National Institute for Health and Care Excellence

Final

Multiple sclerosis in adults: management

[A] Evidence reviews for information and support for patients (including people who may become pregnant), their families and carers

NICE guideline NG220

Evidence reviews underpinning recommendations 1.2.1 to 1.2.18 and research recommendations in the NICE guideline

June 2022

Final

These evidence reviews were developed by the Guideline Development Team NGC

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1.1 Review question

What information, education and support do a) adults with clinically isolated syndrome b) adults with MS (themes relating to coordination of care only) c) adults with MS receiving palliative care d) adults with MS who may become pregnant, and their families and carers find most useful?

1.1.1 Introduction

People with clinically isolated syndrome (CIS) or MS have complex information needs which may change over time. They must be able to make, and keep under review, informed decisions for both the short and long term.

The exact level and type of information needed may depend on a number of factors such as the time since diagnosis, the nature of diagnosis, disease activity and progression, and the individual preferences of the person receiving the information.

People with MS can access palliative care at any stage of their illness to help with for example symptom management. The National Service Framework for long term conditions states that "People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care".

People with MS or CIS may be considering planning for a family, or be pregnant, and will have additional information and support needs relating to multiple aspects of becoming a parent.

Their family and carers are also faced with uncertainty about the future and will need additional information and support. Their needs will change over time and require review.

There are no up-to-date systematic reviews concerning the information desired by people with CIS, MS and their carers, and this chapter aims to provide a summary of qualitative research in this area.

1.1.2 Summary of the protocol

For full details see the review protocol in Appendix A.

Table 1: PICO characteristics of review question

Objective	To explore perceptions and experiences of patients with MS, their families and carers in order to determine their information and support needs.
Population and setting	Inclusion: Adults (≥18 years) with MS, including: • people receiving palliative care • people with clinically isolated syndrome • people who may become pregnant • their families and carers

	Exclusion: Children and young people (≤18 years)
Context	Perceptions and experiences of adults with MS, including people receiving palliative care and people with clinically isolated syndrome, people who may become pregnant their families and carers regarding the information, education and support they find most useful. Themes may include: • Preferred format of information provision (e.g. face-to-face discussion, remotely, paper, electronic, who gives the information) • Content of information (e.g., symptom reduction, timing of intervention) • Information sources other than healthcare professionals (e.g. support groups, online resources, telephone helpline, Apps) • The need for consistency in the information that is provided (especially when provided from more than one source) • Information needs for carers to be considered independently from the needs of the person they care for • Timing of information (timely, repeated when necessary, adapted to change in progression) • Decision making (sometimes being vague and euphemistic so that people with MS and their families and carers go away unable to plan • Greater understanding of own condition • Confidence in self-management • Impact of treatment on lifestyle and lifestyle on treatment • Impact on family • Impact on sexual function • Impact on cognition • Psychological support (e.g., for support with anxiety, fear, confidence) • Delivery of support (e.g. patient's GP, specialist nurse, peer groups) • Speed of response from nurse, consultant etc. • Transition from relapsing remitting to progressive • Role of the MS nurse or health care professional central to coordination of care and their impact on patient experience • Information needs for adults with MS who may become pregnant
Review strategy	Synthesis of qualitative research. Results presented in narrative, diagram and table format. Quality of the evidence will be assessed by a GRADE CerQual approach for each review finding.

Any relevant themes identified for the subgroups of clinically isolated syndrome, those receiving palliative care and people who may become pregnant will be reported. However, for the general MS population, only themes relevant to coordination of care will be reported, as other themes were already covered extensively in the previous update and recommendations made accordingly. Included studies and findings relating to coordination of care identified as part of this review protocol are presented in the coordination of care evidence chapter (Evidence Review B) rather than this review to ensure all evidence relevant to coordination of care is presented and discussed together. Evidence tables for coordination of care theme studies can be found in appendix D.1 of the current report.

1.1.3 Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual. Methods specific to this review question are described in the review protocol in appendix A and the methods document.

Declarations of interest were recorded according to NICE's conflicts of interest policy.

1.1.4 Qualitative evidence

1.1.4.1 Included studies

We searched for qualitative studies exploring patients' and carers' perceptions of their experiences as well as the information and support they wanted to receive for the following subgroups:

- people with clinically isolated syndrome
- people with MS (coordination of care-related themes only)
- people who may become pregnant
- people receiving palliative care

Thirty-nine qualitative studies or studies with qualitative components were included in the review (from forty papers). This included twenty-six (from twenty-seven papers) that covered some themes relevant to coordination of care in the general MS population (see evidence review B for included studies and findings), ten covering palliative care themes and seven covering themes related to pregnancy or possible future pregnancy. The total number does not add up to thirty-nine across these groups as some studies were relevant for multiple groups. Each of these subgroups were looked at separately and included studies are summarised in section 1.1.5 below, stratified by the subgroups. Included studies and findings for coordination of care themes in the general MS population are presented in evidence review B. Key findings from these studies for palliative care and pregnancy are summarised narratively in section 1.1.6 below. See also the study selection flow chart in Appendix C, study evidence tables in Appendix D, excluded studies lists in Appendix E and GRADE CERQual tables in Appendix F.

Clinically isolated syndrome

No relevant qualitative studies exploring information and support needs specifically in the clinically isolated syndrome population were identified.

General MS population – Coordination of care

See evidence review B for included studies and findings.

Pregnancy or future pregnancy

The population differed slightly between the studies but all studies were considered to be relevant to information and support needs in terms of pregnancy and planning for a family and included without downgrading for relevance. The majority (four studies) specifically aimed to identify experiences and/or needs of people thinking about having children but two studies were also included that covered general experiences of those with MS but reported some comments that were related to pregnancy in terms of disease-modifying therapy.

Palliative care

For the palliative care population, one of the ten included studies (Golla 2016[16]) was a re-analysis of data collected as part of the Golla 2014[15] study, meaning there were nine different studies included but ten different analyses. Where both of these analyses contributed to a particular finding, they have been considered as a single study rather than two separate studies contributing to the finding to avoid double-counting.

The population differed slightly between the studies but all studies were considered to be relevant to the palliative care population in terms of information and support needs and included without downgrading for relevance. Seven studies covered those with severe MS, with three of these studies also including family/carer perspectives, one study covered those with moderate or severe MS and one study focused specifically on family/carer perspectives in those with severe MS. Another study focused on family/carer perspectives in people with MS generally, with end of life care being one of the points raised in the study.

1.1.4.2 Excluded studies

See excluded studies table in Appendix E

1.1.5 Summary of studies included in the qualitative evidence

Included studies tables are presented separately below for the two of the three subgroups evidence was identified for in this review. The included studies table for coordination of care themes is provided in evidence review B. See Appendix D in the current report for full evidence tables for all three subgroups, including coordination of care themes.

Pregnancy and future pregnancy

Table 2: Summary of studies included in the evidence review

Study	Design	Population	Research aim	Comments
Colaceci 2021[5] Italy N=16	Semi-structured interviews with thematic analysis	Women with MS during childbearing age, pregnancy and motherhood. n=10 had given birth to last child within 2 years, n=2 had older children (6 and 13 years), n=3 pregnant women and n=2 seeking to get pregnant;	To explore personal experiences, expectations and fears in women with MS about childbearing age and maternity.	
Ghafoori 2020[12] Iran N=25	In-depth semi-structured interviews with conventional content analysis	Women with MS	To better understand the experiences and concerns of women with MS about pregnancy and motherhood	
Kosmala-Anderson 2013[21] UK N=9	Semi-structured interviews with thematic analysis	Women with MS that had been seen in clinic within last three months regarding planned, current or recent pregnancy	To explore the childbearing experience of women with MS to determine what support and information may be useful to this target group	
Lowden, 2014[23] Canada	Semi-structured interviews with analysis using	People with relapsing-remitting MS with at least 2 relapses	To explore the lived experience of making a first decision about treatment with	

Study	Design	Population	Research aim	Comments
N=9	phenomenological approach.	in the past 2 years	disease-modifying therapies for relapsing-remitting MS	
Manzano 2020[24] UK N= unclear for those discussing pregnancy-related items (N=30 in whole study population)	Semi-structured interviews with thematic analysis.	People with relapsing-remitting MS, with some discussing pregnancy-related items	To gain an increased understanding of people's experiences of decision-making when switching disease-modifying therapies	
Payne 2010[31] New Zealand N=9	Semi-structured interviews with qualitative analysis using interpretive description	Women with MS that had given birth within the last 5 years	To provide a better understanding of the experiences of women with multiple sclerosis in becoming or being a mother	
Smeltzer 1994[37] USA N=15	Semi-structured interviews with qualitative content analysis	Pregnant women with MS	To identify the concerns of pregnant women with MS	

Palliative care

Table 3: Summary of studies included in the evidence review

Study	Design	Population	Research aim	Comments
Borreani 2014[3] Italy N=52 (n=22 people with MS and n=30 carers)	Semi-structured personalised interview (people with severe MS) or semi-structured focus groups (carers), with analysis using grounded theory	People with severe MS and their carers	To identify unmet needs of people with severe MS living at home by qualitative research involving key stakeholders	
Edmonds 2007[7]	Semi-structured interviews with	People with severe MS	To explore the needs of those	

Study	Design	Population	Research aim	Comments
UK N=32	thematic analysis using constant comparative approach.		people severely affected by MS	
Embrey 2013[8] UK N=9	Interviews using Carson's recommendations, with analysis by phenomenological approach	People with moderate and severe MS attending palliative day service	To explore the experience and views of people with moderate and severe MS participating in palliative day care programme in North Staffordshire	
Falet 2020[9] Canada N=29	Semi-structured interviews with inductive thematic analysis	People with severe MS and their informal care providers	To better understand patient and care provider perspectives on the optimal role of their neurologist.	
Galushko 2014[11] Germany N=15	Semi-structured interviews with analysis using constant comparative approach and inductive content analysis with grounded theory methods	People feeling severely affected by MS	To explore the subjectively unmet needs of patients feeling severely affected by MS	
Giovannetti 2018[13] Italy N=27 (n=12 people with MS and n=15 informal caregivers)	Semi-structured interviews with thematic analysis using Framework method	People with severe MS and their informal caregivers	To explore the strengths and challenges of the palliative care intervention, and circumstances that may have influenced its efficacy	
Golla 2014[15] Germany N=15	Semi-structured interviews with analysis using constant comparative approach and inductive content analysis with grounded theory methods	People severely affected by MS	To investigate how severely affected MS patients and their health professionals perceive palliative care to determine how to better approach these patients in Germany	

Study	Design	Population	Research aim	Comments
Golla 2015[17] Germany N=12	Semi-structured interviews with qualitative content analysis	Caregivers of severely affected people with MS	To gain an insight into the subjectively unmet needs of caregivers of severely affected MS patients in Germany	
Golla 2016[16] Germany N=15	Semi-structured interviews with analysis using constant comparative approach and inductive content analysis with grounded theory methods	People severely affected by MS	To investigate whether participants brought up the topic of death and dying	Involves a re-analysis of data collected and analysed in Golla 2014 study, focusing on a specific area.
McCurry 2013[27] USA N=6	In-depth interviews with thematic content analysis	Family caregivers of those with MS	To explore the decisions made by informal caregivers of multiple sclerosis care recipients and the resources they use to inform those decisions.	

1.1.6 Summary of the qualitative evidence

Interpretations and explanations from the original studies were synthesised to gain an insight into themes present across the body of evidence as a whole. The main concepts found in each individual study which were relevant to our review question were drawn together to inform understanding of overarching themes, with subthemes identified within some of these main findings.

Pregnancy and future pregnancy

Narrative summary of review findings

See Appendix F for full GRADE-CERQual tables.

Review finding 1: Content of information and support

Participants highlighted various areas that may be useful to cover in terms of information and support provided to those with MS considering pregnancy or that are already pregnant, as described separately under each heading below.

Possible effect of MS on pregnancy and becoming a parent

Concern about the ways in which MS could affect a pregnancy was commonly highlighted by participants, suggesting people with MS considering pregnancy would benefit from receiving information on this.

One of the main concerns was about how the condition might cause harm to a developing foetus. This included how their MS and physical state might negatively affect a pregnancy and how any treatments might impact the pregnancy, with some highlighted the need for increased and more consistent information regarding MS treatments and pregnancy as they considered there to be conflicting information. One study further highlighted the importance of informing people about treatments during pregnancy as it reported how younger participants planning for pregnancy often temporarily stopped disease-modifying treatments and restarted after pregnancy depending on breastfeeding plans, demonstrating how pregnancies can be planned and navigated. People were also concerned about the possibility of passing on MS to their offspring and wanted to know what the risk of this was.

Labour and delivery, and whether their MS would affect their options, were also mentioned frequently. Participants wanted more information on this, for example whether they would only be able to have a caesarean and whether or not they would be able to have an epidural.

They were also concerned about how MS might affect their ability to care for their child in terms of breastfeeding and wanted to know whether their MS and any treatments they may need would affect their ability to do so. Some appeared to suggest that not being able to breastfeed would negatively affect their ability to care for their child. One participant described being advised against breastfeeding by their neurologist based on the fact that their body had already been stressed by coming off of the drug treatments. Those that did breastfeed sometimes did so against the recommendations of neurologists but felt satisfied that they had been able to breastfeed their child.

Explanation of quality assessment: There was a judgement of moderate confidence in this finding due to concerns about methodological limitations.

Possible effect of pregnancy on MS

When thinking about pregnancy, many participants were concerned about what this might mean for their own health both during and following pregnancy, particularly in terms of relapse and MS symptoms. Some participants reported that the risk of relapse pre-conception, during pregnancy and post-partum was communicated to them before expressing conception plans. Concerns about relapse included the effect that coming off medication might have on their MS in terms of relapse, with some thinking more long-term about what effect an interruption in treatment might have on the progression of their MS. For this reason, some participants highlighted the need for information about whether there would be any suitable treatments during pregnancy either throughout the whole pregnancy or suitable to initiate if they experienced a relapse during pregnancy. Participants also mentioned an increased risk of relapse post-partum as a concern and despite some being told this in consultations, some wanted increased information about the risk and to know whether restarting treatment after pregnancy would reduce this risk. They also wanted referrals to other resources such as societies. A number of studies reported that some participants had temporarily stopped disease-modifying treatments in order to plan for pregnancy and restarted them soon after depending on breastfeeding plans. Some found the period without treatment very long and experienced relapses, further indicating the importance of the risks and benefits of these changes in management being discussed with people considering pregnancy. Some were also concerned about how labour might affect them, for example in terms of fatigue and tiredness and the time needed to fully recover.

Distinguishing between normal changes of pregnancy and MS symptoms was something that some participants commented on, suggesting advice and information in this area would be useful. One participant was also concerned about the effect reproductive assistive technologies might have on the progression of MS.

Explanation of quality assessment: There was a judgement of moderate confidence in this finding due to concerns about methodological limitations.

Self-management advice and planning before birth

Participants across multiple studies highlighted that coping with symptoms during and after pregnancy may be more difficult. Many noted that conserving energy and managing fatigue would be particularly important after having a child and some specifically thought that self-management advice in terms of alleviating symptoms, managing fatigue and planning before the baby arrives would be beneficial.

Explanation of quality assessment: There was a judgement of low confidence in this finding due to concerns about methodological limitations and adequacy.

Effect of MS and treatments on fertility

Concerns about the effect of MS treatments on fertility and their ability to conceive were commonly expressed. Women described how their MS diagnosis meant they planned their pregnancy due to the risk of relapse and their understanding that it might increase over the years. For those with existing fertility issues undergoing assisted reproductive treatments this made the process even more concerning in case of failure. Some felt that their fertility was threatened by MS for various reasons, including medication disrupting menstrual cycles, hormone therapy causing early menopause and infertility and the risk of ovarian insufficiency or cysts that they thought were associated with MS. Some also thought IVF and similar methods of conceiving were not working due to their MS. Others specifically indicated the need for more information about the impact of MS treatments, including disease-modifying therapies, on fertility and wanted to know how long before pregnancy they should be stopped, as well as what the risks of stopping the medications were. One study also highlighted that although pregnancy planning was discussed with women of fertile age, the same could not be said with male participants.

Explanation of quality assessment: There was a judgement of moderate confidence in this finding due to concerns about methodological limitations.

Increased information about fertility/pregnancy required in consultations

Some participants felt that healthcare professionals focused too much on physical symptoms and not a consideration of fertility and the ability to conceive and wanted there to be more counselling and coaching on this after being diagnosed with MS. Some expressed the need for more attention to the perspective of women with MS, suggesting that providers should actively ask women with MS if they want children as this can be important when planning pharmacotherapy and treatments. Similarly, others commented on a lack of information about MS and pregnancy, explaining that they had difficulty finding relevant and reliable information about MS and childbearing. Although some had positive experiences in secondary care as referrals to sources such as the MS Trust and MS Society were given, some described primary care as informing them in line with guidelines but not providing further information or sources of information. One study suggested that pregnancy planning and fertility was not discussed with male participants, who may also have questions about how MS may affect fertility.

Explanation of quality assessment: There was a judgement of low confidence in this finding due to concerns about methodological limitations and adequacy.

Ability to cope with parenthood and support available

The fear of ‘failing’ as a parent and not being able to cope with the demands of having a child alongside MS was common among participants, suggesting the need for increased information about the support that would be available to them. Many were worried about not being able to meet the needs of their child as they felt unable to manage themselves sometimes, with examples including the physical burden of taking them to school and caring for the child in general. For some, this was also associated with a concern about social stigma and being seen as a ‘bad’ mother. Some participants explicitly stated the need for support, which included from family but support organisations and the need for information about where to get practical and professional help in terms of taking care of their baby were also mentioned. Some reported feedback on their experience, describing a sense of solitude and abandonment during the care pathway involving antenatal, childbirth and post-natal care. They also described the need for integrated multi-professional care as they argued that as well as neurological and gynaecological support for those with MS experiencing pregnancy, psychological support should also be considered. Because of the risk of relapse, participants highlighted the post-partum time-point as a period where it was particularly important to have support available to them. The need for information about child healthcare was also mentioned. Some participants were also concerned about the economic effect having children would have on them, particularly as they already had concerns about their employability, and suggested information about available economic support would be beneficial.

Explanation of quality assessment: There was a judgement of moderate confidence in this finding due to concerns about methodological limitations.

Review finding 2: Delivery of information and support

Information obtained from study participants identified factors that should be taken into consideration when having discussions with people with MS about pregnancy in terms of how and when information and support is delivered, as described below under separate headings.

Supportive and open discussions

The importance of support when making decisions about pregnancy was highlighted by participants. Some mentioned the importance of family in this decision making but most comments related to support from healthcare professionals. Support in decision making where experienced helped to reduce anxiety and a discussion with healthcare professionals was considered to be key to making decisions about pregnancy. However, many participants mentioned negative experiences of discussions with healthcare professionals in terms of the sensitivity of those communicating with them – some felt that professionals focused too much on negative factors that may put them off becoming pregnant, such as their ability to care for the child if MS progressed, and others reported that professionals actively advised against becoming pregnant. Examples of professionals suggesting abortion when pregnancy had occurred while taking medication were also reported and considered to be insensitive. One participant highlighted how discussions with healthcare professionals may help people with MS in pregnancy planning, as they highlighted how they did not know when the right time to plan for a pregnancy was. Positive characteristics of healthcare professionals reported by some participants in one study related to kindness, empathy and an ability to respond quickly to doubts or questions.

Explanation of quality assessment: There was a judgement of moderate confidence in this finding due to concerns about methodological limitations.

Having the discussion as soon as possible

Some participants from a single study explicitly expressed the need to have a discussion with healthcare professionals about pregnancy and pregnancy planning as soon as possible after diagnosis and suggested that this should be something the healthcare professional actively asks people about as it was reported that in all cases that conversations about this area were initiated by the women themselves and not brought up by healthcare professionals before this. This topic was also mentioned in a second study, where women highlighted that attention should be given to women’s perspectives in relation to future pregnancies as this is important to understand before planning pharmacotherapy and treatments for MS.

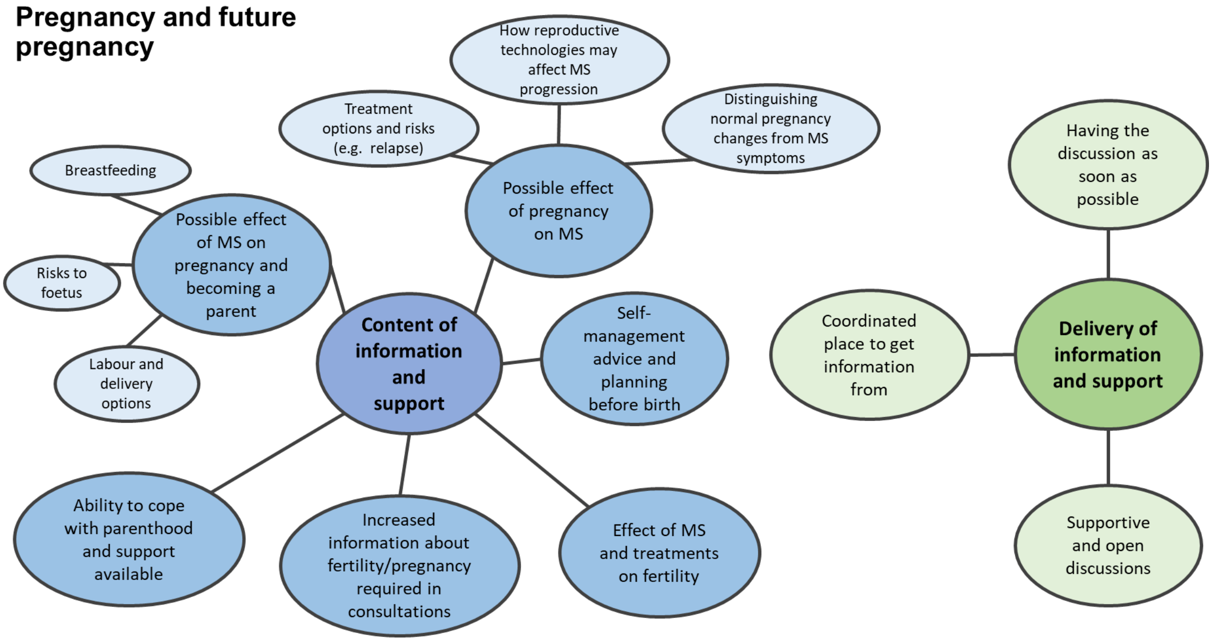
Explanation of quality assessment: There was a judgement of low confidence in this finding due to concerns about methodological limitations and adequacy.

Coordinated place to get information from

The need for information on pregnancy and pregnancy planning was highlighted by the fact that participants from a single study reported that having to look for information in diverse places was time-consuming and frustrating and that having a coordinated place to get information from would be helpful. This further highlights the way in which healthcare professionals can help by providing people with MS with either internal or external sources that can provide further information regarding pregnancy in MS.

Explanation of quality assessment: There was a judgement of low confidence in this finding due to concerns about methodological limitations and adequacy.

Figure 1: Main review findings and details – pregnancy and future pregnancy



Palliative care

Narrative summary of review findings

See Appendix F for full GRADE-CERQual tables.

Review finding 1: Increased access to services and support

Participants highlighted the need for increased access to services in support, which covered physical needs such as physiotherapy and support at home in terms of professional help to reduce carer burden and also home adaptations and mobility aids to promote independence in people with MS, as well as psychological needs and the way in which MS can lead to social isolation in people with MS and their carers.

Physiotherapy and rehabilitation

A number of studies highlighted the importance of physiotherapy and rehabilitation in this population, which emerged both from people with MS themselves and was shared by carers. People with MS expressed the need for more physiotherapy and carers also felt that the people they were caring for would benefit from increased physiotherapy to improve their physical condition. Some participants commented that the rehabilitation facilities usually available did not adequately meet the needs of those with severe MS.

Explanation of quality assessment: There was a judgement of low confidence in this finding due to concerns about methodological limitations and adequacy.

Social isolation and psychological support

Many participants, including people with MS as well as their carers, touched on elements of social interaction and the way in which MS could lead to social isolation and loneliness and negatively affect quality of life. This isolation sometimes led to feelings of depression and inadequacy amongst both groups. Many directly expressed the need for increased social interaction, which included wanting more support from family and friends but also more formal support in terms of psychological support through medical professionals and someone outside of the family to talk to. Some that participated in a programme that included group support by meeting others with MS described beneficial effects of this on their life as they were able to form friendships and conversations without feeling embarrassed. One study focusing on the opinions of people with MS and informal caregivers on the role of the neurologist demonstrated how some participants saw neurologists as an important source of support, both in terms of providing them with information and advice about their illness but also as a form of psychological support. Some participants described how neurologists helped to reassure them about their condition, which meant they felt understood and supported.

Explanation of quality assessment: There was a judgement of moderate confidence in this finding due to concerns about methodological limitations.

Home adaptations and mobility aids

The importance of home adaptations and mobility aids to people with MS was evident and participants wanted assistance in terms of information about them, their suitability for them and how to go about obtaining them, with some feeling like there was a lack of information about them and that they had to fight for them. They were seen as a way of increasing their independence as without them people with MS felt trapped and limited in terms of their ability to get out of the house, with many rarely leaving the house. In some cases, participants also commented on the need for transportation support. Appreciation of this type of support was highlighted by one participant of a group involved in a home-based palliative care programme, as they commented on how they had received advice on a more suitable wheelchair. One study reviewing the role of neurologists highlighted that participants appreciated information about home adaptations and mobility aids, as information about aids that may improve quality of life, rather than solely about medication, was reported as one of the areas participants appreciated information about.

Explanation of quality assessment: There was a judgement of moderate confidence in this finding due to concerns about methodological limitations.

Reducing caregiver burden

The need to reduce caregiver burden was commented on by both people with MS and carers themselves. Participants described how a lot of time was spent on personal care and hygiene at home and how this could be tiring for both people with MS and carers. People with MS often described feeling like a burden for asking this of their carers and sometimes embarrassed. Some people with MS explicitly stated that they wanted their carers to have some support at home to help with this, while others alluded to this as they described how they wanted their carers to be able to have time out away from the responsibility of caring for them.

Carers shared the feeling of needing a break from caring responsibilities, although it was often difficult to admit and some were reluctant to leave the person they were caring for in the hands of someone else. They described how caring responsibilities could impact their working life, social life and ability to look after themselves, for example by attending their own medical appointments or avoiding having surgery due to concerns about whether it would affect their caring abilities. Some carers described previous attempts to obtain help with caring at home, either temporarily to take time out or as a more regular arrangement, as a very difficult process and they felt their specific needs as carers were not considered by doctor's health policy makers.

Participants from a group that took part in a home-based palliative care programme commented on how some elements of the programme had reduced caregiver burden, for example a social worker attending city offices with the caregiver to help with discussions. Some also commented that they wanted doctors or occupational therapists to visit them at home rather than having to go to them all the time, which could possibly help reduce caregiver burden as well.

Explanation of quality assessment: There was a judgement of moderate confidence in this finding due to concerns about methodological limitations.

Review finding 2: Content of information

Participants highlighted the need for information and support in specific areas, including information about and help navigating services, specific information about end of life care as well as more information about illness progression and possible treatments, other areas such as financial support and some discussion of information specifically directed at families and carers. These are described in further detail below under separate headings.

Information about and navigation of services

The need for information about services and assistance navigating them was commonly highlighted by participants, including people with MS as well as carers. This was indicated directly by some as they described how health and social services were scarce and difficult to access, with the feeling of having to fight for services and a general lack of information about what was available to them or would be appropriate for them, particularly when entering a new phase of the disease. Caregivers described how arranging services to cover for when they took time out for respite and self-care was difficult and led to feelings of frustration and that assistance from healthcare professionals with this would be beneficial. Some participants described how in many cases they had found out about services by chance rather than from professionals and they wanted better information about services ideally through a list of all local services available to them, including various areas such as homecare services and transportation services.

Other comments suggested the need for increased information about services more indirectly. For example, some carers were concerned about what would happen to the person they were caring for if they were no longer around or could no longer care for them, something which information about available services could help with to a certain extent.

Explanation of quality assessment: There was a judgement of moderate confidence in this finding due to concerns about methodological limitations.

Increased information for families and caregivers

The need for increased information specifically targeted at the family, friends and caregivers of people with MS was highlighted both by people with MS and their carers. Some people with MS felt that information for carers or relatives was insufficient and wanted there to be more available to allow them to be better informed have an increased understanding of the condition and their needs and abilities, which would allow them to provide them with better support. Another reason for wanting families to be better informed was shared by people with MS and their caregivers. It was explained that sometimes extended family members that did not live with the person did not fully understand their condition making it difficult for them to be positively involved in decision making. An example was given about end of life care decisions often being difficult for relatives not living in the household to come to terms with as they did not fully understand the condition of the person with MS.

Some caregivers highlighted an additional need for themselves in terms increased information and support regarding caring skills and workshops in basic skills were suggested.

Explanation of quality assessment: There was a judgement of low confidence in this finding due to concerns about methodological limitations and adequacy.

End of life decisions, treatment and illness progression

The need for increased information about their condition and possible treatment options, as well as a better understanding of palliative care and possible decisions involved, was identified across multiple studies and was described by people with MS as well as their caregivers.

Many participants wanted further information on the disease including the associated symptoms and progression of MS and treatment options so that they knew what to expect, with some highlighting that assistance in obtaining self-obtained information would also be useful. Participants from a group that received a home-based palliative care programme commented on how practical information provided to them by professionals about managing their condition had been very helpful. Caregivers also described how it could often be stressful making decisions alone on behalf of the person with MS if they were unable to be involved much in decisions about their own care and would appreciate support from professionals in these decisions. Participants from one study focusing on the role of neurologists highlighted an important role for neurologists in providing information about treatment and illness progression, this included information about emerging treatments and research, which they thought should be proactively raised by neurologists so they did not have to ask about this or look into it themselves, and education about different aspects of their disease and its management such as medication, mobility aids and progression in terms of the current stage of their disease and what may happen in the future. One participant saw their encounters with their neurologists as less useful due to their failure to educate them about the disease. Participants also valued the perspective of their neurologist on information they had gathered themselves, for example online, as this helped to differentiate reliable from unreliable information.

The idea of palliative care and what it involved appeared to be poorly understood and different people had different ideas about what it was. Although it was not explicitly mentioned as something they wanted information on, it was noted that some were not aware that death was a possible outcome in MS and it appeared that often participants had given little thought to advance care directives or end of life decisions. Many considered that information about what palliative care was and the process was lacking. They wanted to have these discussions with professionals and to be given information about it, although some felt that there was reluctance currently. Although some noted that end of life decisions were something they found difficult to think about, others found comfort in having a plan.

Explanation of quality assessment: There was a judgement of moderate confidence in this finding due to concerns about methodological limitations.

Financial and other support

The need for information about support in other areas of life such as financial was also highlighted by participants. In terms of financial support, this was sometimes in terms of what reimbursement they could expect for certain aids they obtained, such as electric beds and stairlifts, or for in-home help in terms of nursing, as it was highlighted that often they had to spend money on this. Reimbursement for travel expenses and subsidies for equipping vehicles was also commented on by some participants. For others the need for information about financial support was not directly mentioned but comments about how caring affected the ability of caregivers to work full time suggested that information about what support they could be entitled to would be beneficial.

Other areas that some participants mentioned were housing and administrative processes. Some commented that unsuitable housing sometimes prevented the introduction of devices or adaptations and information about where they could get advice and support for this might be useful for some. Administrative processes such as power of attorney, wills and long-term planning were also mentioned, with some having these in place already but others not realising that this is something they might need to do. Information and advice about these considerations might also be useful in certain circumstances.

Explanation of quality assessment: There was a judgement of moderate confidence in this finding due to concerns about methodological limitations.

Review finding 3: Delivery of information and support

Participants identified three factors that should be considered when delivering information and support to people with MS and their family and carers in terms of palliative care, including coordination of care, information being delivered by people that are knowledgeable about MS and the importance of honest, sensitive discussions in which people with MS and their carers feel engaged in decision-making. These are described in more detail below under separate headings.

Coordination of care and a single point of contact

The need for improved coordination of care and a single point of contact was reported to be important for people with MS as well as their caregivers. The presence of a single person acting as a reference point and who they knew they could go to for advice when needed was considered to be an improvement for those who took part in a palliative care home-based programme. Participants commented that collaboration between services needed to improve and some thought that a case manager who could coordinate health professionals and help people with MS and their carers access available resources would improve coordination and lead to an improved experience.

Explanation of quality assessment: There was a judgement of low confidence in this finding due to concerns about methodological limitations and adequacy.

Delivered by those with increased knowledge of MS

A number of studies highlighted some concerns participants had about the knowledge that professionals communicating with them had about MS, with some commenting that they had difficulty finding neurologists or family doctors that were competent in treating MS and that were up to date with the latest treatments. Overall participants wanted those communicating with them to be knowledgeable in MS and some suggested that family doctors do not feel competent enough to support them as much as they need.

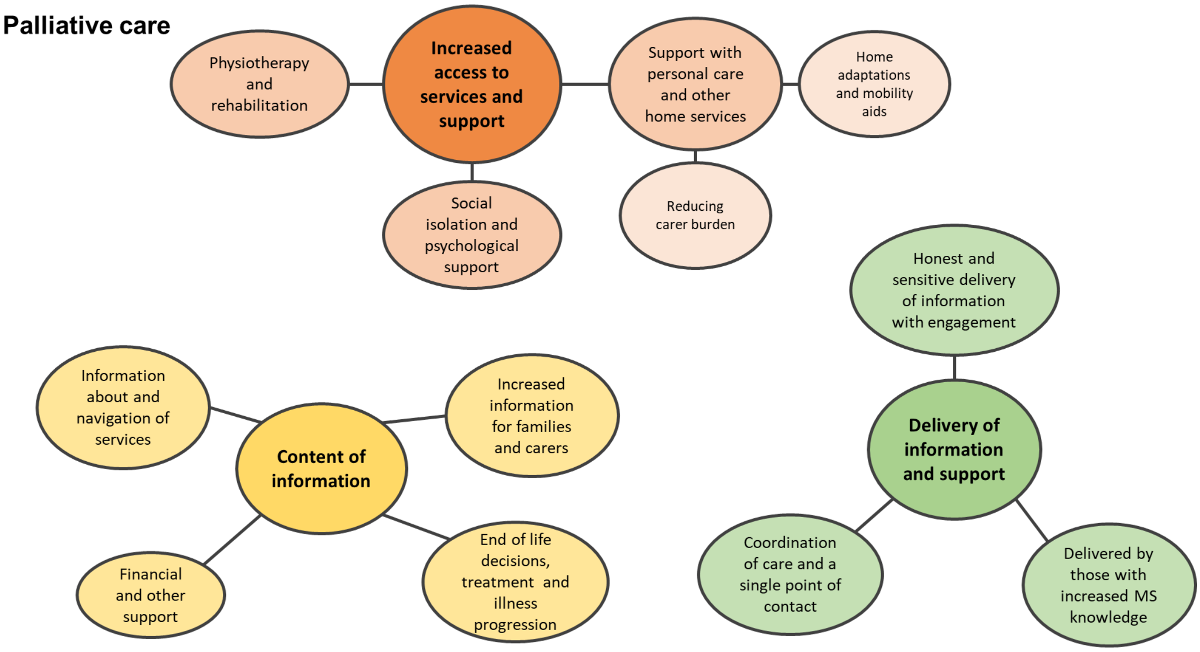
Explanation of quality assessment: There was a judgement of low confidence in this finding due to concerns about methodological limitations and adequacy.

Honest and sensitive delivery with engagement

Of participants that commented on the way in which professionals communicated with them, it was clear that both people with MS and their caregivers wanted to be actively involved in discussions and engaged, though caregivers sometimes felt they were not considered enough in discussions. Those involved in a home-based palliative care programme appreciated the opportunity to participate in discussions with professionals and to exchange opinions as it improved the ability to resolve difficulties. Participants also wanted to be treated sensitively, with more respect and as separate individuals, though some highlighted that they also wanted to be spoken to honestly and for information to be delivered as early as possible. From a study focusing on the role of neurologists, participants saw good listening skills, bedside manner and compassion as key to the supportive role neurologists held. In terms of discussions between participants and neurologists concerning treatment options, several highlighted the importance of neurologists being open-minded and non-judgemental in their approach, with one contrasting the approaches of two neurologists – one that had made them feel supported and informed while the other seen as dismissive and lacking understanding of her decisions.

Explanation of quality assessment: There was a judgement of low confidence in this finding due to concerns about methodological limitations and adequacy.

Figure 2: Main review findings and details – palliative care



1.1.7 Economic evidence

The committee agreed that health economic studies would not be relevant to this review question, and so were not sought.

1.1.8 Evidence statements

All evidence is summarised above in GRADE-CERQual tables in Appendix F, apart from coordination of care themes which is presented in evidence review B appendices.

