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## Patients', carers' and providers' experiences and requirements for support in self-management of multiple sclerosis: a qualitative study

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### Abstract

**Background:** Self-management is a process increasingly promoted for the management of long term conditions, both for ethical reasons of enhancing autonomy and for likely cost-effectiveness, but the nature and scope of self-management strategies are currently highly variable.

**Objective:** To identify patients', carers' and clinicians' current experiences of self-management in multiple sclerosis (MS) and their recommendations for the development of a future MS-specific self-management intervention.

**Methods:** Qualitative study using focus groups and semi-structured one-to-one interviews with a purposive sample. Three focus groups were held with 25 patients with moderate to advanced multiple sclerosis and 4 carers. Ten clinicians were interviewed. Data underwent thematic analysis.

**Results:** Participants perceived multiple aspects of MS to be amenable to self-management, but identified a current lack of service provision to support their abilities to self-manage. Participants felt that to address both the physical and psychosocial challenges posed by MS required better information provision, a strong relationship with healthcare professionals and a toolkit of self-management skills. Participants expressed concern at the lack of consideration currently given to carers, which should be addressed in future provision.

**Conclusion:** The diverse experiences of patients living with MS warrant a multidisciplinary, flexible and proactive approach to improve their self-management capabilities, acknowledging both patients' and carers' unmet needs. The findings can be used to guide the development of future self-management interventions specific to individuals with multiple sclerosis.

### Keywords

Long term conditions, multiple sclerosis, person-centered healthcare, qualitative, self-care, self-management

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## Introduction

The rising prevalence of chronic disease has altered the dynamics of traditional healthcare provision, shifting the focus from acute to long-term conditions [1]. With the current disparity between patients' chronic care requirements and limited healthcare resources widening, self-management may be a potentially efficacious method to bridge this gap [2-4].

Effective self-management leads to improved clinical outcomes, greater perceived control over illness and non-illness related behaviours and an enhanced quality of life

[5-7]. However, many individuals struggle to achieve optimum self-management, as indicated by low levels of treatment adherence [8,9], poor quality of life and reported psychological distress across multiple long-term conditions [10-12]. To ameliorate this, self-management interventions have been designed to empower and educate patients, but often to limited effect [13].

Multiple Sclerosis (MS) is a chronic neurological condition typified by its diverse array of symptoms, presenting as extensive physical, psychosocial and economic burden [14]. There have been significant advances in the treatment of relapsing-remitting MS; however, once patients have progressed to a more

advanced stage of the disease, therapeutic options become limited in their efficacy [15]. With no known cure, limiting the disability and impact that arise from symptoms and impairments are therefore key components of MS management [16].

Existing MS-specific educational and self-help programs typically focus on medication adherence, lifestyle adaptation or symptom control in an attempt to improve resourcefulness, self-efficacy and confidence [17-19]. Studies suggest that these may offer some improvement in self-efficacy and physical and psychological health status [20-22]; however, small effect sizes indicate a need to consider alternative approaches that may produce greater benefits. Current interventions have typically focused their efforts on the self-management requirements of patients with milder forms of the disease, with the differing needs of patients with moderate to advanced stages of MS having been largely overlooked [23-25].

The Consortium of Multiple Sclerosis Centers identified the need for a comprehensive, needs-based self-management program to address the constellation of multi-system symptoms that occur in MS [26]. There has, however, been little research into patients' and providers' perspectives on MS self-management to inform the development of such a program [23,27-29]. The aim of this study was to undertake qualitative research into the complex experience of self-management in MS according to patients, carers and clinicians. We sought to identify these stakeholders' requirements and recommendations for improvement of MS self-management support.

## Methods

We conducted a qualitative study during January and February 2012 among patients, carers and clinicians regarding their perspectives on self-management in MS. Focus groups were employed to explore patients' and carers' perspectives, experiences and beliefs as this method capitalises upon interaction between participants, generating a wealth of informative data which may not emerge in a more structured interview setting [30]. Focus groups are also time-efficient and can trigger forgotten memories and remove inhibitions in participants [30].

