the findings provide unique and novel accounts of the experience of transitioning from RRMS to SPMS, and how this may contribute towards psychological theory and practice.

Braun and Clarke (2006) devised a 15-point checklist for good quality TA, which is displayed in Table 3 on the following page (Braun & Clarke, 2006, p. 96):

**Table 3: Braun and Clarke's checklist for good quality TA (Braun & Clarke, 2006, p. 96)**

Process	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.
Coding	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent, and distinctive.
Analysis	7	Data have been analysed – interpreted, made sense of – rather than just paraphrased or described.
	8	Analysis and data match each other – the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organised story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase

or giving it a once-over-lightly.

- 12 The assumptions about, and specific approach to, thematic analysis are clearly explicated.
  - 13 There is good fit between what you claim you do, and what you show you have done – i.e. described method and reported analysis are consistent.
  - 14 The language and concepts used in the report are consistent with the epistemological position of the analysis.
  - 15 The researcher is positioned as *active* in the research process; themes do not just ‘emerge’.
-



Care was taken to ensure that each of these criteria were met, as outlined under 'Data Analysis' above. For instance, all interviews were listened to several times to ensure accuracy of transcription. To ensure that no data or potential codes had been missed, the researcher reviewed the raw data several times. Input from a second coder served to further ensure the inclusivity and thorough nature of the coding process. Themes and their associated data were reviewed and re-reviewed by the researcher, research supervisor and a group of fellow qualitative researchers to ensure their internal consistency, distinctiveness, and reflectiveness of the dataset. The process of coding and generating themes took place over a period of three months, which provided the researcher with sufficient time to carry out high quality analysis. As demonstrated, the underlying assumptions and analytic process have been clearly outlined. The choice of a critical realist position enabled the researcher to be positioned as an active agent in the research process, through engaging in interpretation of the data.

### **RESEARCHER AS A PERSON-IN-CONTEXT**

I am a 30-year old white Irish Trainee Clinical Psychologist. I am a healthy, able-bodied individual who has previously experienced a number of minor health complaints which, for some time, were outside of my control, and the control of the health professionals that I sought treatment from. The impact of these conditions on my overall quality of life was minimal relative to that of chronic illnesses such as MS, but yet I can recall the frustration and distress I experienced when I was initially unable to alleviate such conditions. These

experiences, coupled with insight into the experiences of one of my closest friends who has been living with a chronic illness for the past decade contributed to my interest in living and coping with chronic health conditions. Such interest is partly underpinned by a sense of relief and gratitude as a result of being able to regain my own health, and admiration for the resilience displayed by my friend in living with a life-long, challenging illness.

My interest in MS specifically stemmed both from the aforementioned factors, as well as interactions that I had with a number of pwMS during my career prior to clinical training. Although brief, such encounters highlighted the disempowering and degrading aspects of the disease. I strove to maintain awareness of this pre-conception throughout data collection and analysis. I informed participants that I did not have previous research experience in MS, and that my clinical experience in this area was limited. This allowed me to carry out the research interviews from a position of naivety and curiosity, whilst positioning participants as experts of their experience. I think that such positioning was conducive towards suspension of my own understandings and experiences. Furthermore, I hope that the use of service user involvement and open questions allowed me to minimise my own assumptions when communicating with the participants.

### **CHAPTER 3: RESULTS**

Four main themes were generated from participants' accounts. These are illustrated below, along with sub-themes (Table 3). Generation of these themes was influenced by several factors. Firstly, they reflect what was central and prevalent across participants' accounts. Furthermore, in ensuring impact and importance (Yardley, 2000), the researcher maintained a focus on themes that were unique and relevant to the research aims, so as to capture the most salient and unique aspects of the transition to SPMS.

Themes are presented as a narrative account of the data, as recommended by Braun and Clarke (2006). Verbatim extracts from participants have been presented throughout. These were selected as they were felt to best capture the theme being described, enabling evaluation of the degree of 'fit' between the data and interpretation (Elliott et al., 1999). The number of participants contributing to each theme is presented in Table 3.

To ensure a clear account, some quotes have been edited. The omission of non-relevant data is indicated by '.....' When dialogue from the interviewer is included within quotes, this is indicated by 'I'.

**Table 4: List of Themes**

<b>Theme</b>	<b>Sub-Themes</b>	<b>Number of participants contributing to the theme<sup>3</sup></b>
<b>1: Is this Really Happening?</b>	• Noticing a gradual decline	9 pwMS; 7 HPs
	• I couldn't really make sense of it	7 pwMS; 6 HPs
	• Soldiering on	5 pwMS; 6 HPs
	• Preparing oneself	6 pwMS; 7 HPs
	• Limbo	7 pwMS; 6 HPs
	• I wish they had prepared me	6 pwMS; 7 HPs
<b>2: Becoming a Reality</b>	• Shock and devastation	5 pwMS; 7 HPs
	• It makes sense	7 pwMS; 5 HPs
	• Turning point	7 pwMS; 1 HP
	• What does this mean?	9 pwMS; 7 HPs
	• It needs to be done in the right environment	8 pwMS; 5 HPs
<b>3: A life of struggle</b>	• It's all downhill from here	8 pwMS; 7 HPs
	• This can't be happening	5 pwMS; 4 HPs
	• One's world just shrinks	8 pwMS; 4 HPs
	• Living with frustration	8 pwMS; 6 HPs
<b>4: Brushing oneself off and moving on</b>	• I accepted it because I'd already resigned myself to it	5 pwMS; 4 HPs
	• Living differently	5 pwMS; 3 HPs
	• Drawing on support	8 pwMS; 7 HPs
	• Doing all I can do and accepting the rest	7 pwMS; 6 HPs
	• Making the most of it	8 pwMS; 5 HPs

<sup>3</sup> Numbers are out of a total of 9 pwMS and 7 HPs

## **THEME 1: IS THIS REALLY HAPPENING?**

Participant accounts indicated that before being reclassified with SPMS the majority of pwMS noticed changes in their disease pattern. Whilst there was some variation in how pwMS made sense of and responded to these changes, what was central to participant accounts was a lack of clarity about the meaning of these changes. This theme captures this process of noticing changes in one's disease pattern, and its associated lack of certainty. It also captures the responses of some pwMS to such uncertainty through striving to make sense of such changes, and the struggles of some pwMS to face the potential for a reclassification of SPMS. The title of this theme aims to encapsulate all of this: the reality of the changes in one's condition, the associated uncertainty, and the varied responses of pwMS in trying to cope with, and make sense of, this uncertainty.

### **Noticing a gradual decline**

The accounts of pwMS indicated that they had all noticed changes in their MS before being reclassified with SPMS. This was also reflected by HPs. The changes were often described as a slow, gradual decline in one's physical abilities as pwMS gradually lost control over their bodily functioning. The following quote captures the subtly evolving, yet conspicuous, nature of these changes:

*I noticed a gradual declining of my health, my ability to walk and balance, and I noticed that it was harder to, for example, walk in curves. I had to stop, walk in straight lines, turn, you know, each time,*

*stop and turn, and then walk, stop and turn and walk..... And sometimes, I mean, my legs would behave a bit like supermarket trolley wheels. They, kind of, didn't go the direction I was walking in..... It's gradually though - nothing happened very suddenly. PwMS 3*

Many pwMS described noticing, often in hindsight, that they had been struggling to carry out their usual activities. Given the gradual nature of their declining abilities, awareness of such a decline may have been more readily apparent via such retrospective observations:

*But, with hindsight I've noticed that each year there are things that I could have done fairly easily the previous year that I would now be struggling with this year. PwMS 6*

Several participants described becoming aware of a lack of “ups and downs” (pwMS 9) in their condition, which had characterised the RRMS phase. Instead, participants described a gradual and irreversible accumulation of disability:

*I did relapsing, but I didn't do remitting..... if I did a relapse that was - that was where I stayed. Um, and nothing ever got any better. PwMS 4*

Some HPs added that family members would sometimes point out these changes to pwMS, further contributing to their awareness of such changes:

*...their family members might start, um, to pick up on things, and will constantly reactivate the whole process of “Are you sure you’re ok?”*  
*That kind of thing... **HP1***

### **I couldn't really make sense of it**

Participants' accounts captured how the period before the official reclassification was often characterised by uncertainty about the underlying cause or meaning of the changes described above. They described how such uncertainty stemmed, in part, from the subtle, transitory nature of the transition, making it difficult to determine if progression was, in fact, taking place:

*I think people do fluctuate from day to day, and week to week. So sometimes it takes some time for people - like a number of weeks or months, perhaps - to start to think about is this a slow progression, or is this that I've just had a bad few weeks? **HP 6***

Many participants indicated that there was often no clear-cut line between RRMS and SPMS, and that even with hindsight it could be difficult to determine at what point one had transitioned into SPMS:

*I think it's very hard to say when you cross the line... um... so there isn't any difference. It's a gradual declining, rather than anything very sudden. **PwMS 3***

Several participants described a lack of clarity about the underlying cause of the aforementioned changes in one's disease pattern. Although they had noticed such changes, some pwMS were not aware of the potential for disease progression:

*...we do get patients who - they'll say that their symptoms have been getting worse for a few months, and it's obviously not a relapse, but they might not realise that actually it's just their condition deteriorating.*

## **HP 2**

This is further highlighted by the account of one pwMS, whose RRMS had previously been described as 'Benign'<sup>4</sup> by her MS team. As a result she thought that her deterioration was a consequence of nerve damage stemming from a previous relapse, and did not appear to have been aware of the possibility of SPMS:

*... the sense I made of it was I think it's because the first relapse, which was so bad, that compared to the rest of me, or the rest of my experience, um, I just thought it was nerve damage. PwMS 7*

## **Soldiering on**

This sub-theme captures how some pwMS struggled to face or acknowledge the underlying cause of the changes in their disease pattern and to seek

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<sup>4</sup> Benign MS is a form of RRMS, still characterised by periods of relapse and remission, but involving relatively milder symptoms initially, or greater effects on one's sensory experience compared with mobility.



appropriate help. It highlights how some pwMS responded to the uncertainty surrounding the changes in their condition by attempting to ignore or deny the possibility of transitioning to SPMS.

A number of participants described how some pwMS attempted to attribute the changes in their disease pattern to causes other than a transition to SPMS, such as the effects of a relapse, or insufficient physiotherapy. Their accounts suggested that this may have been due to a view of SPMS as the worst possible outcome:

*I thought that it was a relapse, and that they would get better..... I couldn't face the fact that it would just - that that's it. That's too, kind of, a final thing. **PwMS 9***

A number of participants also described how many pwMS at this stage struggled for some time without accessing support from services:

*I never went to the GP... I wasn't really in touch with anyone about it. **PwMS 2***

*... quite often there'll be people that come to the attention here, that maybe have been floundering out in the community, that they weren't known about..... that's the difficulty. **HP 4***

## Preparing oneself

This sub-theme captures how some pwMS responded to uncertainty regarding the meaning of the changes in their condition by psychologically bracing themselves for a reclassification of SPMS. This sub-theme also acknowledges a residual uncertainty stemming from a lack of confirmation of a reclassification.

Although lacking in certainty about the meaning of the changes in one's condition, a number of participants described a process of adjusting one's mind-set in relation to one's disease, in which pwMS acknowledged the possibility of a transition to SPMS:

*...sometimes I just thought I can't move from my car, I'm just so tired. So I suppose the experience then... I was preparing myself thinking my MS is getting worse. **PwMS 2***

As part of this process, some pwMS sought information about SPMS in order to further their understanding of it and prepare for what potentially lay ahead:

*...at that stage then you start looking at what to expect if you're entering that phase. And that's when I starting reading things about fatigue and heaviness in the legs..... I read up bits and I thought yes..... I think I am. **PwMS 2***

PwMS and HPs indicated that this process of preparing oneself was often

accompanied by anxiety and dread about the possibility that one was transitioning to SPMS:

*I: And what sense did you make of it - the fact that it was getting worse?*

*P: I must be..... I must have gone through the Relapsing Remitting - I must be at the Secondary Progressive stage, and this is going to get - you know, this is bad news. **PwMS 4***

## **Limbo**

This sub-theme captures the consequences of interplay between some pwMS' desire to receive clarification regarding the changes in their condition, and the challenges faced by HPs in reaching the level of certainty required to provide such clarification. The title of this sub-theme aims to encapsulate the uncertainty inherent in the resulting delay in clarification.

Some pwMS sought clarification from their MS team regarding the changes in their disease pattern, and asked if such changes could be attributed to a transition to SPMS:

*And it's not unusual for people with MS to actually ask me whether I think they've started progressing - started to enter the progressive phase. **HP 5***

Many participants described reluctance on the part of HPs to officially reclassify patients with SPMS. This was viewed by several participants as

hindering one's process of acceptance and adjustment to living with SPMS:

*... you're waiting all that time knowing in your head that I'm not getting better, but not being able to have that label..... it makes the acceptance process a lot longer, because you're sitting there and not knowing for ages. **HP 2***

A number of reasons for such delays in reclassifying pwMS were described by both HPs and pwMS. They highlighted how the complex and ever-changing nature of MS may have posed challenges for MS consultants in determining whether pwMS met diagnostic criteria for SPMS:

*... there's always been people who it looked like their MS was changing, they were going through that transition phase, and then suddenly they're having very clear relapses again. **HP 4***

Such reluctance to reclassify patients also stemmed from concern regarding the psychological impact that such a reclassification could have on patients:

*... it is one of the main reasons why, um, clinicians are hesitant with giving a diagnosis of, um, transition, but it's quite a devastating - there's no way of lessening that blow once you do actually give it. **HP 1***

One consultant described the difficult impact that reclassifying patients could have on HPs themselves, which may have further contributed to their

reluctance to reclassify pwMS until a sufficient degree of certainty had been reached:

*...the person delivering the news will be demonised. And, um, however much they don't want to be in that role..... everyone wants to be liked..... wants to do something positive. And actually being in the role of a doctor often means you're bringing quite negative things to a discussion... and it is not nice. Um, and it takes a while for people to recognise that, at some level, it's not personal. **HP 5***

Overall, this sub-theme captures the unresolved nature of the waiting period experienced by many pwMS in advance of being reclassified with SPMS. Although pwMS shed some light on the barriers to resolving this 'limbo' period, the added insights and perspectives of HPs provided further clarification regarding these issues.

### **I wish they had prepared me**

In light of the above, this sub-theme captures the need to have sufficiently prepared pwMS for the potential transition, expressed by both pwMS and HPs. It links with the overall theme in its acknowledgement of the confusion and uncertainty experienced by many pwMS regarding their changing condition, and the role that education could have had in resolving this to some extent.

Both pwMS and HPs described forewarning and education about SPMS as

important, but sometimes lacking, in preparing pwMS for the transition:

*...what would be helpful is if the consultants or the medics had actually said well this is where it goes..... this is how it can go - steel yourself.*

**PwMS 4**

A number of barriers to preparing pwMS for the transition were identified.

Given that the transition is not inevitable, some HPs were reluctant to inform patients of its potential occurrence as they did not want to worry them:

*...when they're Relapsing Remitting, you don't want to really go on too much about Secondary Progression, because it's a bit of a negative way of looking at things. You want to be optimistic, and you don't want to emphasise that too much, because the patient will go away feeling very depressed. **HP 7***

Furthermore, it may have been difficult for pwMS to take on board information about a potential transition to SPMS, particularly at an early stage of the disease:

*...it's very difficult for someone to take that on board early on, um... and probably even when things are stable, because they don't want to be reminded about it, and it's natural to put, um, less palatable outcomes to one's side... **HP 5***

In light of these challenges, several participants suggested that although preparatory education about the transition should be routinely provided, it ought to occur following the initial diagnosis of MS, after pwMS have had time to process the news of their diagnosis:

*I think at some level it should be introduced very early on as well, but not with the initial diagnosis - there's enough to deal with there. But I think there may well be a role for follow up briefing sessions a year or two down the line when people are settled into where they are with the diagnosis, understand what that means for them, and now want to know what that means for the longer term. **HP 5***

## **THEME 2: BECOMING A REALITY**

This theme encapsulates participants' accounts of how, regardless of the extent to which pwMS expected it, the reclassification of SPMS served as a point of confirmation of one's disease status. It captures the shock and distress experienced by many pwMS on being reclassified, given prevalent understanding of SPMS. It highlights how being reclassified provided often long-awaited clarification regarding the changes that pwMS had noticed in their disease pattern, and frequently served as a turning point towards greater acknowledgement of their condition. This theme also acknowledges the importance of careful consideration on the part of HPs regarding how the reclassification was communicated, given its significance for pwMS, and the varying degrees to which they may have expected it. The title of this theme aims to encapsulate all of this, through its capturing of the clarification and confirmation regarding one's condition provided by the reclassification, and the implications of this.

### **Shock and devastation**

This sub-theme captures participants' accounts of shock, fear and a loss of hope experienced by many pwMS on being reclassified with SPMS. Several pwMS described the reclassification as having arrived completely out of the blue. The extent of the shock experienced by some pwMS was captured by one participant who referred to the reclassification as comparable to her initial diagnosis:



*Um, it was a shock. Once I'd sort of absorbed, processed the information it was a shock. It was a bit like hearing you've got MS for the first time, honestly. PwMS 3*

This sense of shock was also described by several HPs:

*... then others it's a complete, um, shock for them, and they had no idea, and it takes a lot of getting over, so. HP 2*

As demonstrated by the following quote, some pwMS hid their shock from the health professional who delivered it:

*I just shrugged it off, and ..... [ doctor] said to me at the time "how are you with this news?" And I just said "yeah, yeah, I'm fine - it doesn't change anything" PwMS 3*

Several participants referred to a process of gradually coming to terms with the shock of the reclassification over time:

*... initially it may just be a mental block in not understanding what's actually been discussed. It can take some time for them to... to process it. HP1*

Several participants described the reclassification as associated with a loss of hope in light of a lack of treatment options for SPMS. As a consequence many

pwMS may experience fear about their prognosis:

*... most people see the Secondary Progression as the bit that "oh they're going to tell me to come off the drugs, and now there's nothing else I can take for my MS... nothing else is going to slow it down," and they get really anxious about it. **HP 4***

### **It makes sense**

For some pwMS, the reclassification helped to provide clarification about the changes that they had noticed in their disease pattern. A few pwMS described how their new diagnostic label felt more in line with their experience than their previous label of RRMS had:

*Um, it was kind of just... well, that makes sense more than up and down. It's not up and down. It just made sense to me, in what was happening to me..... it just described the condition more. **PwMS 9***

HPs also acknowledged how the reclassification may have enabled pwMS to make sense of their condition:

*Some of them, um, they're quite happy to have that diagnosis because it helps them understand why their condition's getting worse without having relapses, and why they're feeling as bad as they do, whereas they'd been quite steady for a while just having relapses and then*

*going back to their normal. So, sometimes it's nice to have a label for it.*

## **HP 2**

Some participants described how the reclassification served to confirm pwMS' suspicions about the nature of their condition. For some, the experience had been somewhat expected, and was described as not much of a shock:

*Secondary Progressive one was a bit like - it was more expected. It was more expected. It wasn't really a huge shock. PwMS 6*

Several participants' accounts highlighted how although, for some, the reclassification was somewhat expected, it still served as a psychological blow:

*I don't think it's so unexpected for most people. But the other side of that is that it's the last thing they want to hear. HP 3*

## **Turning point**

Several participants' accounts highlighted how the reclassification served as a turning point for many pwMS, leading to greater acknowledgement of their MS. A small number of participants described how they had not taken much heed of their initial diagnosis of MS, but when reclassified with SPMS they had begun to consider the implications of their condition on a new level:

*... being told I had MS just washed over me. I just ignored it. But uh, I didn't feel the same when he told me it was Progressive. [I: In what way? How was it different?] Um, it just felt more serious. Yeah, I thought I'd better start doing something about it. **PwMS 8***

For instance, some participants described how the reclassification signalled a need to put safeguards in place for the future:

*I think it's made me, eh, want to be more aware of what could happen. I've always, um, not wanted to know..... I didn't want to know what was around that corner, and I suppose being reclassified I now want to know what's around the corner so that I can be prepared for it. **PwMS 3***

For many, the reclassification signalled a need to adjust one's lifestyle in accordance with one's degree of disability:

*I started then to rethink..... well I am now in Secondary Progressive MS... I have got to rethink my life. **PwMS 2***

Some participants described how this turning point was accompanied by a sense of relief. This appeared to reflect the extent to which pwMS had been struggling with the deterioration in their condition up until that point, and the difficulty that they had been experiencing in fulfilling their roles. The account of one pwMS suggested that the reclassification signalled a form of permission to withdraw from many of the roles that she had been struggling

with:

*... it was a relief because I was able to then rethink, and think well actually I can't do all those things now, I know I can't do all those things, and I'm not going to be able to do them. So I've had to redesign my social life. PwMS 2*

The accounts of several participants highlighted how, even for those who had been expecting it, the reclassification provided confirmation about the need to make adjustments in one's life. In this sense, it served as a turning point at which pwMS felt it was at last appropriate to make the necessary adjustments:

*I was ready for my wheelchair a long time ago. But it's a big step to go in a wheelchair..... I think if the doctor would have confirmed to me earlier that I had, um, Secondary Progressive MS, I probably would have looked into those aids quicker..... I always thought if it's Relapsing Remitting, what do I do with a wheelchair? I have to just give it back again. But then, when it's confirmed you think, yeah, now I want all of this. PwMS 5*

### **What does this mean?**

Several participants highlighted the value of providing pwMS with information and support to enable them to negotiate life with SPMS. This sub-theme links with the overall theme in its implicit acknowledgement of the significance of the reclassification of SPMS for pwMS, and the importance of factors

contributing to their experience of this process.