1.1.9 The committee's discussion and interpretation of the evidence

1.1.9.1 The quality of the evidence

The qualitative evidence included in this review covered multiple populations specified in the review protocol, with the evidence for each of these groups being presented and considered separately:

- Palliative care (n=10 studies)
- Pregnancy or future pregnancy (n=7 studies)
- General MS population – themes related to coordination of care only (n=26 studies from 27 papers)

The quality of evidence for each of these groups is discussed separately below.

No qualitative studies covering people with clinically isolated syndrome, which was an additional population included in the protocol, were identified. In the absence of any existing evidence a research recommendation was therefore made for qualitative research to identify perceptions and experiences of adults with clinically isolated syndrome and their families and carers regarding the information, education and support they find most useful. It was not thought appropriate to apply recommendations for MS to those with clinically isolated syndrome as it was noted that clinically isolated syndrome is a single episode of symptoms where MS has not yet been diagnosed and although the committee noted that ~90% of people with clinically isolated syndrome may go on to develop MS within 10 years, it is not yet considered a chronic condition and information needs may be different for people with clinically isolated syndrome; for example, information about pregnancy planning and palliative care may not be as important and evidence informing information needs for this population is required.

Pregnancy or future pregnancy

A total of seven qualitative studies (all interview-based) were included in the review for this population. Two of the studies were UK-based, while the remaining studies were based in Italy (n=1), Iran (n=1), USA (n=1), Canada (n=1) or New Zealand (n=1).

Of the nine findings that were identified and presented, moderate confidence was present for five of the findings and low confidence for four of the findings based on GRADE CERQual, which reflects downgrading of quality by one and two increments, respectively. Concerns about methodological limitations, which were moderate across all findings, was one factor contributing to downgrading of evidence quality. Common factors contributing to methodological limitations were a lack of consideration and/or discussion of the role of the researcher and how this may have affected study design and subsequent results, and concerns raised in the papers about generalisability. For those where the confidence in the finding was low, this was because fewer studies reported on that finding, meaning that in addition to methodological concerns there were also concerns about adequacy and there was less confidence in the finding compared to those where there were no concerns about adequacy. For all findings, there were no concerns about coherence or relevance. Even for studies that were non-UK based there were no concerns about relevance as the country the study was performed is unlikely to affect what information and support people need or prefer in terms of pregnancy or future pregnancy.

The population differed slightly between the studies, but all were considered to be relevant to information and support needs in terms of pregnancy and planning for a family. The majority specifically aimed to identify experiences and/or needs of people thinking about having children but two studies were also included that covered general experiences of those with MS but reported some comments that were related to pregnancy in terms of disease-modifying therapy.

Palliative care

A total of 10 qualitative studies (n=9 interview-based and n=1 where interviews were performed with people with MS focus groups performed with carers) were included in the review for this population.

Two of the studies were UK-based, while the remaining studies were based in Italy (n=2), Germany (n=4), Canada (n=1) or the USA (n=1). One study was a re-analysis of data collected as part of an initial study already included in the review, meaning there were 9 different studies but 10 different qualitative analyses. Where both of these studies contributed to a particular finding, they have been considered as a single study rather than two separate studies contributing to the finding to avoid double-counting.

Of the eleven findings that were identified and presented, moderate confidence was present for six of the findings and low confidence for five of the findings based on GRADE CERQual. Concerns about methodological limitations, either minor or moderate depending on the finding, was one factor contributing to downgrading of evidence quality. Common factors contributing to methodological limitations were a lack of consideration and/or discussion of the role of the researcher and how this may have affected study design and subsequent results, and concerns raised in the papers about generalisability. For those where the confidence in the finding was low, this was because fewer studies reported on that finding, meaning that in addition to methodological concerns there were also concerns about adequacy and there was less confidence in the finding compared to those where there were no concerns about adequacy. For all findings, there were no concerns about coherence or relevance. Even for studies that were non-UK based there were no concerns about relevance as the country the study was performed is unlikely to affect what information and support people need or prefer in terms of palliative care.

The population differed slightly between the studies, but all were relevant to the palliative care population in terms of information and support needs. Seven studies covered those with severe MS, with three of these studies also including family/carer perspectives, one study covered those with moderate or severe MS and one study focused specifically on family/carer perspectives in those with severe MS. Another study focused on family/carer perspectives in people with MS generally, with end-of-life care being one of the points raised in the study

1.1.9.2 Findings identified in the evidence synthesis

Pregnancy or future pregnancy

The qualitative review identified eleven findings that were considered and discussed by the committee related to pregnancy or planning for a family. Moderate confidence was present for the following five findings: possible effect of MS on pregnancy and becoming a parent; possible effect of pregnancy on MS; effect of MS and treatments on fertility; ability to cope with parenthood and support available; and supportive and open discussions. Existing recommendations in the guideline already covered a number of these areas, including the possible effect of MS on pregnancy (the risk of the child developing MS, pain relief during delivery and breastfeeding), the possible effect of a pregnancy on MS (medication use during pregnancy, the risk of relapse during and after pregnancy and effect on disease progression), effect of MS on fertility and ability to cope with parenthood (caring for the child). The committee agreed these points should be retained in the recommendations. However, existing recommendations were edited to incorporate some additional factors that were identified from the review. The committee noted that breastfeeding is safe for MS but women taking medications for MS should be discussed it with their healthcare professionals.

The committee discussed the importance of including partners of people with MS planning to have children. They agreed that where appropriate information obtained in the review could be extrapolated to partners. Studies reporting on themes related to pregnancy or having children from the perspective of partners of those with MS would have been included but none were identified.

It was noted that people with MS, regardless of whether or not they may become pregnant themselves, may want information about having children. For example, this would include those that may become pregnant themselves and also those who will not become pregnant but will be caring for a child (such as those who are partners of people that may become pregnant or those considering adoption). Therefore, the wording in recommendations was changed from ‘women with MS’ to ‘people with MS’ as appropriate to ensure that recommendations are applied to all people with MS. The inclusion of those that will not become pregnant themselves in this recommendation was because the committee noted that there may still be aspects they would want to discuss, such as possible impact of caring for a child and effects on symptoms such as fatigue. Recommendations were therefore edited to acknowledge this option so that they were not specifically focused on people planning their own pregnancy.

Two additional recommendations were added to cover points that the committee did not feel were addressed in the existing recommendations. The first was a recommendation to proactively raise and discuss imminent or future plans people with MS may have in terms of having children or adopting soon after diagnosis, as they noted that many not have thought about it or may assume that they are not able to have children with their condition and not ask for advice. A new recommendation was made to advise that a healthcare professional should be informed when a person knows that they are pregnant. This should be straight away if the person is taking disease modifying therapies. Although there was only one study and low confidence for the finding of wanting information as soon as possible in this area, the committee agreed that it was important these discussions were had sooner rather than later to ensure people had sufficient time to make decisions and plan for the future. The second recommendation builds on this as it states that it should be explained to people with MS and their partners that MS should not be a barrier to planning a family, as pregnancy can be well-managed in those with MS and support may be available in terms of caring for and supporting children. This recommendation was added as it was noted that a limited understanding of how pregnancies can be managed in those with MS and concerns about their own ability to cope may mean many people feel they can’t have children even if they really want to and people should be fully informed of the ways in which they can be supported if they do want to have children before making this decision. It also links to the ‘supportive and open discussions’ finding from the review, as it highlights that having children is an option for people with MS and encourages open discussions that does not focus on factors that may discourage them.

In terms of the points that should be discussed with those thinking about having children, either through conception or adoption, the committee noted that concerns about fertility in men should also be addressed, as evidence from one study in the review suggested that fertility was not discussed with men and the committee highlighted that often people incorrectly assume that MS affects fertility, particularly in men. The committee also highlighted that another important point to discuss is the possible impact that caring for a child may have on MS symptoms, for example fatigue, and the ways in which this could be managed. Information about birth options was also added as a point that people with MS should be able to discuss with someone with knowledge of MS, as the evidence identified concerns about how MS may affect birth options such as the need for caesarean among people with MS. The need for information about self-management for symptoms such as fatigue was highlighted in the evidence although there was only low confidence in the finding. Despite the lower confidence the committee felt that it was still an important consideration and should be included in any discussions. The committee also referred to the NICE guideline on maternal and child nutrition in terms of folic acid before and during pregnancy as they agreed it was important to advise the use of folic acid as with pregnancies in people without MS.

The only finding identified from the qualitative review in this population not yet discussed is the need for information on pregnancy to be in a coordinated place so that people do not have to look in different places for information. The fact that the recommendations for this population include the opportunity to talk with a healthcare professional with knowledge of MS about a wide range of factors in pregnancy and having children covers this as it recommends access to someone that can help advise on these areas rather than having to look for information themselves from multiple different sources.

Palliative care

The qualitative review identified eleven findings that were considered and discussed by the committee related to the advanced MS or palliative care population. Moderate confidence was present for the following six findings: social isolation and psychological support; home adaptations and mobility aids; reducing carer burden; information about and navigating services; end of life decisions, treatment and illness progression; and financial and other support. Feelings of social isolation were common among people with MS and carers, with some specifically mentioning the need for psychological support, suggesting people would benefit from discussing this with a healthcare professional and being informed of available services and support. The availability and suitability of home adaptations and mobility aids, as well as how to obtain them, was mentioned as important in terms of maintaining independence and therefore suggests providing people with MS about these options may improve patient experience. Carer burden was a concern for people with MS and carers themselves and therefore making them aware of what they are entitled to in terms of support may improve the experience of those caring for people with MS. Difficulty understanding and navigating available services, increased information about end of life care, MS treatments options and illness progression and other areas such as financial and other support were also areas where information and support could be provided to improve the experience of those with MS and their carers as it may allow them to be more informed about their prognosis, options and support available and allow increased control over their situation.

Based on these findings, a recommendation about ensuring carers are aware of their right to a carer’s assessment and available information and support was made. A similar recommendation was already part of the existing guideline under the comprehensive review recommendations, with reference to the NICE guideline on supporting adult carers, but it was thought important to highlight it in the information and support section as well. A further recommendation about providing information and support in line with changing needs or circumstances was made to ensure people have access to the information and support they need depending on their individual circumstances. This included when approaching more advanced disease but also when considering having children, as it was noted in both cases that people may want this information ahead of time to allow time to plan or adjust but that this also may depend on the individual. Based on the review findings, the committee also recommended key areas that should be covered in terms of information and support for advanced disease and end of life care for people with MS and their carers, which included social isolation and feelings of depression, mobility aids and home adaptations and support available (such as legal rights, employment rights and benefits) and a further recommendation was made to inform people with MS and their carers about services they are entitled to and support accessing them, for example occupational therapy, palliative care and social services. The committee discussed adding information about treatment options and disease progression to the list of factors that people with advancing MS and their families or carers should be provided with information about, but it was agreed that this is something that in practice people would be referred on to the most appropriate person for and information then provided. Recommendations in the patient experience guideline also cover this type of information. An existing recommendation about explaining advance care planning and power of attorney was also retained as it was consistent with some of the findings of the review and the committee agreed it was still an important recommendation. However, the committee added the importance of discussing advance care planning at the earliest opportunity, if appropriate.

Low confidence was present for the remaining five findings. These included physiotherapy and rehabilitation, in which people with MS and their carers suggested that increased access to physiotherapy would be ideal or that existing rehabilitation services were not suitable for those with more severe MS. Increased information and support specifically directed at families and carers was also suggested as important; this included targeted information that would help them understand decisions made by the person with MS and others involved in decision making and carers also suggested that increased information about basic caring skills would be useful. The remaining three findings concerned the way in which information and support is delivered, with coordination of care and a single point of contact, wanting healthcare professionals communicating with them to be knowledgeable and confident in dealing with MS and wanting to be actively involved in decisions and treated sensitively and with respect. Although physiotherapy access was not specifically mentioned in recommendations, a recommendation was made to inform people about services they are entitled to and support accessing them. Information and support for families and carers has been covered throughout recommendations on information and support, with families and carers included in many recommendations and a recommendation specific to carers also made in terms of carer’s assessment and information and support. The finding about coordination of care and a single point of contact was addressed by recommendations made under the coordination of care section of the guideline, and involvement in decisions and the way in which healthcare professionals communicate with people with MS and their carers is covered by the reference to the NICE patient experience guideline in adults.

The committee also acknowledged the existence of the NICE guideline on end-of-life care for adults: service delivery and made a recommendation to refer to this guideline as it was relevant to the population covered in this subsection of the review.

1.1.9.3 Cost effectiveness and resource use

Cost effectiveness evidence was not sought as this is a qualitative review question.

The recommendations or edits to recommendations made as a result of this review primarily concerned the content of information that should be provided in specific situations, and it was agreed that these should not have a substantial resource impact.

1.1.9.4 Other factors the committee took into account

Recommendations on information and support include references to various other existing NICE guidelines as appropriate, including the patient experience guideline, end of life care for adults, supporting adult carers and maternal and child nutrition.

The committee discussed that people in rural areas may find it difficult to access sources of support locally. In line with the recommendation in the patient experience guideline people should be informed of all sources of support even if they are not available locally.

A recommendation to highlight the importance of informing people with MS and their carers of the comprehensive review, with reference to the specific recommendations, was added. This was not based on evidence included in the review, but the committee agreed it was important people with MS and their carers are informed of this to allow them to raise it with healthcare professionals if it has not already taken place.

In terms of pregnancy in MS, the committee were aware of the existence of some specialist MS clinics involving a collaboration between maternity services and neurologists; however, it was noted that these were not available in all areas of the country and as the evidence for these services was not reviewed, recommendations could not comment on these services.

The committee were aware the allied health professionals can complete a Health and Work Report.

The committee made a research recommendation to explore the information and support needs of people diagnosed with clinically isolated syndrome.

1.1.10 Recommendations supported by this evidence review

This evidence review supports recommendations 1.2.1 to 1.2.18 and the research recommendation on information and support.

1.1.11 References

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Appendices

Appendix A – Review protocols

Review protocol for information and support for patients (including people who may become pregnant), their families and carers

Any relevant themes identified for the subgroups of clinically isolated syndrome, those receiving palliative care and people who may become pregnant will be reported. However, for the general MS population, only themes relevant to coordination of care were be reported, as other themes were already covered extensively in the previous update and recommendations made accordingly. This decision was made after the protocol had been drafted but prior to studies being extracted and results analysed. Included studies and findings from these coordination of care-related studies are reported in evidence review B.

ID	Field	Content
0.	PROSPERO registration number	CRD42021229745
1.	Review title	Information and support for MS patients, their families and carers.
2.	Review question	2.1 What information, education and support do a) adults with clinically isolated syndrome b) adults with MS c) adults with MS receiving palliative care d) adults with MS who may become pregnant, and their families and carers find most useful?
3.	Objective	To explore perceptions and experiences of patients with MS, their families and carers in order to determine their information and support needs.
4.	Searches	Key papers: Davies F, Edwards A, Brain K, Edwards M, Jones R, Wallbank R, et al. BMJ Open. 2015;5(7): e007674. O'Loughlin E, Hourihan S, Chataway J, Playford ED, Riazi A. Disabil Rehabil. 2017;39(18):1821-8.

		Davies F, Wood F, Brain KE, Edwards M, Jones R, Wallbank R, et al. International Journal of MS Care. 2016;0(0) The following databases will be searched: • Cochrane Central Register of Controlled Trials (CENTRAL) • Cochrane Database of Systematic Reviews (CDSR) • Embase • MEDLINE • CINAHL • PsycINFO • Epistemonikos Searches will be restricted by: • Date limitations: 2010 onwards. The MS patients experience has changed significantly over the years particularly with the advent of the MS nurse specialists. Clinically isolated syndrome also became a possible diagnosis around this time. • English language studies • Human studies • Any other filters The searches may be re-run 6 weeks before the final committee meeting, and further studies retrieved for inclusion if relevant. The full search strategies will be published in the final review.

		Medline search strategy to be quality assured using the PRESS evidence-based checklist (see methods chapter for full details).
5.	Condition or domain being studied	Multiple Sclerosis
6.	Population	Inclusion: Adults (≥18 years) with MS, including: - people receiving palliative care - people with clinically isolated syndrome - people who may become pregnant, - families and carers Exclusion: Children and young people (≤18 years)
7.	Phenomena of interest	Perceptions and experiences of adults with MS, including people receiving palliative care and people with clinically isolated syndrome, people who may become pregnant their families and carers regarding the information, education and support they find most useful.
8.	Comparator/Reference standard/Confounding factors	Not applicable
9.	Types of study to be included	Qualitative interview and focus group studies (including studies using grounded theory, phenomenology or other appropriate qualitative approaches, including survey data or other types of questionnaires only if they provided analysis from open-ended questions).
10.	Other exclusion criteria	Quantitative studies (i.e., closed questionnaire surveys) Non-English language studies.

		Conference abstracts will be excluded because they are unlikely to contain enough information to assess whether the population matches the review question in terms of previous medication use, or enough detail on outcome definitions, or on the methodology to assess the risk of bias of the study.
11.	Context	This review will inform the update of recommendations 1.2.2-1.2.9 in CG 186
12.	Primary outcomes (critical outcomes)	Themes will be derived from the evidence identified for this review and may include: • Preferred format of information provision (e.g. face-to-face discussion, remotely, paper, electronic, who gives the information) • Content of information (e.g., symptom reduction, timing of intervention) • Information sources other than healthcare professionals (e.g. support groups, online resources, telephone helpline, Apps) • The need for consistency in the information that is provided (especially when provided from more than one source) • Information needs for carers to be considered independently from the needs of the person they care for • Timing of information (timely, repeated when necessary, adapted to change in progression) • Decision making (sometimes being vague and euphemistic so that people with MS and their families and carers go away unable to plan • Greater understanding of own condition • Confidence in self-management • Impact of treatment on lifestyle and lifestyle on treatment • Impact on family • Impact on sexual function • Impact on cognition • Psychological support (e.g., for support with anxiety, fear, confidence) • Delivery of support (e.g. patient’s GP, specialist nurse, peer groups) • Speed of response from nurse, consultant etc.

		• Transition from relapsing remitting to progressive • Role of the MS nurse or health care professional central to coordination of care and their impact on patient experience • Information needs for adults with MS who may become pregnant
13.	Secondary outcomes (important outcomes)	Not applicable
14.	Data extraction (selection and coding)	All references identified by the searches and from other sources will be uploaded into EPPI reviewer and de-duplicated.10% of the abstracts will be reviewed by two reviewers, with any disagreements resolved by discussion or, if necessary, a third independent reviewer. The full text of potentially eligible studies will be retrieved and will be assessed in line with the criteria outlined above. A standardised form will be used to extract data from studies (see Developing NICE guidelines: the manual section 6.4). Additional qualitative studies will be added to the review until themes within the analysis become saturated; i.e. studies will only be included if they contribute towards the development of existing themes or to the development of new themes. The point at which data saturation is reached will be noted within the review. 10% of all evidence reviews are quality assured by a senior research fellow. This includes checking: • papers were included /excluded appropriately • a sample of the data extractions • correct methods are used to synthesise data • a sample of the risk of bias assessments Disagreements between the review authors over the risk of bias in particular studies will be resolved by discussion, with involvement of a third review author where necessary. Once saturation is considered to have been reached (all the themes are already covered in the data extraction) data from other included papers will not be

<table>
<tr><td></td><td></td><td colspan="2">extracted or critically appraised, but the paper will still be read to check for any additional themes and will be noted in the included studies. The point at which data extraction is reached will be noted within the review.</td></tr>
<tr><td>15.</td><td>Risk of bias (quality) assessment</td><td colspan="2">Risk of bias will be assessed using the Critical Appraisal Skills Programme (CASP) qualitative checklist, as described in Developing NICE guidelines: the manual.</td></tr>
<tr><td>16.</td><td>Strategy for data synthesis</td><td colspan="2">The synthesis of qualitative data will follow a thematic analysis approach. Information will be synthesised into main review findings. Results will be presented in a detailed narrative and in table format with summary statements of main review findings.
GRADE CERQual will be used to synthesise the qualitative data and assess the certainty of evidence for each review finding.</td></tr>
<tr><td>17.</td><td>Analysis of sub-groups</td><td colspan="2">If suggested by the evidence and where possible, themes may be reported separately for:
- patients, families and carers
- adults with clinically isolated syndrome
- adults with MS
- adults with MS receiving palliative care
- adults with MS who may become pregnant</td></tr>
<tr><td rowspan="7">18.</td><td rowspan="7">Type and method of review</td><td>☐</td><td>Intervention</td></tr>
<tr><td>☐</td><td>Diagnostic</td></tr>
<tr><td>☐</td><td>Prognostic</td></tr>
<tr><td>☒</td><td>Qualitative</td></tr>
<tr><td>☐</td><td>Epidemiologic</td></tr>
<tr><td>☐</td><td>Service Delivery</td></tr>
<tr><td>☐</td><td>Other (please specify)</td></tr>
</table>

19.	Language	English		
20.	Country	England		
21.	Anticipated or actual start date	October 2020		
22.	Anticipated completion date	July 2022		
23.	Stage of review at time of this submission	Review stage	Started	Completed
		Preliminary searches	☑	☐
		Piloting of the study selection process	☐	☐
		Formal screening of search results against eligibility criteria	☐	☐
		Data extraction	☐	☐
		Risk of bias (quality) assessment	☐	☐
		Data analysis	☐	☐
24.	Named contact	5a. Named contact National Guideline Centre 5b Named contact e-mail MultipleSclerosisUpdate@nice.org.uk 5e Organisational affiliation of the review National Institute for Health and Care Excellence (NICE) and the National Guideline Centre		

25.	Review team members	From the National Guideline Centre: Dr Sharon Swain [Guideline lead] Dr Saoussen Ftouh [Senior systematic reviewer] Nicole Downes [Systematic reviewer] Sophia Kemmis Betty [Senior health economist] Lina Gulhane [Information specialist] Emma Clegg [Information specialist]
26.	Funding sources/sponsor	This systematic review is being completed by the National Guideline Centre which receives funding from NICE.
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website.
29.	Other registration details	
30.	Reference/URL for published protocol	
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as:

		• notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.	
32.	Keywords		
33.	Details of existing review of same topic by same authors	None	
34.	Current review status	☒	Ongoing
		☐	Completed but not published
		☐	Completed and published
		☐	Completed, published and being updated
		☐	Discontinued
35..	Additional information		
36.	Details of final publication	www.nice.org.uk	

Appendix B – Literature search strategies

This literature search strategy was used for the following review:

- Information, education and support for a) adults with clinically isolated syndrome b) adults with MS (themes relating to coordination of care only) c) adults with MS receiving palliative care d) adults with MS who may become pregnant, and their families and carers.

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual.[30]

For more information, please see the Methodology review published as part of the accompanying documents for this guideline.

B.1 Clinical search literature search strategy

Searches for patient views were run in Medline (OVID), Embase (OVID), CINAHL, PsycINFO (OVID) and Epistemonikos. Search filters were applied to the search where appropriate.

Table 4: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (OVID)	01 January 2010 – 08 September 2021	Qualitative studies Exclusions (animal studies, letters, comments, children)
Embase (OVID)	01 January 2010 – 08 September 2021	Qualitative studies Exclusions (animal studies, letters, comments, conference abstracts, children)
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	01 January 2010 – 08 September 2021	Human; Clinical Queries: Qualitative - High Sensitivity; Age Groups: All Adult; Exclusions (Medline Records)
PsycINFO (Ovid)	01 January 2010 – 08 September 2021	Qualitative studies
Epistemonikos (The Epistemonikos Foundation)	01 January 2010 – 08 September 2021	Systematic Reviews Exclusions (Cochrane Reviews)

Medline (Ovid) search terms

1.	exp Multiple Sclerosis/
2.	((multiple or disseminated) adj2 scleros*).ti,ab.
3.	encephalomyelitis disseminata.ti,ab.
4.	MS.ti.
5.	Myelitis, Transverse/
6.	transverse myelitis.ti,ab.
7.	or/1-6
8.	*Demyelinating Diseases/

9.	*Demyelinating Autoimmune Diseases, CNS/
10.	(Demyelinat* adj2 (syndrome* or disease* or autoimmun*)).ti,ab.
11.	(Chronic Cerebrospinal Venous Insufficiency or CCSVI).ti,ab.
12.	Venous Insufficiency/cf, co, di, dg, et [Cerebrospinal Fluid, Complications, Diagnosis, Diagnostic Imaging, Etiology]
13.	(Devic* adj (disease or syndrome)).ti,ab.
14.	((clinical* isolat* or radiological* isolat*) adj2 syndrome*).ti,ab.
15.	exp Optic Neuritis/
16.	((neuromyelitis or neuritis or neuropapillitis) adj2 (retrobulbar or optic*)).ti,ab.
17.	(NMO or NMOSD).ti,ab.
18.	or/1-17
19.	letter/
20.	editorial/
21.	news/
22.	exp historical article/
23.	Anecdotes as Topic/
24.	comment/
25.	case report/
26.	(letter or comment*).ti.
27.	or/19-26
28.	randomized controlled trial/ or random*.ti,ab.
29.	27 not 28
30.	animals/ not humans/
31.	exp Animals, Laboratory/
32.	exp Animal Experimentation/
33.	exp Models, Animal/
34.	exp Rodentia/
35.	(rat or rats or rodent* or mouse or mice).ti.
36.	or/29-35
37.	18 not 36
38.	limit 37 to English language
39.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
40.	38 not 39
41.	exp Information-Services/ or Publications/ or Books/ or Pamphlets/
42.	mobile applications/ or social networking/ or electronic mail/ or text messaging/ or hotlines/
43.	Patient Education Handout/
44.	*"Health Services Needs and Demand"/
45.	exp consumer health information/ or exp patient education as topic/
46.	communication/ or communication barriers/
47.	Health Communication/
48.	exp Consumer Health Information/
49.	information dissemination/
50.	exp social support/
51.	Self-Help Groups/

52.	exp counseling/
53.	psychosocial support systems/
54.	peer group/
55.	Health Knowledge, Attitudes, Practice/
56.	Needs Assessment/
57.	Patient Satisfaction/
58.	Attitude to Health/
59.	Patient Preference/
60.	(information or education or support).ti.
61.	(app or apps or blog* or booklet* or brochure* or discussion group or dvd* or elearn* or e-learn* or email* or e-mail* or facebook or facetime or face time or factsheet or forum* or handout* or hand out* or helpline* or hotline* or infopack or internet* or ipad* or iphone* or leaflet* or literature or magazine* or message board or mobile phone* or newsletter* or pamphlet* or palm pilot* or myspace or personal digital assistant* or pocket pc* or podcast* or poster or posters or skype* or smartphone* or smart phone* or seminar or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or workshop or youtube*).ti.
62.	(advisor or advisors or counsel* or rescoure center* or resource centre* or training).ti,ab.
63.	((mobile* or portable) adj4 application*).ti.
64.	(computer* adj4 (handheld or palm top or palmtop or pda or tablet*)).ti.
65.	((internet or online) adj3 (chat* or communit* or discuss* or help or network* or support*)).ti,ab.
66.	(selfhelp group* or self help group* or self manage* or support group* or support service*).ti,ab.
67.	(peer adj2 support*).ti,ab.
68.	(follow up adj2 support*).ti,ab.
69.	((lifestyle or pregnan* or prenatal* or psych*) adj3 (education or information or intervention* or support* or therap*)).ti,ab.
70.	((education* or information) adj3 (access* or barrier* or care or content* or co-ordinat* or disseminat* or electronic* or face to face or format* or help or intervention* or material* or need* or program* or provision or remote* or resource* or require* or seek* or session* or source* or support* or timing* or understand*)).ti,ab.
71.	((clinician* or doctor* or health professional* or nurs* or physician* or specialist*) adj3 (carer* or caregiver* or client* or famil* or patient*) adj2 communic*).ti,ab.
72.	((carer* or caregiver* or client* or famil* or patient*) adj3 (awareness or confidence or decision mak* or knowledge or misconception* or misunderstand* or understanding)).ti,ab.
73.	((carer* or caregiver* or client* or famil* or patient* or education* or information or clinician* or doctor* or health professional* or nurs* or physician* or specialist*) adj3 (attitud* or belief* or choice* or expectation* or experience or experiences or opinion* or perception* or perspective* or preference* or priorit* or satisfact* or view*)).ti,ab.
74.	"health literacy".ti,ab.
75.	*Caregivers/px [Psychology]
76.	Patients/px [Psychology]
77.	or/41-76
78.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp "Surveys and Questionnaires"/ or Health care surveys/
79.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
80.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or

	grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
81.	or/78-80
82.	40 and 77 and 81

Embase (Ovid) search terms

1.	exp Multiple Sclerosis/
2.	((multiple or disseminated) adj2 scleros*).ti,ab.
3.	encephalomyelitis disseminata.ti,ab.
4.	MS.ti.
5.	myelitis/
6.	transverse myelitis.ti,ab.
7.	or/1-6
8.	demyelinating disease/
9.	(Demyelinat* adj2 (syndrome* or disease* or autoimmun*)).ti,ab.
10.	(Chronic Cerebrospinal Venous Insufficiency or CCSVI).ti,ab.
11.	vein insufficiency/co, di, et [Complication, Diagnosis, Etiology]
12.	(Devic* adj (disease or syndrome)).ti,ab.
13.	((clinical* isolat* or radiological* isolat*) adj2 syndrome*).ti,ab.
14.	exp optic neuritis/
15.	((neuromyelitis or neuritis or neuropapillitis) adj2 (retrobulbar or optic*)).ti,ab.
16.	(NMO or NMOSD).ti,ab.
17.	or/1-16
18.	letter.pt. or letter/
19.	note.pt.
20.	editorial.pt.
21.	(conference abstract or conference paper).pt.
22.	case report/ or case study/
23.	(letter or comment*).ti.
24.	or/18-23
25.	randomized controlled trial/ or random*.ti,ab.
26.	24 not 25
27.	animal/ not human/
28.	nonhuman/
29.	exp Animal Experiment/
30.	exp Experimental Animal/
31.	animal model/
32.	exp Rodent/
33.	(rat or rats or rodent* or mouse or mice).ti.
34.	or/26-33
35.	17 not 34
36.	(exp child/ or exp pediatrics/) not (exp adult/ or exp adolescent/)
37.	35 not 36
38.	limit 37 to English language

39.	information service/ or publication/ or book/
40.	exp mobile phone/ or exp mobile application/ or exp social network/ or e-mail/ or text messaging/ or hotline/
41.	patient education/
42.	patient decision making/
43.	patient information/
44.	medical information/
45.	information dissemination/
46.	consumer health information/
47.	communication barrier/
48.	social support/
49.	peer group/
50.	self help/
51.	psychosocial care/
52.	exp counseling/
53.	health personnel attitude/ or nurse attitude/ or physician attitude/ or consumer attitude/
54.	patient attitude/ or patient preference/ or patient satisfaction/
55.	attitude to health/
56.	needs assessment/
57.	(information or education or support).ti.
58.	(app or apps or blog* or booklet* or brochure* or discussion group or dvd* or elearn* or e-learn* or email* or e-mail* or facebook or facetime or face time or factsheet or forum* or handout* or hand out* or helpline* or hotline* or infopack or internet* or ipad* or iphone* or leaflet* or literature or magazine* or message board or mobile phone* or newsletter* or pamphlet* or palm pilot* or myspace or personal digital assistant* or pocket pc* or podcast* or poster or posters or skype* or smartphone* or smart phone* or seminar or social media or social network* or sms or text messag* or twitter or tweet* or video* or web* or wiki* or workshop or youtube*).ti.
59.	(advisor or advisors or counsel* or rescoure center* or resource centre* or training).ti,ab.
60.	((mobile* or portable) adj4 application*).ti.
61.	(computer* adj4 (handheld or palm top or palmtop or pda or tablet*)).ti.
62.	((internet or online) adj3 (chat* or communit* or discuss* or help or network* or support*)).ti,ab.
63.	(selfhelp group* or self help group* or self manage* or support group* or support service*).ti,ab.
64.	(peer adj2 support*).ti,ab.
65.	(follow up adj2 support*).ti,ab.
66.	((lifestyle or pregnan* or prenatal* or psych*) adj3 (education or information or intervention* or support* or therap*)).ti,ab.
67.	((education* or information) adj3 (access* or barrier* or care or content* or co-ordinat* or disseminat* or electronic* or face to face or format* or help or intervention* or material* or need* or program* or provision or remote* or resource* or require* or seek* or session* or source* or support* or timing* or understand*)).ti,ab.
68.	((clinician* or doctor* or health professional* or nurs* or physician* or specialist*) adj3 (carer* or caregiver* or client* or famil* or patient*) adj2 communic*).ti,ab.
69.	((carer* or caregiver* or client* or famil* or patient*) adj3 (awareness or confidence or decision mak* or knowledge or misconception* or misunderstand* or understanding)).ti,ab.