The perspectives of clinicians and other stakeholders were explored through one-to-one semi-structured interviews primarily for convenience of scheduling. This method also enabled researchers to gather in-depth, focused attitudinal information, whilst allowing the interviewee to develop their own agenda in a setting in which they felt comfortable when discussing potentially sensitive issues.

## Recruitment

This study aimed to inform the development of a self-management program for patients with moderately disabling MS. By focussing the study on a particular aspect of MS, rich, in-depth information, could be obtained from

a relatively modest sample size. While the topic of self-management is explicit, it encompasses a range of stakeholders, which required a diverse sample. Based upon these factors, the study aimed to recruit 35-45 participants and include both service users and providers.

Ethical approval was granted by the South-East Wales (UK) Ethics Committee [Ref: 11/WA/0300]. Subject participation was solicited *via* the MS Society (Cymru) and a purposive sample of patients and carers was recruited *via* MS Society branch meetings. These are groups of MS sufferers who meet on a weekly/monthly basis. Members of support groups have typically been diagnosed for a long time [31] and experience significant suffering due to their condition [32]. Using pre-existing groups is also advantageous as patient familiarity facilitates group discussions, particularly of sensitive issues [33].

The inclusion criteria were informed by discussions with MS specialists. To be eligible for study inclusion, patients had to: (i) be aged 18 or older; (ii) have a clinical diagnosis of MS; (iii) be able to speak English to enable participation in group discussions; (iv) be able to give informed consent and (v) have a Kurtzke Expanded Disability Status Scale (EDSS) score [34] of between 3.0 and 8.0.

We used the EDSS to determine a cut-off point for level of disability. The perspectives of patients with moderate to advanced disability (EDSS > 3.0) were explored, as self-management becomes the mainstay of treatment when disease-modifying therapies are no longer an option. Severely disabled patients (EDSS > 8.0) were excluded, as it was not feasible for them to attend focus groups. Carers of people with moderate to advanced MS were invited to attend the focus groups.

Clinicians were identified through the local hospital's neurology department and approached *via* email to participate in one-to-one interviews. Initially, consultant MS neurologists, MS specialist nurses, occupational therapists and physiotherapists were identified as relevant stakeholders. After reviewing the focus group data it was noted that general practitioners (GP), incontinence nurses and clinical psychologists should also be included in the sample frame (Table 1). No clinicians who were approached to participate declined.

## Data collection

Three focus groups were conducted in January 2012, with 6-12 participants per group; this was sufficient to generate ideas and motivate discussion, but allowed participants equal opportunity to contribute. A total of 29 patients and carers participated in focus groups, held at the location of the branch meetings, to facilitate access and address patients' apprehensions. After the researchers had explained the focus group procedure, participants gave written informed consent and completed a demographic questionnaire. The participant characteristics are summarised in Table 2.

Two impartial researchers conducted the focus groups. The moderator (FD) facilitated the discussion while an observer collected written field notes to enhance data analysis. An exploratory literature review of self-

Table 1 Focus group profiles

Participant Characteristics	Group 1	Group 2	Group 3
Age (years)	50.2 SD 12.3	53.3 SD 9.7	49.1 SD 12.1
Gender	6M/ 4F	6F	5M/ 4F
Time since diagnosis (years)	6.8 SD 6.5	9.8 SD 8.4	11.7 SD 9.9
Carers participating in focus group	1 husband		2 husbands 1 female carer

**Type of MS:** Relapsing-remitting (7), Primary progressive (4), Secondary progressive (12), Benign (1), Unknown (1)  
**Marital Status:** Single (1), Married (14), Divorced (8), Widowed (2)  
**Mobility:** Wheelchair (9), Walker or stick (14), Independent (2)  
**Employment Status:** Employed (1), Retired (11), Unable to work (13)  
**Level of Education:** High school (7), College (5), Bachelors degree (7), No formal qualifications (6)