Both pwMS and HPs emphasised the importance of providing pwMS with sufficient information about SPMS and its implications for their lives. This was described as often lacking, with some pwMS being left uncertain about the implications of their new diagnostic label. The accounts below suggest a sense of abandonment by professionals at this stage:

*I had one patient who, um, she got told by the registrar "oh you're Secondary Progressive now," and that was it..... Didn't get told anything about it, didn't get told what it was, what it meant for her - nothing. **HP 2***

Several pwMS and HPs highlighted the value of providing pwMS with a sense of hope about their prognosis. Participants identified a number of means through which this could be achieved, such as by emphasising the variability of SPMS, informing pwMS about potential future treatments, and presenting them with options for participation in clinical trials:

*... she was going to write to a couple of consultants to ask if I could join, um, some research programmes. So I actually did find that really reassuring, because I thought well..... she's now saying there may be a disease modifying drug out there that can slow down the progression.*

**PwMS 2**

*I certainly emphasise the variability, so that even though you're..... in the Secondary Progressive phase, it's still a very variable phase.*

*Some people do get worse quite quickly, others plateau for a long time, so I focus on doing all you can to have as good an outcome as you can. **HP 3***

Additionally, several participants highlighted the importance of signposting to sources of support to assist them with their current and future needs:

*I think they should give you a little bit more support, I suppose, with, um, pointing you in the right direction to somebody who can give you the advice that you need..... maybe more information about the kit that's available to you - either through social services, or through, you know, mobility shop type... **PwMS 3***

Likewise, several participants, both pwMS and HPs, emphasised the value of follow-up support following the reclassification, both immediately following the reclassification (e.g. a debriefing session with a MS nurse), and in the weeks, months and years beyond. This was regarded as important, in providing pwMS both with further information and emotional support, but often lacking compared to the initial diagnosis, once again contributing to a sense of abandonment by professionals:

*... rather than wandering out and queueing at the desk to make another appointment, I suppose it would be useful sometimes if*

*somebody was around to say..... "how are you doing? Is there anything you want to talk about?" Or "how can I help you?" ..... that would have been helpful. **PwMS 2***

*I think one of the big differences as well is that at diagnosis there is a lot of support there... there's follow-up, um, nursing support..... there's lots going on..... But then, I think a lot of them are just left to it when they get the Secondary Progressive diagnosis. **HP 2***

A number of HPs highlighted some of the challenges in providing pwMS with appropriate signposting and follow-up support. These included lack of familiarity with pwMS' local services, in terms of what is available, and local referral processes:

*I mean, one barrier for us here is that we're a tertiary referral centre, so we see people from a massive geographical distance. And so the question is whether you follow them up here, or whether you try and link in with local support systems. But I think because you're not practising in the locality, you don't necessarily know all the systems that are there. So you're having to work across barriers of, you know, who's the MS nurse who works in Berkshire? And what hospital are they in? And how do I get a referral to that MS nurse? Is it the GP, or can I directly refer? **HP 6***

In spite of the shortcomings and challenges described above, a small number



of pwMS described a degree of satisfaction with some of the follow-up support and signposting provided. Once again, this highlights the importance of these factors in supporting pwMS through the reclassification process:

*I think the most helpful thing for me throughout this whole journey.....  
and the most comforting thing, has been having phone numbers for  
people you can contact, and know that they will come back to you.*

**PwMS 6**

In light of the above, many participants described the availability of a specialised clinic aimed at supporting pwMS through the transition as helpful in addressing the needs of pwMS, in both the short- and long-term:

*... she referred me to the transitions clinic, which was really helpful,  
because it plugged me into loads of other things. PwMS 7*

**It needs to be done in the right environment**

This sub-theme captures participants' accounts of the importance of creating an appropriate space for delivering the news of the reclassification. Whilst the focus of the previous sub-theme was on provision of information and support, this sub-theme concentrates on the environmental and interactional aspects of the reclassification process highlighted by participants. Like the previous sub-theme, this sub-theme links with the overall theme in its acknowledgement of the significance of the reclassification for pwMS in its focus on the implications of this.

The accounts of several participants captured the importance delivering the news of the reclassification in an empathetic manner. While some pwMS described how helpful their consultant's empathy was during their reclassification, other pwMS and one HP, a MS nurse, described this as sometimes lacking:

*I think the medics need better training around communication and empathy. I think they don't realise - they don't think what that would mean to them if they were told that. **HP 2***

A number of pwMS described the meeting in which they were reclassified as too brief, explaining that it did not allow them enough time for them to ask all their questions. This was also acknowledged by HPs:

*I didn't have room to ask all the questions I needed to at the time.*

**PwMS 7**

*... sometimes their consultations are really rushed and they don't get time to ask questions with the consultants. **HP 2***

A few HPs and one pwMS acknowledged the challenges faced by HPs in allocating sufficient time for delivering the news of the reclassification, given service limitations:

*... the diagnosis is often delivered in an outpatient department, where our clinics are generally fairly heavily booked or overbooked, where, um, the news is broken in as sensitive a way as it possibly can be, but with full awareness that this person only has a limited amount of your time allocated to them..... it's very difficult to carve out extra time to do that, even though you would want to. **HP 5***

A number of participants highlighted the value of continuity of care when delivering the news of the reclassification of SPMS. This was regarded as important, as it could enable the development of familiarity and trust between patient and HP:

*... it can be through their MS nurse specialist. They may have built up a bond with one particular nurse specialist. In some centres they have their own dedicated nurse specialist who they get to know well, and they trust. Um, it's best done by someone they know, really - who they've met before, ideally - who knows their condition. **HP 7***

Continuity of care was also described as important in ensuring consistency in the information delivered to pwMS, so as to avoid conflicting messages:

*I think such discussions need to be led by the physicians who are in charge of patients, um, because obviously it's a matter of trust..... if it's done randomly by different people that trust is often lost, and so it's important that such a sensitive topic is done by physicians..... or else*

*you can get into a lot of trouble where there is conflicting information...*

**HP 1**

A number of participants highlighted the importance of the reclassification being delivered by sufficiently experienced HPs. Experience was regarded as important, both for ensuring a correct diagnosis, and that the reclassification was delivered in an appropriate manner:

*... sometimes if patients are being seen by junior doctors there may be not an understanding of what's going on, so it may be interpreted in a different fashion, or it may be interpreted more negatively than what a clinician who has seen a spectrum of disorders might..... experience is definitely needed on how to have this consultation. **HP 1***

A small number of participants described privacy as valuable during communication of the reclassification. One pwMS recounted how the meeting in which she was reclassified was attended by a visiting doctor, which impacted on her ability to process the news in the meeting and provide genuine feedback to her consultant about its impact on her:

*I had a student doctor - no, a visiting doctor from ... [hospital] who... [consultant] had asked to be in the room, and I'd said yes..... I think I just shrugged it off, and ... [doctor] said to me at the time "how are you with this news?"... and I just said "yeah, yeah, I'm fine... it doesn't change anything"..... had the visiting doctor not been in the room I may*

*have thought about it a bit more while I was in there..... I think having  
the visitor in the room probably wasn't right for me personally. **PwMS 3***

### **THEME 3: A LIFE OF STRUGGLE**

This theme captures some of the challenges described in participants' accounts of life following the reclassification itself, as well as some of the emotional and behavioural responses of pwMS. As the title of this theme suggests, the focus of this theme is on the struggles captured in many participants' accounts of the transition, including its negative consequences for the lives of pwMS and their families. This theme also incorporates some of the emotional and behavioural responses of pwMS to the transition, which may have inadvertently compounded the extent to which they struggled with this process.

#### **It's all downhill from here**

The title of this sub-theme aims to encapsulate some of the reactions to the transition described by participants, characterised by a sense of fear and dread about the future, and a gloomy resignation towards an inevitable decline in one's condition.

Some participants described a sense of giving up and resigning oneself to the loss of one's abilities. Given the withdrawal of treatment associated with SPMS, participants described a view of SPMS as unstoppable, resulting in a loss of self-efficacy. This may have led some pwMS to have assumed a passive stance in relation to the deterioration of their condition:

*... some give up hope ..... they don't see that there's much that they can do, so they say "oh physiotherapy's not going to help me..." ... there's nothing for me now. **HP 2***

One HP described how, in response to a reclassification of SPMS, pwMS experienced anxiety about the implications of having SPMS on their ability to fulfil their roles in the future:

*I think people often worry about the future, and if they've got young children, how they're going to fulfil that role as a parent. **HP 6***

Both HPs and pwMS described excessively dwelling on the implications of one's condition, and catastrophizing about the future as unhelpful:

*I think dwelling too much on the worst case scenario is not going to be good. Um, so yeah, that's probably not a good way to deal with it. **HP 7***

Several participants described how some pwMS withdrew from others following the reclassification, and refused support:

*a lot of patients report that as the disease progresses they lose a lot of people around them, and I think that is partly because they won't accept help, and they do push them away a bit. **HP 2***

A number of pwMS and HPs highlighted how this may have stemmed from a

desire not to burden others:

*Umm, and then they don't want to be a burden on their children etcetera. There's lots of baggage which surrounds it. **HP 1***

One HP described how, for a particular pwMS, the future implications of having SPMS were so intolerable that she felt that she had no choice but to end her life:

*I had a really lovely, lovely lady who, eh, I saw in my old job who was quite desperate to end her life..... she decided that she could not live with the Secondary Progressive MS..... I think she made a conscious decision that she would die... so she just, bit by bit, stopped eating. And went, you know, went from being this, sort of, quite upbeat person sitting in the wheelchair... she'd had her first line treatment, she'd been on the tysabri infusions... and suddenly it went into Secondary Progressive, and she was quite adamant..... that she didn't want to be granny in a wheelchair. And, nine months later her body just gave out ago. **HP 4***

### **This can't be happening**

This sub-theme focuses on participants' accounts of the difficulty experienced by many pwMS in coming to terms with the irreversibility of SPMS. A number of pwMS described struggling to accept the new stages of disability which accompanied their SPMS. Their accounts often captured a sense of



resistance against letting go of previous activities and approaches, and making adjustments in line with the extent of their disability:

*... at some stage I'm going to have to look into getting a stair lift. I mean I'm resisting it..... if I can struggle up those stairs, I will. PwMS 4*

The accounts of several participants captured how, following the reclassification, some pwMS attempted to ignore the reality of their condition and tried to soldier on in spite of it:

*I had a chap..... he's a black cab driver. And I would say even now, he's probably still crawling across his gravel front lawn to climb into his taxi, which has been adapted, to go to work..... and you've got some people who will battle on, and battle on, and they'll do things by, you know, like that chap..... literally crawling out across a gravel front drive to get into a taxi to then go to work. HP 4*

Some participants described high levels of distress which accompanied being confronted with new levels of disability, and all that it entailed. One pwMS described difficulty integrating a new stage of disability into her self-concept:

*So like, when I started to use an intermittent self-catheterisation to go have a wee, um, I was off sick from work for three weeks, because I was just like "I can't \*\*\*\*ing do this! I'm not a disabled person. This is not me." PwMS 7*

Some participants described efforts of pwMS to identify means of alleviating SPMS. These sometimes included invasive and potentially painful measures, which was likely to reflect the extent to which pwMS were struggling to accept the irreversibility of their condition:

*... they're getting more desperate about the fact that they are getting more disabled, so they will try all the faddy things that are out there on the internet, be it the extreme diets, or, eh, I had somebody who went to Dubai and had their atlas bone - a bit of bone chipped out of their neck because somebody on the internet said that would stop their MS in its tracks. **HP 4***

One pwMS described this response as “bargaining”, whose definition captured a degree of superstition inherent in its implication that engagement in certain practices will lead to an alleviation of her condition:

*And I've done an awful lot of bargaining. I've done an awful lot of, you know, diets..... Bargaining means for me, um, well if I do this, then I'll be better. **PwMS 7***

A small number of participants described escapism from the reality of one's condition through substance use, which is likely to have reflected the challenges faced by pwMS in accepting the reality of having SPMS:

*I would say a lot of them probably smoke and drink too much. I think there's huge escapism with the help of cannabis. **HP 4***

### **One's world just shrinks**

The accounts of a number of participants captured increasing restriction in the lifestyles of pwMS arising from worsening disability associated with the transition. As a consequence, many pwMS described having to adopt a less active lifestyle, compared with their previous experience of RRMS:

*So now my life is very, very different..... I've withdrawn from all the groups I used to sing with. I didn't take part in the festival this year..... I don't go shopping now because I'm frightened I might fall. **PwMS 2***

Such increasing restriction was also reflected by several participants who described difficulty with planning ahead, and a loss of spontaneity associated with the transition:

*it just means that you can't think oh well, you know, I can't plan to do this in... go on holiday in X many months' time because I'll probably be better then. Because I know I won't be. I'll just be worse. **PwMS 4***

A number of participants described how this heightened restriction limited their ability to engage in a social life, resulting in increased social isolation:

*the lack of being able to go out and support. And the fatigue. I nap all the time, and that limits my - that has made me, um, not be sociable, perhaps when I would be. So that has really cut off a lot. PwMS 9*

Several participants described a sense of sadness arising from the consequences of this restriction. Their accounts captured a sense of grief regarding loss of one's previous way of life:

*... you have to just say goodbye to the previous life, I think. To me, anyway, my spontaneous, quickly... I go for a trip here or there... that isn't possible anymore. PwMS 5*

This was also reflected by HPs:

*I suspect, as with the initial diagnosis, that there's a degree of grieving, um, for lost opportunities. HP 5*

### **Living with frustration**

Many participants described frustration in response to the transition, stemming from several sources. The accounts of some participants highlighted frustration associated with the decline in one's physical functioning, and the irreversibility of one's condition:

*And now I can't even say what's frustrating me the most... the balance, or no muscles, because I have no more muscles left..... It isn't going*

*anywhere. It's just going to stick around, the \*\*\*\*\*.* **PwMS 5**

Some participants described frustration at the current lack of treatment options for SPMS:

*...“oh well, I’ve got Secondary Progressive so I can’t take anything anymore”..... people get very angry and get really frustrated about it.*

**HP 4**

Several pwMS described barriers to meeting their practical needs since the reclassification, such as challenges involved in applying for benefits, blue badges, and so forth:

*... the bits and bobs - filling in forms, having to have appointments with people..... some of those things are quite stressful... processes that take forever to do are very stressful.* **PwMS 9**

Several pwMS described frustration at delays in service provision:

*Someone said they’re going to come around the house and see if it was suitable for me. But uh, I haven’t heard anything from them.* **PwMS**

**8**

The accounts of some participants, both pwMS and HPs, highlighted the impact of service limitations on HPs’ abilities to provide pwMS with timely

input:

*... the resources that you would require.....in terms of neurologists and MS nurses, eh, psychologists, and therapists..... it's difficult to access any of these services in a timely, responsive manner. **HP 3***

*But you know that if you've been referred you're not going to get an appointment next week..... because it's so busy. **PwMS 6***

#### **THEME 4: BRUSHING ONESELF OFF AND MOVING ON**

The title of this theme aims to encapsulate the flexibility and resilience captured by many participants' accounts of the responses of some pwMS to the reclassification. In this sense, it may be viewed as an opposing theme to Theme 3, whose focus was on the negative consequences of the transition, and the responses of pwMS which may have inadvertently further exacerbated their struggle. Whilst it is acknowledged that pwMS could move back and forth between the experiences captured in these two themes, or indeed experience them simultaneously, it was felt that this division of themes both reflected the content of participants' accounts, and may prove useful for deriving conclusions and recommendations. The current theme acknowledges the potential for initial responses of shock and devastation described in Theme 2, but focuses on the subsequent process of moving forward with one's life, in spite of the transition. It incorporates both the agency and flexibility of pwMS, in addition to the arguably more passive stance of accepting the irreversibility of SPMS.

##### **I accepted it because I'd already resigned myself to it**

This sub-theme encapsulates the buffering effect that adjustment to living with MS had against the impact of a reclassification of SPMS. This links with the overall theme via its acknowledgement of the resilience of some pwMS, through capturing factors enabling their acceptance of the reclassification.

Several participants indicated that the reclassification was often less of a shock compared to the initial diagnosis of MS. Given that the reclassification

typically occurs several years after the initial diagnosis, pwMS may have become somewhat resigned to living with the disease and may have mentally prepared themselves for a worsening of their condition:

*Since then I've got older and I've nursed people with MS. So, I think it's just natural to prepare myself over those years that I could get that bad.*

**PwMS 2**

Several pwMS described having reached a point of acceptance of their condition which had taken place over the years since their initial diagnosis. They recounted how such acceptance of their MS enabled them to better adjust to living with SPMS:

*... there isn't anything else to do but to accept it, and to be calm, and to... which I think only really does come once you've been used to having the disease. PwMS 6*

Some participants spoke about how, by the time they were reclassified, they had built a knowledgebase about MS, and were familiar with MS services and professionals, which buffered them against the shock of the reclassification:

*I knew about MS then ..... I knew the MS nurses, I knew the hospital, I knew my infusion nurse, I knew I had people. So it actually was a*



*softer diagnosis in all respects, because it was a..... I knew what I was dealing with. **PwMS 6***

This was also reflected by HPs:

*... going from Relapsing Remitting to Secondary Progressive, they should already have a knowledge base, if they've been appropriately treated and counselled by the nursing team in their centre that they're followed up. So they should have come from a situation where they have a decent knowledgebase of MS. **HP 7***

A number of participants spoke about how prior expectation of being reclassified with SPMS enabled some pwMS to accept the reclassification when it finally did occur. A few pwMS referred to a process of coming to terms with having SPMS long before they were officially reclassified:

*...as these things get worse, you know, you're kind of slowly having to accommodate it, and having to accept it, because you have no damn choice. But it's not easy. So when you're then told it's Secondary Progressive you think well - yeah well, I've finally got to terms with all of this anyway. So there's a bit of a 'so what' about it..... I don't welcome this news ..... life is really going to be horrible, but I'm not surprised. **PwMS 4***

## **Doing all I can do and accepting the rest**

This sub-theme captures participants' descriptions of a balance between accepting one's condition, and a focus on what one could control. Indeed, several participants described having reached a point of acceptance of their condition, which involved letting go of their previous struggle against the disease. As indicated by the previous sub-theme, for some, this process of acceptance had been taking place long before the reclassification. However, other participants described this process of acceptance as taking place since the reclassification itself:

*since the summer of 2014, and I have kind of accepted my illness on a different level. I'm much, much, much more at peace with it than I was.*

### **PwMS 7**

Acceptance of one's condition did not mean that pwMS adopted a passive stance in relation to the transition, however. On the contrary, a number of participants described focusing on doing as much as they could do to optimise their condition, whilst accepting what was outside of their control. Several participants described focusing their attention and energy on symptom management and maximising functioning, through diet, exercise, physiotherapy, and so forth:

*I do go to the gym quite a lot, so I'm trying to do things to help my physical state, and I've been going up to [name of hospital] to see the physios... so to help with balance. PwMS 2*

Some pwMS also found it helpful to educate themselves about SPMS, including potential treatment options:

*I think there's some people who like to read, and like to use the internet for information, and use that as a means of coping. **HP 6***

A number of participants described a balance between focusing one's energies on what was within their control, whilst accepting what was outside of their control. This involved an acceptance of the limits of what one's efforts could achieve in controlling the inevitable deterioration associated with SPMS:

*... once you've done everything you can do, and you really are sort of doing as much exercise as you can do, you've looked up where you should be with drugs, the medications, this, that and the other, there isn't anything else to do but to accept it, and to be calm. **PwMS 6***

### **Living differently**

This sub-theme captures the flexible and resourceful nature in which some pwMS responded to the transition, through adapting their lives in accordance with their current and projected levels of disability. It links with the overall theme through its focus on the flexibility which characterised the responses of many pwMS described in participants' accounts. Its connection to the overall theme also lies in its capturing of the efforts of pwMS towards continued engagement in life as much as possible, albeit differently. Although often

described in positive terms, there was also a sense of inevitability and a lack of choice in some participants' accounts of this response. This is likely to have reflected the overarching power of SPMS, against which pwMS and HPs had little control.