70.	((carer* or caregiver* or client* or famil* or patient* or education* or information or clinician* or doctor* or health professional* or nurs* or physician* or specialist*) adj3 (attitud* or belief* or choice* or expectation* or experience or experiences or opinion* or perception* or perspective* or preference* or priorit* or satisfact* or view*)).ti,ab.
71.	"health literacy".ti,ab.
72.	or/39-71
73.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
74.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
75.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
76.	or/73-75
77.	38 and 72 and 76

CINAHL (EBSCO) search terms

S1.	(MH "Multiple Sclerosis+")
S2.	TI ((multiple or disseminated) n2 scleros*) OR AB ((multiple or disseminated) n2 scleros*)
S3.	TI (encephalomyelitis disseminata or disseminated encephalomyelitistis or ADEM) OR AB (encephalomyelitis disseminata or disseminated encephalomyelitistis or ADEM)
S4.	TI MS
S5.	(MH "Myelitis, Transverse")
S6.	TI transverse myelitis OR AB transverse myelitis
S7.	(MM "Demyelinating Diseases")
S8.	(MM "Demyelinating Autoimmune Diseases, CNS")
S9.	TI (Demyelinat* N2 (syndrome* or disease* or autoimmun*)) OR AB (Demyelinat* N2 (syndrome* or disease* or autoimmun*))
S10.	TI (Chronic Cerebrospinal Venous Insufficiency or CCSVI) OR AB (Chronic Cerebrospinal Venous Insufficiency or CCSVI)
S11.	(MM "Venous Insufficiency/CF/CO/DI/ET")
S12.	TI ((clinical* isolat* or radiological* isolat*) N2 syndrome*) OR AB ((clinical* isolat* or radiological* isolat*) N2 syndrome*)
S13.	(MH "Optic Neuritis+")
S14.	TI ((neuromyelitis or neuritis or neuropapillitis) N2 (retrobulbar or optic*)) OR AB ((neuromyelitis or neuritis or neuropapillitis) N2 (retrobulbar or optic*))
S15.	TI (NMO or NMOSD) OR AB (NMO or NMOSD)
S16.	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15
S17.	MH Information-Services OR MH Publications OR MH Books OR MH Pamphlets
S18.	MH mobile applications OR MH social networking OR MH electronic mail OR MH text messaging OR MH hotlines
S19.	MH Patient Education Handout OR MH "Health Services Needs and Demand" OR MH consumer health information OR MH patient education as topic OR MH communication OR MH communication barriers OR MH Health Communication OR MH Consumer Health Information
S20.	MH information dissemination OR MH social support OR MH Self-Help Groups OR MH counseling OR MH psychosocial support systems OR MH peer group OR MH Health Knowledge, Attitudes, Practice OR MH Needs Assessment OR MH Patient Satisfaction

	OR MH Attitude to Health OR MH Patient Preference OR MH "Patients/PF" OR MH "Caregivers/PF" OR OR MH "Attitude of Health Personnel" OR MH "Nurse Attitudes" OR MH "Physician Attitudes" OR MH "Family Attitudes" OR MH "Patient Attitudes" OR MH "Caregiver Attitudes"
S21.	TI (information or education or support) OR TI (app or apps or blog* or booklet* or brochure* or discussion group or dvd* or elearn* or e-learn* or email* or e-mail* or facebook or facetime or face time or factsheet or forum* or handout* or hand out* or helpline* or hotline* or infopack or internet* or ipad* or iphone* or leaflet* or literature or magazine* or message board or mobile phone* or newsletter* or pamphlet* or palm pilot* or myspace or personal digital assistant* or pocket pc* or p ...
S22.	TI (mobile* or portable) AND TI application*
S23.	TI computer* AND TI ((handheld or palm top or palmtop or pda or tablet*)
S24.	TX (internet or online) AND TX (chat* or communit* or discuss* or help or network* or support*)
S25.	TX selfhelp group* or self help group* or self manage* or support group* or support service*
S26.	TX (peer or follow up) AND TX support*
S27.	TX (lifestyle or pregnan* or prenatal* or psych*) AND TX (education or information or intervention* or support* or therap*)
S28.	TX (education* or information) AND TX (access* or barrier* or care or content* or co-ordinat* or disseminat* or electronic* or face to face or format* or help or intervention* or material* or need* or program* or provision or remote* or resource* or require* or seek* or session* or source* or support* or timing* or understand*)
S29.	TX (clinician* or doctor* or health professional* or nurs* or physician* or specialist*) AND TX (carer* or caregiver* or client* or famil* or patient*) AND TX communic*
S30.	TX (carer* or caregiver* or client* or famil* or patient*) AND TX (awareness or confidence or decision mak* or knowledge or misconception* or misunderstand* or understanding)
S31.	TX (carer* or caregiver* or client* or famil* or patient* or education* or information or clinician* or doctor* or health professional* or nurs* or physician* or specialist*) AND TX (attitud* or belief* or choice* or expectation* or experience or experiences or opinion* or perception* or perspective* or preference* or priorit* or satisfact* or view*)
S32.	TX health literacy
S33.	S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32
S34.	S16 AND S33

PsycINFO (Ovid) search terms

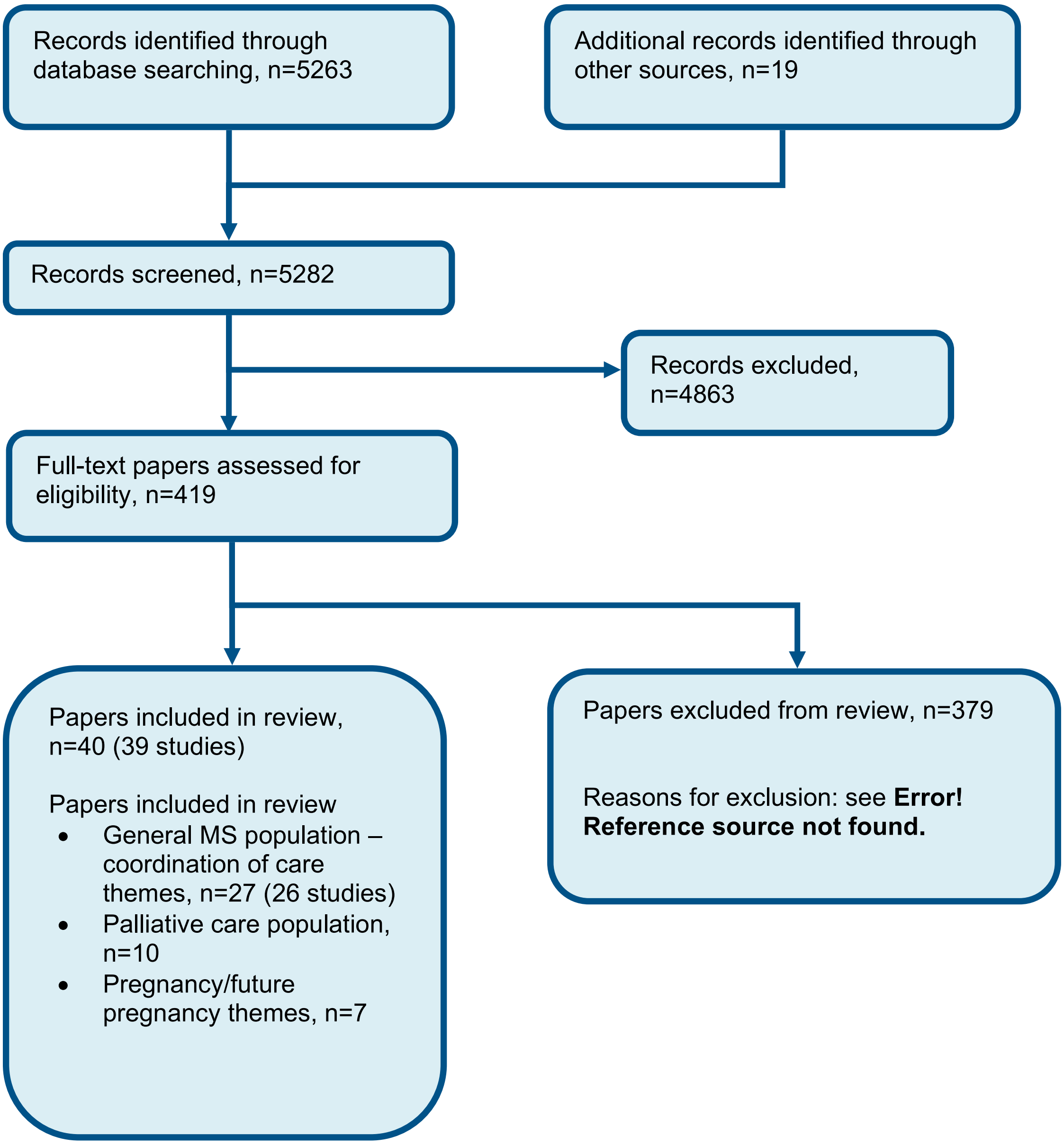
1.	exp Multiple Sclerosis/
2.	((multiple or disseminated) adj2 scleros*).ti,ab.
3.	encephalomyelitis disseminata.ti,ab.
4.	MS.ti.
5.	*myelitis/
6.	transverse myelitis.ti,ab.
7.	or/1-6
8.	Demyelination/
9.	(Demyelinat* adj2 (syndrome* or disease* or autoimmun*)).ti,ab.
10.	(Chronic Cerebrospinal Venous Insufficiency or CCSVI).ti,ab.
11.	(Devic* adj (disease or syndrome)).ti,ab.
12.	((clinical* isolat* or radiological* isolat*) adj2 syndrome*).ti,ab.
13.	exp Optic Neuritis/

14.	((neuromyelitis or neuritis or neuropapillitis) adj2 (retrobulbar or optic*)).ti,ab.
15.	(NMO or NMOSD).ti,ab.
16.	or/1-15
17.	Case report/
18.	letter/
19.	exp Mice/
20.	exp Rodents/
21.	exp Animals/ not (exp Human Males/ or Human Females/)
22.	(rat or rats or mouse or mice or rodent*).ti,ab.
23.	or/17-22
24.	16 not 23
25.	limit 24 to English language
26.	First posting.ps.
27.	24 and 26
28.	25 or 27
29.	exp Qualitative Methods/
30.	exp Narratives/
31.	exp Questionnaires/
32.	exp Interviews/
33.	exp Health Care Services/
34.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
35.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical-sampl* or purposive-sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
36.	or/29-35
37.	28 and 36

Epistemonikos search terms

1.	((advanced_title_en:(multiple sclerosis) OR advanced_abstract_en:(multiple sclerosis)) AND (advanced_title_en:(patient information) OR advanced_abstract_en:(patient information)) OR (advanced_title_en:(patient education) OR advanced_abstract_en:(patient education))

Appendix C –Qualitative evidence study selection



Appendix D – Qualitative evidence

D.1 General MS population – coordination of care themes

Study	**Aspinal 2012**[1]
Aim	To assess the effect of English National Service Framework on integrated services on integrated services and continuity of care
Population	People with a long-term neurological condition who lived in the area covered by the six Primary Care Trusts involved in the study were invited to take part unless they were <18 years old or had cognitive impairment meaning they were unable to give informed consent. Participants were recruited via a range of organisational sources, including via statutory health and social care professionals/services, neurology-specific voluntary organisations, advocacy services and community groups. n=71 (n=19 with MS, n=12 with Parkinson's disease, n=8 with motor neurone disease, n=12 with brain injury, n=4 with spinal injury, n=4 with epilepsy, n=3 with neuromuscular conditions, n=4 with multiple neurological conditions and n=5 other); no further characteristics reported.
Setting	Six neurology 'service systems' in the UK representing geographic and demographic diversity – conducted in six Primary Care Trusts in England and their associated local authorities, public hospitals and other relevant agencies
Study design	Qualitative interview study – part of a mixed methods approach but paper reports only the results of the qualitative study
Methods and analysis	Telephone or face-to-face interviews conducted depending on participant preference. These were in-depth, lasting around 1 h and covered issues including impact of condition on lives, services they received or gaps in service provision and what factors contributed to continuity of care. Audio-recorded with participant's consent and transcribed. Data analysis was performed using Framework method, involving matrix-based approach producing a 'paper trail' to ensure clarity and transparency and maintain consistency of individual accounts while allowing cross-subject themes to be developed. MAXqda used to extract data from interviews into framework and facilitate development of themes and subthemes. Initial themes based around conceptual framework of continuity of care and additional themes developed by team reading same transcripts and identifying common issues and concepts. Extracted into appropriate themes by one person and checked for accuracy and compliance by another. In the event of anomalies, most appropriate theme was discussed as a team and edits made where necessary.
Findings	**Continuity of care and neurological nurse specialists:** • Longitudinal – care delivered by as few professionals as possible, as needed. Repeating themselves and juggling appointments was frustrating.

Study	Aspinal 2012[1]
Note that only those areas thought to be relevant to coordination of care have been extracted.	○ Provide expert advice and reduce need to attend other services ○ Care coordination role ○ Point of contact • Relational/personal/therapeutic continuity ○ Developing a consistent relationship ○ Increased time to listen ○ Increased personal understanding, not just of condition – increased freedom to discuss impact on whole lives ○ Comparisons with other professionals (DR, neurologist) ○ Point of contact ○ Responding to changing needs ○ Supporting, educating, guiding and helping to access services ○ Resulted in trust, communication and responsiveness to changing condition • Long-term continuity ○ Regular follow-up and review led to feeling supported and able to cope ○ Reassurance of telephone and email contact possible ○ Care coordination – patients permanently on their list and allowed gaps/continuity of care issues to be picked up ○ Responding as and when patients need it • Cross-boundary continuity ○ Regular, long-term contact meant able to keep up to date with patient condition ○ Kept other professionals informed ○ Care coordination role across different levels of care ○ Resolving breakdowns of communication and correcting discontinuity in care ○ Point of contact ○ Guiding/organising access to services • Flexibility continuity ○ Flexibility with when, where and how to contact them – responsive to service users needs ○ Increased feeling of support and ability to cope • Information continuity ○ Educating/advising on services ○ Flexibility allowed information to be available as and when needed • Social context – supporting patients to continue usual activities ○ Support using invasive medications at home therefore limiting need for hospital attendance

Study	Aspinal 2012[1]
	○ Supporting and advising family and carers ○ and carers • Personal agency ○ Helping service users and families cope and manage themselves ○ Confidence to self-manage ○ Promoted personal agency - allowed choice and control ○ Tailored support to individual needs – users at heart of decisions
Funding	Commissioned by Department of Health Policy Research Programme based at the National Institute for Health Research Central Commissioning Facility (NIHR CCF) and funded by the NIHR Service Delivery and Organisation programme based at NIHR Evaluations, Trials and Studies Coordinating Centre at University of Southampton.
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including there being no mention of data saturation and no discussion of the role of the researcher in terms of methods and results. This study was considered to be indirectly relevant as it included a mixed population and did not limit only to those with MS, as it included people with various types of long-term neurological conditions.

Study	Blundell Jones 2014[2]
Aim	To explore how women with MS coped with their emotions
Population	Inclusion criteria were a. diagnosis of MS and b. aged between 18 and 65 years. Exclusion criteria included other additional serious physical or medical conditions, a serious mental health difficulty (e.g. borderline personality disorder or psychosis) or receipt or an MS diagnosis less than 1 year ago. Participants recruited by consultant neurologists from an MS clinic based within a regional neuroscience centre serving catchment population of 1.8 million people. Systematic sampling used to select patients resident in one city – every 5th patient aged 18-65 years was sent an introductory letter outlining research aims, with initial mailing of 60 letters yielding sufficient responses for planned sample size. Upon receipt of consent to be contacted form, researcher screened individuals by telephone or email. Fourteen expressed interest but four were excluded due to having a second medical condition. N=10; all females; age: n=4 30-39 years, n=2 40-49 years, n=3 50-59 years and n=1 60-65 years; type of MS was relapsing-remitting in n=7, secondary progressive in n=1, secondary progressive with relapse in n=1 and unknown in n=1; time since diagnosis was 4-5 years in n=2, 8-9 years in n=3, 12-13 years in n=3 and 20-22 years in n=2; last symptom flare-up was 1-week ago in n=1, 1 month ago in n=3, 6 months ago in n=3, 12 months ago in n=1 and over 12 months ago in n=2; level of currently disability according to Guy's Neurological Disability Scale was <10 in n=2, 10-19 in n=1, 20-29 in n=3 and 30-39 in n=4.
Setting	Single MS clinic based in the UK

Study	Blundell Jones 2014[2]
Study design	Qualitative interview study
Methods and analysis	Semi-structured interviews lasting between 45 and 90 min conducted, tape-recorded and transcribed verbatim. Majority were conducted in participant homes with written informed consent obtained prior to interviews. Interview schedule used to guide interviews, with ordering followed flexibly with additional spontaneous questions asked as needed. Analysis used was interpretative phenomenological analysis (IPA), which starts with participant-by-participant analysis and specific examples. Through refinement, themes move from descriptive to interpretive, from individual to group until a single set of themes providing coherent account of data across all interviews is formed. Smith's four-stage cyclical protocol for data analysis was followed: 1. Line-by-line analysis 2. Emergent theme notation 3. Theme clustering for each transcript and 4. Clustering of themes across all interviews. All interviews read once initially to give an overview or experiences before analysis began. Validity of study enhanced as it was designed and conducted in accordance with qualitative research guidance. First author used reflexive journal to document pre-conceptions, motivations, personal thoughts and reactions in order to maximise possibility that premature or inappropriate interpretations were not placed onto the data. This supported the analysis process and thinking. Ongoing supervision by another author and other peer researchers with expertise in these qualitative methods further helped to maintain the quality of the research process. Three-fold method was used to refine and deepen data interpretation and perform triangulation – field experts, peer auditors and the participants. Eight interviews were audited by a combination of two experts (one expert in IPA and other working professionally with MS patients) and a group of peer auditors (peer researchers undertaking separate IPA projects). Audit protocol had the aim of checking whether themes warranted and grounded in raw data and whether anything was imposed or missing. Additionally, all participants given opportunity to participate in individual discussions about the findings, with two declining. Content of eight individual theme tables discussed with corresponding participants along with group themes, with all comments being considered and analysis reviewed as necessary.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	**Uncomfortable dependence** • MS symptoms meant help was needed and for some this was mostly during a relapse – MS nurses were seen as invaluable but wider service experiences varied
	Valuing support • Most women felt NHS offered very good service for their physical needs, making extra referrals efficiently as needed. Having access to MS nurses was very important and seen as a 'lifeline' for some. • Service experiences were not always good, with one participant feeling angry about having to facilitate exchange of information between services and many feeling that GPs and their practice staff did not have enough knowledge about MS. Anxious responses from practice staff left the women feeling ostracised and unsupported.
	Invisible emotions • Most felt emotions were neglected by services and wanted a more holistic approach to be taken • Some found services helpful emotionally and two received support from mental health professionals for MS-related issues, though others stated psychological input was never offered • Some women were reluctant to share feelings either with family or clinicians due to a fear of not being understood and a desire to be self-reliant, or did not want to burden others

Study	**Blundell Jones 2014[2]**
	- Some primarily sought emotional support through MS nurses or others with MS, with one person commenting that she would rather talk to her MS nurse than family and described the MS nurse as the most supportive - One person noted that it was difficult to ask for psychological help and when women did not know where to turn they were left feeling unsupported and alone - Seeking support was seen as requiring a lot of effort and the feared or expected reactions of others could influence decisions around seeking formal support
Funding	Research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including the fact that the specific population may limit generalisability as discussed in the paper itself As this was UK-based study it was considered to be highly relevant in terms of coordination of care

Study	**Browne 2015[4]**
Aim	To explore in depth how bladder dysfunction interferes with quality of life for people with MS.
Population	Diagnosis of MS, aged between 37 and 64, English-speaking and had at least one bladder dysfunction symptom (any voluntary leakage of urine, voiding frequency >8 per 24 h, nocturia, any voiding dysfunction such as hesitancy, straining, poor stream, increased post-void residual volume). Recruited from one branch of the Multiple Sclerosis Society of Ireland using purposive sampling techniques. N=19; 11 females, 8 males; aged 37-64 years (mean 53.42, SD 6.99); n=9 had relapsing-remitting, n=7 had secondary progressive, n=2 had primary progressive and n=1 unknown; most participants needed assistance with mobility (n=17), with only n=2 walking independently; time since diagnosis ranged between 2 and 35 years (mean 17.55, SD 9.59).
Setting	Recruited from one branch of Multiple Sclerosis Society of Ireland.
Study design	Qualitative interview study
Methods and analysis	Audio-recorded semi-structured interviews conducted by three physiotherapy research students and lasted 40-90 min. Verbal summaries of interviews were provided at the end of interviews to allow participants to add, clarify or revise comments. As interviews progressed, topics arising in earlier interviews were explored among subsequent participants to allow for refinement of ongoing thematic analysis. Although a sequential procedure, research analysis was an iterative and reflexive process, which can enhance the transparency, accountability and general trustworthiness of qualitative research. Numerous procedures put in place to enhance reflexivity: reflexive statement produced by first author to acknowledge personal beliefs, thoughts and feelings in relation to the research; field notes used

Study	Browne 2015[4]
	to capture areas of interest and allow exploration of why certain thoughts and interpretations occurred; methodological log of research decisions produced; detailed discussions between all three authors took place throughout the research process to produce a more nuanced understanding of the participants' narratives; and all other analytical decisions were documented continuously throughout the process. Thematic analysis involved a process of engaging with the data and performed in a series of steps: 1. Verbatim transcription, checking text for accuracy and importing into Nvivo10 2. Generation of initial codes from narratives, fieldnotes and discussion between authors. All authors read and coded two transcripts 3. Searching for themes within the data – concepts discussed between authors with codes clustered into key ideas and discussed how they may combine to form an overarching theme 4. Potential themes checked across thematic map and strength of each concept discussed across the software. Concept map refined 5. Themes reviewed to make sure coherent pattern. Transcripts re-read multiple times and ongoing discussions between all authors. Final definitions for themes documented and quotes best illustrating them were selected. 6. Report produced allowing final analysis of data and cohesion of themes. Member checking performed by participants by sending each a summary letter containing key points of interview. No requests to change the findings were received.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	**Ways of knowing** • Lack of knowledge around current healthcare services was portrayed suggesting people with MS may be self-managing without professional advice from healthcare professionals • Perception of limited services exists and participants do what they can to self-manage symptoms in fractured and inconsistent service system
	Medical knowledge • Perception among some participants (n=5) that bladder dysfunction that there is not a cure for bladder dysfunction and nothing that can be done about it • Feeling that no specific help available for bladder dysfunction in people with MS • Perceived healthcare professionals to have limited knowledge about management of bladder dysfunction (quote suggesting GP had limited knowledge and found technique they suggested did not help) • Discusses issues with knowing who to contact and whose responsibility it is (which clinician), suggestion that each was leaving it to another person to deal with • Discussed lack of information available about bladder dysfunction through current services. Limited available services for some was a barrier to asking for help. • Gap in knowledge about accessing and navigating current healthcare system became clear, creating barriers to self-managing • Of those reporting bladder symptoms, most were never asked by any healthcare professional about bladder symptoms and when it was raised they felt it was dismissed, being sent away and told to monitor it. Some felt it was the responsibility of the healthcare professional to ask about bladders symptoms to inform and educate them about this symptom, with some feeling to embarrassed to raise it themselves. Some commented that it appeared to be a lower priority for healthcare professionals. N=9 said they didn't report symptoms as they did not know who to turn to. • Some were asked by GPs about bladder symptoms but were too embarrassed to admit they had them and to discuss it.
Funding	Funded by Irish Research Council.

Study	Browne 2015[4]
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including there being no mention of data saturation and the fact that population included those with self-reported bladder symptoms meaning it may not represent the full spectrum of those with this symptom given many may be too embarrassed to admit to having this symptom As this was UK-based study it was considered to be highly relevant in terms of coordination of care

Study	Defriez 2003[6]
Aim	To explore the patients' perception of their current care provision and unmet needs
Population	People with MS, their carers and healthcare professionals – for the purpose of this review only findings from patient interviews were included as we were interested in the patient and/or carer perspective rather than healthcare professionals. Recruitment involved writing to all GP practices in North Hillingdon Primary Care Group describing the project. Letter sent to each individual GP with copies to practice manager and practice nurse. Practices willing to cooperate asked to search database to establish disease register for all MS patients. Nine agreed to participate and contacted their MS patients with details of the study. N=18 people with MS and n=6 carers. No further participant characteristics given.
Setting	Nine GP practices within North Hillingdon Primary Care Group (patients recruited from 7 out of 9 of these).
Study design	Qualitative study with interviews (n=18) and focus groups (three, with one being for people with MS, n=6)
Methods and analysis	Semi-structured interviews, focus groups, patient and doctor questionnaires. Participatory action research methodology used, meaning findings fed directly back to participants (patients and healthcare professionals) and process is ongoing. Allows data to be reflected on and analysed in cyclical process. Cycle of feedback and analysis allows increased validity of data. N=16 interviewed at home and n=2 being interviewed at a health centre. Carers present at n=6 interviews and keen to share their experience of being a carer. Two researchers (lead researcher and another experienced researcher) performed all of the interviews between them using an agreed format to maintain consistency. Pilot interview schedule was produced and interview prompts agreed by all researchers. Schedules and prompts covered following areas: 1. Patient story of illness 2. Their perceptions of the difficulties of living with MS 3. Sources of care/support 4. Their perception of the extent of communication between healthcare professionals and with social services and 5. Views on improving provision of MS services in the local population. Interview format piloted and refined, with two further prompt areas added covering the type of follow-up patients would like and the usefulness of written information. Interviews were taped and transcribed. Open questions asked to allow for maximum interaction and feedback of individual experiences. Average duration of interviews was 1 h (range 40 min to 2 h). Sample size was small but believed to have reached the saturation point in collecting data from interviews cited by DePoy and Gitlin 1993 paper.

Study	Defriez 2003[6]
	One of the focus groups covered people with MS, with n=6 included (four females and two males). This focus group took place in a special MS centre where patients with all degrees of disability were catered for, and transport was provided. Facilitator used key themes that had emerged from interviews to prompt where needed. Taped and transcribed. As part of the cyclical process in participatory action research, feedback sent to all interviewees and focus group participants with a questionnaire asking for comments and suggestions on the data and emerging themes. Eight replies were received from n=18 interviewees and n=6 from the healthcare professional focus group. Data from this questionnaire was collated with previous data and analysed. Due to small sample size did not feel appropriate to use a software package to analyse data. Text was reviewed for key words and concepts. Coding framework then developed using these and thematic analysis performed to identify themes.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	**Lack of continued and co-ordinated care** • Consensus that some care not well coordinated and poor communication between professionals • Patients who required nursing and personal care would have preferred one regular professional to be responsible for their care, with carers also commenting on this
	Lack of expertise amongst health professionals • Most valued GP and found them supportive but general feeling that most GPs did not have enough knowledge about MS • Some liked to see neurologist on regular basis and valued their expertise and continuity of care offered • Many said they would like someone to contact, such as a nurse, that would understand their condition
Funding	Funding by West London Research Network.
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including there being no discussion of the role of the researcher and possible impact on methods and results, limited discussion of data analysis methods and possible limitations in applicability given results were only from a single area highlighted within the paper. As this was UK-based study it was considered to be highly relevant in terms of coordination of care.

Study	Edmonds 2007[7]
Aim	To explore the needs of those people severely affected by multiple sclerosis
Population	Purposive sample of people with MS and their informal carers. Participants identified as ‘severely affected’ by their MS based on basis of clinical need as identified by referring person. Referral criteria left open to enable people to make their own interpretation of severely affected but suggested to referrers that participants might have an EDSS score >8.

Study	Edmonds 2007[7]
	Recruited to study through referrals from neurologists, MS nurse specialists, residential care homes, rehabilitation and intermediate care centres, local MS Society branches and carer organisations. Information sheets sent to potential participants. N=23 people with MS and n=17 informal carers (overall details about n=32 people with MS obtained, with some obtained indirectly through carers). Eight of the carers were caring for someone that was also involved in the interviews. Carers were most commonly a spouse (n=10 wives and n=4 husbands), n=2 were parents and n=1 was a full time carer (not a relative). Median age 55 years (range 18-74 years). Median time from diagnosis was 14.5 years (range 1-48 years); majority Caucasian (27/32). N=25 living at home (n=7 alone and n=18 with someone else).
Setting	All participants lived in Southeast London
Study design	Qualitative interview study
Methods and analysis	Tape-recorded, semi-structured interviews carried out by one research fellow, which lasted between 30 and 90 min. Interview schedule was used to form the basis of interviews. In most cases people with MS interviewed separately from their carers except where the layout of the home did not permit this. N=13 people with MS interviewed at home, n=3 at rehabilitation units, n=5 in long-stay institutions and n=2 on acute neurology ward where they were long-term patients. N=16 informal carers were interviewed at home and n=1 at their workplace. Taped interviews were transcribed verbatim and entered into Nvivo 2.0 software. Interview data initially analysed for themes by hand using constant comparative approach, followed by crosschecking and refinement using Nvivo. Initially coded as ‘free nodes’ then grouped into broader themes. Quotes selected for results section to illustrate main themes and were broadly representative.
Findings As this study was relevant to the palliative care subgroup, all relevant findings were extracted, including those relevant to coordination of care as well.	**‘Fighting for everything’** • Many felt they had to fight for the services, benefits and aids that they received, with quotes highlighting this commenting on not knowing what is around, the feeling of not being told things, it being a battle to get things done and having to fight for care for example in terms of social services and needing someone to be an advocate for this as well as aids and adaptations.
	Continuity and co-ordination of care • Many commented on perception of lack of continuity or coordination of care within and between social and healthcare services, which was frustrating. Quotes included comments about compartmentalisation of care, including MS nurses, and lack of ‘thread’ and ‘intermix’ between them. One participant as a carer commented they felt like they had to facilitate the exchange of information between services and found this frustrating – he describes the difficulty they had arranging carers to help when he needed a break from caring and the relief felt when eventually a social services care manager helped with this. • Some participants commented on one the effects of this compartmentalisation, which was having to repeat themselves to multiple times to different people, again leading to frustrating. • Some commented that despite the constant repetition of information, nothing seemed to happen in response due to the lack of continuity in care and seeing a new person the next time there was an appointment.
	Information

Study	Edmonds 2007[7]
	- Repeatedly stated they had not been provided with enough information about what was available to them and instead had to find out by chance through for example by overhearing things. - Some had come across useful information through chance conversations with others rather than interactions with health or social care practitioners. - One carer described being unaware of what her husband was entitled to and what support was available for herself, despite working for a carers' organisation herself as a social worker. - Two interviewees commented specifically on a lack of information about end-of-life care for people with MS, with one being a carer and the other a person with MS. Quotes included comments about whether MS could kill you and knowing what was going to happen at the end with feeling that the final progression of the illness was not discussed enough. - Another two mentioned general issues relating to end-of-life, with one person with MS being worried about dying alone and another highlighting her wish to plan for death in terms of writing letters to her sons.
Funding	Not reported.
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including there being no discussion of the role of the researcher and possible impact on methods and results, no mention of data saturation and it being unclear if any data validation processes were included. As this was UK-based study it was considered to be highly relevant in terms of coordination of care.

Study	Falet 2020[9]
Aim	To better understand patient and care provider perspectives on the optimal role of their neurologist.
Population	Patients with MS (judged to be severely affected by neurologist) and care providers Patients recruited by neurologist treating their MS if they were >18 years, able to communicate meaningful information about their opinions and severely disabled as judged by their neurologist. Suggested that neurologists recruit patients with scores of 6.0 or more since these patients are most likely to experience severe disability, but they could recruit patients with lower scores if they judged disability to be severe in aspects unaccounted for by the EDSS. Patients contacted by phone and invited to participate in an in-person interview. Suggested that patients bring their care providers with them, but this was not required given not all patients may have someone that could accompany them. N=29 participants (n=19 patients and n=10 care providers) recruited via three neurologists. Care providers were a spouse (n=6), a child (n=2) or a parent (n=2). Recruitment halted after 29 participants based on thematic saturation. Patient demographics as follows: mean (range) age, 57 (44-80) years; n=4 relapsing-remitting MS, n=4 progressive-onset MS and n=11 secondary progressive MS; Mean (range) EDSS score, 6.5 (3.0-8.0); mean (SD) SDMT score, 29.0 (15.0); n=1 each on interferon beta-1a and beta-1b, n=2 taking glatiramer acetate, n=2 on fingolimod, n=2 on natalizumab and n=7 taking none of these.

Study	**Falet 2020**[9]
Setting	Study based in Canada
Study design	Qualitative interview study
Methods and analysis	Semi-structured interviews conducted by one author. These were audio-recorded and transcribed verbatim. Inductive thematic analysis of interview transcripts performed by the interviewer. Data extracts within transcripts were coded at semantic level. Themes relating to desired role of neurologist identified within each transcript, clustered into subthemes and into overarching themes. Analysis reviewed by second author and differing opinions resolved by discussion. Cross-interview analysis conducted by separate author throughout the study by pooling thematic analyses of all interviews into a common thematic map. This was reviewed through discussion and modified until satisfactorily represented all authors' interpretation of the data.
Findings	**General comments** Most patients and all care providers felt at least some aspect of their neurologist's role was useful and could not be replaced by another healthcare professional. One felt that his neurologist was not useful and could be replaced by his family physician. Another participant felt current neurologist was useful but contrasted this with another neurologist who did she not feel had been useful. Reasons included not fulfilling three roles subsequently discussed in headings below. **Neurologist as a source of hope for therapeutic advances** 13 patients and 8 care providers highlighted role of neurologist as provider of hope for therapeutic advances, which was their most important role for 9 patients and 5 care providers. Hope was most commonly associated with the link the neurologist has to information about research and novel therapies. Several participants wanted their neurologist to share information on this proactively without having to request it and without having to research it themselves. **Neurologist as an educator about the disease and its management** 12 patients and 6 care providers felt neurologist is useful through education about different aspects of their disease and its management, with 5 patients and 3 care providers describing this as the most important role. This information included advice on measures to improve their quality of life (for example, suggesting aids that might improve life rather or as well as medication), updates on the stage of their disease (stage currently at and what might happen in terms of progression). One patient described encounters with their neurologist as less useful due to their failure to educate him about his disease (they saw it as an important role of the neurologist and wanted to be told more information). Some participants valued the perspective of their neurologist on information they

Study	Falet 2020[9]
	had gathered themselves, for example online (this helped differentiate reliable from unreliable information, which was noted to be difficult particularly online). **Neurologist as a source of support** 11 patients and 5 care providers saw the neurologist as an important source of support. One patient and one care provider felt this was their most important role. The neurologist is thought to be well placed to accompany the patient through progression of their disease. Quotes highlighted how this included reassurance about progression of disease and whether worsening symptoms are part of the natural progression. Quotes highlight the sense of psychological support and reassurance with one person being reassured by the neurologist stating that they will deal with it together, and others also highlighting how their neurologist understands them and makes them feel supported. Good listening skills, bedside manner and compassion enabled the supportive role of neurologists. Several participants highlighted the importance of them being open-minded and non-judgemental in their approach, which was crucial to the support they receive. One patient discussed her experience discussing chronic cerebrospinal venous insufficiency with two different neurologists, with contrasting experiences in relation to angioplasty. One was open and explained his concerns beforehand but supported her nonetheless, while the other was dismissive and suggested a lack of understanding.
Funding	Received no financial support for the research, authorship, and/or publication of this article.
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including concerns about focusing on three neurologists from the same centre and possible recruitment bias in terms of patients with more positive relationship with neurologists Despite being non-UK based, this study was considered to be highly relevant given the topics it reports are likely to be similar across countries and not covering areas such as organisation of care which likely differs between countries.

Study	Forbes 2007[10]
Aim	To identify what people with multiple sclerosis believed would be helpful in meeting their current needs
Population	All those having a diagnosis of MS at centres were invited to participate. Sample estimated to account for ~50% of total MS populations in these areas. Recruitment from 7 neurological care centres from 5 English regions (two in southeast, one in the east, one in the southwest, one in the midlands and two in the north).

Study	**Forbes 2007[10]**
	N=435 people answered the question at 12 months and N=424 at 24 months (n=270 responded on both occasions); mean age 48.3 years (SD 10.9); 69% female and 31% male; 29% relapsing-remitting MS, 60% progressive MS and 11% other type of MS; 17% minimal severity, 20% mild MS, 35% moderate severity and 28% severe MS; time since diagnosis, mean (SD) 11.01 (8.76) years; 17% living alone and 83% living with others.
Setting	7 neurological care centres from 5 English regions (two in southeast, one in the east, one in the southwest, one in the midlands and two in the north).
Study design	Qualitative analysis of data collected via one open-ended question in a 17-page postal questionnaire.
Methods and analysis	Data collected via one open-ended question in a 17-page postal questionnaire that also included health and care measures including standardised measure of disease impact (MSIS-29). The question was ‘what one thing would be most helpful in meeting your current needs?’. Questionnaires posted in spring and summer of 2001 and 2002, with two reminder questionnaires sent at 3-weekly intervals to improve response. First stage of analysis involved categorisation of the open responses to the question, with quantitative content analysis performed following a 9-step procedure described by Feher Waltz et al 1991. Only manifest and unambiguous responses were included and responses that were unclear coded as miscellaneous. Primary units of analysis were codes defined as neutral labels describing content of the response. No sampling necessary as all relevant responses were included in the analysis. Data coded inductively. Catergorisation performed at two levels – subcategory level and category level. Group of 4 researchers initially reviewed responses independently and generated prototype codes, which were discussed until there was agreement among researchers and coding schedule produced. Coding scheduled was tested with two people outside of the research team who reviewed and coded 40 responses using the coding schedule (no difficulties were encountered). Data were independently coded by 2 researchers with 89% agreement achieved – disagreements were reviewed with independent researchers and codes agreed. Analysis performed by 2 of the researchers
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	**Enhanced care provision** • Requests for improvements in accessibility, continuity and availability of health and social care, with most common request in this category relating to provision of MS nurse or increased access to one • Someone with increased knowledge of MS – need for professionals to have increased knowledge of MS and skills needed for its management was identified • Many wanted increased coordination of services with a central point of contact
Funding	Funded by MS Society for Great Britain
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including there being no discussion of the role of the researcher and possible impact on methods and results, limited discussion of why this study design was

Study	**Forbes 2007[10]**
	selected and concerns about data collection as it was obtained through a single open-ended question, the wording of which may have limited the number of areas participants commented on. As this was UK-based study it was considered to be highly relevant in terms of coordination of care.

Study	**Goicochea Briceno 2021[14]**
Aim	To learn the experience of patients and their caregivers of the medical care received in the Gregorio Maranon Hospital Demyelinating Unit
Population	People with MS and their family members/caregivers receiving treatment or follow-up at the unit. Those that were adults and had a diagnosis of MS were included in the patient focus groups. For carers to be included, they had to be adults and be the main carer for the person with MS. Patient and family member/carer sampling was incidental from those that had attended the clinic within the 3 weeks prior to the start of the study. Contacted by telephone to explain aims of study and to invite them to participate. Family members were selected by the neurologist of the unit taking into account the viability of attendance and intention to collaborate with potential participants in the study. N=16 people with MS and n=10 family members/caregivers; group 1, 75% in employment, mean 9 years evolution of disease and most with relapsing-remitting phenotype; group 2, longer disease evolution (15.3 years), main phenotype secondary progression MS and 62.5% having occupational disability arranged; mean age in family group was 56 years with half being retired.
Setting	Unit of Demyelinating Diseases at Hospital General Universitario Gregorio Maranon in Spain
Study design	Qualitative focus group study
Methods and analysis	Two patient focus groups were planned (one with EDSS up to 3.5 and the other with EDSS between 3.5 and 7.0) and one focus group with family members/carers. Whole sessions were recorded in audio and written notes on major aspects were collected. Discussion guide was created for focus group containing specific aspects relating to the healthcare team of the unit. Contained breakdown of issues to be addressed in the session in the form of open questions that guide free group discussion. Issues selected by research team through discussion and consensus based on their everyday experience of caring for people with MS and families. Focus groups conducted separately and moderated by two members of research team who were trained in qualitative methods, did not know the participants or intervened in any of their healthcare. Held at the hospital lasting around 60 min. Family and carer group held first followed by the two patient groups simultaneously in separate rooms and moderated by one researcher each. Moderator briefly explained the session and encouraged freedom to discuss opinions. Moderator began by suggesting one theme and the group

Study	**Goicochea Briceno 2021**[14]
	developed the contents of this, jumping from one theme to another spontaneously. Moderator did not intervene unless observed something not covered by the guide or that something in the guide had not been covered. Following sessions, transcriptions of each group were analysed. Semantic analysis performed with coding for each person, analysis of the data, assessing the significance of each quote and dividing them into themes.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	**Care** • When suffering outbreak or worsening of symptoms in general people with MS felt care was appropriate • Some family members reported bad experiences due to poor communication between healthcare professionals • Families reported a lack of response from the email and telephone services at the unit but people with MS described these services positively.
	Healthcare team • Aspects that could be improved at the unit within the healthcare team included increased multidisciplinarity – families felt that they should be more effectively referred to different specialists when specific problems arose and could not see any existing forethought or teamworking by different healthcare teams. Also commented that more staff were needed at the unit to fulfil this.
Funding	Not reported
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including concerns about data collection as role of moderators as described may have prevented themes that were not pre-identified by the researchers being considered, it being unclear whether findings were validated in any way and potential limitations in applicability described in the paper. This study was considered to be indirectly relevant as it was a study based in Spain and it is unclear how coordination of care elements may differ to the UK healthcare system.