Table 2 Clinician sample

Professional	n	Justification
MS Specialist Nurse	3	Identified through the literature search as the most likely to provide self-management support to patients, therefore important to interview multiple nurses.
MS Occupational Therapist	1	Involved in the provision of fatigue-management programmes. Only one specialist OT available for interview.
Consultant Neurologist	1	Identified by patients as having little involvement in helping patients to self-manage, which was confirmed in the interview, therefore, only necessary to interview one neurologist.
Incontinence Nurse	1	Only one specialist incontinence nurse available for interview.
General Practitioner	2	Identified through focus groups as a pertinent subgroup to include in sampling frame. Two were interviewed: one with a known interest in self-management and one with no specialist interest.
MS Physiotherapist	1	Significant role in supporting patients with mobility and exercise. Only one specialist available for interview.
MS Society Representative	1	Research identified the charity's important role in helping to support patients in their self-management, therefore, a pertinent subgroup to include in the study.
Clinical Psychologist	-	The post is currently not filled in South Wales, UK

management resources [18,21,35-42], discussion and consensus among the authors and observations made when attending MS symptom-management clinics, informed the development of the interview schedule. We used semi-structured open-ended questions covering aspects of self-management and probes to generate in-depth discussions. The focus groups lasted 60-90 minutes and were digitally sound recorded.

In February 2012, 10 clinician stakeholders were interviewed in their offices to enable interviewees to express their views confidentially. Interviews lasted 30-45 minutes, again digitally recorded with consent. Separate interview schedules were used for the focus groups and clinician interviews, but both explored similar topics (Appendix 1).

The recordings were professionally transcribed *verbatim* to produce an anonymised, orthographic transcript. Data saturation was achieved following completion of the third focus group and tenth interview, when upon reviewing the transcripts no new themes emerged.

## Data analysis

The transcribed data and field notes were interpreted according to the principles of inductive thematic analysis defined by Braun and Clarke as, "a method for identifying, analysing and reporting patterns (themes) within data" (p.79) [43]. Using interview and observation data allowed reflexive analysis of the data from 2 separate perspectives.

Two investigators (FD and ME) familiarised themselves with 5 content-rich transcripts and field-notes; 40% of the data were dual-coded to enhance inter-rater reliability. Each investigator independently identified an initial coding frame, which reflected key issues in the data. Field notes were used to supplement this analytic step by providing context for interpretation. The researchers conducted regular meetings to develop an agreed final list of codes. The primary investigator (FD) coded the remaining transcripts using the qualitative software N-Vivo version 8.0.

Data from the focus groups were initially analysed independently from the interview data and a coding frame was created for each dataset. Following the initial coding

and collation of data, thematic analysis was used to *identify themes which integrated substantial sets of codes*, generating 3 overarching themes and several sub-themes from patient, carer and clinician perspectives. Themes underwent regular review and were assigned labels and definitions. Analysing the focus group and interview data independently and later collectively allowed the researchers to identify areas of congruency and disparity both within and between the separate groups.

## Results

The 3 overarching themes and several sub-themes that represent patient, carer and provider perspectives are presented in detail below.

### Living with MS

#### Visible vs. invisible symptoms

Despite patients' stoic outlook, with most assuming an attitude of "*getting on with it*", patients and carers shared detailed accounts of how MS affects their everyday lives. Living with MS had restricted many patients' daily activities including their ability to work, resulting in a loss of functional independence and financial wellbeing:

"I couldn't have carried on with the job I had; the cognitive function is absolutely rubbish." (F4-FG2)

Clinicians recognised that in addition to managing the disease's extensive physical symptoms which include fatigue, incontinence, spasticity and sensory disturbances, patients often struggled to cope with the ubiquitous psychosocial impairment characteristic of MS. Very few had sought professional advice, with all patients perceiving a lack of support to help manage the 'invisible symptoms' such as depression and cognitive decline. For some this resulted in profound consequences:

"I tried topping myself to be honest...if people only knew what it was like inside...otherwise you look perfect." (M1-FG3)

#### The changing illness trajectory

Patients provided illustrative examples of the unpredictable disease course. Some experienced a gradual decline, whereas others suffered rapidly deteriorating disability. Priorities with respect to health promotion strategies varied according to stage of disease:

"somebody at an earlier stage might be concentrating on how to get through a working day, somebody at a later stage on how can I not spent 20 hours in bed." (M7-FG1)

Clinicians depicted the transition from relapsing to progressive stages as equivalent to "*being diagnosed again*". They adjusted their management approach

according to a patient's changing disease trajectory. In the progressive phase, symptom management became a priority, with the combination of skills and medication therapies necessitating a high degree of self-management:

"Treatment options become limited once they've gone through secondary progressive stage, it becomes all symptom-based." (Consultant Neurologist)

### Self-management skills and practices

Participants identified 3 areas of self-management which could be instrumental in reducing the restrictions that MS imposes on someone's life. Effective support networks were also identified as a key facilitator to developing effective self-management practices.

#### Information seeking

Knowing where and how to obtain credible up-to-date information on MS was viewed as a crucial component of self-management, but patients recognised that their information requirements were not uniform:

"Different people manage [MS] in different ways...a lot of people look on the internet... I've never been on the internet." (M3-FG1)

While patients were keen to access new information to inform their health knowledge, they noted a scarcity of information available for persons with more advanced MS. Participants regarded the transition period between relapsing-remitting and progressive MS as a critical time for information provision for both patients and their caregivers. The lack of support was a source of contention for patients and resulted in many seeking information independently, with little understanding of how to appraise information quality:

"When you're newly diagnosed there are people who'll help you...You go on to secondary progressive and there's nothing to tell you what's happening and what's what." (F1-FG3)

"The internet if you get on the wrong thing can panic you; it might not even be accurate as well." (F2-FG1)

Clinicians acknowledged their key role in information provision, particularly regarding symptom and lifestyle management and signposting patients to self-care resources. They expressed concern at the apparent lack of information, education and support available for carers, a consternation broached by carers themselves. Clinicians felt that if carers were practicing maladaptive techniques such as hoisting or transferring, this could put carers and patients at risk:

"Some carers don't know how to do something but they muddle along; they may end up hurting themselves, so we have to help them as well." (MS Nurse)

## Symptom management

Group discussions revealed a number of strategies, which some individuals had developed independently to manage their symptoms on a daily basis. Typical examples included: napping to combat fatigue, exercising to build strength and walking aids to support impaired mobility. For those attempting to manage their MS, a lack of knowledge often hindered the development of effective self-management practices:

“When should you push yourself, when shouldn’t you? I push myself to do more exercises but I shouldn’t because that’ll bring on fatigue.” (M5-FG1)

It was noted that for most patients, symptoms rarely occurred in isolation; instead a self-management intervention which addressed the constellation of symptoms would be more beneficial:

“Pain, fatigue, cognition, depression all seem interlinked: when people are fatigued they experience pain...fatigue and pain affects cognition...depression affects cognition and makes fatigue worse.” (MS Society Representative)

## Coping and adjusting

For some individuals coping with their changing self, particularly as their condition advanced, was particularly challenging. One woman’s inability to swiftly perform simple tasks led to her husband assuming many of these responsibilities and this exacerbated her frustration and sense of lost independence. Clinicians recognised this as a common complaint, attributable primarily to insufficient education for carers in how to promote autonomy in those they care for:

“Some people [carers] want to be doing everything...so we [MS nurses] in terms of education say, ‘They can still do that for themselves, you don’t have to be doing everything for them just because they have MS’.” (MS Nurse)

Carers described how a diagnosis of MS was a major life adjustment for both patients and their families. Cognitive issues including mood swings and memory loss were cited as the most difficult symptoms for carers to adjust to. This was predominantly due to their lack of understanding and awareness of the scope of cognitive impairment in MS:

“A lot of people don’t recognise there are problems in planning or memory... I’ve been finding it frustrating that I’m not clued in to [wife with MS]’s responses she needs from me.” (Male carer-FG3)

## Effective support networks

All participants advocated the need for effective support networks to encourage self-management. Identified sources of support ranged from family and friends, peer

support groups and charitable organisations to specialist MS medical teams. Individuals who lacked a source of support, for example, through divorce, family estrangement or bereavement, reported a lack of knowledge of available MS services and had become very isolated, with reduced ability to cope with their condition.