Several pwMS described adapting their approach to everyday activities in line with their worsening disability:

*I have adapted, so I have hoodie tops with zips. I don't have cardigans with buttons that need to be done up. **PwMS 7***

The helpfulness of adapting in such a way was also reflected by a number of HPs:

*I think helpful is where people remain active. You know, where, em, they're not frightened to try and do the things they did before, but in a different way. **HP 4***

Additionally, several participants spoke about modifying their physical environment and obtaining necessary equipment to meet their needs:

*I've got a rail at the front of - at the front steps, which he put in. And I've got the stool there, which he got for me. He went around the house, and he got me a thing for - because I can't stand up in the shower anymore - so he got me a bath board to sit on. **PwMS 4***

A number of participants also described identifying alternative hobbies to replace those that they were no longer able to do. Although sometimes described as difficult given the extent of one's disability, there was a sense of necessity in participants' accounts of this process:

*... you have to think of other things. And that's been hard. That's been really hard, actually, finding other things to do - that you can do, particularly when you've got numb hands and fingers, and stuff. I mean I'm doing patchwork now... PwMS 6*

### **Drawing on support**

This sub-theme captures participants' accounts of how some pwMS turned to others for support, both practical and emotional, in coping with the transition to SPMS. In adapting to living with increasing disability, some pwMS described relying on friends and family for support with practical tasks that they were struggling with, or no longer able to do:

*I could walk the children to school, and I could pick them up, but I couldn't do any more that day..... so I became dependent on, um, my eldest child going to get them. PwMS 4*

Both pwMS and HPs regarded the presence of a supportive social network as helpful in managing the emotional and psychological impact of the condition:

*I think the people who go through that transition well generally have got a good support network, um, where there is genuinely a supportive family there, saying "you know, come on, it's really not that bad, you know, we're in this together." **HP 4***

Peer support was also regarded as helpful, although sources of such support (e.g. groups) were sometimes lacking:

*I do think that patients value meeting up with each other and getting peer support. I think, when we've put on education sessions for people I think they've possible gained more out of the peer support than they have from the information that we've given them. **HP 6***

### **Making the most of it**

The title of this sub-theme aims to encapsulate participants' accounts of optimising one's present circumstances in spite of being reclassified with SPMS. This includes encapsulation of the cultivation of positivity, gratitude and hope described by some pwMS when recounting their experiences of the transition to SPMS.

A number of participants described taking each day in turn, and not focusing too far into the future as helpful in coping with the transition:

*... some people do just take the disease as it comes and just get on with their day to day life, and will take the change in diagnosis in the*

*same way, and they'll just ... whatever happens happens, and they'll deal with it as it comes. **HP 2***

Several participants described viewing SPMS as a mere label in the context of an overall progressive illness as helpful. As captured below, viewing the reclassification in this way enabled pwMS not to worry too much about the meaning and implications of their new diagnostic category. Instead they were able to view it as a mere continuation of what they had already been experiencing:

*MS is progressive, no matter which way you do it. No matter if it's Primary, Relapsing Remitting, Secondary... um... it's all progressively deteriorating. And really the classification of it all doesn't really mean a lot. **PwMS 6***

Some participants explained that since being reclassified they had refrained from researching SPMS too much in order to avoid dwelling on what may lie ahead:

*And actually now I've been diagnosed, I haven't actually gone in to look for any more research about it. I've just carried on. In a way, I don't want to know too much about it... I'm carrying on. **PwMS 6***

A number of participants also spoke about holding onto positivity and hope about the future. Whilst some described hope about being able to maintain

their current level of functioning for as long as possible, others referred to the potential for new treatments for SPMS as a source of hope:

*Well, for me personally, it's all about looking to the future. And hope for the future, and drugs in the future. PwMS 6*

Several participants described a number of sources of gratitude in their lives, including a greater level of predictability associated with SPMS compared with RRMS, given the slow nature of progression. Others described experiencing gratitude when comparing themselves to those with greater levels of disability than themselves:

*... there's a little bit of me that thinks how lucky have I been, because I've got a friend who's got Secondary Progressive MS and she's just gone downhill quite quickly after being diagnosed. So I suppose I weigh it all up and think actually I'm very lucky. PwMS 2*

Several participants, including both pwMS and HPs, spoke about the helpfulness of making the most of one's current level of functioning so as to not miss out on opportunities:

*I've still got to make the most of the time I've got while I can walk around and do things..... So I suppose I'm still using the same strategy as I used when I was first diagnosed. Do as much as you can while you can. PwMS 2*



Some participants described doing what one is able to do, and taking pleasure in this exerting of one's independence:

*I think doing things that one is able to do. Even like things that I can do, like making a cup of tea, is - when you can do something you do it - and anyone will tell you, when they're limited in what they can do, usually, I think, they enjoy doing what they can do. **PwMS 9***

Several participants spoke about not allowing one's condition to take over their entire life. For instance, some spoke about striving towards a balance between managing one's condition and enjoying a life beyond SPMS:

*I put myself on this autoimmune paleo-diet as recommended in that book in January..... And by then I kind of got to the point where I was thinking it would be quite nice actually, if I could have a friend around for dinner, or Sunday lunch, and we could have a bottle of wine..... you've also got to enjoy life a bit, haven't you? Otherwise, what's the point of being here?.....you kind of got to find your own middle-ground. **PwMS 7***

## **CHAPTER 4: DISCUSSION**

Given the gaps in the existing literature, the current study aimed to explore the following research questions:

- 1) How do pwMS experience transitioning from RRMS to SPMS?
- 2) How do pwMS cope with this transition?
- 3) What are the needs of pwMS during this transition, and the barriers to these?

This chapter aims to summarise the findings of the current study and link these to the research aims. The findings will also be discussed in relation to existing theory and research. Finally, the clinical implications, and limitations of this study will be outlined.

### **Summary of Findings**

Four main themes were generated from participant accounts:

- Is this really happening?
- Becoming a reality
- A life of struggle
- Brushing oneself off and moving on

### **How do pwMS experience transitioning from RRMS to SPMS?**

In summary of the first research question, the period before reclassification of SPMS was characterised by pwMS noticing subtle changes in their disease pattern, and uncertainty regarding the meaning of such changes. Regardless of the extent of pwMS' expectations of SPMS, the reclassification served as a point of confirmation of one's disease status, often associated with heightened acknowledgement of one's current and projected levels of disability. This was frequently accompanied by shock and fear in relation to one's prognosis. Following the reclassification, pwMS experienced uncertainty and anxiety about the future, increasing restriction, isolation and frustration. These experiences will now be discussed in greater detail, and in relation to existing theory and research.

#### ***Uncertainty***

Uncertainty emerged as a key theme throughout the transition, both in advance of, and following the reclassification of SPMS. Uncertainty in relation to one's illness has been shown to be associated with poor adjustment in MS (e.g. MnNulty, Livneh, & Wilson, 2004). Its emergence in the period before the reclassification, as pwMS gradually became aware of changes in their disease pattern, appeared to stem from the often subtle nature of such changes, inhibiting pwMS' ability to make sense of these changes. These results built on those of Hourihan (2013) who did not describe a sense of uncertainty in response to such changes. These findings are echoed by qualitative studies of pwMS' experiences of the initial MS diagnosis however,

which reported feelings of uncertainty about one's diagnosis during the pre-diagnostic phase of the disease (Koopman & Schweitzer, 1999; Johnson, 2003; Edwards et al., 2008). Compared to becoming aware of novel symptoms during the pre-diagnostic phase of MS, leading pwMS to seek professional support (e.g. Edwards et al., 2008), the subtle and transient nature of the changes during the transition made it difficult for some pwMS to be certain if their disease had in fact changed.

Mishel's (1988) theory of uncertainty in illness may serve to clarify the uncertainty associated with the pre-reclassification stage, described above. This theory resonates with Leventhal's (1984) self-regulation model, which proposed that individuals tend to actively construct their own representations of their illness. Mishel (1984) argued that uncertainty arises from situations where one is unable to assign a definite value to items or events and/or is unable to make accurate predictions regarding outcomes. Mishel (1988) proposed that uncertainty stems from three components: symptom pattern, event familiarity, and event congruence. The term 'symptom pattern' refers to the degree of consistency of one's symptoms, which determines one's ability to detect a particular symptom pattern and attribute meaning to this. The subtle, transitory nature of the changes described by participants is likely to have inhibited pwMS' ability to detect a consistent pattern, and attribute meaning to such changes with much confidence. Establishing greater consistency as their disease progressed over time may have potentially increased pwMS' ability to make sense of such changes, enabling them to consider the possibility that they were transitioning to SPMS.

The second component of illness uncertainty, according to Mishel (1988), is 'event familiarity', or the extent to which one is familiar with a particular symptom pattern. Familiarity, according to this theory, enables one to connect current events to previous similar experiences stored in memory, through which meaning may be derived. Given the novel nature of the SPMS pattern for pwMS, a lack of previous similar experiences with which to compare their current symptom pattern may have further contributed to uncertainty regarding the meaning of observed changes.

Finally, 'event congruence,' according to Mishel, refers to the degree of consistency between one's expectations, and current experience, of illness. High levels of congruence facilitate interpretation and understanding of one's illness experience, whilst low levels inhibit such processes. Whilst some pwMS appeared unaware of the possibility of the transition, which may have stemmed from a lack of preparatory education (Hourihan, 2013), it is also plausible that knowledge of the fact that not all pwMS transition to SPMS may have resulted in low expectations of transitioning to SPMS among some pwMS. In accordance with this theory, these factors are likely to have hindered pwMS' ability to make sense of the changes in their disease pattern. Conversely, awareness of the common nature of this transition may have underpinned other pwMS' expectations of it, enabling them to begin making sense of these changes, and attribute them to SPMS.

As stated, uncertainty also emerged following the reclassification itself. This appeared to stem from the variable nature of SPMS, leading to uncertainty regarding one's projected rate of deterioration, once again reflecting Mishel's

(1984) conceptualisation described above. Throughout the transition, uncertainty was often accompanied by anxiety. According to Miceli and Castelfranchi's (2005) conceptual framework, anxiety is an emotional response to uncertainty regarding the outcome of events, or one's ability to handle a potential threat. Furthermore, perceived lack of control over potential threats has been linked to the establishment of anxiety (Barlow, 2002). Given pwMS' uncertainty and lack of control over the course of their condition, these conceptualisations may serve to clarify participants' accounts of anxiety that accompanied the uncertainty associated with the transition.

### ***The role of expectation***

As highlighted above, for some pwMS, the reclassification was completely unexpected, with some participants reporting a lack of pre-existing awareness of the potential for transitioning to SPMS. These results reflect those of Hourihan (2013) who found that the majority of participants had not been expecting to be reclassified, and had not been aware of the potential for this. A lack of expectation of being reclassified was likely to have contributed to some pwMS' feelings of shock on receipt of this news. Feelings of shock in response to the initial diagnosis of MS have also been reported (e.g. Johnson, 2003). The degree of shock associated with the reclassification was sometimes described as comparable to that experienced at the initial MS diagnosis. This may have stemmed from the extent of pwMS' lack of expectation of being reclassified which, as discussed above, may have been underpinned by factors such as a lack of 'event familiarity' and 'event congruence' (Mishel, 1988), described above. This may have stemmed from

a lack of sufficient preparatory education about the transition (Hourihan, 2013).

Whilst the reclassification was unexpected for some, for others it was more expected, and described as less of a shock. Hence this study demonstrated a wider range of responses to the reclassification than Hourihan (2013), who found that the reclassification had been unexpected for all participants. These results are reflected by research regarding the experience of the initial MS diagnosis, which indicated that prior suspicions of being diagnosed with MS appeared to mitigate against shock on being diagnosed (e.g. Johnson, 2003). Miceli and Castelfranchi (2005) suggest that by anticipating a negative outcome, individuals may be somewhat buffered against its occurrence, as one would have had already come to terms with it to some extent. This may explain why some participants reported that they had not been particularly shocked in response to the reclassification. In spite of the mitigating effect of prior expectations, the news of the reclassification often still resulted in fear and distress among many pwMS. Similar emotions have been reported in response to the initial MS diagnosis (e.g. Johnson, 2003; Edwards et al., 2008), and in response to the reclassification (Hourihan, 2013). This suggests that prior expectations of SPMS may not entirely mitigate against negative emotional responses to the reclassification itself. This is likely to reflect the significance of the reclassification itself for pwMS, which will now be discussed.

### ***The role of the diagnostic label***

For many pwMS the reclassification served as a turning point, enabling them to make sense of the changes in their disease pattern. This sense of clarification provided by the SPMS diagnosis was also reflected by Hourihan's (2013) results. According to Charmaz (1995), for those who have been struggling with chronic illness, provision of a diagnostic label may serve to legitimise one's illness experience, and enable redefining of one's illness. Legitimation provided by diagnostic labels has also been reported elsewhere (e.g. Meyer, Leventhal & Gutmann, 1985). Regardless of the extent of pwMS' prior expectations of transitioning to SPMS, the reclassification signalled a need to acknowledge their condition, and make necessary adjustments. This latter finding was not reported by Hourihan (2013), and hence appears to be unique to the current study. According to Charmaz (1995) once one's illness has been redefined through receipt of a diagnosis, individuals may adapt to their condition through comparing their current and former degrees of impairment, revising their goals, and altering their identity in line with the degree of impairment stemming from their condition. Charmaz argued that this forms part of the process of adapting to chronic illness.

For some, the reclassification was accompanied by a sense of relief, which may have stemmed from legitimisation of the extent of one's disability provided by the reclassification. For some, such legitimisation may have signalled a form of permission to relinquish many of the roles that pwMS had been struggling with up until the point of reclassification, and to make adjustments in line with the extent of their disability. According to Charmaz



(1995) given the importance of goals linked to one's identity, individuals will strive to maintain such goals until forced to relinquish them by the effects of chronic illness. It is possible that pwMS' previous hesitance to relinquish such roles may have been underpinned by Western societal values regarding the importance of activity and productivity (Murphy, 1995). For some, the reclassification of SPMS appeared to signal sufficient reason for making such adjustments. Additionally, given the intolerable nature of uncertainty (Miceli & Castelfranchi, 2005), pwMS' relief on being reclassified may have reflected the alleviation of uncertainty provided by the reclassification. Although relief has been reported in response to the initial MS diagnosis (e.g. Edwards et al., 2008), this was not reported by Hourihan (2013) in relation to the reclassification of SPMS. Relief was also not included in Dennison et al.'s (2009) model of adjustment, which posited that critical events initially lead to distress and disruption of pwMS' well-being.

### ***Loss and frustration***

The transition was also often accompanied by a sense of loss, stemming from the deterioration in pwMS' ability to conduct their lives as before. In contrast with the periodic regaining of functioning associated with RRMS, the irreversible deterioration inherent in SPMS meant that many pwMS were forced to permanently withdraw from valued activities. As a result, many experienced heightened isolation, sadness and grief. This finding reflects those of Hourihan (2013) who reported grief in response to loss of participation in meaningful activities as a result of the transition to SPMS. A sense of loss has also been reported in response to the initial diagnosis of MS

(e.g. Miller, 1997), and in relation to living with MS across the disease trajectory (e.g. Wollin et al., 2006; Edmonds et al., 2007). Grief is commonly regarded as a normal response to loss of physical function (Stewart & Shields, 1985), which may reflect consequent losses and revision of one's goals and identity (Charmaz, 1995).

Like Hourihan (2013), the current results demonstrated frustration among pwMS in response to the irreversibility of SPMS, the unwanted adjustments imposed by the transition, and deterioration in pwMS' ability to pursue meaningful activities and goals. Frustration has also been reported in response to the diagnosis of RRMS (e.g. Edwards et al., 2008; Dennison et al., 2010), although this was reported to stem from disappointment at how the diagnosis was communicated. This study builds on previous results, by reporting additional frustration arising from a lack of disease modifying treatments for SPMS, and delays in service provision.

### **How do pwMS cope with the transition?**

In summary of question two, the results indicated a wide range of cognitive and behavioural responses to the transition to SPMS. Some of these were described as helpful by participants in coping with the transition, in enabling pwMS to adjust and move forward with their lives in spite of the transition. Other coping strategies were referred to as suboptimal, or even maladaptive however, perhaps inadvertently leading to increased distress and difficulty in the long term. The responses of pwMS to the transition will now be discussed in relation to Dennison et al.'s (2009) model of adjustment, and other theory

and research.

### ***Avoidance***

Some pwMS responded to the transition via avoidant emotion-focused coping, which, according to Dennison et al.'s (2009) model, is associated with poor adjustment outcomes. Prior to the reclassification some pwMS attempted to ignore the changes in their disease pattern, or denied that these changes were due to SPMS. Attributing these changes to causes other than SPMS may have reflected a process of 'displacement' described by Miceli and Castelfranchi (2005), whereby individuals attempt to transfer anxiety stemming from uncertainty onto more definite and controllable objects. This may enable people to direct their attention away from threats which they sense, but which are deemed too frightening to face, onto more controllable, less overwhelming sources. Threats to one's self-worth, such as those which impact on one's ability to pursue goals from which one derives self-esteem, are particularly threatening, according to Miceli and Castelfranchi. The irreversible deterioration in physical and cognitive abilities associated with SPMS may have been highly threatening to pwMS in this regard. This may have been underpinned by Western societal values and ideals regarding strength, health, and independence, which are in direct opposition to the nature of disability (Murphy, 1995). As a consequence, pwMS may have displaced their anxiety onto less threatening, more controllable explanations, such as the effects of a relapse or insufficient physiotherapy.

Such responses may also have represented pwMS' efforts to repress thoughts about the possibility of SPMS. A body of literature has highlighted

individual variability in people's responses to threat, including a tendency towards denial, or 'repression', of potential threat (e.g. Lomont, 1965; Lazarus & Alfert, 1965). 'Soldiering on' among some pwMS may have reflected such individual variability. Research has indicated that although 'repressers' may report low levels of anxiety, they demonstrate higher levels of autonomic disturbance than individuals with a low tendency towards denial (Lomont, 1965).