Study	**Hunter 2021**[18]
Aim	To develop an in-depth understanding of the experiences of individuals living with MS and its impact upon the family system from the perspective of the person with MS
Population	People with MS – aged at least 18 years, diagnosis of MS and no other co-morbid life-threatening conditions. N=14 (n=9 females and n=5 males); aged between 25 and 63 years reflecting a range of MS presentations (n=7 relapsing-remitting, n=5 secondary progressive, n=2 primary progressive)
Setting	All resided in the UK
Study design	Qualitative interview study

Study	**Hunter 2021**[18]
Methods and analysis	Completed by two students as part of a masters degree programme. Semi-structured interviews conducted face-to-face at preferred location of participant, with most conducted at home or via online video call. Interview schedule consistent of 9 open-ended questions starting with 'can you tell me a little bit about when you first started experiencing symptoms?'. Other topics addressed included experience of illness onset and process of being diagnosed, family reactions to the diagnosis, dealing with MS in daily life and the positives and negatives of having a chronic illness. Prompts used to encourage participants to elaborate on their response and to clarify responses. Interviews were between 30 and 90 min. Verbatim transcripts analysed individually using inductive thematic analysis described by Braun and Clarke 2006/2012. Initial thoughts and ideas noted down and transcribed data read multiple times to ensure accuracy and data immersion. Subsequently codes and textual units generated. Analysis then focused on broader themes with relevant quotes selected to support each theme. Same unit of text could be included in more than one category. Systematically reviewed data to ensure a name, definition and exhaustive set of data to support each theme were available. Overarching themes and subthemes emerged and validated by discussion and checks made back to raw data.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	**Lack of understanding and acknowledgement** • Ongoing lack of knowledge about MS among primary care physicians contributed to feelings of being misunderstood and increased isolation, leading to detrimental effects on the beliefs about and relationships with medical professionals, though they did acknowledge that they didn't expect them to know much more than they did given they were general practitioners • Many reported negative experiences with MS nurses as they felt the consultations were impersonal and focused on physical symptoms rather than the emotional impact of the condition • Participants described having to navigate challenges and emotional impact of MS largely alone,
Funding	Not reported
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including no mention of data saturation and no discussion of the role of the researcher and how this may have affected the methods and results. As this was UK-based study it was considered to be highly relevant in terms of coordination of care.

Study	**Johnson 2003**[19]
Aim	To gain insights into MS-specialist nurse roles
Population	Two cohorts of 12 people with MS identified and interviewed – first took place before local MS nursing service was fully established though two of these interviewees were diagnosed once the MS specialist nurse was in post and second cohort interviewed once MS nurse had been in post 18 months.

Study	**Johnson 2003**[19]
	Invitations to take part sent to people on a hospital database, stratified according to MS disability severity and volunteers chosen at random for each group. First group, n=6 females and n=6 males; mean age 50.6 years (37-67 years); mean age of onset 38 years (24-59 years); mean time since diagnosis 6.9 years (0.4-26 years). Second group, n=8 females and n=4 males; mean age 50.5 years (34-66 years); duration since diagnosis was 10.5 years (0.4-33 years); mean age of onset 36.9 years (21-51 years).
Setting	Southeast of England
Study design	Qualitative interview study – one element of the consultation
Methods and analysis	Interviews with people with MS, carers and representatives of professionals and voluntary organizations formed part of a consultation with local MS 'stakeholders' in an MS nurse case study in the southeast of England. Interviews lasting between 45 minutes and 1.5 hours took place in people's homes or by telephone. Large proportion of interview involved people describing their experiences surrounding time of diagnosis, reactions and thoughts at the time and subsequent sources of help and support. Interviews were recorded, transcribed verbatim and analysed concurrently using the framework of data reduction, data display and conclusion drawing/verification. Interviewees then given opportunity to comment on accuracy of main themes arising from analysis.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	**Experience of being diagnosis with MS** • Many patients felt that once neurologists had confirmed a diagnosis and where there was little need for immediate intervention there was a tendency for neurologists to withdraw and see their work as done • A few described less distressing experiences – one felt very support by her GP at this time, another 5 were recently diagnosed and informed of the MS nurse, one of whom was informed of the MS nurse on the day of diagnosis and found this very supportive. Others found telephone contact in the weeks following diagnosis reassuring.
	Importance of MS knowledge – MS knowledge and professionals • Frustration with professionals' levels of knowledge was frequently raised, as they expected healthcare professionals to be their first source of help and guidance. Some GPs' lack of knowledge was found to be frustrating, often relating to what support services and practical help was available. However, patient did acknowledge difficulties that GPs faced. • Some occupational therapists, physiotherapists and community nurses were seen to be quite knowledgeable often providing key information if they happened to come in contact with them, though this could be a chance occurrence.
Funding	Not reported.
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including no mention of data saturation, no discussion of the role of the researcher and how this may have affected the methods and results and limited description of data collection methods. As this was UK-based study it was considered to be highly relevant in terms of coordination of care.

Study	Kirker 1995[20]
Aim	To assess workload and benefits of a single MS liaison nurse
Population	People with MS and their carers receiving care from a single MS liaison nurse – GPs also surveyed but not relevant to review population. N=67 people with MS and n=51 carers (representing n=71 patients as some feedback gained indirectly through carers only).
Setting	To improve the management of patients with MS in the Lothian region, a liaison nurse service was funded from 1 May 1990 to 30 April 1992 by the MS Society of Scotland. The views of the patients, their carers and GPs were sought in order to assess the value of this service.
Study design	Survey of patients/carers receiving care from an individual, including a qualitative element but appear to be no formal methods of qualitative analysis
Methods and analysis	After the project had been running for 16 months, interviews were attempted with all of those patients the liaison nurse had seen up to that point. Involved written questionnaires rating multiple factors on a Likert scale but also opportunity to comment verbally on how they had benefitted or not from the liaison nurse service.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	• Significantly more patients and carers found the nurse ’helpful’ or ’very helpful’ than outpatient care – likely quantitative • Improved mobility was reported primarily by those recently diagnosed and who were told about the mobility allowance or other assisted travel schemes. • Some reported better job prospects due to information about training schemes and working from home provided by the nurse • Newly diagnosed patients found general support and reassurance was the most common single benefit, whereas specific aids or services were more important among those previously diagnosed • Many patients emphasized that they felt it was easier to talk to the liaison nurse in their homes than to a doctor in the outpatient clinic as they often felt rushed and too embarrassed to discuss sensitive matters such as incontinence or sexual dysfunction. • Many patients and carers preferred to contact the nurse for advice rather than a doctor because it was quicker, more direct and they had concerns about wasting the time of doctors • Carers felt more comfortable discussing worries or concerns at home rather than at the clinic. Carers particularly appreciated the nurse’s support and much of her time was spent talking to them as well as to the patients. • Her practical advice and tips often obtained from other people with MS were often of more help than going to see a doctor, particularly as they might have little experience or knowledge of MS • Patients appreciated how quickly she supplied appliances on loan, particularly if they had experienced delays with other sources in the past. Many patients emphasized how she lifted their morale.
Funding	Funded by a grant from The MS Society of Scotland

Study	**Kirker 1995**[20]
Limitations and applicability of evidence	Severe methodological limitations were considered to be present, with factors contributing to this rating including it being unclear why there were only limited options for qualitative responses to be provided, no mention of ethical considerations, qualitative data analysis not described and issues with statement of findings for qualitative statements and applicability concerns based on all participants experiencing care from the same healthcare professional Despite being a UK study, there were moderate concerns about the applicability/relevance of this study based on the fact it is quite an old study and elements of coordination of care may have changed in this time

Study	**Learmonth 2017**[22]
Aim	To explore the needs and wants of patients with MS regarding exercise promotion through healthcare providers
Population	People with MS – age over 18 years, confirmed diagnosis of MS, no MS relapse within past 30 days, self-report EDSS score ≤5.5 and willingness to be audio-recorded during the interview. Recruited from the Midwest of the United States. Informed of study through online advertisement on the Greater Illinois, Gateway (Missouri) and Indiana Chapters of the National MS Society websites, presentations by our research staff at National Multiple Sclerosis Society meetings and events or online advertisement on the laboratory website. To gain representative sample, those with mild-moderate MS disability included and sought to include people with varying current levels of exercise. N=50 (n=33 females and n=17 males); mean age 49.2 years; diagnosis made mean 13.0 years ago; majority had relapsing remitting MS (n=41); visits with healthcare providers in the last 12 months were with neurologists (n=50), general practitioners (n=35), physical therapists (n=9), psychiatrists (n=7), MS nurses (n=3) and occupational therapists (n=2); Participants reported a health promotion (mHPES) mean score of 2.9 (2.4) points on a scale of 0 through 11, and this score indicates that the majority of participants had not received health promotion and education from a healthcare provider in the past year.
Setting	Midwest of United States.
Study design	Qualitative interview study
Methods and analysis	One-on-one semi-structured interviews. Interviews were conducted in a private room on the research site. To avoid influencing participants, the research site was not associated with any healthcare institution and the room was void of any healthcare or exercise information. Interview questions developed based on discussions among the entire research team that included researchers, persons with MS and healthcare providers. Interviewers had more than 3 years of experience conducting research in MS. Standardised prompts used within interviews using same basic outline for each interview. Interviewers could use inductive reasoning throughout to ensure rich data generated. After interviews participants received a journal containing the main interview questions for collecting further reflections. Each received a personalised take-home summary sheet containing the interviewer's immediate interpretation of the

Study	**Learmonth 2017[22]**
	interview. Journal was returned 1 week after the interview and analysed alongside the transcriptions. Interviews averaged 45 min and n=18 returned journals. Interviews transcribed and analysed using interpretive description methodology. Data organised using spiral analysis. Included organising the data, reading and memo-ing the data, describing, classifying and interpreting data into codes and themes and representing and visualising the data. Analysis was performed by three researchers. After discussing among the three researchers to refine coding based on 6 randomly selected interviews, met with wider research team who represented patients and healthcare providers and discussed the initial findings and made appropriate modifications. Three researchers then coded remaining interviews and had ongoing discussions about any further edits to coding needed.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	**Needs and wants of participants** • Patients wanted healthcare providers to promote exercise and be educated about MS and exercise. • Some of the participants wanted the promotion of exercise to be part of coordinated healthcare, which would involve neurologists, physical therapists and occupational therapists. These persons wanted referrals to professions who were experts in exercise within the context of MS.
Funding	Supported by a mentor-based post-doctoral fellowship from the National Multiple Sclerosis Society (MB 029) and a pilot grant from the National Multiple Sclerosis Society (IL 0017).
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including no discussion of the role of the researcher and how this may have affected the methods and results. This study was considered to be indirectly relevant as it was a study based in the USA it is unclear how coordination of care elements may differ to the UK healthcare system.

Study	**Lowden 2014[23]**
Aim	To explore the lived experience of making a first decision about treatment with disease-modifying therapies for relapsing-remitting MS
Population	People with MS – diagnosis of relapsing-remitting MS, had two relapses within last 2 years and EDSS <7.0, had been told by physician that they were eligible for disease-modifying treatments and needed to make a decision about whether to take them or not, and made a decision about whether to accept, postpone or decline within the last 3 months or currently in decision-making process, as well as ability to speak English or French. Excluded if had cognitive changes that would impair ability to provide informed consent or fully describe their experience of decision-making and/or did not consent to be audio-recorded.

Study	Lowden 2014[23]
	Purposive sample of adults with MS recruited from an MS program in a university teaching hospital. Physicians and clinical nurse specialists in the MS program invited to identify and contact potential candidates meeting criteria. Pamphlets also left in waiting areas so people could self-refer to the study if they wished. N=9 (n=2 males and n=7 females); age 29-57 years; diagnosed with MS from 6 weeks to 9 years ago; all Canadian born except one, two of Middle Eastern descent and one of Italian descent.
Setting	Participants recruited from a single MS centre in Canada.
Study design	Qualitative interview study
Methods and analysis	Patients recruited and interviewed until no new information was produced and redundancy obtained. Semi-structured interviews where they were encouraged to discuss their decision-making experience in 90-120 min interview. Took place at participant's home or at the hospital depending on preference. Phenomenological method of data collection and analysis used. Questions were purposefully explanatory and open-ended to elicit rich descriptions. Researcher had 10 years experience in MS field and had been involved in the care of some participants so attempts were made so bracket preconceived beliefs or opinions regarding experiences for participants. Interviews started with broad question followed by further prompts to encourage expansion of the discussion and to provide examples. Three participants contacted after the interview to validate themes that the researcher was starting to develop. Following verbatim transcription, Colaizzi's 7-step method used to analyse data: 1. Read narratives and start to gain understanding of experiences 2. Significant statements related to treatment experiences extracted and coded 3. Data analysed and themes developed 4. Statements grouped according to meanings researcher attributed to the statements 5. Interpretations so far shared with three participants for review and validation 6. Organisation into themes and categories 7. Themes integrated into description of decision-making in those with MS. More than one reviewer analysed data and provided peer debriefing.
Findings As some comments in this study were relevant to the pregnancy subgroup, all relevant findings relating to pregnancy or coordination of	**Pregnancy considerations** • Young woman shared family struggles with decisions about timing of starting medication, as she describes trying to weigh up options and difficulties as changing plans endangered something else, including such as school, career, baby and medication. She described wanting to have children but didn't know which was the right order to do things in. • Another woman described deferring treatment in favour of becoming pregnant
	Relationship with healthcare providers • Participants reported the need for help with decision-making about treatments as well as information about the therapies, as it was difficult for them to make a decision alone • Some participants turned to their MS nurse as a source of unbiased information and reported that the nurse made things feel more 'tangible' and helped solidify their decision • One participant that did not have access to an MS nurse identified this as a gap in her care

Study	Lowden 2014[23]
care were extracted	
Funding	Supported by a grant from the Eureka! Fellowship in Nursing Research at the McGill University Health Centre funded by Richard and Satoko Ingram of the Newton Foundation and the Foundations of the Royal Victoria, Montreal General and Montreal Children's Hospitals. Study also supported by a grant from the Canadian Nurses Foundation.
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including limited discussion about how the role of the researcher may have affected the methods and results. This study was considered to be indirectly relevant as it was a study based in Canada it is unclear how coordination of care elements may differ to the UK healthcare system.

Study	Markwick 2014[25]
Aim	To perform content analysis on the views of people with MS about MS services, focussing on physiotherapy provision
Population	People with MS recruited via advertising the audit on MS Trust website and members notified by MS Trust newsletter. National MS Society and MS Therapy Centres were notified, invitation cards distributed by MS nurses, specialist neurologists and therapists and information also posted on websites, forum and discussion groups known to be used by people with MS. Letters also sent to regional and local newspapers advertising the audit. Aim was to include sample of people with MS from whole geographic area with full range of disabilities. N=757 people with MS added a free-text comment regarding MS services; 76% female and 24% male; age range 18-86 years old with majority (51%) between 51 and 69 years; time since diagnosis was between 1 and 50 years with largest proportion (32%) having been diagnosed 1-5 years before the questionnaire was carried out; most rated that their MS had a major impact on their lives (52%).
Setting	Sample represented 95 different postcodes across England and Wales
Study design	Qualitative analysis of free-text comments as part of a questionnaire sent as part of an audit
Methods and analysis	Data obtained from a 2008 audit by Clinical Evaluation and Effectiveness Unit (CEEU) of the Royal College of Physicians (London) in collaboration with the MS Trust. Using triangulation strategy, data collected via electronic questionnaire from four sources across England and Wales, including people with MS, NHS Trusts, primary care trusts and local health boards and strategic health authorities and regional officers – **only reports results for people with MS and this is the only group relevant to our review.** Permission to access and analyse qualitative data of audit granted and obtained in format of Microsoft Excel sheet. All responses were made anonymous. Qualitative data imported into NVivo 9.0 for categorisation and coding of information. Content analysis was used to examine qualitative data obtained from the audit. Scanned by primary researcher and themes, categories and subcategories established. Clarity of categories and coding system was tested as the researcher coded 10% of the data and a second researcher independent of the study coded the same 10% sample. Strength of agreement determined using Altman's criteria. Full dataset coded

Study	**Markwick 2014**[25]
	by primary researcher. To avoid errors, no more than 10% data were coded in the same sitting. Two 20% samples systematically selected and analysed by primary and second researcher. To avoid bias, both waited a week before coding. Once content analysis was complete, data were manipulated and analysed to address research aim specific to this study. Following discussion of ambiguities, some subcategories were added, altered and/or reworded but it no creation of any new themes or categories was required.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	Majority of positive comments were regarding healthcare professionals (n=234, 49%), specifically MS nurses (n=137, 58%): • Quotes highlighting importance in offering support. Other healthcare professionals mentioned in this regard but unclear if had coordinating role. Some negative comments about a lack of information on services, though unclear if had access to MS nurse/other coordinator of care
Funding	Not reported.
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating concerns about data collection in terms of the wording of the question, no mention of ethical considerations and limited information in terms of the analysis. As this was UK-based study it was considered to be highly relevant in terms of coordination of care.

Study	**Masoudi 2015**[26]
Aim	To identify continuity of care from the experience and perspective of patients with MS at two teaching hospitals and the MS Society in Ahvaz, Iran
Population	People with MS chosen using purposive sampling from various settings to gather a wide range of perspectives – diagnosis of MS confirmed by neurologist; having medical records at MS Society; being able to communicate in Persian; >18 years old; and willing to provide written consent. Reasons for non-participation included being too ill, feeling too exhausted and being unfamiliar with the Persian language. N=23; age 20-50 years (mean 27 years); disease duration 2 months – 19 years (mean 7 years).
Setting	Study conducted at two teaching hospitals and MS Society in Iran
Study design	Qualitative interview study
Methods and analysis	In-depth, unstructured interviews starting with core question ‘please describe how you spend a typical day with regard to your MS disease’. Probing questions then asked based on answers to enrich the data. Interview sessions were between 45 and 100 min. Tempo of dialogue was flexible and conversation proceeded based on physical and mental conditions of the participants and their

Study	**Masoudi 2015**[26]
	tolerance. First author performed face-to-face interviews. Data collection and constant comparative analysis allowed a researcher to ask more probing questions in next interview. Thematic analysis approach used to identify patterns in texts. Interviews transcribed verbatim and reviewed multiple times for data immersion. Text read several times to determine differences and similarities and after all interviews were complete a list of codes was merged into themes with analysis continuing until all thematic categories were saturated. Field notes primary tool used to gather data. Transcripts of each interview and field notes read several times to gain deeper understanding of data. Second and third researchers listed to audio files and studied written transcripts. After constant comparative analysis, member checking performed 2 months after start of interview process. During sampling process prolonged engagement and maximum variation were ensured. Reflective memos used to enhance audit trial of decision-making during research process.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	**Caring with purposeful planning** • Participant experiences showed that they need experienced and qualified staff to provide care, with a quote highlighting the need for them to know the types of problems they face and range of symptoms
	Obligation as an insufficient function of caring • The patients complained about the insufficient training provided by their nurses related to their disease problems and difficulties - lack of information provided by nurses across different elements of condition (e.g. diet)
Funding	Supported financially by Ahvaz Jundishapur University of Medical Sciences.
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including limited discussion about how the role of the researcher may have affected the methods and results. This study was considered to be indirectly relevant as it was a study based in Iran and it is unclear how coordination of care elements may differ to the UK healthcare system.

Study	**McCurry 2013**[27]
Aim	To explore the decisions made by informal caregivers of multiple sclerosis care recipients and the resources they use to inform those decisions.
Population	Informal caregivers of those with MS. Those with longitudinal experience with informal caregiving. Purposive sampling used to identify informal caregivers. Recruited through key informant at a hospital-based MS centre and an MS caregiver support group, allowing in-depth exploration of small number of information-rich participants.

Study	McCurry 2013[27]
	N=6; age 48-76 years; n=3 females and n=3 males; all were White and non-Hispanic; n=4 were spouses, n=1 was a fiancée and n=1 a longtime friend; n=5 were retired and n=1 worked as registered nurse; none received a salary for their caregiving, though the fiancée and friend reported the care recipient would often provide reimbursement for shared meals and travel expenses; number of years caring for the recipient was between 4 and 25 years; and % of total daily care ranged from 50% to 100%.
Setting	Study performed in the USA with recruitment via a single centre and MS support group
Study design	Qualitative interview study
Methods and analysis	Two in-depth interviews conducted with each participant. First was between 2 and 2.5 hours long. Open-ended questions were asked to gain understanding of types of decisions caregivers were making and identify resources used to inform decisions. Follow-up questions vaired depending on topics introduced by the participant. Memos detailing thoughts of investigator, mood of subject and any issues identified by caregivers were made after interview. Interviews transcribed verbatim and preliminary analysis identified emerging themes. After each initial interview was complete, in-depth second interview lasting 1-1.5 hours was performed with each person to validate accuracy of thematic survey from initial interviews, follow-up incomplete answers and further explore emerging themes. Qualitative content analysis performed. Transcriptions read multiple times to gain overall sense of data, with line-by-line coding being completed. Initial descriptions of codes grouped into related subcategories and categories, which were then grouped into themes. Themes, categories and subcategories were discussed and verified with another investigator familiar with the data. Direct quotes used to illustrate themes, categories and subcategories. Data collection and analysis met Lincoln and Guba's 1985 criteria for credibility, dependability, transferability and confirmability. Credibility assessed by member checking, triangulation and prolonged engagement in the field with each person having multiple interviews. Dependability shown by audit trial of decisions. Transferability ensured by validating with another investigator and analysing findings across cases. Confirmability established by articulating biases and assumptions about data, using direct quotes and clearly explaining methodological decisions.
Findings As some comments in this study were relevant to the palliative care subgroup, all relevant findings relating to palliative care or coordination of	**Coordination of care related points** • Highlighted one area that was lacking was ability to have a 24-7 contact that could help triage acute situations – not specific about a single point of contact but indirectly touched on that
	End of life/palliative care points • Need for support when making decisions about treatment, particularly where patients can't be involved much – reported that making decisions alone was stressful • Caregiver burden – needing respite and self-care – difficult to arrange and led to feelings of frustration and isolation – health care professional assistance with this • Information about financial support – financial worries when patients stopped working and they had to work less to care for them were a concern • Also issues like power of attorney/wills/long-term planning - some had organised this but others had not realised they might need to

Study	**McCurry 2013**[27]
care were extracted	- Impact on social lives – feeling isolated. Taking time to socialise was important and including meeting friends/attending MS society groups - Concern about what would happen to patients if they were no longer around - End of life decisions particularly difficult to discuss but others had comfort in having a plan - Information for extended families/those not living with the patient to help them be positively involved in decision making – e.g. end of life care decisions difficult for other family members who did not live with the patient and therefore understand - 24-7 access to healthcare services identified as something that would be useful to have - Home visits from occupational therapists would also be useful - Lists of all resources/services available in community also identified as a need
Funding	Not reported
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including limited discussion about how the role of the researcher may have affected the methods and results and comments that the small sample size may limit generalisability For coordination of care elements, this study was considered to be indirectly relevant as it was a study based in USA and it is unclear how coordination of care elements may differ to the UK healthcare system.

Study	**Methley 2017**[29]
Aim	To explore perspectives and experiences of people with MS and healthcare professionals of UK healthcare services for MS
Population	People with MS – GPs also interviewed and recruited via different methods but not relevant for this review question. Patients recruited through contact by their GP (n=1) or community recruitment methods including the MS Society (n=23). N=24 people with MS; no further characteristics available.
Setting	Took place within Northern England (four Primary Care Trusts and five Foundation Trusts)
Study design	Qualitative interview study
Methods and analysis	Participants were interviewed using semi-structured interviews between October 2012 and April 2014 at their preferred venue – usually at work for professionals and home for patients. Interviews lasted 23-150 minutes for people with MS. Interview topic guides were developed from relevant literature and discussion within the research team. The patient interview topic guide explored the experience of living with MS and experiences of health care services, and iteratively evolved to cover specific examples of health care consultations. Interviews were audio-recorded and transcribed verbatim before anonymisation. Prompts were used to further lines of enquiry. Data collection and analysis were contemporaneous to ensure an iterative process.

Study	Methley 2017[29]
	Constant comparison analysis was used to code, categorise and analyse data from transcribed interviews. Lead author conducted all interviews and re-read the transcripts to ensure familiarity with the data. Codes were derived from the data a posteri, starting with descriptive codes and moving to analytical codes. Selective coding was used to focus analysis on the key research question and identify factors relevant for further, more purposeful sampling. Broader and more conceptual categories were created through comparing codes within and between transcripts. Codes were compared both within and across patient datasets. Analysis was iterative and inductive; after coding was completed suggesting access was the most salient topic; the theoretical framework of candidacy was used to further interrogate the data. Once category saturation had been achieved, recruitment was closed. A service-user with MS consulted at all stages of the project.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	**Access to primary care** • Finding out which additional services were available, and how to access them, could be difficult and lengthy process for both people with MS. Once people with MS felt they had a well-defined support network of professionals, their confidence in accessing them improved and their experiences of care were more positive • Increasing awareness of services helped people with MS to assess candidacy for available care. • All participants with MS were aware of GPs and their geographical closeness, making them a highly utilised service, perceived as relatively easy to access
	Access to secondary care • Many participants discussed delays in access to secondary and community services including diagnostic testing, specialist services, neurologist services and physiotherapy which limited their perceived permeability • Long waits and frequent rearrangement of appointments in secondary care led to frustration. The fast onset and severe disability caused by MS relapses meant that services needed to be highly responsive to prevent avoidable disability and distress • Participants with MS reported the need to stay “in the loop” by maintaining contact with services, to increase access to information and emergency treatment – feeling abandoned without regular follow-up (differed depending on what could be done for their MS and the severity) • People with MS therefore felt it was key that services were flexible and able to vary according to type of MS, thus patient, need.
	Interpersonal interactions • Positive descriptions of professionals included someone who took responsibility for the responsiveness of care
	Continuity of care • Continued contact with a single professional was valued - reassurance and ability to access services. • Most participants reported poor relational continuity with neurologists, causing confusion and frustration. Experiences of relational continuity varied by geographical area, whilst most reported long term continuity, others saw varying specialist nurses at scheduled reviews. Two participants travelled long distances to stay with their original specialist nurse, despite moving out of the official catchment area.
Funding	Not reported

Study	Methley 2017[29]
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including limited discussion about how the role of the researcher may have affected the methods and results and unclear whether a data validation step was included As this was UK-based study it was considered to be highly relevant in terms of coordination of care.

Study	Methley 2017[28]
Aim	To explore perspectives and experiences of people with MS and health care professionals of mental health support for MS in the UK.
Population	People with MS – healthcare professionals also included but not relevant to this review. People with MS recruited through GP practices, MS charities, online MS forums and community recruitment materials (e.g. posters in shops). Maximum variation sampling focused on characteristics that have been noted to affect experiences of receiving or providing healthcare in the literature (age, gender, ethnicity, subtype of MS and level of MS disability for people with MS). Snowball sampling used to recruit men with MS and people with progressive MS who may not commonly respond to community recruitment strategies. N=24 people with MS; n=23 White British, n=1 Iranian.
Setting	Conducted in North-West England through four Primary Care Trusts and one Foundation (hospital) Trust
Study design	Qualitative interview study
Methods and analysis	Semi-structured interviews between October 2013 and April 2014 with each lasting 23-150 min. Patient preference determined location of interviews – telephone interviews or face to face interviews in participants' homes, work place, a university building, or a private quiet space within a public area (e.g. an MS society group). All interviews recorded and transcribed verbatim. Topic guide inductively modified in light of emerging themes. Field notes recorded to incorporate context into analysis. Data collection was stopped upon achievement of data saturation. Constant comparative analysis used. Transcripts read multiple times whilst listening to the audio-recording to ensure familiarity with the data. Codes derived from data through open coding with analytical codes were possible. Following open coding, selective coding more focused on key research question. Codes compared within and across participants with aim of grouping codes into a higher, broader category. Constant comparison allowed identification of categories and themes across entire dataset. Participants sought who represented deviant or disconfirming cases, which were used to test and refine categories and themes by illuminating imitations and boundaries, giving richer insight into limitations of themes and analysis and allowed alternative interpretations to be explored. Contemporaneous data collection and analysis were used. Service-user consultant with MS involved in all stages of project. Analysis comprised both an inductive and a deductive approach. Theoretical framework of candidacy selected. Epistemological position taken was an interactionism approach using elements of phenomenology and social constructionism.

Study	**Methley 2017[28]**
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	**Management choices** • Healthcare professionals were central in helping many people with MS navigate multiple services, including those for mental health needs – quote highlighting role MS nurse had in helping inform and access various services such as psychologist and physiotherapy
Funding	Fully funded by a National Institute of Health Research (NIHR) School for Primary Care Research (SPCR) PhD studentship.
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including limited discussion about how the role of the researcher may have affected the methods and results and unclear whether a data validation step was included As this was UK-based study it was considered to be highly relevant in terms of coordination of care.

Study	**Pearce 2020[32]**
Aim	To explore patient experiences with the uncertainty that MS introduces to their lives and the role of communication with their physicians for managing uncertainty.
Population	People with MS. Recruited via MS Society of Canada's online Research Portal, in person during an MS Society meeting and via email circulated to South Western Ontario chapter of MS Society. N=16; n=5 males and n=11 females; age range 26-75 years; relapsing-remitting MS (n=7), primary progressive MS (n=2) and secondary progressive MS (n=7).
Setting	Study based in Canada
Study design	Qualitative interview study
Methods and analysis	In-depth interviews performed in English at time and location convenient for the participant. Convergent interviewing process used where questions could be added or removed over process based on patterns emerging from collected data. Probing questions were refined over interview process to become more detailed. Participants involved in data interpretation by inviting them to challenge, change or confirm emerging interpretations of data. Questions ranged from open-ended to more specific questions on emerging patterns. One author conducted interviews while both were involved in coding and analysis.

Study	Pearce 2020[32]
	Interviews transcribed verbatim and analysed in three phases: 1. Open-coding interviews descriptively following each interview to allow interview questions to be edited as patterns emerged 2. Codes organised into similar categories and then theme-based categories 3. Coding framework applied to data based on Mishel's TUI to identify data relevant to patient experiences with uncertainty and role of communication with physicians for managing uncertainty. Layder's adaptive theory used to guide this process and TUI applied post-hoc.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	**The role of physicians and patients in communication to reduce uncertainty** • Participants reported physicians assisting them with managing vast amount of information through various sources regarding diagnosis, symptoms, treatments and long-term management plans. Describe their role in navigating information they had obtains, verifying what they had read or explaining if the information was relevant to their particular circumstances. The provider may be identified as critical for managing uncertainty given inaccurate or misinformation some described online or translating technical written information. Physicians also seen to have a role in monitoring new and emerging research relevant to their patients, for example new treatments or trials. Providers seen to relieve some responsibility of chasing ever-emerging information about MS.
	Limitations with physician-patient communication and managing uncertainty • One barrier to knowledge sharing was only seeing neurologists once or twice a year, suggesting the need for a point of contact in between neurologist appointments. Several described feeling rushed and not wanting to interrupt information they were receiving with questions they had or knowledge they wanted to share. • Participants also noted that physicians not always the best placed to ease uncertainty due to lack of personal experience with MS, and instead other people with MS were excellent sources of pragmatic information about day-to-day life with MS.
Funding	Not reported.
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including convergent interviewing technique used for data collection, concerns about recruitment highlighted by the paper as all likely to be treated by the same service providers and no mention of data saturation. This study was considered to be indirectly relevant as it was a study based in Canada and it is unclear how coordination of care elements may differ to the UK healthcare system.

Study	Petrin 2020[33] and Petrin 2021[34]
Aim	To investigate the health-care access experiences of Ontarians with MS as they manage their condition.
Population	People with MS – focus groups screened to ensure met following criteria: self-reported having a definite diagnosis of MS from a neurologist; at least 18 years of age; able to tolerate a 90 min discussion; able to communicate in English; and able and willing to attend one focus group. For interviews, people were screened to meet criteria described above for focus groups with following amendments: able to tolerate a 60 min discussion by telephone.

Study	Petrin 2020[33] and Petrin 2021[34]
	Focus group participants recruited purposefully from five communities of different sizes. N=21 people with MS who had previously consented to be re-contacted were contacted. Study information also distributed through the MS Society's research portal, social media platforms, local chapters' email lists, support groups and educational events, and by distributing flyers in local communities. People involved in telephone interviews were people with MS living in rural communities in Northern Ontario (at least 3 h from tertiary care) through Ontario Division of the MS Society of Canada. N=48; mean age 49.6 years (range 27-71 years); duration of disease mean 15.0 years (range 3-42 years); n=32 female and n=16 male; 94% Caucasian; 46% relapsing-remitting MS; all but one had regular family physician and all had a neurologist; most saw neurologist at MS speciality clinic; 60% considered main source of care to be neurologist while 31% selected their family physician.
Setting	Study based in Canada
Study design	Qualitative study – focus groups and interviews
Methods and analysis	Initial data collection involved five focus groups. Semi-structured telephone interviews (n=10) were added to explore emerging concepts with participants in communities in Northern Ontario. Interviews allowed in-depth exploration of access issues related to rural geography and self-management. Recruitment, data collection and analysis occurred between November 2017 and April 2018. Focus groups ranged from 5-12 participants and lasted 90-110 min. The sessions were facilitated using a semi-structured interview guide which was informed by previous MS access research and healthcare access theory grounded in biopsychological approach. Guide piloted with five people with MS for clarity and relevance prior to use and adjusted iteratively to reflect emerging concepts and themes. First author conducted individual interviews by telephone lasting 51-116 min. Same semi-structured guide used however additional follow-up questions added to get more in-depth information about certain concepts. Focus groups and interviews recorded and transcribed verbatim. Transcripts verified to ensure accuracy. Analysis started after first focus group. Concurrent data collection and analysis allowed comparisons of concepts and ideas between focus groups and interviews using constant comparison analysis with interpretive description methodology. First author read and re-read transcripts to become familiar with the data. Data continually questions, looking for similarities and differences across ideas, perceptions, attitudes and experiences. Open coding was initiated with the assistance of the focus group co-facilitators and an additional arms-length individual. All individuals coded independently and then met to discuss and explore interpretations. The first and senior author met on a weekly basis to discuss the ongoing coding process. Initial open codes examined for patterns across incidents and sessions allowing coding to be more specific. Narrower codes examined for similarities and differences allowing clearer understanding of categories and themes. Overall analytical process deepened by using sorting and query functions of ATLAS data management programme. All focus group participants invited to be part of member-check process where summary of group discussions were reviewed – no major changes were suggested. Analytical and reflexive journal kept throughout. All meetings, notes and coding steps kept as an audit trail. To ensure credibility, triangulation of data sources (interviews and focus groups) and researchers (multiple on analysis team) employed.
	Provider knowledge

<table>
<tr><th>Study</th><th>Petrin 2020[33] and Petrin 2021[34]</th></tr>
<tr><td rowspan="6">Findings

Note that only those areas thought to be relevant to coordination of care have been extracted.</td><td>Wanted those they contacted about their MS to have sufficient knowledge of the condition (limitations sometimes when contacting general physician). They understood that generalists could not be specialised in MS but expected them to know the basics and provide symptom management or referrals. Experiences were described where negative interactions with family physicians that did not have the MS knowledge required to help them were reported. They also highlighted that even MS specialists lacked the lived experiences and impacts of MS.
Past experiences of providers' MS-related knowledge contributed to anticipated outcomes of seeking care. Negative past experiences and poor outcomes led to development of poor anticipated outcomes of future care, with some no longer seeking care because they anticipated no help.</td></tr>
<tr><td>Complicating factors
Other factors also impacted decision of whether or not to access care, including availability and coordination of care.
Described shortage of MS neurologists meaning care was not timely. Reported seeing them annually and in between relying on other providers (including family physicians – described by one as not ideal due to them being less knowledgeable/trained in MS) or dealing with MS-related issues alone. Others reported relying on multiple healthcare providers for care – said to be suboptimal as required more energy to schedule and attend each appointment. Reported getting lost between providers or receiving conflicting treatments from providers lacking communication and coordination of care.</td></tr>
<tr><td>Navigation (from 2021 paper)
Once decided they should seek care, then had to determine how and when to seek care appropriate for their health concern
Required work and knowledge on the part of participants
Barriers to this described included a lack of knowledge regarding services available for their health concern about their community, a lack of physical accessibility of buildings and offices where services were available, a lack of available services to deal with MS- related issues in or near their community, and financial restrictions including non- funded services and costs related to transportation and loss of work
Navigating the system was described as 'exhausting' often</td></tr>
<tr><td>Permeability (from 2021 paper)
Choice of service often solely depended on ease of access, with many defaulting to services that were most permeable – those with the fewest qualifications to gain entry, such as emergency departments and walk-in clinics.
they preferred care from an MS specialist or neurologist, however, low availability of these providers led to permeability barriers. This led to them to resort to relying on more permeable services, including their family physicians.</td></tr>
<tr><td>Appearances at healthcare (from 2021 paper)
Once deciding where to seek care, participants had to assert themselves and their candidacy for care.
Participants described confidence with conveying health concerns to practitioners, with many considering themselves experts in their own condition. Most described that they felt comfortable discussing any health concern with their healthcare provider, including fatigue and bladder symptoms.</td></tr>
<tr><td>Adjudication (from 2021 paper)</td></tr>
</table>

Study	Petrin 2020[33] and Petrin 2021[34]
	• Convincing providers of their candidacy for care was seen as challenging, with all having shared experiences of having their claims invalidated or dismissed. • Factors influencing healthcare provided adjudications described by participants were: preconceptions held regarding the parameters and management related to MS, over or under attribution of health concerns to MS and knowledge about MS and experiences with MS patients. • Many recalled experiences with providers having the perception that there is nothing that can be offered to persons with MS, and thus they were considered unfit candidates for care. A quote provided suggests from a participants perspective that many concerns are put down to MS immediately with other possibilities not being considered.
	Operating conditions (from 2021 paper) • Participants were aware of the effect of operating conditions, including local context and policies, on the functioning of healthcare systems and providers, with commonly reported issues being low time allowance during appointments, poor coordination and continuity of care, and a lack of funding for allied services and assistive devices
	Patient-centred care and care outcomes (from 2021 paper) • Highlighted importance of providers taking patient-centred approach. Elements of this approach considered positive were: healthcare provider viewing their patient as a whole, including all facets of health in the evaluation and creation of appropriate management plan; healthcare provider engaging in active communication and shared decision making; and healthcare provider respecting and using the persons with MS' lived experience and knowledge to care plan. • When this approach was not taken, often they were left without viable management options • When this approach was used, they more often received offers of care aligning with their goals and meeting needs • Positive care outcomes associated with improved functioning, participation and independence. Positive care outcome was also described as appeasing their concerns and meant that they felt heard. When a patient-centred approach was not taken, negative care outcomes were reported. Feelings of being a bother, being invalidated and left with concerns were described. These feelings led to the idea that there was no help to be had.
Funding	Not reported.
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including concerns mentioned in the paper about recruitment and therefore generalisability given many had similar characteristics (location and education) and no discussion of the role of the researcher and the possible impact on methods and results. This study was considered to be indirectly relevant as it was a study based in Canada and it is unclear how coordination of care elements may differ to the UK healthcare system.