Peer collaboration was seen not only as a source of support, but was also viewed by some patients as an educational resource “*we can understand from other people [with MS] how other people cope with it*” (F1-FG1).

As well as the MS groups, another source of peer support was through internet forums and email contact. These alternative forms of communication were viewed by some patients as invaluable due to the disabling and isolating nature of MS:

“There are some very good forums...And on there you can get so many different people answering your questions you get a little bit off each one.” (M5-FG1)

## Requirements for a self-management program

Participants were encouraged to make suggestions for a future MS-specific self-management intervention.

### Engaging and motivational

Patients wanted an engaging and interactive program, one that was “*not just going to be a useful experience but also enjoyable*” (M7-FG1). Clinicians proposed setting individualised, realistic goals to motivate participants to incorporate newly learned self-management techniques into their everyday lives. Patients advocated the implementation of goal-setting; however, they felt that to accommodate the unpredictability of MS, the goals must be flexible. Despite the overall endorsement of goal-setting, one clinician was wary that if patients failed to achieve their incrementally challenging goals it could have a detrimental effect on their psychological wellbeing:

“Be careful of goal-setting...I always remember one lady...she was trying to do more and more exercises and actually was just tiring herself out; she then couldn’t function normally.” (Physiotherapist)

### Peer and professional input

Patients felt strongly that they wanted to retain an element of lay leadership. It was important to patients to have a role model to identify with, somebody “*who’s been through it; who knows exactly what it’s all about*” (F4-FG3). However, patients and clinicians agreed that a program would benefit from a clinician delivering the educational components.

### Informal and formal learning opportunities

Patients advocated the need for a formal educational component to inform them of available medication therapies and symptom management strategies.

Within the groups, individuals' abilities to communicate with clinicians varied. Patients who worked in partnership with their doctor felt empowered; they were inspired to take control of their MS and develop the skills required to reap the maximum benefit from each consultation:

"I'd say it was a partnership...that's why I feel I get the best out of them by treating them that way, go in prepared." (M4-FG1)

However, most patients were averse to actively engage in their medical consultations, citing their GP's lack of understanding of MS as a major barrier. Patients were keen to learn how to improve their relationship with their doctor and develop the skills to autonomously produce and make informed decisions:

"There's only so much [healthcare professionals] can do and the rest we have to do ourselves...we need to educate ourselves in how we can get the information from them." (M4-FG1)

Patients relished the opportunity to discuss their experiences and ideas in a group setting and felt that provisions should be made in the program to allow participants to share their experiences with one another in an informal learning context.

#### Logistical considerations

Participants expressed concern that existing interventions were not easily accessible and were reliant on patients travelling to the programs independently, "*getting there and back can be too much sometimes*" (Occupational Therapist). Clinicians felt that a program would require a greater level of promotion than exists currently. Their suggestions included: through information leaflets, meetings with GPs and *via* the communication channels of the MS Society.

Patients wanted an opportunity to revisit the program to consolidate their learning, potentially leading to the production of long-term outcomes:

"You get out of the habit and forget... I think little boosts, frequent reminders would be useful." (F2-FG3)

#### Recognise the limitations

Patients' and clinicians' main concerns were the variability in MS with regards to symptoms, level of disability and disease unpredictability and how to address these within a program. Some participants felt that if the program was supported by accessible learning materials in a variety of formats such as online modules or handbooks, the program would appeal to a broader demographic:

"If there was a structure online that you could start and go at your own pace a lot of people would find that helpful." (M3-FG1)

Clinicians raised the issue of socioeconomic differences between patient groups and the need to consider language requirements, literacy levels and the prevalence of self-management practised in less affluent areas:

"You could look at prevalence in certain groups and assess the need for information surrounding self-management in those languages." (GP)

Despite the overall endorsement by participants for enhancing current levels of self-management, 2 clinicians were wary that extensive promotion of the self-care agenda could place an undue onus on patients to become wholly responsible for the management of their condition, which they may not want, or be able to manage:

"There is a risk that individuals could be given too much responsibility or not know when to seek extra help and when not to try and work through it themselves." (GP)

## Discussion

All participants perceived the somatic and cognitive symptoms of MS to be amenable to self-management. However, this study found the self-management support requirements of patients with moderate to advanced MS to have largely been overlooked. Participants identified information provision, symptom management and coping with changing self as key areas to focus on in a future intervention. Patients clearly articulated their requirements for a self-management program, while recognising a number of logistical considerations to address. These findings supplement other research regarding the physical and emotional challenges faced by a person with MS and the respective gaps in current service provision.