Following the reclassification, some pwMS attempted to ignore the reality of SPMS and its implications. This finding was not demonstrated by Hourihan (2013), although accounts of individuals refusing to admit the losses resulting from their chronic illness do exist (Albrecht, 1992; Herzlich, 1973; Radley & Green, 1987). This response may have reflected a process of 'struggling against illness' (Charmaz, 1995, p. 663), where people refuse to accept the irreversibility of the losses they have suffered as a result of chronic illness. According to Charmaz (1995), individuals may ignore their illness when it exerts minimal effects on their life, when they can control its effects, or when other goals take precedence over their illness. As one's illness progresses however, people may increasingly struggle to ignore its implications. In response, some pwMS demonstrated resistance against the progression of their MS, and strove to identify ways of alleviating this. This is reflected by Charmaz (1995), who highlighted how some individuals with chronic illness may hold onto the hope of regaining lost health and functioning in spite of the unlikelihood or impossibility of this. According to Charmaz, struggling against one's illness may reflect resistance against incorporating one's disability into

one's sense of self, which hinders adjustment to one's condition. This resonates with literature regarding prolonged grief, which acknowledges the normative nature of responses, such as protest and denial, against unwanted losses (Bowlby, 1961; Goodall et al., 2003), but argues that if prolonged, such responses may inhibit adaptation and lead to chronic dysfunction (Prigerson et al., 2013).

Escapism through drugs and alcohol was used by some pwMS in response to the transition, and may have further reflected the difficulty they faced in accepting the irreversibility of their condition. Murphy (1995) argued that people with physical disabilities may experience a range of negative emotions as a result of not meeting internalised cultural ideals. This was reflected by participants' descriptions of feeling distressed and overwhelmed in response to new stages of disability. It is possible that substance use provided pwMS with a temporary means of escape from such difficult emotions. Coping through avoidance and/or escape has been shown to be related to poor outcomes for psychological well-being and quality of life in MS (McCabe, McKern, & McDonald, 2004; McCabe, 2006).

### ***Cognitive appraisal***

There was some variation in pwMS' appraisals of the meaning and implications of having SPMS. According to Dennison et al.'s (2009) model, an individual's appraisal of MS has consequences for their adjustment to the condition. Appraisal, in this context, is defined as one's interpretation of a stressor, its associated degree of threat, challenge and controllability (Lazarus & Folkman, 1984). For some, SPMS was viewed as an unstoppable force

against which one was entirely powerless. This appeared to be associated with a loss of self-efficacy and a sense of giving up, or assuming an entirely passive stance towards disease progression. This is likely to have stemmed from the nature of SPMS which, in contrast with RRMS, is associated with irreversible deterioration and withdrawal of treatment. Indeed, low self-efficacy has been shown to be linked with a reduction or ceasing of one's efforts to persist in the face of obstacles (Bandura & Schunk, 1981). Similarly, illness representations comprising beliefs of lack of personal control over the illness, and perceptions of severe illness consequences have been shown to be associated with worse adjustment in MS (Moss-Morris, Weinman, Petrie, Horne, & Cameron, 2002). Furthermore, helplessness has been shown to be a strong predictor of depression in MS, even after controlling for disease severity (Shnek et al., 1997; Shnek et al., 1995).

By contrast, viewing SPMS as a mere label in the context of an overall progressive condition may have enabled pwMS to draw upon their existing experiences and resources, and apply these to coping with the transition. Although Dennison et al.'s (2009) model regarded positive reappraisal as beneficial for adjustment to MS, this specific appraisal was not included in their model, given its relevance to the transition itself. This finding was not demonstrated by Hourihan (2013), and appears to be unique to the current study. Such an appraisal of one's condition may have reflected a degree of adjustment to MS preceding the reclassification, which will now be discussed.

## ***Acceptance***

A key finding was that pwMS' prior adjustment to life with MS may have buffered pwMS against the impact of the reclassification. This was in contrast to the initial diagnosis of MS, prior to which pwMS would have had no experience of living with, and adjusting to, MS. This finding was not reported by Hourihan (2013), or included in Dennison et al.'s (2009) model, and appears to be unique to the current study. While this may have been due to knowledge about MS and familiarity with MS services, it may also have reflected a process of adjustment to the disease in advance of the transition to SPMS. According to Charmaz (1995) adapting to chronic illness involves altering oneself and one's life to accommodate its associated changes and losses, and creating a new sense of self which accounts for one's degree of impairment. Charmaz highlighted how, after many years of attempting to ignore or struggle against one's illness, some, but not all, people begin a process of adapting to illness. This process may have enabled pwMS to adjust to the reclassification, given previous accommodation and altering of their sense of self in line with their MS.

Adaptation to, and acceptance of, one's condition are closely related concepts, according to Charmaz (1995). Several participants described reaching a point of acceptance of their condition, either in advance of, or following, the reclassification. Acceptance of disability, which is often viewed as a marker of psychological adjustment (Antonak & Livneh, 1995; Charmaz, 1991; Li & Moore, 1998), has been shown to be associated with better quality of life and health outcomes in MS (Burton, 1995; Stuifbergen, Seraphine, &

Roberts, 2000). In light of this, acceptance of one's illness was described in Dennison et al.'s (2009) model as related to successful adjustment in MS.

This association may be understood in light of a link between higher levels of acceptance and health-promoting behaviours, resulting in greater well-being (Stuifbergen et al., 2000).

Some pwMS responded to the transition by adapting their lives in line with their degree of disability, such as by obtaining necessary equipment to meet their needs, and identifying alternative activities. This finding was demonstrated by Hourihan (2013), as well as by studies exploring the experience of living and coping with MS in general (e.g. Reynolds & Prior, 2003). Like Hourihan, the current study reported a sense of lack of choice in relation to such adaptation. Dennison et al. (2009) regarded acceptance of one's condition, including integration of necessary changes into one's way of life, as beneficial for adjustment. Similarly, altering one's identity and goals in the face of irreversible disability forms part of the overall adjustment process according to Charmaz (1995).

### ***Problem-focused strategies***

The use of problem-focused strategies (i.e. strategies aimed at reducing the source of stress) emerged at various points during the transition. As discussed in the Introduction, Dennison et al. (2009) regarded such strategies as beneficial for adjustment to MS. For instance, in response to the uncertainty regarding changes in their disease pattern described above, some pwMS attempted to prepare themselves for transitioning to SPMS, and sought confirmation of a SPMS diagnosis from their MS team. Such responses may



have represented pwMS' attempts to reduce uncertainty, which, according to Miceli and Castelfranchi (2005), is intolerable, and may lead individuals to seek certainty, even if its implications are negative.

As demonstrated, the transition involved a range of unwanted changes which were outside pwMS' control. Charmaz (1995) proposed that adjustment entails ceasing one's struggle to control one's illness, whilst striving to maintain as much independence as possible. Letting go of struggling against what was outside of one's control was sometimes balanced with a focus on areas within one's control, such as diet, exercise and engagement in physiotherapy. These may have represented problem-focused strategies, given their aim of reducing the rate of the inevitable deterioration in SPMS. A number of studies have found that adjustment was positively correlated with self-efficacy regarding management of one's MS symptoms (Riazi, Thompson, & Hobart, 2004; Shnek et al., 1997). Given limited control over one's SPMS, focusing on doing what one could to manage their symptoms may have been associated with enhanced self-efficacy, enabling adjustment.

### ***The role of social support***

The results highlighted the value of social support in coping with the transition. This was also reported by Hourihan (2013), as well as by qualitative studies exploring the experience of MS in general (e.g. Kirkpatrick-Pinson et al., 2009). A number of quantitative studies have also demonstrated a relationship between social support and better adjustment in MS (e.g. Pakenham, 1999; McCabe, 2006). The current results also reflect Dennison et al.'s (2009) model, which regarded seeking social support as beneficial for

adjustment. Conversely, some pwMS responded to the transition by withdrawing from others, and refusing their support, which may reflect a form of avoidance and struggling against one's illness, discussed above.

### ***Optimism, hope and benefit-finding***

Cultivation of positivity, gratitude and hope emerged as another potential response to the transition. Although not reflected by Hourihan's (2013) findings, coping through maintaining a sense of optimism, hope and benefit-finding has been demonstrated in relation to living with RRMS (e.g. Koopman & Schweitzer, 1999) and throughout the MS trajectory (e.g. Reynolds & Prior, 2003). Dennison et al. (2009) posited that such responses are associated with successful adjustment in MS.

For instance, Charmaz (1995) argued that in spite of needing to form new identities which account for one's increased restriction, individuals with chronic illnesses may often identify positives and value in their restricted lives. Similarly, Evers et al. (2001) proposed that the ability to identify benefit in one's illness is associated with positive long-term outcomes. Benefit finding is regarded as an adaptive coping strategy whereby people positively evaluate their circumstances in spite of adversity (Pakenham, 2005). It is possible that, in the face of adversity, benefit finding may be culturally anticipated as a means of seeking maturation and growth (Tennen & Affleck, 2002). Several participants described gratitude when comparing themselves to those less fortunate than themselves. Downward comparison theory suggests that when under threat, people may enhance their subjective well-being through making downward social comparisons (Wills, 1981). Enhancing or restoring of one's

self-esteem through comparing oneself to those with greater levels of difficulty has been demonstrated in chronic illness (Taylor, 1983).

Research has also demonstrated a link between optimism about the future and better adjustment outcomes in MS (de Ridder et al., 2000; Fournier et al., 2002). Such findings may be understood as a result of optimists' tendency to continue with adaptive activities when confronted with adversity (Carver et al., 1993). According to hope theorists, positive emotions are driven by the belief that one can find pathways and the required motivation to achieve desired goals (Snyder, Rand & Sigmon, 2002). Taylor's (1983) cognitive theory of adaptation posits that optimistic beliefs about one's prognosis are conducive towards good mental health, even if such beliefs are proven to be unrealistically optimistic. By comparison, according to Groopman (2004), 'true hope', as opposed to naïve optimism, involves incorporating acknowledgement of potential threats into one's optimistic perspective, and is also associated with heightened well-being. Participants' accounts of hope may have reflected a mixture of naïve and true hope, given variability in pwMS' acknowledgement of the implications of SPMS.

Making the most of one's current circumstances, in spite of the transition, was described as helpful by several participants. This included making the most of one's current level of functioning and independence, which has been demonstrated by other studies of the experience of living with SPMS (Olsson et al., 2010), and MS in general (e.g. Reynolds & Prior, 2003). This finding was not demonstrated by Hourihan (2013), however. A few participants spoke about how, in spite of transitioning to SPMS, they strove not to allow

their condition to take over their entire lives. According to Charmaz (1995) successful adaptation to chronic illness entails living with the illness whilst not allowing it to entirely dominate one's life. Successful adaptation, in this sense, means that individuals maintain whatever level of independence and autonomy that their condition permits. Related to this, several participants described focusing on taking each day at a time, as opposed to worrying about the future, as helpful in managing the transition. According to Dennison et al.'s (2009) model, catastrophizing is associated with poor adjustment outcomes, and has been shown to be positively correlated with depression in MS (Shnek et al., 1997; Shnek, Foley, LaRocca, Smith, & Halper, 1995).

### **What are the needs of pwMS during the transition, and the barriers to these?**

In summary of the final research question, the results highlighted a range of unmet needs of pwMS throughout the transition process, including sufficient provision of information, both in advance of, and at the point of, reclassification, adequate time and care in communicating the reclassification, and support following the transition. Barriers to meeting these needs stemmed primarily from factors related to HPs and service limitations. The findings suggested that in terms of support from services, the transition may be a relatively neglected area compared with the initial diagnosis. These needs and barriers will now be discussed in turn.

#### ***Pre-reclassification***

As reported by Hourihan (2013), whilst education across the disease

trajectory is recommended as best practice in MS care (NICE, 2003), provision of sufficient preparatory education about the transition was sometimes lacking. This appeared to contribute to some pwMS' sense of shock on being reclassified. A number of challenges for provision of preparatory education were suggested by the results. Several participants acknowledged how difficult it may be for some pwMS to process such news, particularly around the time of the initial MS diagnosis. Some suggested that whilst such education is important, it may be more appropriate following the initial MS diagnosis, once pwMS have had time to come to terms with their MS diagnosis. As discussed under 'Future Research', careful consideration of the timing of such education is paramount, given the potential distress associated with receipt of such news.

Additionally, many pwMS experienced a sense of delay on the part of HPs in providing clarification regarding the changes in their disease pattern via reclassification. Although this was not reported by Hourihan (2013), research has reported delays in receiving the initial diagnosis of MS, as pwMS seek clarification and legitimization of their symptoms (Edwards et al., 2008; Kralik, Brown, & Koch, 2001).

Both of these findings may have been underpinned by several factors. Whilst the unpredictable and variable nature of MS may have contributed to delays in reclassifying patients, HPs' desire to protect pwMS against the potential impact of bad news may have played a role. This is reflected by research regarding the initial MS diagnosis which highlighted the role of uncertainty in diagnostic test results, and HPs' desire to protect pwMS from the full truth

about their diagnosis, in contributing to delays in communication of the diagnosis (Elian & Dean, 1985; Mushlin et al., 1994). HPs' desire to protect pwMS from worry and distress may also have influenced provision of preparatory education about the transition.

The results suggested that the process of communicating with pwMS about the transition was difficult for some HPs. These findings are echoed by studies indicating that the process of giving bad news to patients is potentially stressful for HPs, and may relate to their well-being (Buckman, 1984; Holland, 1989). It is possible that the emotional impact of this role on HPs may have further influenced provision of preparatory education, and contributed to delays in reclassifying subsequent patients.

### ***Reclassification***

The manner in which the reclassification is communicated was regarded as important by most participants. Research demonstrates that the quality of communication between patients and HPs may influence patients' abilities to manage their symptoms and maximise their overall health (Buckley, Vacek, & Cooper, 1990; Simpson et al., 1991; Thorne, 1993). Furthermore, the nature of communication from professionals regarding MS may have the potential to increase or mitigate fear about one's prognosis (Thorne et al., 2004).

Providing pwMS with a sense of hope about the future, allowing sufficient time and privacy for communication, continuity of care, and demonstrating empathy were also regarded as helpful, but sometimes lacking, by several participants. This echoes the results of Hourihan (2013), as well as studies suggesting pwMS' desire for care and reassurance during the initial MS

diagnosis process (e.g. Kralik et al., 2001). This may be important in the transition, given the relative lack of such support compared with the initial diagnosis suggested by the results, as well as the distress and hopelessness often associated with the transition. It is likely that service resource limitations partly underpinned these findings. Reports of a lack of empathy among some HPs may have also arisen from a degree of emotional detachment, due to the difficult nature of relaying bad news to patients (Statham & Dimavicius, 1992; Ptacek, Fries, Eberhardt, & Ptacek, 1999).

### ***Since reclassification***

Some pwMS remained uncertain about the implications of SPMS following the reclassification, which also reflected Hourihan's (2013) results. These findings were in spite of the fact that education across the disease trajectory is recommended as best practice in MS care (NICE, 2003). Immediate access to information following diagnosis has been reported as crucial for allaying pwMS' fear about their prognosis (Thorne et al., 2004), and enabling patients to make sense of their illness experience and participate in active management of their condition (Ziebland, 2004). Although provision of sufficient and accurate information about MS and its management has been shown to be a common problem for pwMS throughout the disease trajectory (Baker, 1998; Somerset, Campbell, Sharp, & Peters, 2001), the current results suggested a relative lack of this in relation to the reclassification, compared with the initial diagnosis.

Follow-up support and signposting were also regarded as crucial, but often lacking by many participants. This reflects the findings of Hourihan (2013),

and studies of the initial MS diagnosis (e.g. Thorne et al., 2004). As suggested by Olsson et al. (2010), identifying ways to maintain engagement in meaningful activities is important in helping people cope with SPMS. Fleming-Courts et al. (2004) highlighted a need for rehabilitation at points of change in MS. The current results and those of Hourihan (2013) suggested that compared with the initial diagnosis, follow-up support and signposting following the reclassification of SPMS could be particularly poor. As suggested by Hourihan (2013) a sense of impotence among HPs in the face of SPMS may have possibly contributed to this. The current study suggested that availability of a specialised clinic aimed at supporting pwMS through the transition may have been one potential remedy to a lack of perceived support surrounding the transition. Given the emotional impact of the reclassification for many pwMS, providing pwMS with an option of immediate follow-up support following the reclassification (e.g. a debriefing session with a MS nurse) may have proved helpful. Referring patients to sources of support to meet their physical, psychological, and practical needs was regarded as crucial.

### **Theoretical Implications**

As demonstrated, many of the current results resonate with Dennison et al.'s (2009) model of adjustment to MS. Additionally, a number of key findings have been identified which appear to be unique to the transition. Such findings will now be summarised in relation to Dennison's model.



The process of becoming aware of changes in one's disease pattern, and the experience of being reclassified, were both often associated with uncertainty, anxiety and distress among pwMS. As a consequence, one could argue that the transition to SPMS may potentially involve two 'critical events' (Dennison et al., 2009), given their associated disruption to pwMS' emotional equilibrium. The extent of the disruption associated with the reclassification arose, in part, from how pwMS had previously made sense of, and responded to, becoming aware of the changes in their disease pattern. Greater expectations of transitioning to SPMS appeared to mitigate against the impact of being reclassified. The likelihood of such expectations may have been influenced, in part, by the extent of preparatory education provided by HPs. This, in turn, was often influenced by HPs' desire to protect pwMS from distress associated with such news.

The extent of the disruption stemming from the reclassification was also influenced by the degree of pwMS' previous adjustment to MS. Prior adjustment to MS appeared to buffer pwMS against the impact of the reclassification. Although Dennison et al. (2009) acknowledged the influence of one's previous life experiences on one's beliefs, values and behaviours, it did not include such a buffering effect. This is due to the model's primary focus on the initial diagnosis of MS, prior to which pwMS would not have previous experiences of adjusting to MS to draw upon. Hence, an extension of Dennison et al.'s model in relation to the transition is proposed, which incorporates this buffering effect, including psychological preparation for the transition and acceptance of one's MS prior to the reclassification.

Dennison et al. (2009) proposed that critical events initially lead to negative psychological consequences, such as emotional distress. However, the current findings demonstrated that in addition to negative emotional responses, the reclassification of SPMS was also sometimes accompanied by initial feelings of relief. Hence, incorporation of this potential response in relation to the transition is proposed.

As discussed, Dennison et al.'s model viewed positive appraisals of MS as beneficial for adjustment. The current findings suggested that viewing SPMS as a mere label within the context of an overall progressive illness may have enabled pwMS to draw on their existing experiences and resources when coping with the transition. Hence, this particular appraisal appears to be uniquely relevant to the transition.

### **Implications for Clinical Practice**

A key finding was the variation in pwMS' appraisal of the transition to SPMS. As a result clinicians ought to explore individual appraisals of the transition, given the consequences of such appraisals for pwMS' coping responses to the transition. Additionally, in light of the buffering effect that previous adjustment to MS had against the impact of the transition, it would be helpful to explore pwMS' existing resources and coping strategies. This could enable supporting pwMS to draw upon such resources in coping with the transition. Fraser, Kee and Minick (2006) highlighted the value of recognising and building upon patients' existing experiences and coping mechanisms for managing chronic illness. Such input may potentially enable pwMS to

reappraise the transition as merely another label in the context of an overall progressive illness, and lead to a sense of empowerment through recognising the experiences and resources that they have already developed in coping with MS.

Given that peer support was regarded by some participants as potentially helpful in coping with the transition, provision of peer support interventions in this context may prove useful. Some evidence indicates the potential value of peer support for pwMS' quality of life and depression levels (e.g. Mohr, Burke, Beckner & Merluzzi, 2005). However, other research suggests that peer support (e.g. support groups, telephone support) may place those with better mental health at risk for deterioration in such groups (Uccelli, Mohr, Battaglia, Zagami, & Mohr, 2004). Whilst peer support interventions may benefit those with affective problems (Schwartz, 1999), groups aimed at developing pwMS' coping skills may prove more beneficial for pwMS with fewer affective problems (Schwartz, 1999).

CBT has emerged as an effective approach for treating mood disorders in MS (e.g. Mohr, Boudewyn, Goodkin, Bostrom, & Epstein, 2001). As suggested by Dennison et al. (2009), it is recommended that when working with pwMS clinicians ought to remain mindful of the coping responses associated with successful and unsuccessful adjustment. For instance, given the potential for apathy and withdrawal as a result of the transition to SPMS, aspects of CBT such as modified behavioural activation and challenging unhelpful appraisals and cognitive errors may prove useful.