Study	Rintell 2012[35]
Aim	To obtain MS patients' report on their experience receiving mental health care

Study	**Rintell 2012**[35]
Population	People with MS -selected for reporting either high satisfaction or low satisfaction with the mental health care they had received, as detailed from their responses to the questionnaire they previously took part in. Recruited from those participating in a previous study about mental health and multiple sclerosis. Recruitment was by mail and phone. N=54; n=44 females and n=10 males; all had received some type of mental health treatment in past 2 years – some at MS centre and others from community provider.
Setting	Study based in USA
Study design	Qualitative focus group study
Methods and analysis	Semi-structured focus groups (n=7 in total) facilitated by two professionals with experience in mental health and MS care – none of moderators were affiliated with the institutions where participants received care. Two groups convened at each site – one with people reporting high satisfaction with mental health care and another with those who indicated low satisfaction (except at one site where two groups were combined). Discussion guides prepared to elicit patient experiences and satisfaction with mental health care and opinions about what was useful and effective care. Facilitators too knots following protocol, recording comments verbatim where possible. After each session facilitators compared and reconciled notes and prepared detailed summary of discussion. Data summarised and analysed by allocating and coding comments under specific themes and categories determined through examining data. Similarities and differences between groups with high and low quality experiences were identified. Comments by two groups were similar and therefore not divided for most of the analysis.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	**Identification of need** • Some reported emotional problems only address when reached a crisis, with one reaching a breakdown before being offered mental health assistance. Others asked physicians for help only after struggling with depression/anxiety for years or when other life stresses overwhelmed them. Some offered medication for depression but not counselling. Others said emotional needs were identified by the various professionals at the MS centres.
	Connecting with a provider • Connecting with a provider could be difficult – hard to find one that was a good fit for them and wait time to see them at the centre or in community was considerable. • Self-referral was most common entry route – most sought counselling alone due to depression, anxiety or family issues related to MS. Referrals were obtained from friends, relatives and family physicians, and other sources • Some were referred to mental health providers with limited understanding of their illness and who did not understand their MS-related concerns – meeting with several providers before they found one that would meet their needs. Having to tell stories repeatedly became exhausting and discouraging.
	Integration of behavioural healthcare

Study	Rintell 2012[35]
	• Access to care easier when mental health services were available at or through MS centre. Having in the same building smoothed initial entry into seeing a counsellor. Mental health professionals at MS centres often provided appropriate referrals to counsellors in the community when it wasn't practical for them to provide care directly due to geography, scheduling or other factors. • However, some don't offer mental health services and the centres that do often can't meet the need. Several noted that a centre with only one mental health provider was a problem as different people had different needs. Centres with mental health professionals involved do not have enough numbers for the need. • One patient described how her neurologist provided her with counselling – she found this compassionate and supporting and he also prescribed antidepressant medication
	Provider characteristics • Communication and collaboration between neurologists and mental health providers seen as important, particularly for those taking psychotropic medication. • Those attending services outside MS centres reported they had to act as their own advocates as there was no direct communication between mental health providers and neurologists. Having one associated with an MS centre had advantages including mental health providers ability to consult with other treatment team members and collaboration on treatment. Another mentioned mental health provider could go down the hall to ask a question of the neurologist about medication side effects. Use of shared medical records in their care also described as an asset. One that did not live near an MS centre with mental health services described wishing for one that understood her disease and better communication between mental health provider and primary care team.
Funding	Funded by Health Services Research Grant HC 0059 from National MS Society.
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including no reasoning behind choosing focus groups given and saturation not mentioned, possible role of researcher and impact on methods and results not discussed, unclear if any validation process to confirm findings and authors highlight that may not be generalisable to all populations This study was considered to be indirectly relevant as it was a study based in USA and it is unclear how coordination of care elements may differ to the UK healthcare system.

Study	Senders 2016[36]
Aim	To further understand how stress is addressed in the MS medical visit with a neurologist
Population	People with MS – any type of confirmed MS scoring >15 on Perceived Stress Scale. Those with any type of confirmed MS scoring >15 on Perceived Stress Scale (0-40) during prior study conducted at Oregon Health and Science University invited to take part in study.

Study	**Senders 2016[36]**
	N=34; mean age 53.3 years; 88% female; 53% relapsing-remitting, 20% secondary progressive, 15% primary progressive and 12% unknown; time since diagnosis mean 12.9 years; 59% using disease-modifying therapy; 59% using medication for stress, depression of anxiety; 3% with none/minimal disability, 31% with mild disability, 24% with moderate disability, 24% needed some support, 6% used a walker or two-handed crutch, 9% were unable to walk and 3% unclear; 100% were White.
Setting	Study based in USA
Study design	Qualitative focus group study
Methods and analysis	N=5 semi-structured focus groups conducted. Descriptive, qualitative approach. Each group asked same overarching questions though facilitator allowed flexibility of dialogue depending on unique chemistry of the group and follow-up questions asked as appropriate to group discussion. Lead author facilitated all 5 groups, with each lasting 1-1.5 h. Focus groups were audio recorded and transcribed verbatim. The lead author read each transcript several times to gain a strong, overall sense of the data. Two authors performed initial coding and applied labels generated by data. Continually refined and hierarchically organised as parent and child codes. Final codebook developed. Each transcript coded in duplicate by two authors using Dedoose web-based qualitative software. Prior to coding each author completed at least one inter-rater agreement test through training module. Discrepancies discussed amongst team and disagreements resolved by consensus. Discussions supported refinement of codes. Authors blinded to each other's work until coding complete Discrepancies in final codes discussed and resolved by consensus. Thematic analysis performed according to Braun and Clarke to group patterns of codes into categories/themes. All three coders were involved in this part of the analysis. Neurologist familiar with coded transcripts contributed content expertise and ensured inter-disciplinary team approach to data evaluation.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	**Facilitators and barriers to discussing stress: The medical system** • Case manager described as a feature of system encouraging people to discuss stress with medical personnel and to connect them with supportive community resources - Two people had case managers who provided regular contact every 2 months ○ Answer questions and provide resources ○ Some frustration from one person at high turnover of case managers and having to re-establish relationship ○ Agreement that this would be welcome addition for other patients under ideal circumstances – some acknowledged unease about asking too much of their neurologist and favoured a secondary person involved in the clinical setting • Lack of time in appointments with neurologists to discuss all issues, meaning stress often not talked about with providers as had to cover physical issues and insufficient time to also cover psychosocial issues – another point of contact would be useful for this reason • Medical system separating physical and mental health discourages whole-person conversations – left one woman frustrated as multiple specialists within same healthcare organisation attended to her care but they lacked coordination • Lack of coordination among different departments of health care – ideally saw primary care physician as someone that would coordinate care but often deferred to neurologist for most care following diagnosis
Funding	This work was supported by the Oregon Clinical & Translational Research Institute [Grant number UL1 RR024140 from the National Center for Research Resources and the National Center for Advancing Translational Sciences of the National Institutes of Health]; the

Study	**Senders 2016[36]**
	National Center for Complementary and Alternative Medicine of the National Institutes of Health [Grant numbers AT002688 and 2R25AT002878-05A1]; and the Agency for Healthcare Research Quality [Grant number 5T32HS017582-05].
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including the paper mentioning that saturation may not be reached, no mention of researcher role and possible impact on methods and results and possible limitations in generalisability described in the paper This study was considered to be indirectly relevant as it was a study based in USA and it is unclear how coordination of care elements may differ to the UK healthcare system.

Study	**Sweet 2013[38]**
Aim	To examine the preferred sources and methods for acquiring physical activity information of individuals with multiple sclerosis
Population	People with MS – diagnosed by physician or specialist; 18-80 years of age. Participants recruited through word of mouth, advertisements on local websites, local MS Society of Canada chapters (e.g. MS support group and newsletters) and posters in locations frequently visited by people with MS (exercise facilities, doctors' offices and coffee shops). Recruited from Southern Ontario. N=21; no further characteristics described.
Setting	Study based in Canada – Southern Ontario
Study design	Qualitative study – focus groups and interviews
Methods and analysis	Focus groups (n=7 people) and telephone interviews (n=14 people). Two focus groups conducted with those with MS that were in same city as researchers and able to come to the university to participate at designated times. Semi-structured interview guide based on study identifying information preferences of people with spinal cord injury. Questions modified so relevant to adults with MS and incorporating components from Comprehensive Model of Information Seeking (CMIS) framework. Each focus group began with series of questions asking people to discuss general physical activity messages and ways in which physical activity can be delivered. Follow-up questions used to prompt discussion. At end of each group session, participants asked to recommend how to improve delivery of physical activity information to those with MS including content, messengers and methods of delivery. Also asked about preferred quantity and depth of physical activity information. Final set of questions included barriers and facilitators to physical activity information seeking. All interviews and focus groups transcribed verbatim after being recorded. Direct content analysis approach using CMIS as guide framework. Initial codes developed followed by line by line analysis of each transcript. All information received a code and information in each category reviewed to see if subcategories were required. Two investigators performed analysis on each transcript and compared coding upon completion. Disagreements discussed and consensus

Study	**Sweet 2013**[38]
	reached. Interviews and focus groups rooted in theory the analysis was not completely deductive as qualitative approach allowed unanticipated themes to be expressed. Abductive approach to analysis taken.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	**Physician** • Majority considered healthcare professionals as most important and helpful messengers in terms of physical activity information, identifying them often as credible source of information. Some also described physicians as unhelpful sources of information as they "have too many other issues" to think about. Also described as least accessible source due to reduced availability
	Allied healthcare professionals • Other health professionals such as physiotherapists and nurses identified most commonly as credible sources or messengers for physical activity information. Nurses appeared to be more accessible and willing to discuss this with patients.
	Barriers and facilitator to information seeking • Some described not knowing who to go to for physical activity information
Funding	Supported by a grant from Canadian Institutes of Health Research.
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including saturation not being mentioned, no mention of researcher role and the possible impact on methods and results and possible limitations in generalisability This study was considered to be indirectly relevant as it was a study based in Canada and it is unclear how coordination of care elements may differ to the UK healthcare system.

Study	**Ward-Abel 2010**[39]
Aim	To perform an audit of patient experiences of MS nurse role
Population	People with MS and access to an MS nurse recruited directly through MS nurse via posted questionnaire N=750 questionnaires returned but proportion with free-text response unclear
Setting	MS nurse services across ten MS centres in England and one in Northern Ireland (patients from 12 experienced MS nurses)
Study design	Audit with qualitative responses included in questionnaire
Methods and analysis	Audit tool took form of a questionnaire to be completed by service users. Content informed by previous work that had investigated what people wanted from a specialist nurse – turned into statement against which quality of service could be assessed by the service user. Carried out retrospectively by service users. Questionnaire posted to 150 last patient contacts of each nurse involved (clinic appointments, home visits or those seen as ward patients). Pilot questionnaire with 11 questions and 4-point Likert scale produced and free-text space was available. To pilot, each nurse used a convenient sample of users of their service – many spent considerable time and effort completing the pilot questionnaire and

Study	Ward-Abel 2010[39]
	responses and comments were important in final data collection tool. Final questionnaire taken by each nurse to governance department for approval and input. Each MS nurse recorded her results individually using Excel spreadsheet. Results automatically fed into histogram that continually updated with new information. Once each nurse had collated their own data, results were collated nationally.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	• Majority felt MS nurses had better understanding of their condition and therefore they preferred to contact them rather than any other healthcare professional
Funding	Postage costs funded by National MS Society
Limitations and applicability of evidence	Severe methodological limitations were considered to be present, with factors contributing to this rating including concerns about data collection including wording of questions and saturation, possible impact of researcher on the methods and results, ethical considerations not being mentioned, lack of formal qualitative methods and no quotes to support findings, as well as limitations in how results might be interpreted described in the paper As this was UK-based study it was considered to be highly relevant in terms of coordination of care.

Study	Warner 2005[40]
Aim	To audit patient pathway into treatment following a relapse
Population	Cases purposefully selected and recruited to study as exemplars of service users – included people with MS experiencing a relapse that were using an altered service following previous audit
Setting	Within a single district general hospital in UK – evaluating improvements in service offered to those with a relapse of MS
Study design	Qualitative study – audit and interviews
Methods and analysis	Data collection forms designed which included demographic data as well as markers of patient pathway to treatment and recovery, as well as patient experience of the day-case service. Single-question telephone interview also used – participants telephone weekly from receiving intravenous methylprednisolone until 6-week review and asked ‘do you think you are still recovering?’. Structured interviews designed to test satisfaction of relapsing patients with outpatient services. Covered various themes associated with service delivery (coordination of care, access and waiting, information and communication, relationships with healthcare professionals and clinical environment). Most patient interviews conducted by project nurse and analysed by lead researcher. General principles of data reduction, data display followed by conclusion-drawing and verification were followed.

Study	Warner 2005[40]
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	Patients valued the following: • Close working relationship between nurse and neurologist – communication • Nurse as a point of contact during a relapse • Nurse role in organising appointments with neurologist and other treatments • Access to people with clinical knowledge of MS
Funding	Not reported
Limitations and applicability of evidence	Severe methodological limitations were considered to be present, with factors contributing to this rating including concerns about data collection and saturation, no mention of role of researcher and possible effect on methods and results, possibly no formal qualitative methods used and unclear if findings confirmed by second person As this was UK-based study it was considered to be highly relevant in terms of coordination of care.

Study	While 2009[41]
Aim	To describe perceived role of nurses and other MS carers from perspective of different stakeholders
Population	People with MS – includes healthcare professionals as well but not relevant to this review. People with MS identified through MS Trust's database. N=65
Setting	UK-based study
Study design	Survey data collected previously in 2002 were reanalysed – includes qualitative data
Methods and analysis	Questionnaire developed using literature regarding role, skills and knowledge for different dimensions of the MS nurses' role. Participants presented with list of potential care providers (general nurse, MS specialist nurse, GP, neurologist, occupational therapist, physiotherapist, friends/family, social worker, people with MS, paid carer and other) and asked to identify most appropriate providers for each care need. Up to four for each could be nominated. People with MS also asked open questions about identifying three people most helpful in providing support and if they had been in contact with a nurse what type of support they had received. Draft questionnaire refined with reference to an expert panel with MS expertise. Recommended improvements were incorporated. Questionnaires were mailed. Non-response followed up with further mail out.

Study	While 2009[41]
	Unstructured questionnaire data were content analysed comprising search for meaningful segments (thematic categories) and unites (subthemes). All analysis was performed by one researcher independent and checked by second researcher. Any disagreements resolved through discussion. Thematic categories identified and coded.
Findings Note that only those areas thought to be relevant to coordination of care have been extracted.	• 36% listed GP as one of three most important people for support/advice/care, multidisciplinary team by 30%, neurologist 30%, MS specialist nurse 28% • Those that had any contact with a nurse reported what role they had had: ○ Education/advice about MS (63%) ○ Providing accessible service (29%) ○ Continence management (38%) ○ Coordinating care (29%) ○ Counselling/psychological support (25%) ○ Medication management (17%) ○ Continuity of care/ongoing assessment (13%) ○ Personal care (8%) ○ Advice about services (8%) ○ Skin care (4%) • MS specialist nurse was most nominated across care needs (ranging from information about MS and general health advice to advice about finances) • Low level of nominations across these categories for general nurse – suggesting someone with more in depth knowledge of MS preferable • Contribution of MS nurses to care: ○ Specialist knowledge ○ Emotional/psychological support ○ MDT team working – organisation? ○ Symptom management ○ Continuity of care ○ Planning/coordination
Funding	MS Trust funded original work that led to collection of the data.
Limitations and applicability of evidence	Severe methodological limitations were considered to be present, with factors contributing to this rating including limited discussion of collection and no mention of saturation, for people with MS appears no qualitative analysis performed and no discussion of role of researcher and possible impact on methods and results As this was UK-based study it was considered to be highly relevant in terms of coordination of care.

D.2 Pregnancy and future pregnancy

Study	**Colaceci 2021**[5]
Aim	To explore personal experiences, expectations and fears in women with MS about childbearing age and maternity.
Population	Women with MS during childbearing age, pregnancy and motherhood. Enrolment took place at MS centre of an Italian hospital located in Rome. Through snowball sampling of healthcare network. Invited to participate during their clinical appointments and contacted by phone once agreement had been given. N=16; mean age 35.9 years (range 29 to 48 years); n=10 had given birth to last child within 2 years, n=2 had older children (6 and 13 years), n=3 pregnant women and n=2 seeking to get pregnant; sample had average of 1.5 children per woman; mean time since diagnosis was 10 years (range 3-27 years).
Setting	Study based in Italy
Study design	Qualitative interview study
Methods and analysis	Face-to-face interviews where possible but a telephone interview was offered where it was not. Conducted by two research midwives experienced in qualitative data collection. Interviews were digitally recorded and audio-transcribed. Separate semi-structured interview guides for those seeking to get pregnant and those that were already pregnant. Length of interview was guided by participants. Conducted between January and April 2019. Descriptive phenomenological study. Reported according to the COREQ checklist. All interviews fully transcribed and coded inductively and deductively using categorical data analysis. Saturation occurred when no new categories emerged from the interviews. QDA Miner qualitative text analysis software used to conduct coding, content analysis and mapping. Data analysed by three researchers to minimise effect of subjective views using Creswell extension, consisting of the following: 1. Identifying research problem, 2. Reviewing literature, 3. Specifying purpose of research, 4. Collecting data, 5. Analysing and interpreting data and 6. Reporting and evaluating research. Three researchers discussed and checked emerging themes and meanings. Remaining members of research group double-checked and monitored entire process to ensure rigor. Themes that emerged were sent through email to participants to obtain feedback, with all agreeing with findings.
Findings	**Experience of MS diagnosis** Experience of diagnosis varied between two extremes of ‘tranquillity’ and ‘tragedy’. Waiting for an MS diagnosis was a common theme and was described as a stressful moment. Despite an initial emotional impact of MS, women demonstrated the ability to adapt and showed resilience, with a quote describing it as ‘like a sleeping volcano that could erupt sooner or later’. This theme is not included in the review as it is not specific to pregnancy or childbearing in MS. **Relationship with partner, children and family**

Study	Colaceci 2021[5]
	Informing their partner and children of the diagnosis was described as challenging by all of those interviews. It was considered a testing ground for the couple but telling children was seen as more intense and painful. Diagnosis was a concern as they grew older and for the mother it became more difficult to hide the relapses. Women often described their partner as a ‘rock’ during relapses and parental support was also a key factor in the acceptance of a diagnosis and living with MS. When parents did not accept the pathology and minimised it, women felt either misunderstood or unsupported. This theme is not included in the review as it is not specific to pregnancy or childbearing in MS. **Pregnancy** An MS diagnosis meant women planned their pregnancy as they were aware of the risk of relapse and how this would increase over the years. Because of this, women with fertility issues had assisted reproductive treatments with more tension and concern in case of failure. Participants described a feeling of general wellbeing, ‘strength’ and ‘energy’ during pregnancy. One experiencing an unplanned pregnancy during an experimental treatment. In terms of fears related to motherhood, they were primarily afraid of the effect of MS on maternity and whether they could care for their children with fatigue and disability. These fears were solely concerned with ‘not being able to follow the child, not being able to run after him’. In terms of labour and months following childbirth, women were worried about the possible effects of MS on labour (fatigue, tiredness) and the time needed to fully recover. They were concerned that ‘after giving birth the disease could go crazy’. **Delivery** Most women gave birth vaginally, while planned C-sections were only performed in a few cases with severe symptoms or concurrent pathologies. In other cases C-sections were performed for obstetrical conditions. **Puerperium** In terms of lactation, only one did not breastfeed based on a recommendation from the neurologist that ‘your body has already been stressed so much… you need to resume the drug treatment immediately’. In all other cases mothers breastfed until relapse occurred, even disobeying the recommendations of neurologists. Despite the relapse, patients were satisfied that they had breastfed their child. A mother who had an early relapse had trouble introducing instant formula to her child and stopped breastfeeding. In terms of therapy compatible with lactation, following the neurologist’s recommendations, one continued to breastfeed after a relapse by ‘skipping the feed closer to the administration’. Emotions about returning to home were generally positive, being expressed as ‘wonderful’ and ‘new’. In terms of negative birth experiences, associated emotions were ‘fear’, ‘tiredness’ and ‘pain’. **Care pathway**

Study	**Colaceci 2021[5]**
	Main feedback expressed was sense of solitude and abandonment during care pathway (antenatal, childbirth and post-natal care). Satisfaction felt referred to personal characteristics of health personnel, such as kindness, empathy and ability to respond quickly to doubts or questions. Women suggested integrated multi-professional care as in their opinion 'pregnancy must be supported not only on gynaecological and neurological levels but also on a psychological one'. Women also called for more attention to the perspective of women with MS, suggesting 'providers should always ask if women with MS want to have children because it's important to understand the perspective and desire of a woman' before planning pharmacotherapy and treatments.
Funding	Research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including no discussion of role of researcher and possible impact on methods and results, and a statement in the paper about possible limited generalisability Despite being non-UK based, this study was considered to be highly relevant given need for information and support in pregnancy or those considering pregnancy is likely to be similar across countries and is not specifically focused on care organisation as with the coordination of care section of this review.

Study	**Ghafoori 2020[12]**
Aim	To better understand the experiences and concerns of women with MS about pregnancy and motherhood
Population	Iranian women with MS referred to the Iran MS Society Centre – women of reproductive age (15-45 years), married women with a definite diagnosis of MS by neurologist, suffering from no other illness other than MS, suffering from the disease for at least a year and willingness to participate were inclusion criteria. Maximum variation purposive sampling used to recruit information-rich candidates with diverse characteristics. N=25; age 20-47 years; MS duration 1-20 years; EDSS score 1.5-8.0.
Setting	Conducted at MS Society in Tehran, Iran
Study design	Qualitative interview study
Methods and analysis	Data analysis was performed concurrently with the data collection and the sampling was continued until data saturation was reached. data were collected through in-depth semi-structured face-to-face interviews. A total of 25 individual interviews were conducted by a research team member in a private and calm atmosphere at the Iran MS Society. Interviews lasted 35-90 min. Started with general questions and open questions such as 'please expand' and 'what do you mean?' were used to get a clearer and more detailed response. Audio-recorded if permission given.

Study	**Ghafoori 2020**[12]
	Data analysed using conventional content analysis described by Lundman and Granheim. After each interview, audio-recordings transcribed verbatim. Following review of transcriptions, initial primary codes identified which were then classified in terms of similarities and differences to define subcategories. Reviewed, compared and grouped to determine main categories. Accuracy of findings assessed using four criteria listed by Goba and Lincoln – credibility, dependability, confirmability and transferability. Credibility achieved through prolonged engagement, adequate time for collection and data analysis and member checking. Dependability met through feedback from two experts and review of text by team members and 17 participants. Confirmability ensured by keeping audit trail for each step of data collection and analysis. Transferability ensured by providing full description of categories, characteristics of participants, data collection and analysis methods and use of participant full quotes.
Findings	• Pregnancy concerns ○ fear of getting pregnant due to its potential negative side effects on their personal health (during pregnancy, post-pregnancy relapse) ○ Avoiding pregnancy due to a fear of harming the foetus (medication, passing on genes, not being able to breastfeed) • Fear of failing as a parent ○ Fear of not being able to meet needs of child as they did not feel able to meet their own sometimes ○ Social stigma of being a 'bad' mother ○ Physical burden such as taking them to school etc. • Feeling of threatened fertility ○ Some felt MS would negatively affect their fertility (e.g. due to disrupted menstrual cycles as a result of medications) ○ Hormone therapy could cause early menopause and infertility ○ MS thought to cause ovarian insufficiency or cysts ○ Limitations of infertility treatment: IVF/similar methods not working due to MS • Lack of social support ○ Need for support from family, spouse and support organisations ○ Felt rehab team focused on physical symptoms and not infertility/getting pregnant ○ Lack of counseling and limited coaching on infertility and pregnancy after being diagnosed with MS. ○ Early postpartum period is the most important time to receive social support because of the probability of an MS relapse ○ Dismay with the lack of child health care provided by the health care system.
Funding	Financially supported by the Tehran University of Medical Sciences, Tehran, Iran (grant number: 9221151003)
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including no discussion of role of researcher and possible impact on methods and results and limited generalisability given all from same centre Despite being non-UK based, this study was considered to be highly relevant given need for information and support in pregnancy or those considering pregnancy is likely to be similar across countries and is not specifically focused on care organisation as with the coordination of care section of this review.

Study	**Kosmala-Anderson 2013**[21]
Aim	To explore the childbearing experience of women with MS to determine what support and information may be useful to this target group
Population	Women with MS – those that had been seen in the clinic within the last three months about planned, current or recent pregnancy Recruited from Neurology Clinic at Cambridge University Hospital. Received letter from MS nurse explaining study and inviting to participate. Opportunistic sample of women. N=9 women; n=3 considering pregnancy, n=3 currently pregnant (3, 5 and 7 months) and n=3 recently had a baby; diagnosed average 3.1 years ago (range 1-8 years); n=8 relapsing-remitting and n=1 secondary progressive; EDSS average score was 3 (1.5-5.0 range); mean age 30.6 years (range 23-37 years); n=3 already had one child; n=7 currently employed and n=2 not employed; all lived with their partners.
Setting	Recruited from single centre at a UK hospital
Study design	Qualitative interview study
Methods and analysis	Semi-structured interviews conducted with women lasting mode 60 min (45-90 min); women asked about their experience of discussing having a baby with their doctor or any other healthcare professional, what information and support they would like to receive to make decisions about having children and effectively managing MS before, during and after pregnancy. All interviews were recorded and transcribed. Analysed independently by two researchers using inductive thematic analysis. Data analysis involved 1. Familiarising with data 2. Generating initial codes 3. Searching for themes 4. Reviewing themes 5. Defining and naming themes and 6 reporting. All disagreements discussed to achieve consensus.
Findings	• Concerns about MS and pregnancy o Concerns about their own health in terms of coming of medication and the effect on MS as well as relapse post-partum o Concerns about the health of their baby – impact of their MS on the baby and also concerns about inheriting MS o Concerns about being able to look after their new baby if/when they suffered a relapse and with their ongoing symptoms o Concerns about employability and therefore how to pay with additional expenses of having children • Lack of information about MS and pregnancy o Difficulty finding relevant and reliable information about MS and childbearing o More positive experiences in secondary care where referrals to sources such as MS Trust and MS Society were given o Primary care experience was that they were informed about possibility of relapse post-partum in line with NCIE guidelines but not given information/referral to other resources such as societies o Limited information about the possible impact of MS on the pregnancy o Having to look for information in diverse places was time-consuming and frustrating o More information needed about DMT and possible impact on ability to get pregnant – how long before should they be stopped and whether there were any suitable medications during pregnancy o Impact of reproductive assisted technologies might have on MS progression for one patient o Impact of pregnancy in terms of relapse and whether any treatment would be possible if this did happen while pregnant

Study	**Kosmala-Anderson 2013[21]**
	○ How the condition would affect labour and delivery and pain relief options (caesarean, not able to have epidural) ○ More information about risk of relapse following pregnancy and whether restarting treatment after having the baby reduces risk ○ Whether they were able to breastfeed or their MS would prevent that, also whether taking medications would prevent that ○ Impact of pregnancy on MS progression and whether stopping DMT to have a baby would increase progression ○ Information about where to get practical and professional help in terms of taking care of their baby ○ Available support in terms of employment ○ Self-management advice in terms of alleviating symptoms, managing fatigue, planning before the baby arrives • Support from others ○ Family and support from professionals helped with decision making and reduced anxiety ○ Having a discussion with professionals about this as soon as possible was important for some – initiated by the women themselves in all cases ○ Some negative experiences in terms of support received from primary care (highlighted their ability to care for child if MS progressed) but secondary care generally supportive
Funding	Not reported
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including no mention of data saturation, no discussion of role of researcher and possible impact on methods and results, and limited generalisability due to small sample Study was UK-based so no concerns about relevance.

Study	**Manzano 2020[24]**
Aim	To increase understanding of people's experiences of decision-making when switching disease-modifying therapies (DMTs)
Population	People with relapsing-remitting MS – some points about pregnancy and decision-making – clinician-confirmed diagnosis; aged at least 18 years; signed written informed consent. MS neurologists in referral centre in teaching hospital in north of England, UK asked to identify people with relapsing-remitting MS who were then approached by a research nurse. Purposive sampling strategy guided by theoretical framework used. Aimed to get heterogenous DMT experiences but allowed flexible criteria to capture and refine emerging knowledge. N= unclear for those discussing pregnancy-related items (N=30 in whole study population); 22 females and 8 males; age range 18-56 years
Setting	Recruitment from single centre in north of England, UK
Study design	Qualitative interview study

Study	Manzano 2020[24]
Methods and analysis	Semi-structured interviews conducted to explore decision-making process about DMTs. Topic guides used and interviews lasted 45-90 min. Conducted face to face (n=22) in participant's home or referred venue or by phone (n=8). Audio-recorded, transcribed verbatim and analysed using thematic analysis. Inertial coding by theme done by same interviewer conducting interviews. Subthemes further developed and coded by two qualitative researchers with NVivo software. Subthemes grouped into broader categories or meta themes specific to people with relapsing remitting MS with switching experience by cross-referencing individual accounts with group of switchers and entire dataset. Metathemes refined through discussions with wider research team which included a person with relapsing-remitting MS.
Findings	• Stopping DMT temporarily was reported by younger female patients due to pregnancy planning • Often resumed same one after depending on breastfeeding plans and disease activity • Women found timeframes without these drugs long, for example suffering relapses during periods not on the drugs • Women of fertile age reported that risks of relapse pre-conception, during pregnancy and post-partum were discussed before expressing conception plans, though similar issues around pregnancy planning not discussed with male patients
Funding	Supported by MS Society UK and by National Institute for Health Research infrastructure at Leeds, UK.
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including no mention of data saturation, no discussion of role of researcher and possible impact on methods and results, and limited generalisability due to small sample Study was UK-based so no concerns about relevance.

Study	Payne 2010[31]
Aim	To provide a better understanding of the experiences of women with MS in becoming or being a mother
Population	Women with MS experiencing becoming a mother – aged 18-45 years; diagnosed with MS by neurologist; given birth within last 5 years; able to converse in English Identified and recruited via area MS nurse specialist or MS Society field officer N=9; aged between 22 and 45 years; n=7 married and lived with spouses and n=2 were separated from partners with n=1 living with mother and siblings and n=1 living with her three children; all but one identified themselves as European or Pakeha (white New Zealander); n=1 had secondary progressive MS and n=8 relapsing-remitting MS; only one was wheelchair dependent during a relapse and several others reported some difficulty walking during relapses; n=1 on immunomodulating medications; n=4 only had one child and n=5 had 2-3 children; n=5 were fulltime mothers and n=4 part time employed.
Setting	Study based in New Zealand
Study design	Qualitative interview study

Study	Payne 2010[31]
Methods and analysis	One-on-one semi-structured interviews performed by principal researcher following flexible interview guide containing prompts. Due to small sample size, two interviews considered to be pilot interviews were included in the results. Interview content and structure were refined following the first two pilot interviews. Interviews audio-taped and transcribed verbatim. Open approach with limited prompts used to ensure women had sense of control over the interview. Interpretive description methods used – transcripts read and reviewed multiple times, with initial analysis occurring immediately after each interview. Categories and themes characterising experience of managing motherhood and MS were suggested. Key concepts further developed, tested and refined in subsequent interviews as data progressively analysed throughout study. Final analysis includes themes relevant and important across the group. Dual analysis by researches, participant feedback and member-checking were performed. Rigor checks included member checking, data saturation and contextual description.
Findings	• Considered impact of MS on pregnancy, childbirth and childbearing • Discussion with healthcare professionals was key to decisions about pregnancy • Some professionals were not very sensitive and advised against having children • Keeping the baby safe in terms of taking medications, breastfeeding – need for more and consistent information • Impact of taking medications on trying to conceive • Risk fo relapse post-partum meant this period was particularly important to have support available • Conserving energy and managing fatigue was particularly important after having a child • Meeting demands and caring for their child, fear of being labelled a ‘bad’ mother
Funding	Not reported
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including no mention of data saturation, no discussion of role of researcher and possible impact on methods and results, and limited generalisability due to small sample mentioned in the paper Despite being non-UK based, this study was considered to be highly relevant given need for information and support in pregnancy or those considering pregnancy is likely to be similar across countries and is not specifically focused on care organisation as with the coordination of care section of this review.

Study	Smeltzer 1994[37]
Aim	To identify the concerns of pregnant women with MS
Population	Women with MS that were pregnant

Study	**Smeltzer 1994**[37]
	Recruited from a study of the course of MS during pregnancy and post-partum period (n=4) and through an announcement in newsletters of two local MS Society chapters (n=11) N=15; n=12 interviewed between 5 and 7 months of pregnancy and n=3 only during post-partum period and within 4 weeks of delivery – n=5 interviewed post-partum as well as during pregnancy; mean age 30.3 years (24-40 years); time since diagnosis was mean 5.8 years (1-14 years); for n=13 this was first or second child and n=2 had three or four children; all but n=2 pregnancies were planned; n=12 had benign or relapsing-remitting MS and n=3 said they had been told they had chronic progressive MS; all were ambulatory but n=3 used cane or wheelchair for ambulation occasionally.
Setting	Conducted in USA
Study design	Qualitative interview study
Methods and analysis	Semi-structured interview guide based on four categories of possible concern was discussed with participants – concerns about their own health, the health of the expected baby, their pregnancy and their MS. Initial question focused on MS history. Each interview continued until all areas covered to satisfaction of investigator and participant. Final question allowed opportunity for additional areas to be raised by participants. Data collection continued until point of saturation. Content analysis used to analyse data. Transcribed and transcripts read to obtain general impression of data collected. Responses were coded using original four categories used to guide the interview. Second coder read transcripts independently and coded them using same four categories – clinical nurse specialist in material-child nursing. They then met to discuss categories and further refine and define them to increase code specificity. Transcripts read again independently, and more specific codes generated. Met again to identify final set of codes and obtained consensus on final coding of all responses. Third coder independently reviewed all transcripts using final codes to decide if additional concerns could be identified.
Findings	• Antenatal pregnancy concerns ○ Consequences of MS treatment before or during pregnancy – need for treatment and risks of not taking it, effects on foetus ○ Distinguishing normal changes of pregnancy and MS symptoms ○ Expectations about MS symptoms during pregnancy ○ Sensitivity not always experienced – suggestions of aborting having got pregnant while taking medication ○ Need for consistent information about medication and pregnancy as differing opinions ○ Impact on delivery/childbirth ○ Breast-feeding ○ Child’s health, coping with a baby and risk of passing on MS, fear of failing ○ Coping with increased fatigue and symptoms alongside a baby
Funding	Not reported

Study	Smeltzer 1994[37]
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including concerns about recruitment, data collection (some only interviewed post-partum), no role of researcher discussion and possible impact on methods and results and limitations in generalisability described in the paper Despite being non-UK based, this study was considered to be highly relevant given need for information and support in pregnancy or those considering pregnancy is likely to be similar across countries and is not specifically focused on care organisation as with the coordination of care section of this review.