Clinicians acknowledged that as the prevalence and permanence of symptoms increases, the focus shifts towards health education, promotion of healthy behaviours and development of self-management skills [44]. The insidious progression of disability and cognitive decline typically experienced by patients at a more advanced stage in the disease trajectory have both been recognised as major determinants of quality of life [45-48]. Hakim *et al.* [49] demonstrated their correlation with reduced functional ability, unemployment status and poor standard of living. This, along with findings from Edmonds *et al.* [50], has highlighted the importance of providing biopsychosocial support to help patients maintain functional independence and emotional wellbeing. Participants in this study considered that current service provision to address the psychological effects of MS was not meeting patients' or carers' requirements.

As reported elsewhere, patients here recognised that accessing current MS information was critical to their empowerment and expressed concern at the perceived lack of information available for patients with advanced MS [51]. Edmonds *et al.* [50] identified a paucity of information available to patients with severe MS

surrounding welfare benefits, aids and adaptations and end-of-life issues. In contrast to these findings, research has focussed primarily on providing newly diagnosed patients with information in various formats [52,53].

This study has confirmed and illustrated the critical role that effective healthcare communication could have in helping patients to practise effective self-management skills and achieve better quality of life. In line with earlier studies, patients expressed a desire for tailored information and self-management support from healthcare professionals that was adaptable to the unpredictable nature of MS and patients' varying approaches to MS management [54].

Informal and formal caregivers provide a strong support network for people with MS [55]. The provision of factual information and guidance on how to use equipment and adaptations specifically for carers has been provided by the (UK) NICE MS Management Guidelines [56]. However, clinicians and carers conveyed concern that the needs of carers were not currently being met, with carers expressing a desire to be included in a future MS self-management program.

Including professional and non-professional carers in the study provided valuable insights into the everyday experience of managing MS. However, due to the feasibility of arranging respite care, carers and patients participated in the same focus groups which may have restricted their freedom of expression. No concerns were raised and in some cases patients were more at ease having their carers present. The opportunity to compare and contrast differing opinions of a broad range of stakeholders is a key strength of this study. However, the recruitment of MS Society members to form a patient sample may not be considered representative of all patients with MS, thus reducing our ability to generalise the study's findings to a larger population. Although members may take a more proactive approach to their MS management, approximately 50% of sufferers belong to the society [57]. Despite this, further corroboration among a wider sample of patients and professionals is required to substantiate our findings.

## Conclusion

This qualitative study is the first to our knowledge which provides patient, carer and clinician insights into current self-management experience in moderate and advanced MS. The findings will guide the development of future multidisciplinary MS self-management interventions, addressing the identified barriers to self-management while promoting recognised facilitators. Future research should focus on incorporating these findings into the development, implementation and evaluation of a self-management program for patients with advanced MS.

Modern chronic disease care has advocated the need for patients to assume an active role in the day-to-day management of their condition [58-61]. Based on the findings of this study and supported by earlier research, a comprehensive self-management program could offer

significant benefit to persons with moderate to advanced MS.

The diverse experiences of patients living with MS warrant a multidisciplinary, flexible and proactive approach to coordinate their care efficiently and address patients' and carers' unmet needs. Future attempts to develop such a program should consider combining professional input with lay resources (expert patients and charitable organisations) to assume a holistic approach to self-management, addressing both the physical and psychosocial challenges faced by patients and carers.

A comprehensive and interactive program would combine the provision of tailored education with skill acquisition, developing competencies in information seeking, symptom management, communication with healthcare professionals, lifestyle adjustments and adapting to the changing disease trajectory. In accordance with the results of this study, there is a lack of self-management support available to MS carers. Consideration should therefore be given to incorporating content designed specifically for carers alongside patient components.