PwMS' avoidance of, and struggling against, the transition may mirror the concept of 'experiential avoidance' (Hayes, Wilson, Gifford, Follette & Strosahl, 1996), which involves deliberate attempts to avoid or escape unpleasant private experiences. Such responses become problematic when they interfere with one's ability to engage in behaviours that are in line with one's values, according to Hayes et al. (1996). Therapeutic approaches such as Acceptance and Commitment Therapy (ACT; Hayes, Strosahl & Wilson, 1999) may facilitate a reduction in unhelpful experiential avoidance, through enabling clients to live in line with their values in spite of unwanted experiences. Preliminary evidence supports the usefulness of ACT in enhancing pwMS' psychological well-being (e.g. Nordin & Rorsman, 2012). Given increasing restriction in their ability to pursue goals as a result of the transition, identifying pwMS' broader values and enabling them to pursue these via alternative avenues in line with their disability, may prove valuable. Furthermore, in light of the potential for catastrophizing about the future in response to the uncertainty associated with the transition, approaches such as ACT (Hayes et al., 1996), and mindfulness (Kabat-Zinn, 1990) may enable pwMS to gain contact with the present moment and lessen such cognitive processes. Mindfulness approaches have also emerged as beneficial for pwMS' quality of life and well-being (e.g. Grossman et al., 2010).

The results highlighted a number of issues related to HPs which may have posed barriers to meeting the needs of pwMS during the transition. As a consequence, HPs may benefit from psycho-education regarding the psychological impact of the transition on pwMS. This could include education

about the potential variation in pwMS' responses to the transition, in order to overcome any biases or misunderstandings among HPs. Furthermore, HPs may benefit from training around sensitive and appropriate communication of the reclassification. Given the impact that delivering the news of the reclassification can have on HPs themselves, and how this may potentially impact on their subsequent interactions with patients, they may also benefit from emotional support, such as education about coping skills (Ptacek et al., 1999), or supportive counselling (Levenstein, 1987).

### **Critical Review**

The aim of this study was to gain rich insight into the experiences of pwMS during the transition to SPMS. As a result of the limited sample size and cross-sectional nature of this study, the generalisability of the results in relation to the wider MS population cannot be determined, and causality cannot be inferred. However, consistency between the accounts of pwMS and HPs, and between many of the current findings and existing research suggest a degree of applicability of the current results.

Given that participants were recruited purposively, participants were essentially self-selecting, which may have led to further bias. Whilst the results demonstrated divergence, it is possible that the degree of heterogeneity of experiences was compromised due to individuals choosing not to participate. Consequently, it could have been useful to record the number of potential participants that were approached in order to potentially establish reasons underlying individuals' choices not to participate.

The fact that participant accounts were generated retrospectively may have affected participants' recall of events. However, as the majority of pwMS were recruited within 12 months of being reclassified with SPMS, this hopefully reduced recall bias somewhat.

Service-user involvement in the development of the interview schedule enabled generation of questions that were relevant, sufficiently open, and ordered appropriately. Furthermore, the use of semi-structured interviews allowed participants to generate rich, and detailed accounts. As with all semi-structured interviews there may have been a potential for participants to generate socially desirable responses (Brink, 1989). However, several participants indicated that they had benefited from being listened to, and often brought up sensitive issues themselves. This suggests that the interviews created a sufficiently safe, empathic environment which hopefully reduced socially desirable responses.

Inclusion of HPs enabled generation of a broad range of data. Comparison of pwMS' and HPs' accounts may have further highlighted barriers to meeting the needs of pwMS during the transition. Guest et al. (2006) argued that in order to establish differences between groups in qualitative research, a minimum of twelve participants per groups is required. The time constraints of this project did not allow for recruitment of sufficient numbers of pwMS and HPs to carry out such a comparison.

Member validation checks, where the researcher checks their analysis with the participants is often recommended in order to maintain quality in

qualitative research (Yardley, 2000). Given time and resource constraints however, this was not possible. Instead the validity of the analysis was checked through peer analysis of interview transcripts, which enabled cross validation, as well as integrating peer and supervisor feedback into theme organisation and titles. Peer and supervisor review of the themes is also likely to have contributed to greater internal coherence and consistency within themes (Braun & Clarke, 2006).

Braun and Clarke (2006) highlighted a number of potential pitfalls in TA, including failure to analyse the data beyond its surface content, and use of the interview schedule questions as the 'themes' that are reported. This study was strengthened by its degree of interpretation of the data, such as through linking it with existing literature, as well as its use of participants' language in the construction of theme labels. Other potential pitfalls may include insufficient examples of data in support of each theme, and a lack of consistency between the analytic claims and the data itself (Braun & Clarke, 2006). As demonstrated by the Results section, a substantial number of participant quotes were provided in support of each theme. Furthermore, the process of reviewing the themes in relation to the entire dataset (discussed in the Methods section) is likely to have strengthened the degree of consistency between the data and the interpretive claims made.

### **Future research**

In light of the limitations, prospective, longitudinal studies examining whether psychological coping factors precede and predict successful and unsuccessful

coping with the transition to SPMS would be useful. In particular, studies which investigate multiple psychological factors may enable identification of the most powerful psychological predictors of coping success. Identification of interactions between psychological factors and other factors, such as demographics, illness severity, and so forth, could allow identification of direct, mediator and moderator influences. The substantial time and resources required for such a study are acknowledged.

In light of the needs of pwMS highlighted by this study, examining the benefit of specific forms of interventions aimed at enhancing supportive mechanisms and addressing unmet needs throughout the transition would be useful. For instance, examining the impact of preparatory education about the transition (e.g. a booklet) on the well-being of pwMS who later undergo the transition could be useful. Although the current results suggested that it may be appropriate to provide such education following the initial MS diagnosis, the optimal timing of such education requires further investigation, given the potential for distress arising from this news. Additionally, the helpfulness of specific forms of follow-up support following the reclassification, such as providing pwMS with the option of an immediate debriefing session with a MS nurse, and provision of peer support interventions, could be useful. Finally, the impact of provision of specialist clinics aimed at addressing the specific needs of pwMS throughout the transition is warranted.

Finally, the accounts of a number of participants highlighted a number of challenges posed to family members by the transition. Such accounts were not included in the final analysis, given the nature of the research questions.



However, these accounts highlighted the value of research exploring the experiences and needs of pwMS' family members, in order to identify means of better supporting them through this process.

## **Conclusions**

The present study explored the experiences of transitioning from RRMS to SPMS, including the coping and needs associated with this transition. Nine pwMS and seven HPs were interviewed and transcripts were analysed using TA.

In summary, although not a discreet stage in itself, the transition to SPMS involved moving from uncertainty regarding subtle changes in pwMS' disease pattern, towards confirmation of their disease status. Such confirmation often served as a turning point for pwMS, leading to heightened acknowledgement of their condition. The reclassification was associated with a range of emotional responses, including shock and fear about one's prognosis. The transition posed a number of challenges for the well-being of pwMS, including a reduction in treatment options, increasing restriction and isolation, and uncertainty regarding one's projected rate of deterioration. Prior adjustment to MS and expectations of being reclassified appeared to buffer some pwMS against the impact of the reclassification. PwMS appeared to cope with the transition via a wide range of responses. These included cognitive and behavioural responses, which may have inadvertently increased the extent to which some pwMS struggled with the transition. In spite of the transition,

some pwMS demonstrated a capacity to move forward with their lives in spite of the transition, which often involved a degree of acceptance of their condition.

This study highlighted a number of potential avenues for better supporting pwMS through the transition. Appropriate preparation for the transition, and provision of adequate information and support were regarded as crucial, but often lacking. The extent to which the needs of pwMS were met often stemmed from limitations to service resources and factors relating to HPs themselves. Overall, the results suggested that the transition to SPMS is a common, yet relatively neglected area, warranting further investigation.

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## **APPENDICES**

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## **APPENDIX A – PARTICIPANT INVITATION LETTER (PWMS VERSION)**

Version 1.1, dated 31/03/2014

[Hospital Logo]



Department of Clinical Psychology  
Royal Holloway, University of London  
Egham  
Surrey  
TW20 0EX

Website: [www.rhul.ac.uk](http://www.rhul.ac.uk)

### **PARTICIPANT INVITATION LETTER (PwMS version)**

To whom this may concern,

**Re: Invitation to take part in an interview study about the experience of transitioning from Relapsing Remitting Multiple Sclerosis to Secondary Progressive Multiple Sclerosis.**

**Emer O'Loughlin, a Trainee Clinical Psychologist is conducting research looking at the experience of people who have recently transitioned from Relapsing Remitting Multiple Sclerosis (RRMS) to Secondary Progressive Multiple Sclerosis (SPMS). This study aims to develop a better understanding of the experiences and needs of people who are making this transition, as well as the perceived barriers to their needs being met at this time. We would like to invite you to take part in this project.** We feel that this research is important because if we can better understand the experiences and needs of people who are making this transition, it will highlight information which will enable services to provide improved support to people at this time.

The study will be carried out by Emer O'Loughlin, who is a Trainee Clinical Psychologist at Royal Holloway, University of London. The research is being overseen by Susan Hourihan, Clinical Specialist Occupational Therapist, and Afsane Riazi, Senior Lecturer in Health Psychology, Royal Holloway, University of London. We hope that up to 20 adults (10 people with MS and 10 health professionals working with people with MS) will be able to meet to be interviewed individually about these issues and to fill in one brief questionnaire. Your clinician thinks you may be suitable to take part in this study and so along with this letter, you have been given a Participant Information sheet which describes the study in more detail.

Please take time to read the following carefully. If you are interested in taking part in the study or have any questions please contact Emer O'Loughlin using the contact details

provided on the participant information sheet. Alternatively, if you would prefer for Emer O'Loughlin to contact you instead, then please complete the participant reply slip at the end of the participant information sheet, and return it using the prepaid envelope.

**Whilst we'd be grateful for your help**, taking part in the research is entirely voluntary and your decision will not impact upon services you receive from [name of hospital] in any way. Thank you for giving this letter your consideration.

Yours sincerely,

Emer O'Loughlin

Trainee Clinical Psychologist  
Royal Holloway, University of London

## **APPENDIX B – PARTICIPANT INVITATION LETTER (HP VERSION)**

Version 1.1, dated 31/03/2014

[Hospital logo]



Department of Clinical Psychology  
Royal Holloway, University of London  
Egham  
Surrey  
TW20 0EX

Website: [www.rhul.ac.uk](http://www.rhul.ac.uk)

### **PARTICIPANT INVITATION LETTER (HPs version)**

To whom this may concern,

**Re: Invitation to take part in an interview study about the experience of transitioning from Relapsing Remitting Multiple Sclerosis to Secondary Progressive Multiple Sclerosis.**

**Emer O’Loughlin, a Trainee Clinical Psychologist is conducting research looking at the experience of people who have recently transitioned from Relapsing Remitting Multiple Sclerosis (RRMS) to Secondary Progressive Multiple Sclerosis (SPMS). This study aims to develop a better understanding of the experiences and needs of people who are making this transition, as well as the perceived barriers to their needs being met at this time. We would like to invite you to take part in this project.** We feel that this research is important because if we can better understand the experiences and needs of people who are making this transition, it will highlight information which will enable services to provide improved support to people at this time.

The study will be carried out by Emer O’Loughlin, who is a Trainee Clinical Psychologist at Royal Holloway, University of London. The research is being overseen by Susan Hourihan, Clinical Specialist Occupational Therapist, and Dr Jeremy Chataway, Consultant Neurologist. We hope that up to 20 adults (10 people with MS and 10 health professionals working with people with MS) will be able to meet to be interviewed individually about these issues and to fill in one brief questionnaire.

Please take time to read the following carefully. If you are interested in taking part in this study, please contact Emer on **01784 414012 (please note: this is a shared phone number. If leaving a voice message, please state that it is intended for Emer O’Loughlin).**

Alternatively, if you would prefer Emer to contact you instead, please complete the participant reply slip at the end of the participant information sheet, and return it using the prepaid envelope provided.

Whilst we'd be grateful for your help, taking part in the research is entirely voluntary and you under no obligation to take part. Thank you for giving this letter your consideration.

Yours sincerely,

Emer O'Loughlin

Trainee Clinical Psychologist  
Royal Holloway, University of London

## **APPENDIX C – INFORMATION SHEET (PWMS VERSION)**

Version 1.2, dated 17/07/2014

[Hospital logo]



Department of Clinical Psychology  
Royal Holloway, University of London  
Egham  
Surrey  
TW20 0EX

Website: [www.rhul.ac.uk](http://www.rhul.ac.uk)

### **PARTICIPANT INFORMATION SHEET (PWMS Version)**

#### **'Qualitative study of the experience of transitioning from Relapsing Remitting Multiple Sclerosis to Secondary Progressive Multiple Sclerosis'**

We would like to invite you to take part in a psychology research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and talk to others about the study to help you decide if you wish to take part (such as your family, friends, your MS specialist team, or the researcher).

Part 1 tells you the purpose of this study and what is involved should you decide to take part.

Part 2 gives you more detailed information about the conduct of the study.

Please contact us if there is anything that is not clear or if you would like more information (please see contact details at the end of this Information Sheet).

#### **Part 1**

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

The main aim of the study is to gain insight into how people cope with the transition from Relapsing Remitting Multiple Sclerosis (RRMS) to Secondary Progressive Multiple Sclerosis (SPMS), what their needs are during this time, and to identify any barriers to their needs being met. This information will be gained through interviewing both people with MS and specialist healthcare professionals working with people with MS. If we can understand more about how people experience this transition, it will help clinicians to provide people with the best support.

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

The research is being overseen by Susan Hourihan, Clinical Specialist Occupational Therapist, and Dr Jeremy Chataway, Consultant Neurologist, from [name of hospital]. The study is being carried out by Emer O'Loughlin who is a Trainee Clinical Psychologist at Royal Holloway, University of London. It will also be supervised by Dr Afsane Riazi, who is a Senior Lecturer in Health Psychology at Royal Holloway.

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

We would like to speak to people who have transitioned from RRMS to SPMS within the last two years. We hope to interview up to 10 people with MS in total, as well as up to 10 specialist MS health professionals.

**Do I have to take part?**

Taking part in this study is voluntary and entirely your choice. Your decision will not affect the standard of care you receive from the NHS. If you decide that you would like to take part, you will be asked to sign a consent form to show you have agreed to take part and will be given a copy of this. You can change your mind at any time and stop participating in the study. You do not need to give a reason for this. This would also not affect the standard of care you receive or any future treatment.

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

If you decide to take part, Emer will meet you on one occasion for approximately 60 minutes at a location which is convenient for you, such as your home. The length of the interview will vary depending on how much you feel you wish to say. The meeting will be arranged to take place at a time that is mutually convenient.

At the meeting, you will be asked to fill out a brief questionnaire asking you to provide some background information, which will include questions such as your age, when you were first diagnosed with MS, and when you received a reclassification of SPMS. Then an interview will take place, in which you will be asked questions about your experience of transitioning from RRMS to SPMS. The sorts of questions that may be asked are about how you coped with this transition, what your needs were at this time, and if you think there were any barriers to your needs being met at this time. There are no right or wrong answers, and you are free to decline to answer any question you do not feel happy to answer. If you give consent, the interview will be audio recorded and only the researcher (Emer O'Loughlin) and an assistant transcriber will be allowed to listen to the recordings. All information that may identify you will be removed from the recordings before being provided to the assistant transcriber. The recording will only be used for the purposes of this research and will be destroyed after this purpose is met. Some of your comments may be directly quoted when the research is written up; however, each comment will be completely anonymous. If you disclose something that suggests you or others are at risk, the researcher is obliged to act in accordance with NHS protocol and respond to the concerns raised. If the researcher felt you would benefit from medical or psychological input, this would be discussed with you and the researcher would recommend that the appropriate person at the hospital contact your GP. After the study has finished, the researcher will send you a brief summary of the findings from the research.

**Expenses and payments**

Taking part in this study is voluntary and you will not be paid for your participation.

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

Risks: There are no direct risks from taking part, although some people may feel uncomfortable talking about their experiences. This is an understandable reaction to discussing a personal subject. However you will not have to say anything you do not want to. If you become distressed at any time, you can take a break or decide to stop talking altogether. You will also be given time at the end to compose yourself if you need. If you feel you need to speak to someone after the meeting, suggestions will be made to help you with this.

Benefits: We cannot promise the study will help you but it is hoped that by taking part in this research, you will be providing valuable information regarding your experiences of transitioning from RRMS to SPMS. This would be extremely helpful, because understanding the experiences and needs of people who are making this transition will help us better support patients in the future who are going through the transition.

**What if there is a problem about taking part in the study?**

Any complaint about the way you have been treated during the study will be addressed. Detailed information on this is provided later in this Information Sheet (please see Part 2).

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

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Detailed information on this is provided later in this Information Sheet (see Part 2).

*If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.*

**Part 2****What will happen if I later change my mind and don't want to carry on with the study?**

Even after you've decided to take part, you can change your mind and withdraw from the study at any time and do not need to give a reason. The researcher will give you her contact number so even after the interview you can let her know if you have changed your mind or wish to have parts of the interview taken out. Again you do not need to give a reason for this. Any data that you do not want included will be destroyed. Choosing to withdraw from the study at any time will not affect the care you receive from the hospital in any way.

**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to either Emer O'Loughlin (Researcher) or Afsane Riazi (Research Supervisor) who will do their best to answer your questions (their contact details are provided at the end of this Information Sheet). If you remain unhappy and wish to complain formally, you can do this: please contact:

Patient Advice & Liaison Service ([name of Hospital Trust]),  
[Address]

Alternatively, please contact the study's local collaborator:



Susan Hourihan,  
Clinical Specialist Occupational Therapist  
[Hospital name and address]  
Tel: XXXXXXXXX

You may also make a complaint to the study's sponsor:

Department of Clinical Psychology,  
Royal Holloway,  
University of London,  
Egham,  
Surrey,  
TW20 0EX  
Tel: 017 8444 3851

Royal Holloway, University of London, is providing negligent indemnity cover for this research. In the unlikely event that something does go wrong, you may have grounds for legal action for compensation but you have to pay your own legal costs. The normal NHS complaints mechanisms will still be available to you.

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

Yes, we will follow ethical and legal guidelines, and all information about you will be kept strictly confidential and known only to the researchers. With your permission, a letter will be written to your GP and MS team informing them that you took part in the study. Also a copy of the consent form you sign will be kept securely in a locked cabinet.

All data collected during the course of the study will be held in accordance with the Data Protection Act (1998). This means that we keep it safely and cannot reveal it to other people, without your permission. Any questionnaires that you fill in, the tape recording of the interview and transcripts of the interview will be given an identification number. So only the researcher will know whose data belongs to whom. The interview will be anonymous since any identifiable information will be deleted when the researcher listens to and transcribes the interview tape. You will not be identified in any report or publication of the results of the research.

All anonymised paper copies of information that you provide will be kept securely in a locked filing cabinet that only Emer O'Loughlin and Afsane Riaz (Research Supervisor) have access to. Similarly, the electronic audio recordings of the interview and any other electronic information such as the interview transcripts will be saved on an encrypted memory stick. On completion of the research, all of the interview tapes will be wiped clean, but transcripts of the interviews will be stored securely for up to 5 years.

Disclosure of information gained from the study will be shared only in exceptional circumstances. If the researcher is concerned about any risk of harm either to yourself or anyone else, then she is legally obliged to share this information with the appropriate people, (a contact person for your MS team, and your GP). The researcher will always try to discuss these concerns with you first, before doing anything.

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

The results of the study will be written up as part of a Doctorate in Clinical Psychology. Anonymised quotes from your interview may be used in the final report to help explain the

key findings. The research may also be published in a journal, or presented at a scientific conference. You will not be able to be identified from any of these. You will also be sent a summary of the research findings.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by Nottingham 2 Research Ethics Committee.

The study has also been reviewed and gained approval from the Research Ethics Committee at Royal Holloway, University of London.

**Contacts for further information**

If you would like further information about taking part, please do not hesitate to contact Emer O'Loughlin, Afsane Riazi or Susan Hourihan. Contact details are below.