D.3 Palliative care

Study	Borreani 2014[3]
Aim	To identify unmet needs of people with severe MS living at home by qualitative research involving key stakeholders
Population	People with severe MS and their carers – also included healthcare professionals but not relevant to this review. Those included were adults with definite MS, primary or secondary progressive form of MS, EDSS scale of at least 8 and that had a carer. Institutionalised patients and those with severe cognitive compromise or impairment precluding communication were excluded. Participants selected purposefully for interviews. Intended to recruit patients varying in age, gender and intensity of care. Participants in carer focus groups recruited from relatives, friends, next of kin and key decision makers usually designated by the patient. Each group had to include at least three carers of MS patients with severe cognitive compromise or inability to communicate. N=22 interviews with people with severe MS; 64% female; 27% primary progressive MS and 73% secondary progressive MS; mean time since diagnosis was 22 years (14-39 years); median EDSS score 9.0 (8.0-9.5). N=30 carers across focus groups. Most carers were full-time caregivers and n=6 cared for those with severe cognitive compromise; most found participation in groups difficult due to having to find substitute carer.
Setting	Three areas across Italy – Genoa, Rome and Catania.
Study design	Qualitative study – interviews and focus groups
Methods and analysis	Home-based semi-structured interviews performed for people with MS and focus groups (n=3 groups in different areas of Italy) held for carers. Five psychologists performed interviews. Minimum of 10 interviews planned and sampling ended when data saturation achieved. Interviews lasted average 51 min (23-102 min), with n=2 having carer present. Patients had to relationship with interviewer prior to study. Psychologists trained to conduct interviews by researchers experienced in qualitative research in fields of oncology and palliative care. Prototype interview guide devised and modified during study based on emerging results. Each interview audio-recorded and transcribed. Duration depended on content of contribution and wiliness/ability to continue. Carers only present in exceptional circumstances in patient interviews. Each focus group aimed to include 6-10 participants and two moderators. One moderator had no previous contact with participants and her task was to engage, promote exchanges, modulate conflicts and ensure all topics covered adequately. Co-moderator took notes, noted relevant non-verbal communication, assisted with logistics and oversaw audio-recording. Focus group guides devised beforehand and modified as required. Focus group reports sent to all participants for approval. Focus groups lasted 126 min (120-140 min) and conducted in Genoa, Roma and Catania. Grounded theory analysis guided interview and focus group transcript analysis. Two researchers independently coded raw transcripts and after joint discussion a coding framework was developed. Constant comparative technique used to identify emergent themes.

Study	**Borreani 2014**[3]
	Second level coding performed to group similar areas into categories. Extensive notes taken about researchers' thinking to guide conceptualisation. After categories established, third level coding performed to produce domains.
Findings	**Expressed needs** **Managing everyday life** • More physiotherapy • Personal care hygiene (bladder/bowel functions) ○ tiring for both patient and carer ○ patients found them embarrassing and the fear of problems in public held them back ○ Some patients felt like a burden because of this. ○ This could disrupt the working lives of carers • Home adaptations and mobility aids were seen as important ○ Increase ability to get out of the house – feeling imprisoned • Burden on relatives ○ Patients wanted someone to help their carers as they felt a burden on them ○ Carers sometimes wanted their own space and felt abandoned with no other help, though sometimes difficult to admit **Psychosocial** • Concerns of carers about what would happen to the patient if they were no longer around • Fear for patient future from carer perspective • Patient loneliness and isolation when carers were absent or dysfunctional and need for social interaction **Organisation** • Health and social care services scarce and difficult to access • Rehab facilities not suited to those with severe MS • Aids and assistive devices a crucial issue – criteria for obtaining, suitability, difficulty accepting/familiarising themselves with them • Caregivers had issues obtaining information on patient rights and knowing what patients and their families were entitled to
	Death and sexuality/intimacy • Patients never brought up the subject of death themselves • Patients expressed a wish not to outlive their carer • Appeared little attention had been given by patients to advance care directives of end of life decisions • Loss of sexuality seen by some as a consequence of disease worsening • Some patients saw the need to adjust to functional limitations including sexual functioning, incontinence, mobility compromise and spasticity • Sexuality did not arise during carer focus groups but may be a result of the setting or other more important needs

Study	**Borreani 2014**[3]
	Carer-specific needs • Lack of time to themselves • Economic consequences for families with someone severely disabled • Social relations and leisure impacted • Lack of time to attend own medical appointments/take care of themselves • Reluctance sometimes to leave in care of someone else who might not be able to cope • Feeling ignored by health policy makers as very patient-focused
Funding	Not reported
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including limited discussion of role of researcher and possible impact on methods and results Despite being non-UK based, this study was considered to be highly relevant given need for information and support in palliative care is likely to be similar across countries and is not specifically focused on care organisation as with the coordination of care section of this review.

Study	**Embrey 2013**[8]
Aim	To explore experience and views of people with moderate and severe MS participating in palliative day care programme in North Staffordshire
Population	People with moderate, severe and advanced MS using palliative day-care programme in North Staffordshire. Non-probability sampling procedure used. Limited to those well enough to contribute. Participants selected based on researcher's knowledge of the population. N=9 people with MS using service
Setting	Single palliative day-care service offered by a single North Staffordshire Hospice, UK
Study design	Qualitative interview study
Methods and analysis	Palliative day-care service for people with MS set up in 2003 in North Staffordshire – programme was designed within a focus group that included patients and professionals with it being piloted for 12 weeks. Success of programme meant it continued and accommodated needs of >60 patients in the region. Views of those involved in the programme were explored using a phenomenological approach. 'Grand tour' approach to interview questions which involved open-ended probing questions from clues and cues to determine patients experiences. Interviews began with question asking individuals to describe experiences of the Douglas Macmillan Hospice palliative

Study	Embrey 2013[8]
	day-care programme. Interviews conducted using Carson’s 1986 recommendations. Interview deemed complete when participant had exhausted their description and no new or recurring themes emerged from the conversation. Data collected over 10 weeks. Tape recorded and transcribed verbatim. Data collection and analysis occurred in tandem. Analysis performed following framework described by Giorgi 1985: 1. Reading and re-reading descriptions and reflecting on each interview with a critical friend 2. Examining text to reveal emergent themes 3. Clarifying and elaborating meaning of themes and comparing with each other and as a whole 4. Reflection and synthesis of descriptions 5. Integration and synthesis of themes into general descriptive structure.
Findings	Group support element of the programme - importance of maintaining contact with others, meeting others with MS, forming connections and affiliations within the group was emphasised and appeared to improve quality of life • **Commonality/friendships:** patients with same condition felt more able to talk to each other, facilitating new friendships. Sharing of joy and sadness with other group members. Group discussions/one on one conversations with others with similar but not identical conditions led to a feeling of being connected. Sharing experiences of suffering allowed mutual experiences to be discussed openly. Not always felt to be the same opportunity at home as didn’t want to complain and often felt more open about discussing with the group that at home. • **Understanding:** established shared understanding with other group members and enjoyed interacting without embarrassment as others understood their difficulties. They felt they could be themselves and often felt misunderstood at home. Developing understanding of one another meant they could sometimes share very personal things that they might not want to with family members. Friendships developed and were maintained outside of the programme and having phone contact with one another was useful for support and advice. Sharing problems meant that they were not only focused on their own problems. • **Initial worries and concerns:** some were wary and apprehensive about attending a hospice and one was terrified about not knowing how to interact with people having spent much time alone. This improved after the first week but some felt that it wasn’t right for them initially. Some were fearful about hospices based on previous experiences and others felt the concept of day care was misunderstood. • **Carer burden:** participants described a benefit for their carers, as they felt it gave them time out from caring for them and to take part in other activities. Also encouraged to take advantage of respite care, providing relief for carers. Some participants described the effect of their MS on their carers and talked about the importance of support for the carer and themselves so that the carer could take care of themselves as well and be able to better support the person with MS.
Funding	Not reported
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including limited discussion of role of researcher and possible impact on methods and results and unclear if a second person was involved in results validation Study was UK-based so no concerns about relevance.

Study	Falet 2020[9]
Aim	To better understand patient and care provider perspectives on the optimal role of their neurologist.
Population	Patients with MS (judged to be severely affected by neurologist) and care providers Patients recruited by neurologist treating their MS if they were >18 years, able to communicate meaningful information about their opinions and severely disabled as judged by their neurologist. Suggested that neurologists recruit patients with scores of 6.0 or more since these patients are most likely to experience severe disability, but they could recruit patients with lower scores if they judged disability to be severe in aspects unaccounted for by the EDSS. Patients contacted by phone and invited to participate in an in-person interview. Suggested that patients bring their care providers with them, but this was not required given not all patients may have someone that could accompany them. N=29 participants (n=19 patients and n=10 care providers) recruited via three neurologists. Care providers were a spouse (n=6), a child (n=2) or a parent (n=2). Recruitment halted after 29 participants based on thematic saturation. Patient demographics as follows: mean (range) age, 57 (44-80) years; n=4 relapsing-remitting MS, n=4 progressive-onset MS and n=11 secondary progressive MS; Mean (range) EDSS score, 6.5 (3.0-8.0); mean (SD) SDMT score, 29.0 (15.0); n=1 each on interferon beta-1a and beta-1b, n=2 taking glatiramer acetate, n=2 on fingolimod, n=2 on natalizumab and n=7 taking none of these.
Setting	Study based in Canada
Study design	Qualitative interview study
Methods and analysis	Semi-structured interviews conducted by one author. These were audio-recorded and transcribed verbatim. Inductive thematic analysis of interview transcripts performed by the interviewer. Data extracts within transcripts were coded at semantic level. Themes relating to desired role of neurologist identified within each transcript, clustered into subthemes and into overarching themes. Analysis reviewed by second author and differing opinions resolved by discussion. Cross-interview analysis conducted by separate author throughout the study by pooling thematic analyses of all interviews into a common thematic map. This was reviewed through discussion and modified until satisfactorily represented all authors' interpretation of the data.
Findings	**General comments** Most patients and all care providers felt at least some aspect of their neurologist's role was useful and could not be replaced by another healthcare professional. One felt that his neurologist was not useful and could be replaced by his family physician. Another participant felt current neurologist was useful but contrasted this with another neurologist who did she not feel had been useful. Reasons included not fulfilling three roles subsequently discussed in headings below. **Neurologist as a source of hope for therapeutic advances**

Study	Falet 2020[9]
	13 patients and 8 care providers highlighted role of neurologist as provider of hope for therapeutic advances, which was their most important role for 9 patients and 5 care providers. Hope was most commonly associated with the link the neurologist has to information about research and novel therapies. Several participants wanted their neurologist to share information on this proactively without having to request it and without having to research it themselves. **Neurologist as an educator about the disease and its management** 12 patients and 6 care providers felt neurologist is useful through education about different aspects of their disease and its management, with 5 patients and 3 care providers describing this as the most important role. This information included advice on measures to improve their quality of life (for example, suggesting aids that might improve life rather or as well as medication), updates on the stage of their disease (stage currently at and what might happen in terms of progression). One patient described encounters with their neurologist as less useful due to their failure to educate him about his disease (they saw it as an important role of the neurologist and wanted to be told more information). Some participants valued the perspective of their neurologist on information they had gathered themselves, for example online (this helped differentiate reliable from unreliable information, which was noted to be difficult particularly online). **Neurologist as a source of support** 11 patients and 5 care providers saw the neurologist as an important source of support. One patient and one care provider felt this was their most important role. The neurologist is thought to be well placed to accompany the patient through progression of their disease. Quotes highlighted how this included reassurance about progression of disease and whether worsening symptoms are part of the natural progression. Quotes highlight the sense of psychological support and reassurance with one person being reassured by the neurologist stating that they will deal with it together, and others also highlighting how their neurologist understands them and makes them feel supported. Good listening skills, bedside manner and compassion enabled the supportive role of neurologists. Several participants highlighted the importance of them being open-minded and non-judgemental in their approach, which was crucial to the support they receive. One patient discussed her experience discussing chronic cerebrospinal venous insufficiency with two different neurologists, with contrasting experiences in relation to angioplasty. One was open and explained his concerns beforehand but supported her nonetheless, while the other was dismissive and suggested a lack of understanding.
Funding	Received no financial support for the research, authorship, and/or publication of this article.
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including concerns about focusing on three neurologists from the same centre and possible recruitment bias in terms of patients with more positive relationship with neurologists

Study	Falet 2020[9]
	Despite being non-UK based, this study was considered to be highly relevant given the topics it reports are likely to be similar across countries and not covering areas such as organisation of care which likely differs between countries.

Study	Galushko 2014[11]
Aim	To explore the subjectively unmet needs of patients feeling severely affected by MS
Population	People with severe MS – reported feeling severely affected by MS regardless of physical state Purposive sampling strategy but as only few severely affected MS patients agreed to participate, inclusion criteria expanded to include anyone willing to participate (convenience sampling). Leaflets distributed through health professionals in Cologne area caring for people with MS. N=15; subjective affectedness ranged 4-10 with mean 6.8 (0-10 higher more severe); EDSS score mean 6.5 (3-9); time since diagnosis was between 4 and 41 years; n=11 were hospitalised for immunosuppressive therapy or comorbidities such as infections.
Setting	Single area in Germany – Cologne
Study design	Qualitative interview study
Methods and analysis	Episodic face-to-face interviews allowed for narratives (episodic knowledge) and for focusing on certain topics (semantic knowledge). Interview guide adapted for use by trained sociologist working as a researcher within the department having experience interviewing palliative care patients as well as professionals. Interviewer had no previous relationship with participants. Interviews performed at home (n=4) and on neurology ward (n=11). Five chose to be accompanied by a caregiver relative whose contributions were also included in analysis. All recorded and transcribed verbatim but not returned to respondents for checking. Field notes made. Interviews ranged 25 min to 2 h duration. Interview quotes translated by native speaker. First interview subjected to the open coding process was with a young, single patient. Five other interviews coded using constant comparison to reveal minimal and maximal contrasts. Next step of qualitative content analysis involved all fifteen interviews and emerging codes were constantly compared and similar content from different interviews combined into preliminary categories. Categories at higher level of abstraction were needed to be applicable to whole dataset. Categories and subcategories were iteratively refined. Inductive approach also considered intercategory findings. Study followed grounded theory approach.
Findings	**Support from family/friends** • Wanting increased support from family and friends through increased contact and understanding of handicaps associated with MS • Some felt information for carers/relatives was insufficient and wanted them to have more available and also psychological support
	Healthcare services

Study	Galushko 2014[11]

	- Difficulties accessing services, need for reduced waiting times, home visits and better disability access and driving services
	- Difficulty finding neurologists/family doctors competent in treating MS and physicians up to date with latest treatments
	- Ideas about other treatment options:
	  ○ Someone outside of family to talk to, psychotherapy/mental health care, crisis support
	  ○ Discussion and information about palliative care

	Physician-patient interaction - want assistance in evaluating self-obtained information and counselling regarding further treatment options - appreciated information delivered early and honestly alongside engagement in future decisions. Patients wanted to be viewed as distinct individuals, be more respected and listened to as well as handled with sensitivity - Time with doctors was limited and wanted homecare services scheduled according to their changing needs - Wanted information on disease course, treatment options and various existing services - Greater support in finding possibly useful services, particularly when entering a new phase of the disease - Information about reimbursement for travel expenses to appointments or subsidies for equipping vehicles - Need for increased social contact
Funding	Supported by a grant from the ‘‘Gemeinnu¨tzige Hertie-Stiftung’’ (grant #1.01.1/06/009). The clinical and academic activities of the Department of Palliative Medicine, University Hospital of Cologne, are substantially supported by German Cancer Aid (Deutsche Krebshilfe e.V.) as well as by the Federal Ministry of Education and Research (BMBF01KN0706)
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including concerns about recruitment as described self as severely affected, concerns about data collection, role of researcher and possible impact on methods and results not described and some limitations in generalisability Despite being non-UK based, this study was considered to be highly relevant given need for information and support in palliative care is likely to be similar across countries and is not specifically focused on care organisation as with the coordination of care section of this review.

Study	Giovannetti 2018[13]
Aim	To explore the strengths and challenges of the palliative care intervention, and circumstances that may have influenced its efficacy.
Population	People with MS that received intervention (home-based palliative care approach) and informal caregivers – healthcare professionals also included via focus groups but not relevant for this review. Purposive sampling used to select participants (at least four pairs from each centre) that obtained greatest and least benefit from the intervention (in terms of primary outcomes). At least two caregivers of those with severe cognitive compromise were selected (patients not interviewed).

Study	Giovannetti 2018[13]
	N=12 people with MS and N=15 informal caregivers; 58% patients and 60% caregivers were female; median age 58 years (43-78 years) for patients and 65 years (23-81 years) for caregivers; EDSS score patients median 8.5 (8.0-9.5); 40% carers were spouse or partner of those they cared for, 20% were parents, 20% were their children and 20% another relative.
Setting	Three centres across Italy – Milan, Rome and Catania of those receiving a home-based palliative care intervention
Study design	Qualitative interview study – part of a mixed methods approach
Methods and analysis	Home-based personal semi-structured interviews were used for patients and caregivers that received the intervention (home-based palliative care approach). Guides for conductive interviews were developed by PeNSAMI qualitative panel with input from steering committee. After piloting, minor changes made to structure and order of questions in interview guide. Interviewed separately patients and carers at patient homes. Took place within 6 months of trial completion and lasted no more than 1 h (patients) or 1.5 h (carers). Minimum of 12 patient and 12 carer interviews planned. Data from each analysed immediately to decide characteristics of next interviewee pair, revise interview guide if needed and indicate when interviewing should end due to data saturation. Interviews conducted in Milan by psychologist trained in qualitative research and in Rome and Catania by specially trained psychologists. Patients and caregivers had not met interviewers previously. Each question asked in turn in open-ended fashion. Follow-up questions used to clarify and explore participant responses. Encouraged to elaborate on themes or views that emerged. Interviewer noted any informative non-verbal gestures. At end, interviewer verbally summarised key points and asked if this was full and correct. Framework analysis using inductive approach to identify themes and categories emerging from interviews. Two psychologists experienced in qualitative research and not involved in MS patient care analysed transcripts in six steps independently and jointly: 1. All propositions thought significant were identified and comments added 2. Comments expanded and related to other points that arose 3. Relations between comments established by reordering and grouping by subcategories 4. Subcategories considered relevant were ordered hierarchically into categories moving to general 5. Analyses of each transcript compared to each other to identify common and one-off subcategories 6. Analysis produced by each researcher were compared and consensus achieved.
Findings	The study describes various met and unmet needs as a result of the intervention. Those possibly relevant to information and support needs of those in this population are listed below: • Information/support about mobility devices/wheelchairs • Emotional support (patient/carer) • Opportunity to communicate and exchange opinions – reassurance (patient/carer) • Information about what they were entitled to and support obtaining it (patient/carer) • Lack of homecare availability (patient/carer) • Need for coordination of care and case managers and a single point of contact (patient/carer) - Improved collaboration between services needed • Need for more physiotherapy (patient/carer) • Increased psychological/social support (patient/carer) o Social integration/connection for both o Reduction of caregiver burden - carers

Study	Giovannetti 2018[13]
	○ Psychological support needed for both in terms of the disease and also family issues • Improved access to services needed
Funding	Not reported
Limitations and applicability of evidence	Minor methodological limitations were considered to be present, with factors contributing to this rating including limited discussion of role of researcher and possible impact on methods and results and limitations in terms of generalisability as is feedback on an RCT intervention Despite being non-UK based, this study was considered to be highly relevant given need for information and support in palliative care is likely to be similar across countries and is not specifically focused on care organisation as with the coordination of care section of this review.

Study	Golla 2014[15]
Aim	To investigate how severely affected MS patients and their health professionals perceive palliative care to determine how to better approach these patients in Germany
Population	People with MS feeling severely affected by the disease – healthcare professionals also included but not relevant to this review Selected using mix of purposeful and convenience strategies. Health professionals in Cologne, Germany and surrounding areas (GPs, in- and outpatient neurologists, nurses, MS clinic team, city/rural area) were asked to help recruit MS patients by distributing leaflets about the study and by querying patients directly during visits to their doctor. N=15; n=10 females and n=5 males; n=5 relapsing remitting, n=4 primary progressive, n=3 secondary progressive and n=3 unknown; age range 23-73 years; EDSS range 3-9.
Setting	Patients recruited from Cologne area of Germany
Study design	Qualitative interview study
Methods and analysis	Semi-structured face-to-face interviews (25 - 120 minutes) were conducted by single researcher at home (n=4) or neurology wards (n=11). If desired, patients could have a relative present during the interview (n=5). Pilot-tested interview guidelines developed. Examples of questions included were 'what ideas do you have about palliative care/hospice? Under which conditions can you imagine to use palliative care services for yourself?'. No definition of palliative care was provided to interviewees. Audio recordings were made of interviews and transcribed verbatim. These were not returned to participants. Fields notes also made. Two researchers worked as researchers at Department of Palliative Medicine and were experienced interviewing palliative care and neurological patients. Analysed for emerging categories of unmet needs. Transcripts separately inductively coded with open codes by one interviewer. Thematic units about attitudes towards palliative care were analysed and categorised using constant comparison method. Second

Study	**Golla 2014**[15]
	researcher verified evolving categories and issues identified by the other researcher. Raw data and related codes discussed at among all authors. Respondent's implicit views then included into coding process. Constant comparison of codes were searched for minimal/maximal contrasts. Results in ongoing refinement from first codes to preliminary categories and categories on a higher abstraction level could be applied to all data. Second researcher checked coding process and plausibility of preliminary categories.
Findings	• Need for more information about palliative care meant/involved – very limited knowledge amongst patients and ideas and understanding of it differed • Some did not know what it meant at all and others associated it in the context of a hospice, critical illness and especially cancer, or dying and characterised it as terminal care or help to die. Patients couldn't imagine it for themselves and felt it would be too early in their life or could not associate it with MS and their own situation • In the context of terminal care for cancer patients, people saw it as positive and palliative care/hospice was well-respected. View was that it stands for qualified care for dying patients including pain treatment and support for both those dying and relatives
Funding	Supported by the Gemeinnützige Hertie Stiftung [1.01.1/06/009]. The Center for Clinical Trials, University Hospital, Cologne, Germany receives support for clinical studies from the Federal Ministry of Education and Research (BMBF01KN0706)
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including a statement that saturation was likely not met, no discussion of role of researcher and possible impact on methods and results and limitations in generalisability mentioned Despite being non-UK based, this study was considered to be highly relevant given need for information and support in palliative care is likely to be similar across countries and is not specifically focused on care organisation as with the coordination of care section of this review.

Study	**Golla 2015**[17]
Aim	To gain an insight into the subjectively unmet needs of caregivers of severely affected MS patients in Germany.
Population	Carers who deemed those they were caring for were severely affected by MS – based on subjective assessment of suffering. Caring relative-like friends could also be included. Convenience sampling approach used as purposive sampling could not be completed due to difficulties recruiting. Carers informed about study by leaflet and personal inquiry in regional MS self-help groups, in a nursing home for young people with disabilities and in the neurological department at the University Hospital of Cologne. One MS outpatient treated at University Hospital offered to act as intermediator between study centre and potential participants by establishing telephone contacts. N=12; n=4 wanted care recipient present during interview and n=1 couple caring for adult child with MS took part together;

Study	Golla 2015[17]
Setting	Study conducted in Germany – possibly limited to Cologne area.
Study design	Qualitative interview study
Methods and analysis	Semistructured face-to-face interviews were conducted by skilled qualitative interviewers who had experience in palliative care at a place preferred by the interviewees (n=8 at home, n=2 at hospital and n=1 at nursing home). Duration between 30 and 90 min. Interviewers had no previous contact with participants. Interview guideline used and fieldnotes taken. Audio-recorded, transcribed verbatim and not returned to participants. Interviews analysed by qualitative content analysis. Global analysis first performed. Parts of interviews identifying carer unmet needs were identified and further analysed. Interviews coded using constant comparison approach to reveal minimal and maximal contrasts. Emerging codes constantly compared and similar content across interviews combined into preliminary categories. Categories at higher abstraction level needed to be applicable to whole dataset. Categories and subcategories iteratively refined. Discussed in multi-professional format among all authors.
Findings	• Physician communication/treatment of patients – need for more sensitivity and involvement of carers in discussions • Caregiver burden and support needed – not being taken seriously by doctors • Wanting physicians treating MS to be knowledgeable in MS • More information/support about caring – workshops in basic skills and someone to talk to for advice (e.g. about will to live) • Need for aids (mobility such as wheelchair or stairlift) as well as transportation support • Psychological support – feelings of insufficiency and depression • Caregiver burden in terms of not being able to have a break or stop thinking about the person they were caring for (said to be rarely mentioned) • Changes in social life and family life, work life (but rarely mentioned) • Information on symptoms, progression and palliative/end of life care • Fears about their own death and who would look after the patient in that circumstance • Social isolation – wish for public to be more knowledgeable about MS to avoid feeling isolated
Funding	Supported by the Gemeinnu¨tzige Hertie Stiftung (grant number 1.01.1/06/009). The Center for Clinical Trials, University Hospital, Cologne, receives support for clinical studies from the Federal Ministry of Education and Research (BMBF01KN0706).
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including a comment that saturation was likely not met, some concern about data collection and no discussion of role of researcher and possible impact on methods and results and limitations in generalisability mentioned in the paper Despite being non-UK based, this study was considered to be highly relevant given need for information and support in palliative care is likely to be similar across countries and is not specifically focused on care organisation as with the coordination of care section of this review.

Study	**Golla 2016**[16]
Aim	To investigate the topic of death and dying in this population of severely affected people with MS – re-analysed of data collected as part of Golla 2014 study also included in review.
Population	People with MS feeling severely affected by the disease – healthcare professionals also included but not relevant to this review Selected using mix of purposeful and convenience strategies. Health professionals in Cologne, Germany and surrounding areas (GPs, in- and outpatient neurologists, nurses, MS clinic team, city/rural area) were asked to help recruit MS patients by distributing leaflets about the study and by querying patients directly during visits to their doctor. N=15; n=10 females and n=5 males; n=5 relapsing remitting, n=4 primary progressive, n=3 secondary progressive and n=3 unknown; age range 23-73 years; EDSS range 3-9.
Setting	Patients recruited from Cologne area of Germany
Study design	Qualitative interview study – Re-analysis of data collected as part of Golla 2014 paper included in this review
Methods and analysis	Semi-structured face-to-face interviews (25 - 120 minutes) were conducted by single researcher at home (n=4) or neurology wards (n=11). If desired, patients could have a relative present during the interview (n=5). Pilot-tested interview guidelines developed. Examples of questions included were 'what ideas do you have about palliative care/hospice? Under which conditions can you imagine to use palliative care services for yourself?'. No definition of palliative care was provided to interviewees. Audio recordings were made of interviews and transcribed verbatim. These were not returned to participants. Fields notes also made. Two researchers worked as researchers at Department of Palliative Medicine and were experienced interviewing palliative care and neurological patients. Analysed for emerging categories of unmet needs. Transcripts separately inductively coded with open codes by one interviewer. Thematic units about attitudes towards palliative care were analysed and categorised using constant comparison method. Second researcher verified evolving categories and issues identified by the other researcher. Raw data and related codes discussed at among all authors. Respondent's implicit views then included into coding process. Constant comparison of codes were searched for minimal/maximal contrasts. Results in ongoing refinement from first codes to preliminary categories and categories on a higher abstraction level could be applied to all data. Second researcher checked coding process and plausibility of preliminary categories. Secondary analysis was performed focusing on whether and how patients addressed death and dying in interviews – thematic units concerning death and dying were identified, analysed and categorised using constant comparison method. First interview coded was that of the patient that ended their life with assisted suicide – a further five coded using constant comparison seeking minimal and maximal contrasts. Process continued as described above. Inductive approach.
Findings	• Information about the disease and progression – some were not aware of the possible outcome of death (though many did not express a wish specifically to have this information) • Psychological support – suggests some struggled so much that they wished for death, with one feeling better after receiving support

Study	Golla 2016[16]
	- Ability to discuss palliative/end of life process with professionals – reluctance currently
Funding	Supported by the Gemeinnu¨tzige Hertie Stiftung (grant number 1.01.1/06/009). The Center for Clinical Trials, University Hospital, Cologne, receives support for clinical studies from the Federal Ministry of Education and Research (BMBF01KN0706).
Limitations and applicability of evidence	Moderate methodological limitations were considered to be present, with factors contributing to this rating including saturation likely not met, no discussion of role of researcher and possible impact on methods and results, limitations in generalisability mentioned and the fact data analysis focused on specific area given recent event Despite being non-UK based, this study was considered to be highly relevant given need for information and support in palliative care is likely to be similar across countries and is not specifically focused on care organisation as with the coordination of care section of this review.

Appendix E – Excluded studies

Clinical studies

Table 5: Studies excluded from the qualitative review

Study	Code [Reason]
Abolhassani, S., Yazdannik, A., Taleghani, F. et al. (2015) Expectations of multiple sclerosis patients and their families: a qualitative study in iran. Iranian Red Crescent Medical Journal 17(2): e18293	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Abolhassani, S., Yazdannik, A., Taleghani, F. et al. (2015) Social aspects of multiple sclerosis for Iranian individuals. Disability & Rehabilitation 37(4): 319-26	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Akbar, N., Turpin, K., Petrin, J. et al. (2018) A pilot mixed-methods evaluation of MS INFoRm: a self-directed fatigue management resource for	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
individuals with multiple sclerosis. International Journal of Rehabilitation Research 41(2): 114-121	
Al-Sharman, A., Khalil, H., Nazzal, M. et al. (2018) Living with multiple sclerosis: A Jordanian perspective. Physiotherapy Research International 23(2): e1709	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Aminian, S., Ezeugwu, V. E., Motl, R. W. et al. (2019) Sit less and move more: perspectives of adults with multiple sclerosis. Disability & Rehabilitation 41(8): 904-911	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Appleton, D., Robertson, N., Mitchell, L. et al. (2018) Our disease: a qualitative meta-synthesis of the experiences of spousal/partner caregivers of people with multiple sclerosis. Scandinavian Journal of Caring Sciences 32(4): 1262-1278	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Archer, Cherie; Morris, Libby; George, Stacey (2014) Assessment and rehabilitation of driver skills: subjective experiences of people with multiple sclerosis and health professionals. Disability and rehabilitation 36(22): 1875-82	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Asano, M., Hawken, K., Turpin, M. et al. (2015) The Lived Experience of Multiple Sclerosis Relapse: How Adults with Multiple Sclerosis Processed Their Relapse Experience and Evaluated Their Need for Postrelapse Care. Multiple Sclerosis International 2015: 351416	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Aubrey, Grace and Demain, Sara (2012) Perceptions of group exercise in the management of multiple sclerosis. International Journal of Therapy & Rehabilitation 19(10): 557-565	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Barabasch, A., Riemann-Lorenz, K., Kofahl, C. et al. (2019) Development of a website with patient experiences of multiple sclerosis (patient experiences of multiple sclerosis (PExMS)). Multiple Sclerosis Journal 25(7): 1046	- Themes not relevant to review - Conference abstract
Barnard, E., Brown, C. R., Weiland, T. J. et al. (2020) Understanding barriers, enablers, and long-term adherence to a health behavior intervention in people with multiple sclerosis. Disability & Rehabilitation 42(6): 822-832	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Barton, J. A.; Magilvy, J. K.; Quinn, A. A. (1994) Maintaining the fighting spirit: veterans living with multiple sclerosis. Rehabilitation Nursing Research 3(3): 86-96	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Bellou, Maro, Vouzavali, Foteini J. D., Koutroubas, Anna et al. (2012) The 'care' in caregiving: The multiple sclerosis experience for the healthy family members. Existential Analysis 23(1): 149-161	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Benjaminy, S., Lo, C., Schepmyer, A. et al. (2019) Perspectives About Time Frames in Stem Cell Research for Multiple Sclerosis: "Time Is Brain". International Journal of Ms Care 21(4): 185-193	- Themes not relevant to review
Beshears, Brenda K. (2010) The experience of young adults living with relapsing-remitting multiple sclerosis. PhD	- Full text paper not available
Bjorgvinsdottir, Katrin and Halldorsdottir, Sigridur (2014) Silent, invisible and unacknowledged: experiences of young caregivers of single parents diagnosed with multiple sclerosis. Scandinavian Journal of Caring Sciences 28(1): 38-48	- Themes not relevant to review

Study	Code [Reason]
Bogenschutz, Matthew, Rumrill Jr, Pillip D., Seward, Hannah E. et al. (2016) Barriers to and facilitators of employment among Americans with multiple sclerosis: Results of a qualitative focus group study. Journal of Rehabilitation 82(2): 59-69	- Themes not relevant to review
Bogosian, A.; Morgan, M.; Moss-Morris, R. (2019) Multiple challenges for people after transitioning to secondary progressive multiple sclerosis: a qualitative study. BMJ Open 9(3): e026421	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Bogosian, Angeliki, Morgan, Myfanwy, Bishop, Felicity L. et al. (2017) Adjustment modes in the trajectory of progressive multiple sclerosis: a qualitative study and conceptual model. Psychology & Health 32(3): 343-360	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Boland, Pauline, Levack, William M. M., Hudson, Sheena et al. (2018) A qualitative exploration of barriers and facilitators to coping experienced by couples when one has multiple sclerosis. International Journal of Therapy & Rehabilitation 25(5): 240-246	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Boland, Pauline, Levack, William M. M., Hudson, Sheena et al. (2012) Coping with multiple sclerosis as a couple: ‘peaks and troughs’ — An interpretative phenomenological exploration. Disability and Rehabilitation: An International, Multidisciplinary Journal 34(16): 1367-1375	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Bonavita, S., Lavorgna, L., Worton, H. et al. (2021) Family Planning Decision Making in People With Multiple Sclerosis. Frontiers in Neurology. 12: 620772	- Study design not relevant to this review protocol