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## Appendix 1

### Patient and Carer Interview Schedule

#### Questions for patients

1. What do you think the term self-management means?
  - a. Is it something that is important is to you?
  - b. Do you manage your MS on your own or do you get support from others and if so who?
  - c. Do you feel you have enough support from healthcare workers?
  - d. Do you think you would find it useful to have some more help from a medical professional to help you manage aspects of your MS?
  - e. Currently how much control do you feel you have over your MS?
2. What symptoms do you suffer with most?
  - a. How does this impact on your daily routine and how do you manage it?
  - b. How do you find out what options are available to you to help you manage these symptoms? Do you look on the internet, ask your GP/ neurologist, don't research it and put it down to your MS?
3. If we were to design a new self-management programme to help address some of these symptoms what qualities do you think would make it a good programme?
4. What aspects of your MS would you most like help to self-manage – social and leisure activities, ADLs, symptoms, communication, relationships
5. How could we encourage patients to continue working at their self-management?
6. How could we improve patient's knowledge of their MS?
  - a. Does everyone have access to the internet; would this be a way to get information to patients?
  - b. Would you use leaflets, information DVDs, group education sessions *etc.*
7. Has anyone been taught any skills or been given advice to help self-manage a symptom of their MS, whether you found it useful or not?
  - a. Has anyone ever been to or heard of the Expert-Patient programme? If yes what do you think are its strengths and weaknesses?
  - b. For those who have only heard of it, what reasons did you have for not going?
  - c. Do you think it benefits from being run by non-medical tutors? Do you think having input from a medical professional would benefit the programme?
8. When you go to see your doctor about your MS do you feel you take part in the consultation or is it more one-sided?
  - a. Would you like to be more involved in the management of your MS?

#### Questions for carers

1. As a carer how do you think you help your partner to self-manage their MS?
2. What are the biggest challenges you have faced as a carer of someone with MS?
  - a. How have you overcome these challenges?
3. Have you even been given any advice on how to care for someone with MS? Do you feel you would benefit from more guidance? Is there currently enough support for MS carers?
4. Do you feel you have a good knowledge of your partner's MS? How have you learnt about their MS and what to expect in the future?
5. Do you think that having an aspect of a new SMP that was tailored towards developing the SM skills of carers would be beneficial?
  - a. What skills would you most be interested in learning – these could be to help your own well-being as well as directly helping the person you care for.

6. Are you in contact with other MS carers, do you think that this would benefit you? Would you feel more comfortable learning new skills in a group or individually?

Clinician Interview Schedule

1. What is your role as a \_\_\_\_\_ in helping patients with MS to self-manage their condition?
2. Do you think this role changes when you are treating patients with progressive MS compared with RRMS?
  - a. Do you think that different skills are required to help patients with PMS self-manage compared with the skills required to manage RRMS?
3. Do you think it is important for patients with progressive MS to learn methods to help them manage their MS effectively?
  - a. Do you think that people with MS are currently aware of the importance of self-management?
  - b. Do you think patients currently feel confident in being able to manage their MS successfully? If not, why not and how could we improve this?
  - c. What do you think the current barriers are to improving self-management amongst patients?
4. Would you refer patients to a SMP?
  - a. How could we encourage patients to attend a SMP?
5. What resources are currently available to patients to help them manage their MS?
6. If we were to develop a SMP specifically for patients with progressive MS, what aspects of SM should it focus on?
7. Do you think that current service provision is adequate to support carers of people with MS?
8. How can we integrate the new skills and techniques that would be taught in a SMP into a person's existing daily routine?
9. In your role as \_\_\_\_\_ could you give an example of some of the goals that would be relevant to set to patients and how you would help them to achieve these goals?
10. Existing SMPs often lead to a small immediate improvement in control over a person's MS but this then diminishes over time, how could we ensure a more long term improvement?
11. In a new SMP do you think HCP can work together with lay tutors or should it be independently run by either professionals or lay-persons?