**Contact detail for further information or to take part**

Emer O'Loughlin, Trainee Clinical Psychologist  
Department of Clinical Psychology  
Royal Holloway, University of London  
Egham Hill  
Egham,  
Surrey  
TW20 0EX

Tel: 01784 414012 (Please note: if leaving a voice message, please state that it is intended for Emer O'Loughlin).

Afsane Riazi, Senior Lecturer in Health Psychology  
Department of Psychology  
Royal Holloway, University of London  
Egham Hill  
Egham  
Surrey  
TW20 0EX  
Tel: 01784 443601

Susan Hourihan, Clinical Specialist Occupational Therapist  
[Hospital name and address]  
Tel: XXXXXXXXX

**If you are interested in taking part?**

If you would like to take part, please contact Emer O'Loughlin (primary researcher) using the contact details provided above. Alternatively, if you would prefer for Emer O'Loughlin to contact you instead, then please complete the participant reply slip below and return it using the prepaid envelope. Emer O'Loughlin will then call you, and will answer any further questions that you may have about the study. If, at this stage, you are still willing to participate in this study, Emer O'Loughlin will speak with you about arranging a convenient time to meet.

*Thank you for taking the time to read this.*

***(Tear off Slip) PARTICIPANT REPLY SLIP***

**Qualitative study of the experience of transitioning from Relapsing Remitting Multiple Sclerosis to Secondary Progressive Multiple Sclerosis**

*Please tick the box to show your response and give your contact details.*

I have read the Participant Information Sheet and I would like to take part in this study. I am happy to be contacted to arrange a time to meet with Emer O'Loughlin ☐

My name is: \_\_\_\_\_

I would like to be contacted by (telephone, email, post?) \_\_\_\_\_

My telephone/mobile number is:  
\_\_\_\_\_

My email address is \_\_\_\_\_

My address is: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Please return this reply slip in the pre-paid envelope, or alternatively you can contact Emer O'Loughlin on 01784 414012 (Please note: if leaving a voice message, please state that it is intended for Emer O'Loughlin).

## **APPENDIX D – INFORMATION SHEET (HP VERSION)**

Version 1.2, dated 17/07/2014

[Hospital logo]



Department of Clinical Psychology  
Royal Holloway, University of London  
Egham  
Surrey  
TW20 0EX

Website: [www.rhul.ac.uk](http://www.rhul.ac.uk)

### **PARTICIPANT INFORMATION SHEET (HPs Version)**

#### **'Qualitative study of the experience of transitioning from Relapsing Remitting Multiple Sclerosis to Secondary Progressive Multiple Sclerosis'**

We would like to invite you to take part in a psychology research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and talk to others about the study to help you decide if you wish to take part (such as your family, friends, colleagues, or the researcher).

Part 1 tells you the purpose of this study and what is involved should you decide to take part.

Part 2 gives you more detailed information about the conduct of the study.

Please contact us if there is anything that is not clear or if you would like more information (please see contact details at the end of this Information Sheet).

#### **Part 1**

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

The main aim of the study is to gain insight into how people cope with the transition from Relapsing Remitting Multiple Sclerosis (RRMS) to Secondary Progressive Multiple Sclerosis (SPMS), what their needs are during this time, and to identify any barriers to their needs being met. This information will be gained through interviewing both people with MS and specialist healthcare professionals working with people with MS. If we can understand more about this transition, it will help clinicians to provide people with the best support.

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

The research is being overseen by Susan Hourihan, Clinical Specialist Occupational Therapist, and Dr Jeremy Chataway, Consultant Neurologist, from [name of hospital]. The study is being carried out by Emer O'Loughlin who is a Trainee Clinical Psychologist at Royal Holloway, University of London. It will also be supervised by Dr Afsane Riazi, who is a Senior Lecturer in Health Psychology at Royal Holloway.

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

In addition to interviewing up to 10 people with MS we would like to speak to up to 10 health professionals who work with people with MS. This is in order to facilitate the development of a more comprehensive understanding of this subject than would be achieved through interviewing people with MS only.

**Do I have to take part?**

Taking part in this study is voluntary and entirely your choice. If you decide that you would like to take part, you will be asked to sign a consent form to show you have agreed to take part and will be given a copy of this. You can change your mind at any time and stop participating in the study. You do not need to give a reason for this.

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

If you decide to take part Emer will meet you on one occasion for approximately 60 minutes at [name of hospital]. The length of the interview will vary depending on how much you feel you wish to say. The meeting will be arranged to take place at a time that is mutually convenient.

At the meeting, you will be asked to fill out one brief questionnaire asking you to provide some background information, which will include questions such as your age, profession, and how long you have been working with people with MS for. Then an interview will take place, in which you will be asked questions about your views of the experience of transitioning from RRMS to SPMS. The sorts of questions that may be asked are about how think patients cope with this transition, what their needs are at this time, and if you think there are any barriers to their needs being met at this time. There are no right or wrong answers, and you are free to decline to answer any question you do not feel happy to answer. If you give consent, the interview will be audio recorded and only the researcher (Emer O'Loughlin) and an assistant transcriber will be allowed to listen to the recordings. All information that may identify you will be removed from the recordings before being provided to the assistant transcriber. The recording will only be used for the purposes of this research and will be destroyed after this purpose is met. Some of your comments may be directly quoted when the research is written up; however, each comment will be completely anonymous.

After the study has finished, the researcher will send you a brief summary of the findings from the research.

**Expenses and payments**

Taking part in this study is voluntary and you will not be paid for your participation.

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

Risks: There are no direct risks from taking part, although some people may feel uncomfortable talking about these issues. You are not required to discuss anything that you do not wish to, and can stop at any time.

Benefits: We cannot promise the study will help you but it is hoped that by taking part in this research, you will be providing valuable information regarding the experience of transitioning from RRMS to SPMS. This would be extremely helpful, because understanding the experiences and needs of people who are making this transition will help us better support patients in the future who are going through the transition.

**What if there is a problem about taking part in the study?**

Any complaint about the way you have been treated during the study will be addressed. Detailed information on this is provided later in this Information Sheet (please see Part 2).

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

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Detailed information on this is provided later in this Information Sheet (see Part 2).

*If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.*

**Part 2****What will happen if I later change my mind and don't want to carry on with the study?**

Even after you've decided to take part, you can change your mind and withdraw from the study at any time and do not need to give a reason. The researcher will give you her contact number so even after the interview you can let her know if you have changed your mind or wish to have parts of the interview taken out. Again you do not need to give a reason for this. Any data that you do not want included will be destroyed. You can choose to withdraw from the study at any time.

**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to either Emer O'Loughlin (Researcher) or Afsane Riazi (Research Supervisor) who will do their best to answer your questions (their contact details are provided at the end of this Information Sheet). If you remain unhappy and wish to complain formally, you can do this: please contact the Department of Clinical Psychology, Royal Holloway, University of London.

Royal Holloway, University of London, is providing negligent indemnity cover for this research. In the unlikely event that something does go wrong, you may have grounds for legal action for compensation but you have to pay your own legal costs.

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

Yes, we will follow ethical and legal guidelines, and all information about you will be kept strictly confidential and known only to the researchers. A copy of the consent form you sign will be kept securely in a locked cabinet.

All data collected during the course of the study will be held in accordance with the Data Protection Act (1998). This means that we keep it safely and cannot reveal it to other people, without your permission. Any questionnaires that you fill in, the tape recording of the interview and transcripts of the interview will be given an identification number. So only the researcher will know whose data belongs to whom. The interview will be anonymous since any identifiable information will be deleted when the researcher listens to and transcribes the interview tape. You will not be identified in any report or publication of the results of the research.

All anonymised paper copies of information that you provide will be kept securely in a locked filing cabinet that only Emer O'Loughlin and Afsane Riazi (Research Supervisor) have access to. Similarly, the electronic audio recordings of the interview and any other electronic information such as the interview transcripts will be saved on an encrypted memory stick. On completion of the research, all of the interview tapes will be wiped clean, but transcripts of the interviews will be stored for up to 5 years.

Disclosure of information gained from the study will be shared only in exceptional circumstances. If the researcher is concerned about any risk of harm either to yourself or anyone else, then she is legally obliged to share this information with the appropriate people. The researcher will always try to discuss these concerns with you first, before doing anything.

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

The results of the study will be written up as part of a Doctorate in Clinical Psychology. Anonymised quotes from your interview may be used in the final report to help explain the key findings. The research may also be published in a journal, or presented at a scientific conference. You will not be able to be identified from any of these.

You will also be sent a summary of the research findings.

#### **Who has reviewed the study?**

This study has been reviewed and given favourable opinion by Nottingham 2 Research Ethics Committee.

The study has also been reviewed and gained approval from the Research Ethics Committee at Royal Holloway, University of London.

#### **Contacts for further information**

If you would like further information about taking part, please do not hesitate to contact Emer O'Loughlin, Afsane Riazi or Susan Hourihan. Contact details are below.

#### **Contact details for further information or to take part**

Emer O'Loughlin, Trainee Clinical Psychologist  
Department of Clinical Psychology  
Royal Holloway, University of London  
Egham Hill  
Egham,  
Surrey  
TW20 0EX

Tel: 01784 414012 (Please note: if leaving a voice message, please state that it is intended for Emer O'Loughlin).

Afsane Riazi, Senior Lecturer in Health Psychology  
Department of Psychology  
Royal Holloway, University of London  
Egham Hill  
Egham  
Surrey  
TW20 0EX  
Tel: 01784 443601

Susan Hourihan, Clinical Specialist Occupational Therapist  
[Hospital name and address]  
Tel: XXXXXXXX

**If you are interested in taking part?**

If you would like to take part, please contact Emer O'Loughlin using the contact details provided above. Alternatively, if you would prefer Emer O'Loughlin to contact you instead, then please complete the participant reply slip below and return it using the prepaid envelope. Emer O'Loughlin will then call you, and will answer any further questions that you may have about the study. If, at this stage, you are still willing to participate in this study, Emer O'Loughlin will speak with you about arranging a convenient time to meet. Please ask your line manager to sign the confirmation letter provided with this information sheet and bring this with you to the interview.

*Thank you for taking the time to read this.*



***(Tear off Slip) PARTICIPANT REPLY SLIP***

**Qualitative study of the experience of transitioning from Relapsing Remitting Multiple Sclerosis to Secondary Progressive Multiple Sclerosis**

*Please tick the box to show your response and give your contact details.*

I have read the Participant Information Sheet and I would like to take part in this study. I am happy to be contacted to arrange a time to meet with Emer O'Loughlin ☐

My name is: \_\_\_\_\_

I would like to be contacted by (telephone, email, post?) \_\_\_\_\_

My telephone/mobile number is:  
\_\_\_\_\_

My email address is \_\_\_\_\_

My address is: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Please return this reply slip in the pre-paid envelope, or alternatively you can contact Emer O'Loughlin on 01784 414012 (Please note: if leaving a voice message, please state that it is intended for Emer O'Loughlin).

## **APPENDIX E – NHS RESEARCH ETHICS COMMITTEE LETTER**



**Health Research Authority**

**NRES Committee East Midlands - Nottingham 2**

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 8839521

25 March 2014

Ms Emer O'Loughlin  
Trainee Clinical Psychologist  
Camden and Islington NHS Foundation Trust  
Doctorate in Clinical Psychology, Royal Holloway, University of London  
Egham Hill, Egham  
Surrey  
TW20 0EX

Dear Ms O'Loughlin

<b>Study title:</b>	<b>Qualitative study of the experience of transitioning from Relapsing Remitting Multiple Sclerosis (RRMS) to Secondary Progressive Multiple Sclerosis (SPMS)</b>
<b>REC reference:</b>	<b>14/EM/0138</b>
<b>IRAS project ID:</b>	<b>145919</b>

The Proportionate Review Sub-committee of the NRES Committee East Midlands - Nottingham 2 reviewed the above application on 24 March 2014.

- The Committee agreed the study is suitable for Proportionate Review
- The Committee acknowledged this is a qualitative study
- The Committee noted this is student research
- The Committee noted the study aims to look at how people cope with the transition from Relapsing Remitting Multiple Sclerosis to Secondary Progressive Multiple Sclerosis
- The Committee acknowledged between 7 and 10 participants with Secondary Progressive Multiple Sclerosis will be recruited
- The Committee noted 7-10 specialist healthcare professionals working with people with Multiple Sclerosis will be recruited
- The Committee noted the healthcare professionals interview will be taking place at work

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Miss Liza Selway, NRESCommittee.EastMidlands-Nottingham2@nhs.net.

### **Ethical opinion**

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above

research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### **Ethical review of research sites**

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

#### **Conditions of the favourable opinion**

- The Committee would like to see consent from a line manager that they approve interviews for healthcare professionals being conducted at the place of work

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

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

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

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

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

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

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

#### **Registration of Clinical Trials**

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

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 contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**You should notify the REC in writing once all conditions have been met (except for site**

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approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

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

#### Approved documents

The documents reviewed and approved were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		13 March 2014
REC application	145919/579106/1/757	13 March 2014
Evidence of insurance or indemnity		02 September 2013
GP/Consultant Information Sheets	1	14 January 2014
Interview Schedules/Topic Guides	PWMS V1	14 January 2014
Interview Schedules/Topic Guides	HP Version 1	14 January 2014
Investigator CV	Emer O'Loughlin	14 January 2014
Letter of invitation to participant	PWMS V1	14 January 2014
Letter of invitation to participant	HP Version 1	14 January 2014
Other: Non-Validated Questionnaire	Demographics PWMS V1	14 January 2014
Other: Non-Validated Questionnaire	Demographics HP V.1	14 January 2014
Other: DR Asfane Riaz CV		14 January 2014
Other: Susan J Hourihan CV		14 January 2014
Participant Consent Form: PWMS	1	14 January 2014
Participant Consent Form: HP	1	14 January 2014
Participant Information Sheet: PWMS Version	1	14 January 2014
Participant Information Sheet: HP Version	1	14 January 2014
Protocol	1	14 January 2014

#### Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

#### Statement of compliance

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

#### After ethical review

##### Reporting requirements

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

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

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

#### Feedback

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

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

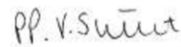
**14/EM/0138**

**Please quote this number on all correspondence**

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/>

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

Yours sincerely



**Dr Martin Hewitt**  
**Chair**

Email: NRESCCommittee.EastMidlands-Nottingham2@nhs.net

*Enclosures: List of names and professions of members who took part in the review*

*"After ethical review – guidance for researchers"*

*Copy to: Dr Andrew McLeod*  
*Ms Tabitha Kavoi, [REDACTED] NHS*  
*Foundation Trust*

## **APPENDIX F – RHUL BOARD OF ETHICS EMAIL**

**From:** Psychology-Webmaster@rhul.ac.uk

**To:** nxjt019@rhul.ac.uk; Riazi, Afsane;

**Cc:** PSY-EthicsAdmin@rhul.ac.uk; Leman, Patrick; Lock, Annette; umjt001@rhul.ac.uk;

**Subject:** 2014/045 **Ethics** Form Approved

**Date:** Mon 28/04/2014 14:26

Application Details:    View the form click [here](#)    Revise the form click [here](#)

Applicant Name:        **Emer O'Loughlin**

Application title:        **Qualitative study of the experience of transitioning from  
Relapsing Remitting MS (RRMS) to Secondary Progressive MS  
(SPMS)**

## **APPENDIX G – R & D ETHICS LETTER**



NHS Foundation Trust

### **Joint Research Office**

**Office Location:**

1<sup>st</sup> Floor Maple House  
149 Tottenham Court Road  
London W1T 7DN

**Postal Address:**



Tel: 020 3447 72177/79833 Fax: 020 3447 9937

Websites:

### **FINAL R&D APPROVAL – NHS PERMISSION**

04/04/2014

Dear Ms Susan Hourihan,

Project ID: 14/0202 (Please quote in all correspondence)

REC Ref: 14/EM/0138

Title: Qualitative study of the experience of transitioning from Relapsing Remitting Multiple Sclerosis (RRMS) to Secondary Progressive Multiple Sclerosis (SPMS)

Thank you for registering the above study with the Joint Research Office (). I am pleased to inform you that your study now has local R&D approval (NHS permission) to proceed and recruit participants at NHS Foundation Trust subject to sponsor confirmation.

Please note that all documents received have been reviewed and this approval is granted on the basis of the key documents provided which are ethically approved by the Research Ethics Committee:

Document	Date
REC approval and REC approved documents	01/04/2014

As Principal Investigator you are required to ensure that your study is conducted in accordance with the requirements on the attached sheet. These include the conditions of your NHS permission.

Do not hesitate to contact a member of the team should you have any queries.

Yours sincerely

**Professor Monty Mythen**  
**Director of Research and Development**  
 Joint Research Office

## **APPENDIX H – NHS ETHICS AMENDMENT APPROVAL LETTER**



### **Health Research Authority**

#### **NRES Committee East Midlands - Nottingham 2**

Royal Standard Place  
Nottingham  
NG1 6FS

Tel: 0115 883 9435

11 September 2014

Ms Emer O'Loughlin  
Trainee Clinical Psychologist  
Camden and Islington NHS Foundation Trust  
Doctorate in Clinical Psychology, Royal Holloway, University of London  
Egham Hill, Egham  
Surrey  
TW20 0EX

Dear Ms O'Loughlin

<b>Study title:</b>	<b>Qualitative study of the experience of transitioning from Relapsing Remitting Multiple Sclerosis (RRMS) to Secondary Progressive Multiple Sclerosis (SPMS)</b>
<b>REC reference:</b>	<b>14/EM/0138</b>
<b>Amendment number:</b>	<b>1</b>
<b>Amendment date:</b>	<b>22 August 2014</b>
<b>IRAS project ID:</b>	<b>145919</b>

The above amendment was reviewed by the Sub-Committee in correspondence.

#### **Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### **Discussion**

There were no ethical issues raised.