Study	Code [Reason]
Booy, M. and Sanders, E. A. C. M. (2012) Multidisciplinairy clinical pathway for patients with multiple sclerosis and bladder dysfunction. Multiple Sclerosis 18(5): 52	- Conference abstract
Borkoles, Erika, Nicholls, Adam R., Bell, Kate et al. (2008) The lived experiences of people diagnosed with multiple sclerosis in relation to exercise. Psychology & health 23(4): 427-41	- Themes not relevant to review
Borreani, Claudia, Giordano, Andrea, Falautano, Monica et al. (2014) Experience of an information aid for newly diagnosed multiple sclerosis patients: a qualitative study on the SIMS-Trial. Health expectations : an international journal of public participation in health care and health policy 17(1): 36-48	- Duplicate reference
Bostrom, K. and Nilsagard, Y. (2016) A family matter--when a parent is diagnosed with multiple sclerosis. A qualitative study. Journal of Clinical Nursing 25(78): 1053-61	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Bourdin, A., Dubois, J., Foley, R. A. et al. (2020) Satisfaction and experiences of patients taking fingolimod and involved in a pharmacy-based patient support program in Switzerland - a qualitative study. BMC Health Services Research 20(1): 425	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Bowen, C.; MacLehose, A.; Beaumont, J. G. (2011) Advanced multiple sclerosis and the psychosocial impact on families. Psychology & health 26(1): 113-27	- Themes not relevant to review
Broadbent, F. J. and Swalwell, J. M. (2020) "I can do more than I thought I could": exploring the online blogs from the Sailing Sclerosis Oceans of Hope journey. Disability & Rehabilitation 42(6): 880-886	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Brown, C.; Kitchen, K.; Nicoll, K. (2012) Barriers and facilitators related to participation in aquafitness programs for people with multiple sclerosis: a pilot study. International Journal of Ms Care 14(3): 132-41	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Brown, Cara L., Colbeck, Melissa, Fogarty, Danielle et al. (2016) Learning to live with multiple sclerosis cognitive impairment and how it influences readiness for group cognitive intervention. Disability and Health Journal 9(4): 638-645	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Browne, Catherine; Kehoe, Maria; Salmon, Nancy (2017) How Beliefs About Bladder Dysfunction Among Health-Care Professionals Infuence Clinical Practice Development. International Journal of MS Care 19(4): 191-198	- Themes not relevant to review
Bruun Helland, Caroline; Holmøy, Trygve; Gulbrandsen, Pål (2015) Barriers and Facilitators Related to Rehabilitation Stays in Multiple Sclerosis. International Journal of MS Care 17(3): 122-129	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Buchanan, Robert J. and Huang, Chunfeng (2012) Caregiver perceptions of accomplishment from assisting people with multiple sclerosis. Disability and rehabilitation 34(1): 53-61	- Full text paper not available
Buchanan, Robert, Radin, Dagmar, Chakravorty, Bonnie J. et al. (2010) Perceptions of informal care givers: health and support services provided to people with multiple sclerosis. Disability and Rehabilitation 32(6): 500-10	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Buesa-Estellez, A., Cano-de-la-Cuerda, R., Ortiz-Gutierrez, R. M. et al. (2019) The impact of pharmacological treatment on patients with multiple sclerosis. Disability & Health Journal 12(4): 615-621	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Bulley, Catherine, Mercer, Thomas H., Hooper, Julie E. et al. (2015) Experiences of functional electrical stimulation (FES) and ankle foot orthoses (AFOs) for foot-drop in people with multiple sclerosis. Disability & Rehabilitation: Assistive Technology 10(6): 458-467	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Burke, Therese; Vucic, Steve; Patching, Joanna (2019) "Taming the Beast": Exploring the lived experience of relapsing remitting multiple sclerosis using a life history approach. Research & Theory for Nursing Practice 33(3): 229-245	- Themes not relevant to review
Burke, Therese; Vucic, Steve; Patching, Joanna (2018) Management of 'surplus suffering' in relapsing remitting multiple sclerosis to improve patient quality of life. British Journal of Neuroscience Nursing 14(6): 265-271	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Burtchell, J., Fetty, K., Miller, K. et al. (2019) Two Sides to Every Story: Perspectives from Four Patients and a Healthcare Professional on Multiple Sclerosis Disease Progression. Neurology & Therapy 8(2): 185-205	- Themes not relevant to review
Busch, A. K.; Spirig, R.; Schnepp, W. (2014) [Coping with multiple sclerosis in partnerships: a systematic review of the literature]. Der Nervenarzt 85(6): 727-37	- Study not reported in English
Butler, Ellen, Thomas, Reena, Carolan, Alison et al. (2019) ‘It’s the unknown’—Understanding anxiety: From the perspective of people with multiple sclerosis. Psychology & Health 34(3): 368-383	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Butler, M., Forte, M. L., Schwehr, N. et al. (2015) Decisional Dilemmas in Discontinuing Prolonged Disease-Modifying Treatment for Multiple Sclerosis. AHRQ Comparative Effectiveness Reviews. Agency for Healthcare Research and Quality (US).	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Buzgova, R. and Kozakova, R. (2019) Informing patients with progressive neurological disease of their health status, and their adaptation to the disease. BMC Neurology 19(1): 250	- Themes not relevant to review
Buzgova, R.; Kozakova, R.; Jurickova, L. (2019) The unmet needs of family members of patients with progressive neurological disease in the Czech Republic. PLoS ONE 14(3): e0214395	- Themes not relevant to review
Cahill, Mairead; Connolly, Deirdre; Stapleton, Tadhg (2010) Exploring occupational adaptation through the lives of women with multiple sclerosis. The British Journal of Occupational Therapy 73(3): 106-115	- Themes not relevant to review
Calabro, R. S., Russo, M., Dattola, V. et al. (2018) Sexual Function in Young Individuals With Multiple Sclerosis: Does Disability Matter?.Journal of Neuroscience Nursing 50(3): 161-166	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Calsius, J., Courtois, I., Feys, P. et al. (2015) "How to conquer a mountain with multiple sclerosis". How a climbing expedition to Machu Picchu affects the way people with multiple sclerosis experience their body and identity: a phenomenological analysis. Disability & Rehabilitation 37(26): 2393-2399	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Cameron, E., Rog, D., McDonnell, G. et al. (2019) Factors influencing multiple sclerosis disease-modifying treatment prescribing decisions in the United Kingdom: A qualitative interview study. Multiple Sclerosis and Related Disorders 27: 378-382	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Carling, A.; Nilsagard, Y.; Forsberg, A. (2020) Making it work: experience of living with a person who falls due to multiple sclerosis. Disability & Rehabilitation 42(7): 940-947	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Carling, Anna; Forsberg, Anette; Nilsagård, Ylva (2018) Falls in people with multiple sclerosis: experiences of 115 fall situations. Clinical Rehabilitation 32(4): 526-535	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Carling, Anna; Nilsagård, Ylva; Forsberg, Anette (2018) Balance exercise facilitates everyday life for people with multiple sclerosis: A qualitative study. Physiotherapy Research International 23(4): e1728	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Casey, B., Hayes, S., Browne, C. et al. (2016) What do people with MS want from a web-based resource to encourage increased physical activity behaviour?. Disability & Rehabilitation 38(16): 1557-66	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Ceuninck van Capelle, A., Meide, H. V., Vosman, F. J. H. et al. (2017) A qualitative study assessing patient perspectives in the process of decision-making on disease modifying therapies (DMT's) in multiple sclerosis (MS). PLoS ONE [Electronic Resource] 12(8): e0182806	- Themes not relevant to review
Chard, S. (2017) Qualitative perspectives on aquatic exercise initiation and satisfaction among persons with multiple sclerosis. Disability & Rehabilitation 39(13): 1307-1312	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Chen, Hannah and Habermann, Barbara (2013) Ready or not: planning for health declines in couples with advanced multiple sclerosis. The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses 45(1): 38-43	- Themes not relevant to review
Cheong, W. L., Mohan, D., Warren, N. et al. (2019) Accessing palliative care for multiple sclerosis: A qualitative study of a neglected neurological disease. Multiple Sclerosis and Related Disorders 35: 86-91	- Population not relevant to this review protocol

Study	Code [Reason]
Cheong, W. L., Mohan, D., Warren, N. et al. (2019) Living with a neglected neurological disease: a qualitative study of patients with multiple sclerosis in Malaysia. Disability & Rehabilitation: 1-7	- Population not relevant to this review protocol
Chiu, C., Bishop, M., Pionke, J. J. et al. (2017) Barriers to the Accessibility and Continuity of Health-Care Services in People with Multiple Sclerosis: A Literature Review. International journal of MS care 19(6): 313-321	- Systematic review used as source of primary studies
Christensen, M. E., Brincks, J., Schnieber, A. et al. (2016) The intention to exercise and the execution of exercise among persons with multiple sclerosis--a qualitative metasynthesis. Disability & Rehabilitation 38(11): 1023-33	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Chung-Yi, Chiu, Bezyak, Jill, Griffith, Desiree et al. (2016) Psychosocial Factors Influencing Lifestyle Physical Activity Engagement of African Americans with Multiple Sclerosis: A Qualitative Study. Journal of Rehabilitation 82(2): 25-30	- Themes not relevant to review
Clarke, Rosemary and Coote, Susan (2015) Perceptions of Participants in a Group, Community, Exercise Programme for People with Multiple Sclerosis. Rehabilitation Research & Practice 2015: 1-7	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Coenen, Michaela, Basedow-Rajwich, Birgit, Konig, Nicolaus et al. (2011) Functioning and disability in multiple sclerosis from the patient perspective. Chronic illness 7(4): 291-310	- Themes not relevant to review
Colombo, C., Mosconi, P., Confalonieri, P. et al. (2014) Web search behavior and information needs of people with multiple sclerosis: focus group study and analysis of online postings. Interactive Journal of Medical Research 3(3): e12	- Themes not relevant to review

Study	Code [Reason]
Conradsson, David, Ytterberg, Charlotte, Engelkes, Catharina et al. (2021) Activity limitations and participation restrictions in people with multiple sclerosis: a detailed 10-year perspective. Disability & Rehabilitation 43(3): 406-413	- Study design not relevant to this review protocol
Cook, Claire and Vuoskoski, Pirjo (2021) 'I just want someone to rub some life into them!': the lived experience of impaired sensation in the feet related to multiple sclerosis. British Journal of Neuroscience Nursing 17(Suppl 1): S48-S54	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Corry, M.; McKenna, M.; Duggan, M. (2011) The role of the clinical nurse specialist in MS: a literature review. British Journal of Nursing 20(2): 86-93	- Systematic review used as source of primary studies
Cowan, Christine K.; Pierson, Jane M.; Leggat, Sandra G. (2020) Psychosocial aspects of the lived experience of multiple sclerosis: personal perspectives. Disability & Rehabilitation 42(3): 349-359	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Crank, H., Carter, A., Humphreys, L. et al. (2017) Qualitative Investigation of Exercise Perceptions and Experiences in People With Multiple Sclerosis Before, During, and After Participation in a Personally Tailored Exercise Program. Archives of Physical Medicine & Rehabilitation 98(12): 2520-2525	- Themes not relevant to review
Davies, F., Edwards, A., Brain, K. et al. (2015) 'You are just left to get on with it': qualitative study of patient and carer experiences of the transition to secondary progressive multiple sclerosis. BMJ Open 5(7): e007674	- Themes not relevant to review
Davies, F., Wood, F., Brain, K. E. et al. (2016) The Transition to Secondary Progressive Multiple Sclerosis: An Exploratory Qualitative Study of Health Professionals' Experiences. International Journal of Ms Care 18(5): 257-264	- Themes not relevant to review

Study	Code [Reason]
de Ceuninck van Capelle, A.; Visser, L. H.; Vosman, F. (2016) Multiple sclerosis (MS) in the life cycle of the family: An interpretative phenomenological analysis of the perspective of persons with recently diagnosed MS. Families, Systems, & Health 34(4): 435-440	- Themes not relevant to review
Dehghani, A. PhD; Dehghan Nayeri, N. PhD; Ebadi, A. PhD (2017) Antecedents of Coping with the Disease in Patients with Multiple Sclerosis: A Qualitative Content Analysis. International Journal of Community Based Nursing & Midwifery 5(1): 49-60	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Dehghani, A.; Dehghan Nayeri, N.; Ebadi, A. (2018) Features of coping with disease in Iranian multiple sclerosis patients: a qualitative study. Journal of Caring Sciences 7(1): 35-40	- Themes not relevant to review
Dehghani, Ali; Khoramkish, Mahsa; Isfahani, Sara Shahsavari (2019) Challenges in the daily living activities of patients with multiple sclerosis: A qualitative content analysis. International Journal of Community Based Nursing & Midwifery 7(3): 201-210	- Themes not relevant to review
Demir, S., Tutuncu, M., Uzunkopru, C. et al. (2021) A comprehensive assessment of patient experience and disease-related awareness in multiple sclerosis: A questionnaire-based nation-wide survey in Turkey. Multiple Sclerosis and Related Disorders 52: 103005	- Study design not relevant to this review protocol
Demirtepe-Saygili, D. (2021) Multiple sclerosis experiences of couples: Examination of patient and partner perspectives. Journal of Health Psychology: 13591053211017192	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Dennett, R., Coulter, E., Paul, L. et al. (2020) A qualitative exploration of the participants' experience of a web-based physiotherapy program for	- Themes not relevant to review

Study	Code [Reason]
people with multiple sclerosis: Does it impact on the ability to increase and sustain engagement in physical activity?. Disability & Rehabilitation 42(21): 3007-3014	
Dennett, R., Hendrie, W., Jarrett, L. et al. (2020) "I'm in a very good frame of mind": a qualitative exploration of the experience of standing frame use in people with progressive multiple sclerosis. BMJ Open 10(10): e037680	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Dennison, L., McCloy Smith, E., Bradbury, K. et al. (2016) How Do People with Multiple Sclerosis Experience Prognostic Uncertainty and Prognosis Communication? A Qualitative Study. PLoS ONE 11(7): e0158982	- Themes not relevant to review
Dennison, Laura, Moss-Morris, Rona, Yardley, Lucy et al. (2013) Change and processes of change within interventions to promote adjustment to multiple sclerosis: learning from patient experiences. Psychology & Health 28(9): 973-92	- Themes not relevant to review
Dennison, Laura, Yardley, Lucy, Devereux, Angela et al. (2011) Experiences of adjusting to early stage multiple sclerosis. Journal of Health Psychology 16(3): 478-488	- Themes not relevant to review
Desborough, J., Brunoro, C., Parkinson, A. et al. (2020) 'It struck at the heart of who I thought I was': A meta-synthesis of the qualitative literature examining the experiences of people with multiple sclerosis. Health Expectations 23(5): 1007-1027	- Systematic review used as source of primary studies
Dewey, Ann; Rice-Oxley, Margaret; tean, Taraneh (2004) A qualitative study comparing the experiences of Tilt-in-space wheelchair use and conventional wheelchair use by clients severely disabled with multiple sclerosis. British Journal of Occupational Therapy 67(2): 65-74	- Themes not relevant to review

Study	Code [Reason]
Dibley, L., Coggrave, M., McClurg, D. et al. (2017) "It's just horrible": a qualitative study of patients' and carers' experiences of bowel dysfunction in multiple sclerosis. Journal of Neurology 264(7): 1354-1361	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Dlugonski, Deirdre; Joyce, Rachel Japp; Motl, Robert W. (2012) Meanings, motivations, and strategies for engaging in physical activity among women with multiple sclerosis. Disability and rehabilitation 34(25): 2148-57	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Donkers, Sarah J., Oosman, Sarah, Milosavljevic, Stephan et al. (2020) Addressing Physical Activity Behavior in Multiple Sclerosis Management: A Qualitative Account of Health Care Providers' Current Practices and Perspectives. International Journal of MS Care 22(4): 178-186	- Population not relevant to this review protocol
Downes, Colleen (2021) African Americans with multiple sclerosis: Perceptions of social work interventions. Dissertation Abstracts International	- Full text paper not available
Driedger, S. M., Maier, R., Marrie, R. A. et al. (2017) Caught in a no-win situation: Discussions about CCSVI between persons with multiple sclerosis and their neurologists - a qualitative study. BMC Neurology 17(1): 176	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
du Plooy, Daniel R. and Pretorius, Chrisma (2014) The caregiver experience: A South African perspective on caring for people with multiple sclerosis. Journal of Psychology in Africa 24(4): 361-369	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Ebrahimi, H., Hasankhani, H., Namdar, H. et al. (2017) Dealing with Chronic Illness: Experiences of Iranian Families of Persons with Multiple Sclerosis-A Qualitative Study. Multiple Sclerosis International 2017: 9243161	- Themes not relevant to review

Study	Code [Reason]
Edwards RG; Barlow JH; Turner AP (2008) Experiences of diagnosis and treatment among people with multiple sclerosis. Journal of evaluation in clinical practice 14(3): 460-464	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Egerod, I.; Wulff, K.; Petersen, M. C. (2018) Experiences and informational needs on sexual health in people with epilepsy or multiple sclerosis: A focus group investigation. Journal of Clinical Nursing 27(1314): 2868-2876	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Embrey N (2013) Exploring the lived experience of palliative care for people with MS, 2: Therapeutic interventions. British Journal of Neuroscience Nursing 5(7)	- Themes not relevant to review
Esmail, Shaniff, Huang, Jane, Lee, Isabel et al. (2010) Couple's experiences when men are diagnosed with multiple sclerosis in the context of their sexual relationship. Sexuality and Disability 28(1): 15-27	- Themes not relevant to review
Fakolade, A., Lamarre, J., Latimer-Cheung, A. et al. (2018) Understanding leisure-time physical activity: Voices of people with MS who have moderate-to-severe disability and their family caregivers. Health Expectations 21(1): 181-191	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Fallahi-Khoshknab, M., Ghafari, S., Nourozi, K. et al. (2014) Confronting the diagnosis of multiple sclerosis: a qualitative study of patient experiences. Journal of Nursing Research 22(4): 275-82	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Fasczewski, K. S., Garner, L. M., Clark, L. A. et al. (2020) Medical Therapeutic Yoga for multiple sclerosis: examining self-efficacy for physical activity, motivation for physical activity, and quality of life outcomes. Disability & Rehabilitation. DOI: 10.1080/09638288.2020.1760364	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Fasczewski, K. S.; Gill, D. L.; Rothberger, S. M. (2018) Physical activity motivation and benefits in people with multiple sclerosis. Disability & Rehabilitation 40(13): 1517-1523	- Themes not relevant to review
Fifolt, M., Richardson, E. V., Barstow, E. et al. (2020) Exercise behaviors of persons with multiple sclerosis through the stepwise implementation lens of social cognitive theory. Disability and rehabilitation 42(7): 948-956	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Finlayson, Marcia; Van Denend, Toni; DalMonte, Julie (2005) Older Adults' Perspectives on the Positive and Negative Aspects of Living with Multiple Sclerosis. British Journal of Occupational Therapy 68(3): 117-124	- Themes not relevant to review
Flensner, Gullvi and Rudolfsson, Gudrun (2016) Learning to fly with broken wings—Forcing a reappraisal of time and space. Scandinavian Journal of Caring Sciences 30(2): 403-410	- Themes not relevant to review
Forbes, A., While, A., Dyson, L. et al. (2003) Impact of clinical nurse specialists in multiple sclerosis--synthesis of the evidence. Journal of Advanced Nursing 42(5): 442-62	- Systematic review used as source of primary studies
Forbes, A., While, A., Mathes, L. et al. (2006) Evaluation of a MS Specialist Nurse Programme. International Journal of Nursing Studies 43(8): 985-1000	- Study design not relevant to this review protocol
Forsberg, A.; Nilsagard, Y.; Bostrom, K. (2015) Perceptions of using videogames in rehabilitation: a dual perspective of people with multiple sclerosis and physiotherapists. Disability & Rehabilitation 37(4): 338-44	- Themes not relevant to review

Study	Code [Reason]
Freeman, J., Gorst, T., Gunn, H. et al. (2020) "A non-person to the rest of the world": experiences of social isolation amongst severely impaired people with multiple sclerosis. Disability & Rehabilitation 42(16): 2295-2303	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Frost, J.; Grose, J.; Britten, N. (2017) A qualitative investigation of lay perspectives of diagnosis and self-management strategies employed by people with progressive multiple sclerosis. Health: an Interdisciplinary Journal for the Social Study of Health, Illness & Medicine 21(3): 316-336	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Gafari, S., Khoshknab, M. F., Nourozi, K. et al. (2017) Informal Caregivers' Experiences of Caring of Multiple Sclerosis Patients: A Qualitative Study. Iranian Journal of Nursing and Midwifery Research 22(3): 243-247	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Garabedian, M., Perrone, E., Pileggi, C. et al. (2020) Support Group Participation: Effect on Perceptions of Patients with Newly Diagnosed Multiple Sclerosis. International Journal of Ms Care 22(3): 115-121	- Themes not relevant to review
Gaskill, Aviva, Foley, Frederick W., Kolzet, Julie et al. (2011) Suicidal thinking in multiple sclerosis. Disability and Rehabilitation: An International, Multidisciplinary Journal 33(1718): 1528-1536	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Ghafari, S., Fallahi-Khoshknab, M., Norouzi, K. et al. (2014) Experiences of hospitalization in patients with multiple sclerosis: A qualitative study. Iranian Journal of Nursing and Midwifery Research 19(3): 255-61	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Ghafari, S., Fallahi-Khoshknab, M., Nourozi, K. et al. (2015) Patients' experiences of adapting to multiple sclerosis: a qualitative study. Contemporary Nurse 50(1): 36-49	- Themes not relevant to review

Study	Code [Reason]
Ghafari, Somayeh, Khoshknab, Masoud Fallahi, Norouzi, Kian et al. (2014) Spousal support as experienced by people with multiple sclerosis: a qualitative study. The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses 46(5): E15-24	- Themes not relevant to review
Ghahari, S., Forwell, S. J., Suto, M. J. et al. (2019) Multiple sclerosis self-management model: Personal and contextual requirements for successful self-management. Patient Education & Counseling 102(5): 1013-1020	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Ghasemi, Vida, Simbar, Masoumeh, Ozgoli, Giti et al. (2020) Sexual life under thesShadow of multiple sclerosis in women: A qualitative study in Iran. Sexuality & Disability 38(4): 715-730	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Giacobbi, Peter R., Jr., Dietrich, Frederick, Larson, Rebecca et al. (2012) Exercise and quality of life in women with multiple sclerosis. Adapted Physical Activity Quarterly 29(3): 224-242	- Themes not relevant to review
Gill, Laura and Hynes, Sinead M. (2021) Disclosing a diagnosis in the workplace: Perspective of people with multiple sclerosis. International Journal of Disability Management 15:E8	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Giovannetti, A. M., Brambilla, L., Torri Clerici, V. et al. (2017) Difficulties in adjustment to multiple sclerosis: vulnerability and unpredictability of illness in the foreground. Disability & Rehabilitation 39(9): 897-903	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Giovannetti, A. M., Pietrolongo, E., Borreani, C. et al. (2020) Conversion to secondary progressive multiple sclerosis: Multistakeholder experiences and needs in Italy. PLoS ONE 15(2): e0228587	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Giovannetti, A. M., Quintas, R., Tramacere, I. et al. (2020) A resilience group training program for people with multiple sclerosis: Results of a pilot single-blind randomized controlled trial and nested qualitative study. PLoS ONE 15(4): e0231380	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Gitto, L. (2019) Long term compliance for ms patients in treatment with disease modifying drugs (DMDs). Open Neurology Journal 13(1): 10-21	- Themes not relevant to review
Golla, Heidrun, Galushko, Maren, Pfaff, Holger et al. (2012) Unmet needs of severely affected multiple sclerosis patients: the health professionals' view. Palliative medicine 26(2): 139-51	- Population not relevant to this review protocol
Gottberg, K., Chruzander, C., Backenroth, G. et al. (2016) Individual face-to-face cognitive behavioural therapy in multiple sclerosis: A qualitative study. Journal of Clinical Psychology 72(7): 651-662	- Themes not relevant to review
Grose, J.; Freeman, J.; Skirton, H. (2012) Value of a confidant relationship in psychosocial care of people with multiple sclerosis. International Journal of Ms Care 14(3): 115-22	- Themes not relevant to review
Hakim, H.; Newland, P.; Oliver, B. J. (2020) Initial User Testing of Decision Aids for Multiple Sclerosis Disease-Modifying Therapies. Journal of Neuroscience Nursing 52(4): 160-165	- Full text paper not available
Hall-McMaster, S. M.; Treharne, G. J.; Smith, C. M. (2016) 'The positive feel': Unpacking the role of positive thinking in people with multiple sclerosis's thinking aloud about staying physically active. Journal of Health Psychology 21(12): 3026-3036	- Themes not relevant to review

Study	Code [Reason]
Hall-McMaster, Samuel M.; Treharne, Gareth J.; Smith, Catherine M. (2016) Positive thinking and physical activity motivation for one individual with multiple sclerosis: A qualitative case-study. New Zealand Journal of Physiotherapy 44(1): 26-32	- Themes not relevant to review
Halstead, Elizabeth J., Stanley, Justin, Fiore, Damian et al. (2021) Impact of Cognitive Impairment on Adults with Multiple Sclerosis and Their Family Caregivers...CMSC Annual Meeting; May 30-June 2, 2018; Nashville, Tennessee. International Journal of MS Care 23(3): 93-100	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Hamed, Razan; Tariah, Hashem Abu; Hawamdeh, Ziad M. (2012) Personal factors affecting the daily functioning and well-being of patients with multiple sclerosis using the international classification of functioning model: A qualitative study. International Journal of Mental Health 41(4): 47-61	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Harrison, A. M., Bogosian, A., Silber, E. et al. (2015) 'It feels like someone is hammering my feet': understanding pain and its management from the perspective of people with multiple sclerosis. Multiple Sclerosis 21(4): 466-76	- Themes not relevant to review
Haubrick, K. K., Gadbois, E. A., Campbell, S. E. et al. (2021) The Lived Experiences of Adults with Multiple Sclerosis. Rhode Island Medicine 104(6): 38-42	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Haynes-Lawrence, Darbi and West, Adam R. (2018) Managing fatigue in parents with multiple sclerosis. Journal of Child and Family Studies 27(5): 1640-1649	- Themes not relevant to review
Held Bradford, E., Finlayson, M., White Gorman, A. et al. (2018) Maximizing gait and balance: behaviors and decision-making processes of	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
persons with multiple sclerosis and physical therapists. Disability & Rehabilitation 40(9): 1014-1025	
Helland, C. B.; Holmoy, T.; Gulbrandsen, P. (2015) Barriers and facilitators related to rehabilitation stays in multiple sclerosis: A qualitative study. International Journal of MS Care 17(3): 122-9	- Themes not relevant to review
Hersche, R., Weise, A., Michel, G. et al. (2019) Development and preliminary evaluation of a 3-week inpatient energy management education program for people with multiple sclerosis-related fatigue. International Journal of MS Care 21(6): 265-274	- Themes not relevant to review
Hind, D., O'Cathain, A., Cooper, C. L. et al. (2010) The acceptability of computerised cognitive behavioural therapy for the treatment of depression in people with chronic physical disease: A qualitative study of people with multiple sclerosis. Psychology and Health 25(6): 699-712	- Themes not relevant to review
Homayuni, A., Abedini, S., Hosseini, Z. et al. (2021) Explaining the facilitators of quality of life in patients with multiple sclerosis: a qualitative study. BMC Neurology 21(1): 193	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Hundza, Sandra, Quartly, Caroline, Kim, Jasmine M. et al. (2016) Similar barriers and facilitators to physical activity across different clinical groups experiencing lower limb spasticity. Disability & Rehabilitation 38(14): 1370-1381	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Hunt, Laura; Nikopoulou-Smyrni, Panagiota; Reynolds, Frances (2014) "It gave me something big in my life to wonder and think about which took over the space … and not ms": Managing well-being in multiple sclerosis through art-making. Disability and Rehabilitation 36(14): 1139-1147	- Themes not relevant to review

Study	Code [Reason]
Hussain-Gambles, M. and Tovey, P. (2004) The experience of complementary alternative medicine use among people with multiple sclerosis. Complementary Health Practice Review 9(1): 21-30	- Themes not relevant to review
Hynes, S. M. and Forwell, S. (2019) A cognitive occupation-based programme for people with multiple sclerosis: A new occupational therapy cognitive rehabilitation intervention. Hong Kong Journal of Occupational Therapy 32(1): 41-52	- Themes not relevant to review
Jarrett, L., Hendrie, W., Dennett, R. et al. (2018) No title provided. Multiple Sclerosis Journal 24(2supplement): 952-953	- Conference abstract
Jellie, Bronwyn, Sweetland, Joanna, Riazi, Afsane et al. (2014) Staying at work and living with MS: a qualitative study of the impact of a vocational rehabilitation intervention. Disability and rehabilitation 36(19): 1594-9	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Johnson, K. L., Kuehn, C. M., Yorkston, K. M. et al. (2006) Patient perspectives on disease-modifying therapy in multiple sclerosis. International Journal of MS Care 8(1): 11-18	- Themes not relevant to review
Jonzon, Alison J. and Goodwin, Donna L. (2012) Daughters of mothers with multiple sclerosis: their experiences of play. Adapted Physical Activity Quarterly 29(3): 205-23	- Themes not relevant to review
Juaton, M. S., Cusack, L., Schultz, T. J. et al. (2019) Patients' perspectives on a changed model of care from out-patients to the home for the infusion of natalizumab. Multiple Sclerosis Journal 25(3): 471	- Themes not relevant to review

Study	Code [Reason]
Juaton, Mahasen (2019) Patients' experiences of natalizumab treatment in a home environment: a qualitative study. Australian Journal of Advanced Nursing 37(1): 14-20	- Themes not relevant to review
Kantor, D.; Bright, J. R.; Burtchell, J. (2018) Perspectives from the patient and the healthcare professional in multiple sclerosis: social media and participatory medicine. Neurology & Therapy 7(1): 37-49	- Themes not relevant to review
Kantor, D.; Bright, J. R.; Burtchell, J. (2018) Perspectives from the patient and the healthcare professional in multiple sclerosis: social media and patient education. Neurology & Therapy 7(1): 23-36	- Themes not relevant to review
Karnoe, Astrid, Pedersen, Lise M., Karlsen, Sashia et al. (2020) How people with multiple sclerosis experience the influence of nutrition and lifestyle factors on the disease. Disability & Rehabilitation 42(24): 3504-3515	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Kayes, Nicola M., McPherson, Kathryn M., Taylor, Denise et al. (2011) Facilitators and barriers to engagement in physical activity for people with multiple sclerosis: a qualitative investigation. Disability and Rehabilitation 33(8): 625-42	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Keramat Kar, M.; Whitehead, L.; Smith, C. M. (2019) Characteristics and correlates of coping with multiple sclerosis: a systematic review. Disability and Rehabilitation 41(3): 1-15	- Study design not relevant to this review protocol
Keramat Kar, M., Whitehead, L., Smith, C. M. et al. (2020) Anticipatory coping: how women deal with the hassles of living with multiple sclerosis. Disability & Rehabilitation. DOI: 10.1080/09638288.2020.1770872	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Kesgin, F., Suddick, K., Heesen, C. et al. (2019) Developing a fall prevention program: what are the views and opinions of people with multiple sclerosis? Disability & Rehabilitation. 43(8): 1065-1073	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Kettaneh, A. A. and Umeasiegbu, V. I. (2016) Specialized housing adaptation in multiple sclerosis: Relationships to demographic variables. Journal of Vocational Rehabilitation 44(2): 191-199	- Systematic review used as source of primary studies
Killner, Lauren and Soundy, Andrew (2018) Motivation and experiences of role transition in spousal caregivers of people with multiple sclerosis. International Journal of Therapy & Rehabilitation 25(8): 405-413	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Kim, S., Foley, F. W., Cavallo, M. et al. (2016) Growth and benefit finding post-trauma: A qualitative study of partners of individuals with multiple sclerosis. Archives of Physical Medicine and Rehabilitation 97(10): e28	- Themes not relevant to review
Kinnett-Hopkins, D., Learmonth, Y., Hubbard, E. et al. (2019) The interpretation of physical activity, exercise, and sedentary behaviours by persons with multiple sclerosis. Disability & Rehabilitation 41(2): 166-171	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Kirk, S. and Hinton, D. (2019) "I'm not what I used to be": A qualitative study exploring how young people experience being diagnosed with a chronic illness. Child: Care, Health & Development 45(2): 216-226	- Population not relevant to this review protocol
Kirk-Brown, A. K. and Van Dijk, P. A. (2014) An empowerment model of workplace support following disclosure, for people with MS. Multiple sclerosis (Houndmills, Basingstoke, England) 20(12): 1624-32	- Themes not relevant to review

Study	Code [Reason]
Klein, O. A., Drummond, A., Mhizha-Murira, J. R. et al. (2019) Effectiveness of cognitive rehabilitation for people with multiple sclerosis: a meta-synthesis of patient perspectives. Neuropsychological Rehabilitation 29(4): 491-512	- Themes not relevant to review
Knaster, E. S., Yorkston, K. M., Johnson, K. et al. (2011) Perspectives on self-management in multiple sclerosis: a focus group study. International Journal of Ms Care 13(3): 146-52	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Knox, K. B., Clay, L., Stuart-Kobitz, K. et al. (2020) Perspectives on walking from people with multiple sclerosis and reactions to video self-observation. Disability & Rehabilitation 42(2): 211-218	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Koutsogeorgou, E.; Chiesi, A. M.; Leonardi, M. (2020) Social capital components and social support of persons with multiple sclerosis: a systematic review of the literature from 2000 to 2018. Disability & Rehabilitation 42(24): 3437-3449	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Kuspinar, Ayse, Bouchard, Vanessa, Moriello, Carolina et al. (2016) Development of a Bilingual MS-Specific Health Classification System. International Journal of MS Care 18(2): 63-70	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Lacerda, E. M., McDermott, C., Kingdon, C. C. et al. (2019) Hope, disappointment and perseverance: Reflections of people with Myalgic encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Multiple Sclerosis participating in biomedical research. A qualitative focus group study. Health Expectations 22(3): 373-384	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Lahelle Af Pt, MSc PhD; Oberg Gk Pt, PhD; Normann B Pt, PhD (2020) Physiotherapy assessment of individuals with multiple sclerosis prior to a	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
group intervention - A qualitative observational and interview study. Physiotherapy Theory & Practice 36(3): 386-396	
Lahelle, A. F.; Oberg, G. K.; Normann, B. (2020) Group dynamics in a group-based, individualized physiotherapy intervention for people with multiple sclerosis: A qualitative study. Physiotherapy Research International 25(3): e1829	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Lahelle, Andreas Falck; Øberg, Gunn Kristin; Normann, Britt (2018) A group-based, individualized physiotherapy intervention for people with multiple sclerosis—A qualitative study. Physiotherapy Research International 23(4): e1734	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Larsen, J. L., Schafer, J., Nielsen, H. H. et al. (2020) Qualitative factors shaping MS patients' experiences of infusible disease-modifying drugs: a critical incident technique analysis. BMJ Open 10(8): e037701	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Learmonth, Y. C., Adamson, B. C., Balto, J. M. et al. (2018) Investigating the needs and wants of healthcare providers for promoting exercise in persons with multiple sclerosis: a qualitative study. Disability & Rehabilitation 40(18): 2172-2180	- Population not relevant to this review protocol
Learmonth, Y. C., Adamson, B. C., Balto, J. M. et al. (2017) Identifying preferred format and source of exercise information in persons with multiple sclerosis that can be delivered by health-care providers. Health Expectations 20(5): 1001-1010	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Learmonth, Y. C., Marshall-McKenna, R., Paul, L. et al. (2013) A qualitative exploration of the impact of a 12-week group exercise class for those	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
moderately affected with multiple sclerosis. Disability and rehabilitation 35(1): 81-8	
Learmonth, Y. C. and Motl, R. W. (2016) Physical activity and exercise training in multiple sclerosis: a review and content analysis of qualitative research identifying perceived determinants and consequences. Disability & Rehabilitation 38(13): 1227-42	- Systematic review used as source of primary studies
Learmonth, Yvonne C., Rice, Ian M., Ostler, Teresa et al. (2015) Perspectives on Physical Activity Among People with Multiple Sclerosis Who Are Wheelchair Users. International Journal of MS Care 17(3): 109-119	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Lee Mortensen, G. and Rasmussen, P. V. (2017) The impact of quality of life on treatment preferences in multiple sclerosis patients. Patient preference & adherence 11: 1789-1796	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Lee, E. J., Ditchman, N., Thomas, J. et al. (2019) Microaggressions experienced by people with multiple sclerosis in the workplace: An exploratory study using Sue's taxonomy. Rehabilitation Psychology 64(2): 179-193	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Lewis, S., Wray, S. E., Evans, E. et al. (2021) Patients' Experiences in Transitioning to Secondary Progressive Multiple Sclerosis: Qualitative Interviews. Neurology & Therapy DOI:10.1007/s40120-021-00265-0	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Lew-Starowicz, Michal and Rola, Rafal (2014) Sexual dysfunctions and sexual quality of life in men with multiple sclerosis. Journal of Sexual Medicine 11(5): 1294-1301	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Lex, H., Weisenbach, S., Sloane, J. et al. (2018) Social-emotional aspects of quality of life in multiple sclerosis. Psychology Health & Medicine 23(4): 411-423	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Lexell, Eva Månsson; Lund, Maria Larsson; Iwarsson, Susanne (2009) Constantly Changing Lives: Experiences of People With Multiple Sclerosis. American Journal of Occupational Therapy 63(6): 772-781	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Lohne, Vibeke, Aasgaard, Trygve, Caspari, Synnove et al. (2010) The lonely battle for dignity: individuals struggling with multiple sclerosis. Nursing ethics 17(3): 301-11	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Lynass, Rosemarie and Gillon, Ewan (2017) A thematic analysis of the experience of person-centred counselling for clients with multiple sclerosis: A pilot study. Counselling Psychology Review 32(4): 49-57	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Lynd, L. D., Henrich, N. J., Hategeka, C. et al. (2018) Perspectives of Patients with Multiple Sclerosis on Drug Treatment: A Qualitative Study. International Journal of Ms Care 20(6): 269-277	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Macdonald, K. C. (1998) Adaptation to physical disability: the experiences of five women aged fifty to sixty. PhD.	- Population not relevant to this review protocol
Maghsoodi, Soodeh and Mohammadi, Naima (2018) Qualitative analysis of the process of restoring social esteem by the women with multiple sclerosis. Quality & Quantity: International Journal of Methodology 52(6): 2557-2575	- Themes not relevant to review