#### **Approved documents**

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Notice of Substantial Amendment (non-CTIMP)		22 August 2014
Participant information sheet (PIS) [PWMS Version]	1.2	17 July 2014
Research protocol or project proposal	1.1	17 July 2014

#### **Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.



### **R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

### **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.

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/>

<b>14/EM/0138:</b>	<b>Please quote this number on all correspondence</b>
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Yours sincerely

  
PP

**Dr Frances Game**  
**Chair**

E-mail: NRESCommittee.EastMidlands-Nottingham2@nhs.net

*Enclosures:*                      *List of names and professions of members who took part in the review*

*Copy to:*                      *Ms Tabitha Kavoi, [REDACTED] NHS*  
   *Foundation Trust*  
   *Dr Andrew McLeod*

## **APPENDIX I – CONSENT FORM (PWMS VERSION)**

Version 1.1, dated 31/03/2014

[Hospital logo]



Department of Clinical Psychology  
Royal Holloway, University of London  
Egham  
Surrey  
TW20 0EX

Website: [www.rhul.ac.uk](http://www.rhul.ac.uk)

### **CONSENT FORM (PwMS version)**

#### **Qualitative study of the experience of transitioning from Relapsing Remitting Multiple Sclerosis to Secondary Progressive Multiple Sclerosis**

Patient Identification Number for this study:

#### **Name of researcher**

Emer O'Loughlin (Trainee Clinical Psychologist)  
Doctorate in Clinical Psychology  
Royal Holloway, University of London  
Egham  
Surrey TW20 0EX

Tel: 01784414012 (Please note: if leaving a voice message, please state that it is intended for Emer O'Loughlin)

Please initial box

I confirm that I have read and I understand the participant information sheet for the above study and that I have been given the opportunity to ask any questions.	<input type="text"/>
I understand that I am under no obligation to participate in this study. It is entirely voluntary and I can withdraw at any time, without giving a reason and that this will not affect any aspect of my care at the hospital.	<input type="text"/>
I consent to an audio recording of the interview being made and understand that it will be destroyed after the purpose of the research is complete.	<input type="text"/>

I understand that an assistant transcriber may assist with the process of transcribing the interview. In this case, I understand that all information that could identify me will be removed from the audio recording prior to it being provided to the assistant transcriber.	<input type="checkbox"/>
I am aware and understand that the researcher, Emer O'Loughlin, may publish direct quotations said by me during the interview, but that these will be anonymised.	<input type="checkbox"/>
I understand that all names, places and anything that could identify me will be removed.	<input type="checkbox"/>
I agree to my GP being informed about my participation in the study.	<input type="checkbox"/>
I agree to my MS team being informed about my participation in the study.	<input type="checkbox"/>
I agree to take part in the above study.	<input type="checkbox"/>

\_\_\_\_\_  
 Name of participant:  
 (Print name)

\_\_\_\_\_  
 Date

\_\_\_\_\_  
 Signature of participant:

\_\_\_\_\_  
 Name of Researcher:  
 (Print name)

\_\_\_\_\_  
 Date

\_\_\_\_\_  
 Signature of researcher:

When completed: 1 for participant; 1 for researcher file; 1 for medical records

## **APPENDIX J – CONSENT FORM (HP VERSION)**

Version 1.1, dated 31/03/2014

[Hospital logo]



Department of Clinical Psychology  
Royal Holloway, University of London  
Egham  
Surrey  
TW20 0EX

Website: [www.rhul.ac.uk](http://www.rhul.ac.uk)

### **CONSENT FORM (HPs Version)**

#### **Qualitative study of the experience of transitioning from Relapsing Remitting Multiple Sclerosis to Secondary Progressive Multiple Sclerosis**

Participant Identification Number for this study:

#### **Name of researcher**

Emer O'Loughlin (Trainee Clinical Psychologist)  
Doctorate in Clinical Psychology  
Royal Holloway, University of London  
Egham  
Surrey TW20 0EX

Tel: 01784414012 (Please note: if leaving a voice message, please state that it is intended for Emer O'Loughlin)

Please initial box

I confirm that I have read and I understand the participant information sheet for the above study and that I have been given the opportunity to ask any questions.	<input type="text"/>
I understand that I am under no obligation to participate in this study. It is entirely voluntary and I can withdraw at any time, without giving a reason.	<input type="text"/>
I consent to an audio recording of the interview being made and understand that it will be destroyed after the purpose of the research is complete.	<input type="text"/>
I understand that an assistant transcriber may assist with the process	<input type="text"/>

of transcribing the interview. In this case, I understand that all information that could identify me will be removed from the audio recording prior to it being provided to the assistant transcriber.	<input type="checkbox"/>
I am aware and understand that the researcher, Emer O'Loughlin, may publish direct quotations said by me during the interview, but that these will be anonymised.	<input type="checkbox"/>
I understand that all names, places and anything that could identify me will be removed.	<input type="checkbox"/>
I agree to take part in the above study.	<input type="checkbox"/>

\_\_\_\_\_  
Name of participant  
(Print name)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of participant

\_\_\_\_\_  
Name of Researcher:  
(Print name)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of researcher:

When completed: 1 for participant; 1 for researcher site file

## **APPENDIX K – GP INFORMATION LETTER**

Version 1.1, dated 31/03/2014

[Hospital logo]



Department of Clinical Psychology  
Royal Holloway, University of London  
Egham  
Surrey  
TW20 0EX

Website: [www.rhul.ac.uk](http://www.rhul.ac.uk)

**GP ADDRESS**  
XXXXXXXXXXXX  
XXXXXXXXXX  
XXXXXX  
XXX

**Dear Dr. XXXX,**

**Re. Patient's Name**  
**Address XXXX**

I am writing to inform you that the above patient who is seen with XXXX clinic will be taking part in a research project. The aim of the research is to explore the experiences of people who have transitioned from Relapsing Remitting Multiple Sclerosis (RRMS) to Secondary Progressive Multiple Sclerosis (SPMS), including how they cope with this transition, their needs at this time, and any perceived barriers to their needs being met. Enclosed is the Participant Information sheet for further details.

We feel this research is important to help us gain a deeper understanding of what it is like for people who are transitioning from RRMS to SPMS, to explore the issues they face and ways of coping that they find more or less helpful.

The study will be carried out by Emer O'Loughlin, Trainee Clinical Psychologist at Royal Holloway, University of London as part of her Doctoral thesis and Susan Hourihan (Clinical Specialist Occupational Therapist) and Dr Afsane Riaz (Senior lecturer in Health Psychology).

Yours Sincerely,

**Emer O'Loughlin**  
***Trainee Clinical Psychologist***

## **APPENDIX L – DEBRIEFING SHEET (PWMS VERSION)**

Version 1.1, dated 31/03/2014

[Hospital logo]



### **Debriefing Sheet** **(PWMS version)**

#### **The experience of transitioning from Relapsing Remitting to Secondary Progressive MS**

*Thank you very much for making this study possible.* This study aimed to explore the experience of people with multiple sclerosis who have recently been told that their diagnosis of Relapsing Remitting Multiple Sclerosis (RRMS) has progressed on to the more progressive form of the disease known as Secondary Progressive Multiple Sclerosis (SPMS).

I was interested in gaining an in-depth understanding of:

1. Your experience of moving from a diagnosis RRMS to a diagnosis of SPMS;
2. Your perceptions of needs and supports at time of diagnosis of SPMS.

While existing research has investigated the experience of being diagnosed with RRMS and, the experience of living with established disability, there has been little investigation of the period of transition between RRMS and SPMS.

It is hoped that this study will lead to a deeper understanding of the issues that pwMS experience as they move from RRMS to SPMS in order that Health Care Professionals better support the needs of such individuals during this process.

**Sources of comfort and help** If talking about your experiences has left you feeling down, you may appreciate the following sources of support:

1. The most immediate sources of comfort and help are likely to be your own family and friends.
2. There are also a number of national organisations who can also offer you support. For example:

- **MS Society UK** (<http://www.mssociety.org.uk>) is the leading UK charity for people with Multiple Sclerosis and their families, providing information, help

and support. Their helpline workers are fully trained, and many have MS or are affected by it personally. They can provide information, will help to explore your options with you and can listen if you feel down. The information they provide is always up to date and backed by evidence. The helpline is open from 9am to 9pm Monday to Friday (except bank holidays). They can be contacted on **0808 800 8000 or email [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)**

- **The Samaritans** (<http://www.samaritans.org>). The Samaritans is a helpline which is open **24 hours a day** is staffed by trained volunteers who will listen in confidence to anyone in any type of emotional distress, without judging or telling people what to do and will help you explore options. They can be contacted on telephone 08457 909090.

3. You are welcome to contact me again to discuss any aspect of your participation in this study, to share any concerns you might have or to ask questions.

**Contact details:**

**Emer O'Loughlin**  
**Trainee Clinical Psychologist**  
**Department of Clinical Psychology**  
**Royal Holloway, University of London**  
**Egham**  
**Surrey**  
**TW20 0EX**

**Tel: 01784 414012 (Please note: if leaving a voice message, please state that it is intended for Emer O'Loughlin)**



## **APPENDIX M – DEBRIEFING SHEET (HP VERSION)**

Version 1.1, dated 31/03/2014

[Hospital logo]



### **Debriefing Sheet** **(HPs Version)**

#### **The experience of transitioning from relapsing remitting to secondary progressive MS**

*Thank you very much for making this study possible.* This study aimed to explore the experience of people with multiple sclerosis who have recently been told that their diagnosis of Relapsing Remitting Multiple Sclerosis (RRMS) has progressed on to the more progressive form of the disease known as Secondary Progressive Multiple Sclerosis (SPMS).

I was interested in gaining an in-depth understanding of:

3. Your experience of moving from a diagnosis RRMS to a diagnosis of SPMS;
4. Your perceptions of needs and supports at time of diagnosis of SPMS.

While existing research has investigated the experience of being diagnosed with RRMS and, the experience of living with established disability, there has been little investigation of the period of transition between RRMS and SPMS. It is hoped that this study will lead to a deeper understanding of the issues that pwMS experience as they move from RRMS to SPMS in order that Healthcare Professionals better support the needs of such individuals during this process.

You are welcome to contact me again to discuss any aspect of your participation in this study, to share any concerns you might have or to ask questions.

#### **Contact details:**

**Emer O'Loughlin**  
**Trainee Clinical Psychologist**  
**Department of Clinical Psychology**  
**Royal Holloway, University of London**

**Egham**

**Surrey**

**TW20 0EX**

**Tel: 01784 414012 (Please note: if leaving a voice message, please state that it is intended for Emer O'Loughlin)**

## **APPENDIX N – SEMI-STRUCTURED INTERVIEW SCHEDULE (PWMS VERSION)**

Version 1.1, dated 31/03/2014

### **Draft Interview Schedule – for PWMS**

- Informed consent, recording it, withdraw, confidentiality. Any questions?
  - I'm not going to say much - like a one sided conversation.
  - Tell me stories/detail about your experiences.
  - There are no right or wrong answers; I am only interested in what is important for you.
  - You are the expert of your experience.
  - As much detail as possible to bring your story to life for me.
  - Take your time in thinking and talking
  - Demographic questionnaire first
- 
- Warm up questions – Can you tell me when you received your initial diagnosis of MS? Can you tell me when you received your subsequent re-classification of SPMS?
  - Before receiving a re-classification of SPMS, had you noticed any changes in your condition? If so, what did you make of this?  
*Prompt: Had you noticed any changes in your physical symptoms (e.g. fatigue, vision, balance, stiffness/spasms)? Did you think anything about this?*
  - Can you tell me what it was like to receive a re-classification of SPMS (following a previous diagnosis of RRMS)?  
*Prompt: How did you feel? How expected/unexpected was it? What sense did you make of this news?*
  - In what way has this transition impacted on your life (e.g. work, home-life etc.)?
  - In what way was the experience of the transition from RRMS to SPMS similar or different to other stages of the disease?  
*For example in what way was this transition similar or different to the receipt of the original diagnosis?*
  - How did you deal with the impact of this re-classification?

*Prompt: Were there certain things that you did to try to cope with it, or ways that you tried to think about it? Were there any coping strategies that you used?*

- Were there ways of dealing with it, or coping strategies, it that you found to be helpful?
- Were there other ways of dealing with it, or coping strategies, that you found to be less helpful or unhelpful?
- Is there anything that was, or would have been, helpful **before** receiving a re-classification of SPMS?

*Prompt: Are there any ways that services could have informed or supported you better?*

- Is there anything that was, or would have been, helpful in the way the news of your re-classification was communicated to you?

*Prompt: How supported or unsupported by services did you feel? What was helpful/unhelpful? Is there anything you would suggest should have been done differently?*

- Is there anything that was, or would have been, helpful following receipt of this news?

*Prompt: How supported or unsupported by services did you feel? What was helpful/unhelpful? Is there anything you would suggest should have been done differently?*

- Do you think there were any barriers to services meeting your needs during this transition? If so, what were they?
- Was there anything you expected me to ask, that I didn't? Anything you'd like to add?
- What has it been like discussing these issues today?

## **APPENDIX 0 –SEMI-STRUCTURED INTERVIEW SCHEDULE (HP VERSION)**

Version 1.1, dated 31/03/2014

### **Draft Semi-Structured Interview Schedule – for HPs**

- Informed consent, recording it, withdraw, confidentiality. Any questions?
  - I'm not going to say much - like a one sided conversation.
  - Tell me stories/detail about the experiences of pwMS.
  - There are no right or wrong answers; I am only interested in what is important for pwMS.
  - Try to talk from the perspective of pwMS.
  - As much detail as possible to bring their story to life for me.
  - Take your time in thinking and talking
  - Demographic questionnaire first
- 
- Warm up question – What is your role? How long have you been working with PWMS?
  - Before receiving a re-classification of SPMS, do you think that PWMS notice any changes in their condition? If so, what sense do you think they make of this?  
*Prompt: Do you think that PWMS notice any changes in their physical symptoms? Do you think they think anything about this? Do they ignore it? Do they worry about it?*
  - What do you think it is like to receive a diagnosis of SPMS (following a previous diagnosis of RRMS)?  
*Prompt: How do you think they feel? How expected/unexpected do you think it is? What do you think pwMS think about the news of their reclassification? What sense do you think they make of this news?*
  - In what way is the experience of the transition from RRMS to SPMS similar or different to other stages of MS?  
*For example, in what way is this transition similar or different to the receipt of the original diagnosis?*
  - How do you think pwMS deal with the impact of this re-classification?

*Prompt: Do you think there certain things that people do to try to cope with it, or ways that they try to think about it?*

- Do you think there are ways of dealing with it or coping strategies that pwMS tend to find helpful?
- Do you think that there other ways of dealing with it or coping strategies that pwMS tend find to be less helpful or unhelpful?
- Do you think that PWMS would identify anything that was, or would have been, helpful before receiving a re-classification of SPMS? What else, in your opinion, do you think would be helpful?

*Prompt: Do you think there any ways that services could inform or support PWMS better at this time?*

- Do you think that PWMS would identify anything that was, or would have been helpful, in the way the news of their re-classification was communicated to them? What else, in your opinion, do you think would be helpful?

*Prompt: How supported or unsupported by services did you think PWMS feel at this point? What do you think is helpful/unhelpful? Is there anything you would suggest should be done differently?*

- Do you think PWMS would identify anything that was, or would have been, helpful following receipt of this news? What else, in your opinion, do you think would be helpful?

*Prompt: How supported or unsupported by services do you think PWMS feel? What do you think is helpful/unhelpful? Is there anything you would suggest should be done differently?*

- Do you think there are any barriers to meeting the needs of PWMS during this transition period? If so, what are they?
- Was there anything you expected me to ask, that I didn't? Anything you'd like to add?
- What has it been like discussing these issues today?

## **APPENDIX P – DEMOGRAPHIC QUESTIONNAIRE (PWMS VERSION)**

Version 1.1, dated 31/03/2014

[Hospital logo]



Idno

### **MS Transition Study** **Socio-demographic Information** **(PWMS version)**

Sex

Male

☐

Female

☐

Date of birth

D D M M Y Y Y Y

		/					
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Q1 Ethnic group

☐

White

☐

Black Carribean

☐

Black African

☐

Black Other

☐

Indian

☐

Pakistani

☐

Bangladeshi

☐

Chinese

☐

Other Asian group

☐

None of these – other, please say

Q2 Marital status

☐

Married

☐

Widowed

☐

Divorced

☐

Cohabiting

☐

Separated

☐

Single

Q3 a) Number of dependents in the home  
(not children)

--	--

Q3 b) Number of children under 5 years

--	--

Q3 c) Number of children aged 5 to 16 years inclusive

Q4 a) Your occupation

--	--

☐ Full-time work

☐ Part-time work

☐ Permanently  
sick/disabled

☐ Unemployed

☐ Retired

☐ Student

☐ Housewife

☐ Other

If 'other' please say

--

--

Q4 b) Current/main employment (write housewife if appropriate)

--

Q4 c) If currently unemployed, last full-time occupation

--	--

--

Organisation function/  
nature of business

Number of people supervised

--

--

Q5 a) Partners occupation (if not applicable please tick 'N/A')

☐ N/A

☐ Full-time work

☐ Part-time work

☐ Permanently  
sick/disabled

☐ Unemployed

☐ Retired

☐ Student

☐ Housewife

☐ Other

If 'other', please say

--

--



Q5 b) Your partner's current/main employment (write housewife if appropriate)

Q5 c) If currently unemployed, what was your partner's last full-time occupation

Number of people supervised

Organisation function/nature of business

Q6 a) Age you left full-time education

Q6 b) Age you left part-time education

Q6 c) Highest exam level

☐ None ☐ CSE ☐ GCSE/O'Level ☐ A'Level ☐ HND ☐ Degree ☐ Other

If 'other', please specify

Q6 d) Still in education

☐ Yes – FT ☐ Yes – PT ☐ No

If still in PT or FT education, title of course

Q7 a)

Accommodation status

☐ Owner-occupied ☐ Council/housing association ☐ Private rental  
☐ Other rented ☐ Lives with parents Other ☐

If other please specify

Q7 b) Type of accommodation

☐ Detached ☐ Semi-detached ☐ End-terrace

☐ Mid-terrace ☐ Flat/maisonette ☐ Bedsitter

☐ Hostel ☐ Halls of residence ☐ NFA

☐ Other please specify

Floor of main accommodation

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Q8 . Roughly, when did your MS symptoms FIRST START? .....month ..... year

Q9. Roughly, when was your MS FIRST DIAGNOSED? .....month ..... year

Q10. a) Roughly, when was your most recent relapse ? .....month ..... year

b) And how severe was it? ....Mild .....Moderate .....Severe

Q11. Roughly, when did you receive a reclassification of Secondary Progressive MS?  
.....month .....year

Q12. Concerning your mobility indoors, do you:

.....walk unaided

.....use a stick or frame, or hold onto furniture or somebody  
when walking

.....use a wheel chair

## **APPENDIX Q – DEMOGRAPHIC QUESTIONNAIRE (HP VERSION)**

Version 1.1, dated 31/03/2014

[Hospital logo]



Idno

### **MS Transition Study** Socio-demographic Information (Health Professionals version)

Sex:

Male ☐ Female ☐

Date of birth:

D	D	M	M	Y	Y	Y	Y
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Q1 Ethnic group:

- |  |  |  |
|--|--|--|
| <input type="checkbox"/> White                                       | <input type="checkbox"/> Black Carribean | <input type="checkbox"/> Black African     |
| <input type="checkbox"/> Black Other                                 | <input type="checkbox"/> Indian          | <input type="checkbox"/> Pakistani         |
| <input type="checkbox"/> Bangladeshi                                 | <input type="checkbox"/> Chinese         | <input type="checkbox"/> Other Asian group |
| <input type="checkbox"/> None of these – other, please specify:..... |  |  |

Q2 a) Your occupation:

- ☐ MS Specialist Consultant
- ☐ MS Specialist Nurse
- ☐ Occupational Therapist
- ☐ Physiotherapist
- ☐ Psychologist
- ☐ Other (please specify:.....)

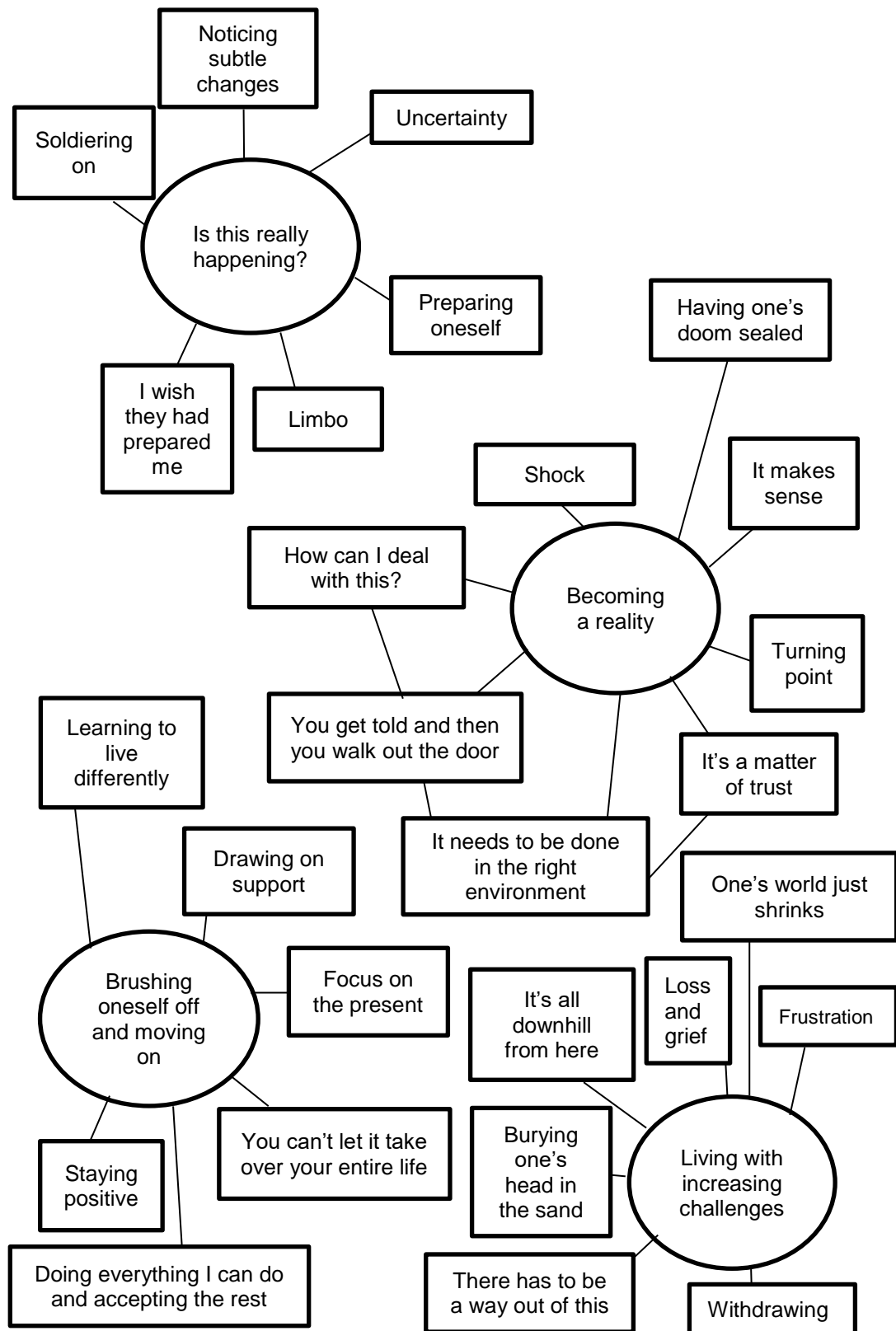
Q3 Number of years working with people with MS:.....

Q6 Roughly number of patients you have worked with who have transitioned from RRMS to SPMS:

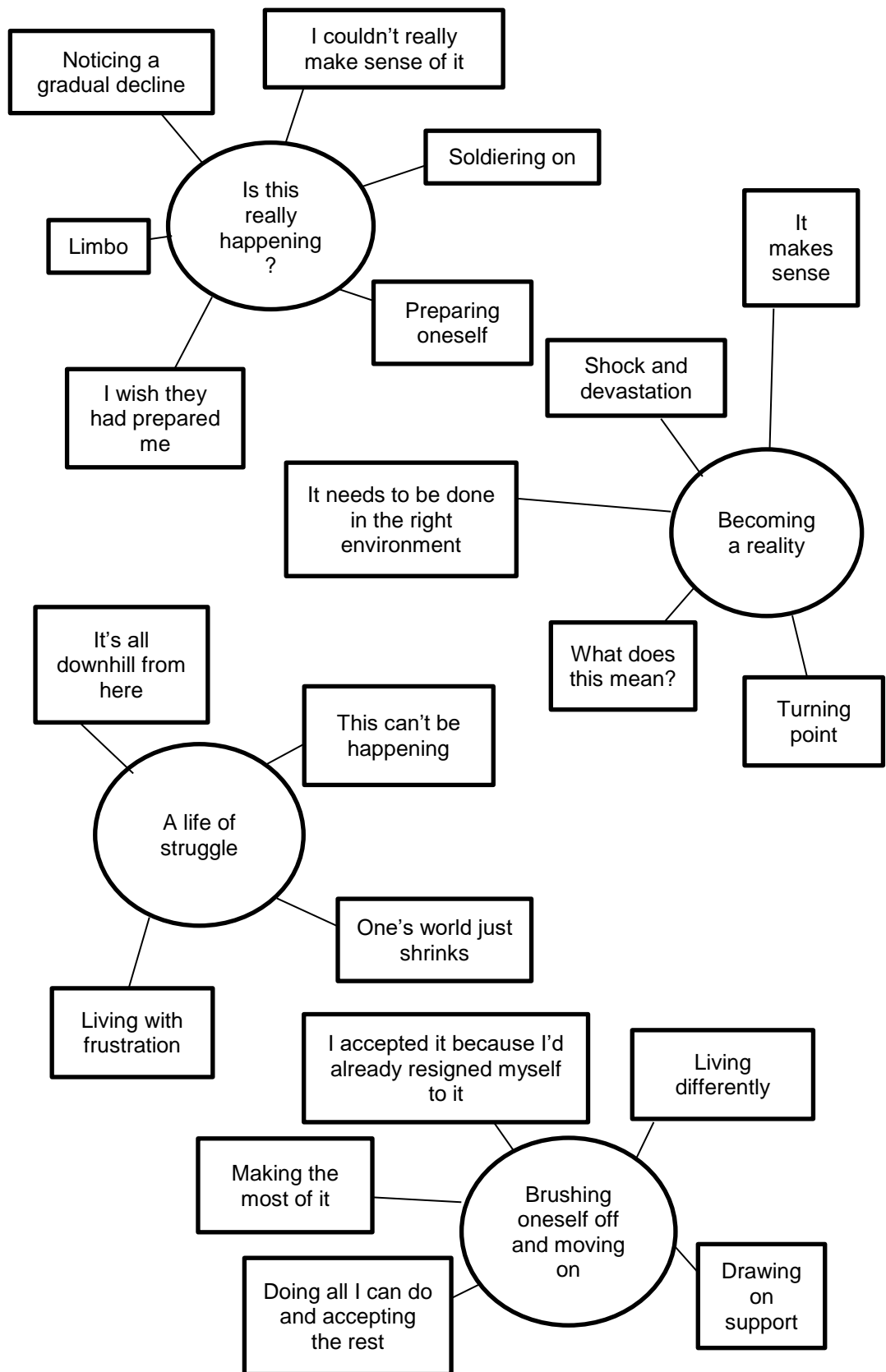
- ☐ <10
- ☐ 11-50
- ☐ >50

## APPENDIX R – Thematic map

### (i) Initial Thematic Map



**(ii) Final Thematic Map**



## **APPENDIX S – Transcription extract**

Interview Transcript Extract	Initial Coding
<p><i>I: Can you tell me when you received your subsequent reclassification of Secondary Progressive MS?</i></p> <p>P: I was told in 2012 I was possibly entering the secondary phase of MS. Um, then last year, by my usual consultant... she didn't want to classify... she didn't want to confirm that... but then this year the consultant told me that she believed I was... um, that I had Secondary Progressive... so it was this year.</p> <p><i>I: This year... ok. So before receiving a reclassification of Secondary Progressive MS had you noticed any changes in your condition? And if so, what sense did you make of this?</i></p> <p>P: Yes. Yes, I had very heavy legs, terrible fatigue... I would go to work and by lunchtime I could have just sat down and gone to sleep. Um, I was struggling with carrying equipment for my job because I was just so tired. I was having problems getting in and out of doors, and I kept thinking is it my imagination? Is it because I think I've got a progression of my MS? Am I imagining all this? So I did... definitely had quite a few symptoms... they were... it wasn't really symptoms so much as just a gradual decline of... of my mobility. I couldn't really understand why.</p> <p><i>I: Mmm. And tell me a little bit more about what you thought about it, or what sense you made of it.</i></p> <p>P: Um, well my profession is a community nurse... so it was very difficult because Relapsing Remitting... I always bounced back to where I was before... and this time I wasn't actually getting worse, that I could notice, but it was when I was looking back over the year I was thinking I could walk further this time last year... I wasn't toppling... I wasn't struggling getting into doors... so I felt I was getting worse. I felt I</p>	<p>Told possibly entering SPMS - uncertainty</p> <p>Consultant reluctance to reclassify – uncertain</p> <p>Fatigue, heaviness</p> <p>Carrying on with work - struggling</p> <p>Is it my imagination?</p> <p>Is it due to progression?</p> <p>Gradual decline in mobility</p> <p>Confusion, uncertainty</p> <p>Bouncing back in RRMS</p> <p>Gradual, silent deterioration- looking back</p> <p>Some awareness of potential SPMS</p>

<p>did probably have Secondary Progressive MS, but I didn't really understand what that was because people with Secondary Progressive MS that I knew were people I nursed in bed and... and in wheelchairs. So I struggled understanding what was going on with me.</p> <p><i>I: Ok. Ok, thank you. So can you tell me what it was like to receive a reclassification of Secondary Progressive MS?</i></p> <p>P: It actually was a relief... it was a relief because I'd been struggling at work for so long. I did have a blue badge, but because I wore a nurse's uniform if I parked in a blue badge space quite often people would stand there and stare at me... in fact I had one lady who stood and watched me with her hands on her hips pointing at the disabled space. And my colleague who was with me said "wave your blue badge at her!" But obviously I didn't. So for me it was a little bit of a relief because I kept imagining... well, I kept thinking I was imagining... um, that I was more tired than I was. It's so... and also it was just like mist... one minute I could walk a bit further than another... so it would come and go. So I couldn't really make sense of it, because it was here today, and then tomorrow I was a bit better... well not a bit better, but not quite so bad as the day before. But I also found that if I was pushing myself and thinking right I've got to walk further today because I've got to keep strength in my legs... what you don't use you lose... I was actually getting worse, and I couldn't make sense of that either. So, yes, going back to your question which... I've forgotten what it was [laughs].</p> <p><i>I: Yeah, just... I guess, tell me about what it was like to receive that reclassification.</i></p> <p>P: Yes. It was relief. And I started then to rethink... if I am entering Secondary... well I am now in Secondary Progressive MS... I have got to rethink my life, because here I am struggling to work... I'm going to work in the mornings, and then coming home in the afternoons... my husband's cooking meals, I'm not walking the dog because I'm so whacked out, I'm going to bed at half seven... and things that I used to do like</p>	<p>SPMS associated with severe disability Struggling to understand changes</p> <p>Relief at reclassification</p> <p>RRMS: Misunderstood due to invisible disability</p> <p>Relief because changes not just imagined Symptoms like a mist - transitory</p> <p>Changes confusing due to variation/changeability Trying to maintain level of functioning – still declining</p> <p>Confusion, struggling to make sense of it</p> <p>Relief at reclassification Need to rethink one's life Struggling with work Struggling with domestic tasks</p>
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<p>singing I can't do, because I can't stand on stage. Um... so I think it mainly... it was a relief because I was able to then rethink and think well actually I can't do all those things now, I know I can't do all those things, and I'm not going to be able to do them. So I've had to redesign my social life. So I have to say relief was probably where I was then.</p> <p><i>I: Ok. Ok. And just about that... how expected or unexpected was it when you received that... that reclassification?</i></p> <p>P: Because it was... it wasn't said to me, um, in a way that... "you are now what we would call in Secondary Progressive MS"... it was as if I would have known anyway, because it was a different consultant... so she told me... um, "have you ever"... well she was asking me questions..." have you had any disease modifying drugs?" and I said "no." Um... "have you never had anything with this weakness?" and "have you ever had any drugs for your fatigue?" and I said "no." And she said "well with Secondary Progressive..." So it was almost as if I knew already, or she thought I knew already, and I never showed any indication that I didn't know already, because I think I probably did. So I just went along with that... I didn't actually question... I went along with it, because I'd already questioned the consultant the year before saying "have I got Secondary Progressive?" and she said "I don't like to classify it." So, I suppose I knew really... so this consultant was just telling me what I knew. But it was a... a definite... "you have Secondary Progressive MS," whereas before I'd never been told that. So... yeah.</p> <p><i>I: Mmm. Ok. So the previous consultant the year before they hadn't wanted to classify you, but what did they say to you exactly?</i></p> <p>P: Gosh, I can't remember. I had the registrar come in and check me over. And he wasn't quite as thorough as my usual consultant anyway, because I had tight trousers on so he didn't, um, check my legs in the same way for sensation. But when she came in and I was asking her... and I just said "I'm really worried because I'm not as strong, I'm not as good as I was," and she said "well your reactions are the same as</p>	<p>Unable to participate in hobbies Adjusting to loss of functioning Relief because one could rethink life Need to redesign social life</p> <p>Lack of continuity of care (change of consultant) – expectation that patient already knew</p> <p>Hiding shock/surprise at reclassification</p> <p>Some expectation of reclassification Reclassification significant (a shock?) despite some expectation of it- becoming a reality</p> <p>Registrar not as thorough as usual consultant</p> <p>Patient expressing concern about changes to consultant</p>
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<p>they were last year.” And I said “could I be entering... or could I be in Secondary Progressive MS?” and that’s when she said “we don’t classify it.” And I suppose I was a little... I came away feeling a bit... hmm, not miffed... but I came away feeling as if I hadn’t really achieved anything, as if that was a waste of a visit, because the thing I was worrying about wasn’t clarified.</p>	<p>Asking if could have SPMS Consultant reluctance to reclassify  Patient miffed at lack of clarification</p>
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## APPENDIX T – Transcription extract: second coder

<p><i>I: Can you tell me when you received your subsequent reclassification of Secondary Progressive MS?</i></p> <p>P: I was told in 2012 I was possibly entering the secondary phase of MS. Um, then last year, by my usual consultant... she didn't want to classify... she didn't want to confirm that... but then this year the consultant told me that she believed I was... um, that I had Secondary Progressive... so it was this year.</p> <p><i>I: This year... ok. So before receiving a reclassification of Secondary Progressive MS had you noticed any changes in your condition? And if so, what sense did you make of this?</i></p> <p>P: Yes. Yes, I had very heavy legs, terrible fatigue... I would go to work and by lunchtime I could have just sat down and gone to sleep. Um, I was struggling with carrying equipment for my job because I was just so tired. I was having problems getting in and out of doors, and I kept thinking is it my imagination? Is it because I think I've got a progression of my MS? Am I imagining all this? So I did... definitely had quite a few symptoms... they were... it wasn't really symptoms so much as just a gradual decline of... of my mobility. I couldn't really understand why.</p> <p><i>I: Mmm. And tell me a little bit more about what you thought about it, or what sense you made of it.</i></p> <p>P: Um, well my profession is a community nurse... so it was very difficult because Relapsing Remitting... I always bounced back to where I was before... and this time I wasn't actually getting worse, that I could notice, but it was when I was looking back over the year I was thinking I could walk further this time last year... I wasn't toppling... I wasn't struggling getting into doors... so I felt perhaps I was getting worse... I felt I did</p>	<p>Informed possibility entering secondary phase Consultant didn't want to classify/confirm new diagnosis This year reclassified by consultant - sense of unknown, and uncertainty – consultant wanting to be certain</p> <p>Experienced changes in condition – heavy legs, fatigue, tired Struggling Impacting job performance</p> <p>Questioning if changes real or in imagination Experienced a gradual decline in mobility Not understanding why experiencing decline</p> <p>Difficult experience of relapsing remitting Functioning always returned to normal – sense of time important Felt like wasn't getting worse, relying on own perception of functioning Looking back over year – recalling memories of previous abilities – comparison to different</p>
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<p>probably have Secondary Progressive MS, but I didn't really understand what that was because people with Secondary Progressive MS that I knew were people I nursed in bed and... and in wheelchairs. So I struggled understanding what was going on with me.</p> <p><i>I: Ok. Ok, thank you. So can you tell me what it was like to receive a reclassification of Secondary Progressive MS?</i></p> <p>P: It actually was a relief... it was a relief because I'd been struggling at work for so long. I did have a blue badge, but because I wore a nurse's uniform if I parked in a blue badge space quite often people would stand there and stare at me... in fact I had one lady who stood and watched me with her hands on her hips pointing at the disabled space. And my colleague who was with me said "wave your blue badge at her!" But obviously I didn't. So for me it was a little bit of a relief because I kept imagining... well, I kept thinking I was imagining... um, that I was more tired than I was. It's so... and also it was just like mist... one minute I could walk a bit further than another... so it would come and go. So I couldn't really make sense of it, because it was here today, and then tomorrow I was a bit better... well not a bit better, but not quite so bad as the day before. But I also found that if I was pushing myself and thinking right I've got to walk further today because I've got to keep strength in my legs... what you don't use you lose... I was actually getting worse, and I couldn't make sense of that either. So, yes, going back to your question which... I've forgotten what it was [<i>laughs</i>].</p> <p><i>I: Yeah, just... I guess, tell me about what it was like to receive that reclassification.</i></p> <p>P: Yes. It was relief. And I started then to rethink... if I am entering Secondary... well I am now in Secondary Progressive MS... I have got to rethink my life, because here I am struggling to work... I'm going to work in the mornings, and then coming home in the afternoons... my husband's cooking meals, I'm not walking the dog because I'm so whacked out, I'm going to bed at half seven... and things that I used to do like singing I</p>	<p>time period – provided new perspective on illness decline</p> <p>Impact of professional knowledge – image of self not matching reality of nursing profession</p> <p>A struggle to understand – struggle to apply knowledge/experience to own situation</p> <p>Reclassification a relief</p> <p>Relief because struggling for so long</p> <p>Meaning of illness and communicating illness – reaction of others, others judging, visibility of illness?</p> <p>Relief – doubting own perception, imaging deterioration</p> <p>Like mist – coming and going- transitory nature of deterioration – metaphor of mist – descending upon her, haze – feeling lost?</p> <p>Here today, gone tomorrow – transitory nature of symptoms</p> <p>Gradual decline – functioning not returning to same level</p> <p>Reaction to decline – push myself, thinking about the future – keeping strength in legs, what don't use you lose – worry for the future?</p> <p>Getting worse – not understanding – couldn't make sense – confusion</p>
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<p>can't do, because I can't stand on stage. Um... so I think it mainly... it was a relief because I was able to then rethink and think well actually I can't do all those things now, I know I can't do all those things, and I'm not going to be able to do them. So I've had to redesign my social life. So I have to say relief was probably where I was then.</p> <p><i>I: Ok. Ok. And just about that... how expected or unexpected was it when you received that... that reclassification?</i></p> <p>P: Because it was... it wasn't said to me, um, in a way that... "you are now what we would call in Secondary Progressive MS"... it was as if I would have known anyway, because it was a different consultant... so she told me... um "have you ever"... well she was asking me questions... "have you had any disease modifying drugs?" and I said "no." Um... "have you never had anything with this weakness?" and "have you ever had any drugs for your fatigue?" and I said "no"... and she said "well with Secondary Progressive".. So it was almost as if I knew already, or she thought I knew already, and I never showed any indication that I didn't know already, because I think I probably did. So I just went along with that... I didn't actually question... I went along with it, because I'd already questioned the consultant the year before saying "have I got Secondary Progressive?" and she said "I don't like to classify it." So, I suppose I knew really... so this consultant was just telling me what I knew. But it was a... a definite... "you have Secondary Progressive MS," whereas before I'd never been told that. So... yeah.</p> <p><i>I: Mmm. Ok. So the previous consultant the year before they hadn't wanted to classify you, but what did they say to you exactly?</i></p> <p>P: Gosh, I can't remember. I had the registrar come in and check me over. And he wasn't quite as thorough as my usual consultant anyway, because I had tight trousers on so he didn't, um, check my legs in the same way for sensation. But when she came in and I was asking her... and I just said "I'm really worried because I'm not as strong, I'm not as good</p>	<p>Reclassification a relief Reclassification catalyst for rethinking life Impact of illness on several areas of life Reclassification – permission to re-evaluate – process of adjustment</p> <p>Reclassification – as if known anyway Experience of a different consultant – knowledge of reclassification implicit, taken for granted, as if known</p> <p>Consultant delivered news as if new already/thought new already Agreeing with consultant Already thinking about secondary progressive – asked questions the year before – prepared for diagnosis? Thinking about it before Already knew, expected diagnosis Definitive diagnosis – new experience - certainty Difference between knowing and expected, and definite diagnosis?</p> <p>Experience of different consultants – new consultant not as through Sharing concerns with medical professionals Asking professionals if entering secondary</p>
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<p>as I was, and she said well your reactions are the same as they were last year." And I said "could I be entering... or could I be in Secondary Progressive MS?" and that's when she said "we don't classify it." And I suppose I was a little... I came away feeling a bit... hmm, not miffed... but I came away feeling as if I hadn't really achieved anything, as if that was a waste of a visit, because the thing I was worrying about wasn't clarified.</p>	<p>progressive- looking for answers, searching for professional opinion  Professionals not providing concrete answers – difficult for patient  Feeling like hadn't achieved anything – difficult experience of medical appointments – difficult not receiving clarification  Worry about reclassification</p>
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