Study	Code [Reason]
Malcomson KS; Lowe-Strong AS; Dunwoody L (2008) What can we learn from the personal insights of individuals living and coping with multiple sclerosis?. Disability and rehabilitation 30(9): 662-674	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Marin, C. E., Kfouri, P. P., Callegaro, D. et al. (2021) Patients and neurologists have different perceptions of multiple sclerosis symptoms, care and challenges. Multiple Sclerosis and Related Disorders 50: 102806	- Study design not relevant to this review protocol
Masoudi, R., Khayeri, F., Rabiei, L. et al. (2017) A study of stigma among Iranian family caregivers of patients with multiple sclerosis: A descriptive explorative qualitative study. Applied Nursing Research 34: 1-6	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Mattarozzi, K., Baldin, E., Zenesini, C. et al. (2017) Effect of organizational features on patient satisfaction with care in Italian multiple sclerosis centres. European Journal of Neurology 24(4): 631-637	- Study design not relevant to this review protocol
Matuska, K. M. and Erickson, B. (2008) Lifestyle balance: how it is described and experienced by women with multiple sclerosis. Journal of Occupational Science 15(1): 20-26	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Mazaheri, M.; Fanian, N.; Zargham-Boroujeni, A. (2011) Experiences of patients with multiple sclerosis from group counseling. Iranian Journal of Nursing and Midwifery Research 16(2): 181-90	- Themes not relevant to review
Mazanderani, F., Hughes, N., Hardy, C. et al. (2019) Health information work and the enactment of care in couples and families affected by Multiple Sclerosis. Sociology of Health & Illness 41(2): 395-410	- Themes not relevant to review

Study	Code [Reason]
McCabe, M., Ebacioni, K. J., Simmons, R. et al. (2015) Satisfaction with service needs among people living with multiple sclerosis. Neurorehabilitation 36(2): 167-73	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
McClurg, D., Beattie, K., Lowe-Strong, A. et al. (2012) The elephant in the room: the impact of bowel dysfunction on people with multiple sclerosis. Journal of the Association of Chartered Physiotherapists in Women's Health. 111: 13-21	- Themes not relevant to review
McGinnis, E., Andrea Nelson, E., Gorecki, C. et al. (2015) What is different for people with MS who have pressure ulcers: A reflective study of the impact upon people's quality of life?.Journal of Tissue Viability 24(3): 83-90	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Meade, Michelle, Rumrill, Phillip, Krause, James S. et al. (2016) Perceptions of quality of employment outcomes after multiple sclerosis: A qualitative study. Journal of Rehabilitation 82(2): 31-40	- Themes not relevant to review
Meehan, M. and Doody, O. (2020) The role of the clinical nurse specialist multiple sclerosis, the patients' and families' and carers' perspective: An integrative review. Multiple Sclerosis and Related Disorders 39: 101918	- Systematic review used as source of primary studies
Meek, C., Topcu, G., Moghaddam, N. et al. (2020) Experiences of adjustment to secondary progressive multiple sclerosis: a meta-ethnographic systematic review. Disability and Rehabilitation DOI: 10.1080/09638288.2020.1734105	- Systematic review used as source of primary studies
Meide, Hanneke van der, Gorp, Dennis van, van der Hiele, Karin et al. (2018) "Always looking for a new balance": toward an understanding of what it takes to continue working while being diagnosed with relapsing-remitting multiple sclerosis. Disability & Rehabilitation 40(21): 2545-2552	- Themes not relevant to review

Study	Code [Reason]
Merali, S., Cameron, J. I., Barclay, R. et al. (2020) Experiences of people with stroke and multiple sclerosis and caregivers of a community exercise programme involving a healthcare-recreation partnership. Disability & Rehabilitation 42(9): 1220-1226	- Population not relevant to this review protocol
Methley, A. M., Chew-Graham, C., Campbell, S. et al. (2015) Experiences of UK health-care services for people with Multiple Sclerosis: a systematic narrative review. Health Expectations 18(6): 1844-55	- Systematic review used as source of primary studies
Miller, C. E.; Karpinski, M.; Jezewski, M. A. (2012) Relapsing-remitting multiple sclerosis patients' experience with natalizumab: a phenomenological investigation. International Journal of Ms Care 14(1): 39-44	- Themes not relevant to review
Minden, S. L., Ding, L., Cleary, P. D. et al. (2013) Improving the quality of mental health care in multiple sclerosis. Journal of the neurological sciences 335(12): 42-7	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Moffat, Fiona and Paul, Lorna (2019) Barriers and solutions to participation in exercise for moderately disabled people with multiple sclerosis not currently exercising: A consensus development study using nominal group technique. Disability and Rehabilitation: An International, Multidisciplinary Journal 41(23): 2775-2783	- Themes not relevant to review
Moore, F. and Bahig, H. (2010) What influences patient's choice of disease-modifying medication for multiple sclerosis?. Canadian Journal of Neurological Sciences 37(3 Suppl 1): 56	- Full text paper not available
Moriya, Rika and Kutsumi, Masami (2010) Fatigue in Japanese people with multiple sclerosis. Nursing & health sciences 12(4): 421-8	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Moriya, Rika and Suzuki, Sumie (2011) A qualitative study relating to the experiences of people with MS: differences by disease severity. British Journal of Neuroscience Nursing 7(4): 593-600	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Morley, Alex, Tod, Angela, Cramp, Mary et al. (2013) The meaning of spasticity to people with multiple sclerosis: what can health professionals learn?. Disability and rehabilitation 35(15): 1284-92	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Mozo-Dutton, Louise; Simpson, Jane; Boot, Julia (2012) MS and me: exploring the impact of multiple sclerosis on perceptions of self. Disability and Rehabilitation 34(14): 1208-17	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Mulligan, H.; Wilkinson, A.; Snowdon, J. (2016) Perceived impact of a self-management program for fatigue in multiple sclerosis: A qualitative study. International Journal of MS Care 18(1): 27-32	- Themes not relevant to review
Mulligan, Hilda; Wilkinson, Amanda; Snowdon, Jessie (2016) Perceived Impact of a Self-Management Program for Fatigue in Multiple Sclerosis. International Journal of MS Care 18(1): 27-32	- Themes not relevant to review
Muston, Cath (2017) An exploratory study of psychodynamic therapists' working with people with multiple sclerosis. Psychodynamic Practice: Individuals, Groups and Organisations 23(2): 133-147	- Themes not relevant to review
Mutch, Kerry (2010) In sickness and in health: experience of caring for a spouse with MS. British journal of nursing (Mark Allen Publishing) 19(4): 214-9	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Mynors, G. (2016) Evaluating the role of the MS specialist nurse. British Journal of Nursing 25(3): 136	- Review article but not a systematic review
Neate, S. L., Taylor, K. L., Jelinek, G. A. et al. (2018) Psychological Shift in Partners of People with Multiple Sclerosis Who Undertake Lifestyle Modification: An Interpretive Phenomenological Study. Frontiers in Psychology 9: 15	- Themes not relevant to review
Neate, S. L., Taylor, K. L., Jelinek, G. A. et al. (2019) Taking active steps: Changes made by partners of people with multiple sclerosis who undertake lifestyle modification. PLoS ONE 14(2): e0212422	- Themes not relevant to review
Neate, S. L., Taylor, K. L., Jelinek, G. A. et al. (2019) On the path together: Experiences of partners of people with multiple sclerosis of the impact of lifestyle modification on their relationship. Health & Social Care in the Community 27(6): 1515-1524	- Themes not relevant to review
Neate, S. L., Taylor, K. L., Nag, N. et al. (2020) Views of the Future of Partners of People with Multiple Sclerosis Who Attended a Lifestyle Modification Workshop: A Qualitative Analysis of Perspectives and Experiences. International Journal of Environmental Research & Public Health 18(1): 24	- Themes not relevant to review
Newland, Pamela K., Flick, Louise H., Thomas, Florian P. et al. (2014) Identifying symptom co-occurrence in persons with multiple sclerosis. Clinical Nursing Research 23(5): 529-543	- Themes not relevant to review
Newland, Pamela K., Thomas, Florian P., Riley, Marguerite et al. (2012) The use of focus groups to characterize symptoms in persons with multiple	- Themes not relevant to review

Study	Code [Reason]
sclerosis. The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses 44(6): 351-7	
Newton, G.; Griffith, A.; Soundy, A. (2020) The experience of fatigue in neurological patients with multiple sclerosis: a thematic synthesis. Physiotherapy 107: 306-316	- Themes not relevant to review
Nilsagard, Y., Denison, E., Gunnarsson, L. G. et al. (2009) Factors perceived as being related to accidental falls by persons with multiple sclerosis. Disability and Rehabilitation 31(16): 1301-1310	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Noormohammadi, Mohammad Reza, Etemadifar, Shahram, Rabiei, Leili et al. (2019) Identification of concepts of spiritual care in Iranian peoples with multiple sclerosis: A qualitative study. Journal of Religion and Health 58(3): 949-964	- Themes not relevant to review
Normann, Britt, Sorgaard, Knut W., Salvesen, Rolf et al. (2013) Contextualized perceptions of movement as a source of expanded insight: People with multiple sclerosis' experience with physiotherapy. Physiotherapy theory and practice 29(1): 19-30	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Normann, Britt, Sorgaard, Knut W., Salvesen, Rolf et al. (2014) Clinical guidance of community physiotherapists regarding people with MS: professional development and continuity of care. Physiotherapy research international : the journal for researchers and clinicians in physical therapy 19(1): 25-33	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
O'Donnell, J. M., Jelinek, G. A., Gray, K. M. et al. (2020) Therapeutic utilization of meditation resources by people with multiple sclerosis: insights	- Themes not relevant to review

Study	Code [Reason]
from an online patient discussion forum. Informatics for Health & Social Care 45(4): 374-384	
O'Keeffe, S., Chowdhury, I., Sinanaj, A. et al. (2021) A service evaluation of the experiences of patients with functional neurological disorders within the NHS. Frontiers in Neurology 12: 656466	- Study design not relevant to this review protocol
O'Loughlin, E., Hourihan, S., Chataway, J. et al. (2017) The experience of transitioning from relapsing remitting to secondary progressive multiple sclerosis: views of patients and health professionals. Disability & Rehabilitation 39(18): 1821-1828	- Themes not relevant to review
Obiwuru, O., Joseph, S., Liu, L. et al. (2017) Perceptions of Multiple Sclerosis in Hispanic Americans: Need for Targeted Messaging. International Journal of MS Care 19(3): 131-139	- Themes not relevant to review
Olsson, Malin; Skär, Lisa; Söderberg, Siv (2010) Meanings of feeling well for women with multiple sclerosis. Qualitative Health Research 20(9): 1254-1261	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Osborne, Lisa A., Middleton, Rodden M., Jones, Kerina H. et al. (2013) Desirability and expectations of the UK MS Register: views of people with MS. International journal of medical informatics 82(11): 1104-10	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Ozen, S.; Karatas, T.; Polat, U. (2021) Perceived social support, mental health, and marital satisfaction in multiple sclerosis patients. Perspectives in Psychiatric Care DOI: 10.1111/ppc.12760	- Study design not relevant to this review protocol
Pakenham, Kenneth I. and Cox, Stephen (2012) The nature of caregiving in children of a parent with multiple sclerosis from multiple sources and the	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
associations between caregiving activities and youth adjustment overtime. Psychology & health 27(3): 324-46	
Pakenham, Kenneth I.; Tilling, Julia; Cretchley, Julia (2012) Parenting difficulties and resources: the perspectives of parents with multiple sclerosis and their partners. Rehabilitation psychology 57(1): 52-60	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Palacios-Cena, D., Ortiz-Gutierrez, R. M., Buesa-Estellez, A. et al. (2016) Multiple sclerosis patients' experiences in relation to the impact of the kinect virtual home-exRrcise programme: a qualitative study. European Journal of Physical & rehabilitation Medicine. 52(3): 347-55	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Papavassiliou-Alexiou, I. and Fotiadou, M. (2019) People with acquired physical disabilities in Greece in recession: How do they cope with issues of vocational (re-)integration?.Journal of Vocational Rehabilitation 50(2): 171-182	- Population not relevant to this review protocol
Parker, L. S., Topcu, G., De Boos, D. et al. (2020) The notion of "invisibility" in people's experiences of the symptoms of multiple sclerosis: a systematic meta-synthesis. Disability & Rehabilitation DOI: 10.1080/09638288.2020.1741698	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Parton, Chloe, Ussher, Jane M., Natoli, Simone et al. (2018) Being a mother with multiple sclerosis: Negotiating cultural ideals of mother and child. Feminism & Psychology 28(2): 212-230	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Pateman, K., Cockburn, N., Campbell, J. et al. (2017) How do Australians living with MS experience oral health and accessing dental care? A focus group study. Community Dentistry & Oral Epidemiology 45(1): 84-91	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Pebdani, Roxanna, Johnson, Kurt, Amtmann, Dagmar et al. (2015) Experiences and Perspectives of Pregnancy in Women with Multiple Sclerosis. Sexuality & Disability 33(1): 47-52	- Themes not relevant to review
Peters, Michele, Fitzpatrick, Ray, Doll, Helen et al. (2013) Patients' experiences of health and social care in long-term neurological conditions in England: a cross-sectional survey. Journal of health services research & policy 18(1): 28-33	- Study design not relevant to this review protocol
Peters, S.; Wilkinson, A.; Mulligan, H. (2019) Views of healthcare professionals on training for and delivery of a fatigue self-management program for persons with multiple sclerosis. Disability & Rehabilitation 41(23): 2792-2798	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Peterson, Elizabeth W., Kielhofner, Gary, Thom, Kerstin et al. (2010) Falls self-efficacy among adults with multiple sclerosis: A phenomenological study. OTJR: Occupation, Participation and Health 30(4): 148-157	- Themes not relevant to review
Petrin, J., Akbar, N., Turpin, K. et al. (2018) The Experience of Persons With Multiple Sclerosis Using MS INFoRm: An Interactive Fatigue Management Resource. Qualitative Health Research 28(5): 778-788	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Ploughman, M., Austin, M. W., Murdoch, M. et al. (2012) The path to self-management: a qualitative study involving older people with multiple sclerosis. Physiotherapy Canada 64(1): 6-17	- Themes not relevant to review
Ploughman, M., Harris, C., Hogan, S. H. et al. (2014) Navigating the "liberation procedure": A qualitative study of motivating and hesitating factors among people with multiple sclerosis. Patient Preference and Adherence 8: 1205-1213	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Ploughman, Michelle, Austin, Mark W., Murdoch, Michelle et al. (2012) Factors influencing healthy aging with multiple sclerosis: a qualitative study. Disability and rehabilitation 34(1): 26-33	- Full text paper not available
Plow, Matthew A. and Golding, Meghan (2016) A Qualitative Study of Multiple Health Behaviors in Adults with Multiple Sclerosis. International Journal of MS Care 18(5): 248-256	- Themes not relevant to review
Plow, Matthew, Bethoux, Francois, Mai, Kimloan et al. (2014) A formative evaluation of customized pamphlets to promote physical activity and symptom self-management in women with multiple sclerosis. Health Education Research 29(5): 883-896	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Plow, Matthew and Finlayson, Marcia (2012) A qualitative study of nutritional behaviors in adults with multiple sclerosis. The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses 44(6): 337-50	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Plow, Matthew and Finlayson, Marcia (2014) A qualitative study exploring the usability of Nintendo Wii Fit among persons with multiple sclerosis. Occupational Therapy International 21(1): 21-32	- Themes not relevant to review
Ponzio, M., Tacchino, A., Vaccaro, C. et al. (2019) Disparity between perceived needs and service provision: a cross-sectional study of Italians with multiple sclerosis. Neurological Sciences 40(6): 1137-1144	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Preissner, K.; Finlayson, M.; Henkel, C. (2012) Recruiting for caregiver education research: perspectives of caregivers of people with multiple sclerosis. International Journal of Ms Care 14(4): 188-96	- Themes not relevant to review

Study	Code [Reason]
Preissner, Katharine (2016) Multiple Sclerosis Fatigue and Identity. American Journal of Occupational Therapy 70(4 Suppl 1): 7011505127p1	- Themes not relevant to review
Preston, Jenny; Ballinger, Claire; Gallagher, Helen (2014) Understanding the lived experience of people with multiple sclerosis and dysexecutive syndrome. British Journal of Occupational Therapy 77(10): 484-490	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Preston, Jenny; Haslam, Simon; Lamont, Lynn (2012) What do people with multiple sclerosis want from an occupational therapy service? British Journal of Occupational Therapy 75(6): 264-270	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Pretorius, Chrisma and Joubert, Ninon (2014) The experiences of individuals with Multiple Sclerosis in the Western Cape, South Africa. Health SA Gesondheid 19(1): 1-12	- Themes not relevant to review
Pust, Gesa E. A., Untiedt, Benthe, Randerath, Jennifer et al. (2020) Exploring adherence to first-line and second-line immunotherapies in multiple sclerosis: An interview study. International Journal of MS Care 22(5): 219-225	- Themes not relevant to review
Quinn, A. A.; Barton, J. A.; Magilvy, J. K. (1995) Weathering the storm: metaphors and stories of living with multiple sclerosis. Rehabilitation Nursing Research 4(1): 19-27	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Rabiei, L., Abedi, H., Abedi, P. et al. (2017) Perspectives and Experiences Related to Help-Seeking Behaviors: A Content Analysis Study of Iranian Patients With Multiple Sclerosis. Journal of Nursing Research 25(3): 251-259	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Rahn, A., Fuest, F., Kopke, S. et al. (2015) Comprehension of confidence intervals in patient information materials: Development and evaluation of patient information for people with multiple sclerosis. Multiple Sclerosis 21(4): 515	- Themes not relevant to review
Ravyn, D.; Goodwin, B.; Lowney, R. (2019) Continuous learning in multiple sclerosis care: a qualitative study of the expanded learning model for systems. International Journal of Medical Education 10: 122-128	- Themes not relevant to review
Reade, Jackie Williams, White, Mark B., White, Carmel Parker et al. (2012) What would you say? Expressing the difficulties of living with multiple sclerosis. The Journal of Neuroscience Nursing 44(1): 54-63	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Reed, Karla S., Meade, Michelle, Jarnecke, Melinda et al. (2017) Disclosing disability in the employment setting: Perspectives from workers with multiple sclerosis. Journal of Vocational Rehabilitation 47(2): 175-184	- Full text paper not available
Reen, G. K.; Silber, E.; Langdon, D. W. (2017) Multiple sclerosis patients' understanding and preferences for risks and benefits of disease-modifying drugs: A systematic review. Journal of the Neurological Sciences 375: 107-122	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Reen, Gurpreet K.; Silber, Eli; Langdon, Dawn W. (2017) Interventions to support risk and benefit understanding of disease-modifying drugs in multiple sclerosis patients: A systematic review. Patient Education and Counseling 100(6): 1031-1048	- Study design not relevant to this review protocol
Renfrew, Linda, Flowers, Paul, Lord, Anna C. et al. (2020) An exploration of the experiences and utility of functional electrical stimulation for foot drop in people with multiple sclerosis. Disability & Rehabilitation 42(4): 510-518	- Themes not relevant to review

Study	Code [Reason]
Riazi, Afsane; Bradshaw, Siobhan A.; Playford, E. Diane (2012) Quality of life in the care home: a qualitative study of the perspectives of residents with multiple sclerosis. Disability and rehabilitation 34(24): 2095-102	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Richardson, Emma V., Blaylock, Sarah, Barstow, Elizabeth et al. (2019) Evaluation of a conceptual model to guide health care providers in promoting exercise among persons with multiple sclerosis. Adapted Physical Activity Quarterly 36(1): 109-131	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Riemann-Lorenz, K., Wienert, J., Streber, R. et al. (2020) Long-term physical activity in people with multiple sclerosis: exploring expert views on facilitators and barriers. Disability & Rehabilitation 42(21): 3059-3071	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Robles-Sanchez, M. A., Cruz-Diaz, V., Amil-Bujan, P. et al. (2020) An expert patient program as a tool to empower people with multiple sclerosis. Journal of Neuroscience Nursing 52(4): 166-171	- Full text paper not available
Roessler, Richard T., Bishop, Malachy, Rumrill, Phillip D. et al. (2013) Specialized housing and transportation needs of adults with multiple sclerosis. Work 45(2): 223-35	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Roessler, Richard T.; Rumrill, Phillip D.; Timblin, Rachel I. (2017) Focus group perspectives on high-priority employment barriers facing Americans with multiple sclerosis. Journal of Vocational Rehabilitation 47(2): 223-233	- Full text paper not available
Rollero, C. (2016) The experience of men caring for a partner with multiple sclerosis. Journal of Nursing Scholarship 48(5): 482-9	- Themes not relevant to review

Study	Code [Reason]
Roubinov, Danielle S.; Turner, Aaron P.; Williams, Rhonda M. (2015) Coping among individuals with multiple sclerosis: Evaluating a goodness-of-fit model. Rehabilitation Psychology 60(2): 162-168	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Russell, R. D.; Black, L. J.; Begley, A. (2020) The unresolved role of the neurologist in providing dietary advice to people with multiple sclerosis. Multiple Sclerosis and Related Disorders 44: 102304	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Russell, R. D.; Black, L. J.; Begley, A. (2021) Navigating dietary advice for multiple sclerosis. Health Expectations 24(3): 853-862	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Russell, R. D., Black, L. J., Sherriff, J. L. et al. (2019) Dietary responses to a multiple sclerosis diagnosis: a qualitative study. European Journal of Clinical Nutrition 73(4): 601-608	- Themes not relevant to review
Salamonsen, A. (2015) Mind the gap! Lay and medical perceptions of risks associated with the use of alternative treatment and conventional medicine. Forschende Komplementarmedizin (2006) 22(1): 24-9	- Themes not relevant to review
Salamonsen, A., Launso, L., Kruse, T. E. et al. (2010) Understanding unexpected courses of multiple sclerosis among patients using complementary and alternative medicine: A travel from recipient to explorer. International Journal of Qualitative Studies on Health and Well being 5(2): DOI: 10.3402/qhw.v5i2.5032	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Salminen, Anna-Liisa; Kanelisto, Katja J.; Karhula, Maarit E. (2014) What components of rehabilitation are helpful from the perspective of individuals with multiple sclerosis?.Disability and rehabilitation 36(23): 1983-9	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Saverino, Alessia and Solaro, Claudio (2012) Pain in individuals with multiple sclerosis, knee prosthesis, and post-herpetic neuralgia: learning from focus group patients' experience. The Clinical Journal of Pain 28(4): 300-8	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Schlegel, V. and Leray, E. (2018) From Medical Prescription to Patient Compliance: A Qualitative Insight into the Neurologist-Patient Relationship in Multiple Sclerosis. International Journal of MS Care 20(6): 279-286	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Shapiro, J.; Wiglesworth, A.; Morrison, E. H. (2013) Views on disclosing mistreatment: A focus group study of differences between people with MS and their caregivers. Multiple Sclerosis and Related Disorders 2(2): 96-102	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Sharifi, M.; Neshat Doost, H. T.; Shayegannejad, V. (2020) 'I want to be with you, but I have MS': Challenges of interpersonal relationships from the MS patients' point of view. Health & Social Care in the Community 28(3): 1030-1037	- Themes not relevant to review
Sharifi, S.; Borhani, F.; Abbaszadeh, A. (2016) Factors affecting dignity of patients with multiple sclerosis. Scandinavian Journal of Caring Sciences 30(4): 731-740	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Shavazi, M. A., Morowatisharifabad, M. A., Shavazi, M. T. et al. (2016) Online Social Support for Patients with Multiple Sclerosis: A Thematic Analysis of Messages Posted to a Virtual Support Community. International Journal of Community Based Nursing & Midwifery 4(3): 188-98	- Themes not relevant to review
Shevil, Eynat and Finlayson, Marcia (2009) Process evaluation of a self-management cognitive program for persons with multiple sclerosis. Patient Education and Counseling 76(1): 77-83	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Sillence, E., Hardy, C., Briggs, P. et al. (2016) How do carers of people with multiple sclerosis engage with websites containing the personal experiences of other carers and patients? Health Informatics Journal 22(4): 1045-1054	- Themes not relevant to review
Silveira, S. L.; Richardson, E. V.; Motl, R. W. (2019) Informing the design of exercise programs for persons with multiple sclerosis who use wheelchairs: a qualitative inquiry of perceived components. Disability & Rehabilitation 43(13): 1838-1848	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Silveira, Stephanie L.; Richardson, Emma V.; Motl, Robert W. (2020) Social cognitive theory as a guide for exercise engagement in persons with multiple sclerosis who use wheelchairs for mobility. Health Education Research 35(4): 270-282	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Silverman, Arielle M., Verrall, Aimee M., Alschuler, Kevin N. et al. (2017) Bouncing back again, and again: a qualitative study of resilience in people with multiple sclerosis. Disability & Rehabilitation 39(1): 14-22	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Simblett, S. K., Evans, J., Greer, B. et al. (2019) Engaging across dimensions of diversity: A cross-national perspective on mHealth tools for managing relapsing remitting and progressive multiple sclerosis. Multiple Sclerosis and Related Disorders 32: 123-132	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Simpson, Robert, Simpson, Sharon, Wood, Karen et al. (2019) Using normalisation process theory to understand barriers and facilitators to implementing mindfulness-based stress reduction for people with multiple sclerosis. Chronic Illness 15(4): 306-318	- Themes not relevant to review

Study	Code [Reason]
Skar, Anne Britt Rundhovde, Folkestad, Helge, Smedal, Tori et al. (2014) "I refer to them as my colleagues": the experience of mutual recognition of self, identity and empowerment in multiple sclerosis. Disability and rehabilitation 36(8): 672-7	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Skovgaard, L. (2016) Use and users of complementary and alternative medicine among people with multiple sclerosis in Denmark. Danish Medical Journal 63(1): b5159	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Skovgaard, L. (2016) Use and users of complementary and alternative medicine among people with multiple sclerosis in Denmark - A sequential mixed methods study. Danish Medical Journal 63(1): 1-28	- Duplicate reference
Skovgaard, L.; Pedersen, I. K.; Verhoef, M. (2014) Exclusive use of alternative medicine as a positive choice: a qualitative study of treatment assumptions among people with multiple sclerosis in Denmark. International Journal of MS Care 16(3): 124-31	- Duplicate reference
Skovgaard, Lasse; Kryger Pedersen, Inge; Verhoef, Marja (2014) Exclusive Use of Alternative Medicine as a Positive Choice. International Journal of MS Care 16: 124-131	- Themes not relevant to review
Skovgaard, Lasse, Launso, Laila, Pedersen, Inge Kryger et al. (2011) Combination treatment of people with multiple sclerosis based on collaboration between conventional healthcare providers and alternative practitioners--patient perspectives on outcomes. Journal of Complementary & Integrative Medicine 8: DOI: 10.2202/1553-3840.1409	- Duplicate reference
Skovgaard, Lasse; Pedersen, Inge Kryger; Verhoef, Marja (2014) Use of bodily sensations as a risk assessment tool: exploring people with Multiple	- Themes not relevant to review

Study	Code [Reason]
Sclerosis' views on risks of negative interactions between herbal medicine and conventional drug therapies. BMC Complementary and Alternative Medicine 14: 59	
Slade, A.; Tennant, A.; Ford, H. (2003) Meeting the information needs of people with multiple sclerosis...including commentary by Scullion P and Mott S. International Journal of Therapy & Rehabilitation 10(5): 211-217	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Smith, Catherine M.; Fitzgerald, H. Jane M.; Whitehead, Lisa (2015) How fatigue influences exercise participation in men with multiple sclerosis. Qualitative Health Research 25(2): 179-188	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Smith, Catherine M., Hale, Leigh A., Mulligan, Hilda F. et al. (2013) Participant perceptions of a novel physiotherapy approach ("Blue Prescription") for increasing levels of physical activity in people with multiple sclerosis: a qualitative study following intervention. Disability and Rehabilitation 35(14): 1174-81	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Smith, Catherine, Olson, Karin, Hale, Leigh Anne et al. (2011) How does fatigue influence community-based exercise participation in people with multiple sclerosis? Disability and Rehabilitation 33(2324): 2362-71	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Smith, L., Elwick, H., Mhizha-Murira, J. R. et al. (2021) Developing a clinical pathway to identify and manage cognitive problems in multiple sclerosis: Qualitative findings from patients, family members, charity volunteers, clinicians and healthcare commissioners. Multiple Sclerosis and Related Disorders 49: 102563	- Themes not relevant to review

Study	Code [Reason]
Smith, M., Neibling, B., Williams, G. et al. (2019) A qualitative study of active participation in sport and exercise for individuals with multiple sclerosis. Physiotherapy Research International 24(3): e1776	- Themes not relevant to review
Snyder, Jeremy, Adams, Krystyna, Crooks, Valorie A. et al. (2014) "I knew what was going to happen if I did nothing and so I was going to do something": faith, hope, and trust in the decisions of Canadians with multiple sclerosis to seek unproven interventions abroad. BMC Health Services Research 14: 445	- Themes not relevant to review
Solheim, A. M.; Mygland, A.; Ljostad, U. (2017) Quality of multiple sclerosis out-patient health care services with focus on patient reported experiences. BMC Research Notes 10(1): 250	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Somerset, M., Campbell, R., Sharp, D. J. et al. (2001) What do people with MS want and expect from health-care services? Health Expect 4(1): 29-37	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Soundy, Andy, Benson, James, Dawes, Helen et al. (2012) Understanding hope in patients with multiple sclerosis. Physiotherapy 98(4): 344-50	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Spessotto, C. V., Cavalli, H., Eboni, A. C. et al. (2016) Patients' satisfaction with and views about treatment with disease-modifying drugs in multiple sclerosis. Arquivos de Neuro-Psiquiatria 74(8): 617-20	- Themes not relevant to review
Squires, L. A.; Williams, N.; Morrison, V. L. (2019) Matching and accepting assistive technology in multiple sclerosis: A focus group study with people with multiple sclerosis, carers and occupational therapists. Journal of Health Psychology 24(4): 480-494	- Themes not relevant to review

Study	Code [Reason]
Starks, Helene, Morris, Megan A., Yorkston, Kathryn M. et al. (2010) Being in- or out-of-sync: Couples' adaptation to change in multiple sclerosis. Disability and Rehabilitation: An International, Multidisciplinary Journal 32(3): 196-206	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Steadman, J. and Pretorius, C. (2014) The impact of an online Facebook support group for people with multiple sclerosis on non-active users. African Journal of Disability 3(1): 132	- Themes not relevant to review
Stennett, Andrea; De Souza, Lorraine; Norris, Meriel (2020) The meaning of exercise and physical activity in community dwelling people with multiple sclerosis. Disability & Rehabilitation 42(3): 317-323	- Themes not relevant to review
Stennett, Andrea; De Souza, Lorraine; Norris, Meriel (2020) A qualitative exploration of physiotherapists' perceptions about exercise and physical activity: reflections on the results from a Delphi Study. Disability & Rehabilitation 42(22): 3142-3151	- Themes not relevant to review
Stern, Brocha Z. and Goverover, Yael (2018) Everyday technology use for men with multiple sclerosis: An occupational perspective. British Journal of Occupational Therapy 81(12): 709-716	- Themes not relevant to review
Strickland, K.; Worth, A.; Kennedy, C. (2017) The liminal self in people with multiple sclerosis: an interpretative phenomenological exploration of being diagnosed. Journal of Clinical Nursing 26(1112): 1714-1724	- Themes not relevant to review
Strickland, K.; Worth, A.; Kennedy, C. (2015) The experiences of support persons of people newly diagnosed with multiple sclerosis: an interpretative phenomenological study. Journal of Advanced Nursing 71(12): 2811-21	- Themes not relevant to review

Study	Code [Reason]
Swinnen, E., Deliens, T., Dewulf, E. et al. (2018) What is the opinion of patients with multiple sclerosis and their healthcare professionals about lower limb orthoses? A qualitative study using focus group discussions. Neurorehabilitation 42(1): 81-92	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Synnot, A. J., Hill, S. J., Garner, K. A. et al. (2016) Online health information seeking: how people with multiple sclerosis find, assess and integrate treatment information to manage their health. Health Expectations 19(3): 727-37	- Themes not relevant to review
Synnot, Anneliese, Hill, Sophie, Summers, Michael et al. (2014) Comparing face-to-face and online qualitative research with people with multiple sclerosis. Qualitative Health Research 24(3): 431-438	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Tabassum, Kinza, Fox, Jackie, Fuller, Sara et al. (2021) Dating with a diagnosis: The lived experience of people with multiple sclerosis. Sexuality and Disability. DOI: 10.1007/s11195-021-09698-9	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Tabuteau-Harrison, S. L.; Haslam, C.; Mewse, A. J. (2016) Adjusting to living with multiple sclerosis: The role of social groups. Neuropsychological Rehabilitation 26(1): 36-59	- Themes not relevant to review
Takalu, Mohammad Taghi Mohseni, Hosseini, Seyed Ali, Khankeh, Hamid Reza et al. (2020) How primary caregivers of individuals with multiple sclerosis cope with social isolation: a grounded theory study in an Iranian context. International Journal of Therapy & Rehabilitation 27(6): 1-13	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Tehranineshat, B., Yektstalab, S., Momennasab, M. et al. (2020) The experiences of multiple Sclerosis patients' family caregivers at the first	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
hospitalization of their patients: A qualitative study. Patient Preference & Adherence 14: 1159-1172	
Thompson, Laura, Ford, Helen, Stroud, Amanda et al. (2019) Tortoise or hare? Supporting the chronotope preference of employees with fluctuating chronic illness symptoms. Psychology & Health 34(6): 695-714	- Population not relevant to this review protocol
Thomson, A.; Rivas, C.; Giovannoni, G. (2015) Multiple sclerosis outpatient future groups: improving the quality of participant interaction and ideation tools within service improvement activities. BMC Health Services Research 15: 105	- Themes not relevant to review
Todd, Ana and Stuifbergen, Alexa (2011) Barriers and facilitators related to breast cancer screening: A qualitative study of women with multiple sclerosis. International Journal of MS Care 13(2): 49-56	- Themes not relevant to review
Topcu, G., Buchanan, H., Aubeeluck, A. et al. (2016) Caregiving in multiple sclerosis and quality of life: A meta-synthesis of qualitative research. Psychology & Health 31(6): 693-710	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Topcu, G., Buchanan, H., Aubeeluck, A. et al. (2021) Informal carers' experiences of caring for someone with multiple sclerosis: A photovoice investigation. British Journal of Health Psychology 26(2): 360-384	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Turpin, Merrill, Kerr, Georgina, Gullo, Hannah et al. (2018) Understanding and living with multiple sclerosis fatigue. British Journal of Occupational Therapy 81(2): 82-89	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Twomey, Frances and Robinson, Katie (2010) Pilot study of participating in a fatigue management programme for clients with multiple sclerosis. Disability and rehabilitation 32(10): 791-800	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Uccelli, Michele Messmer (2014) The impact of multiple sclerosis on family members: a review of the literature. Neurodegenerative Disease Management 4(2): 177-85	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Ulas-Kilic, Ozlem and Aktas, Emine Feyza (2021) Perceptions of individuals with multiple sclerosis about their career and illness: The case of Turkey. Rehabilitation Counseling Bulletin 64(4): 248-260	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
van der Smissen, D., Rietjens, J. A. C., van Gemert-Pijnen, L. et al. (2021) Information needs of patients with chronic diseases and their relatives for web-based advance care planning: a qualitative interview study. BMC Palliative Care 20(1): 77	- Population not relevant to this review protocol
Van Reenen, E., Van Der Borg, W., Visse, M. et al. (2019) Fear, fight, familiarize: the experiences of people living with relapsing-remitting multiple sclerosis and taking oral medication. International Journal of Qualitative Studies on Health and Well-being 14(1): 1648946	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
VanRuymbeke, B. and Schneider, M. A. (2013) The perceived influence of a targeted group exercise program on the well-being of women living with multiple sclerosis: A qualitative study. Critical Reviews in Physical and Rehabilitation Medicine 25(12): 23-43	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Vasileiou, Konstantina, Barnett, Julie, Barreto, Manuela et al. (2017) Experiences of loneliness associated with being an informal caregiver: A qualitative investigation. Frontiers in Psychology 8: 11	- Population not relevant to this review protocol

Study	Code [Reason]
Vickers, Margaret H. (2012) “For the crime of being different…”: Multiple sclerosis, teams, and stigmatisation at work—lessons from a case study. Employee Responsibilities and Rights Journal 24(3): 177-195	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Vickers, Margaret H. (2014) Disability and dirty workers: Stories of physical, social and moral taint. Disability & Society 29(9): 1356-1368	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Vickers, Margaret H. (2017) Dark secrets and impression management: Workplace masks of people with multiple sclerosis (MS). Employee Responsibilities and Rights Journal 29(4): 175-195	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Vijayasingham, Lavanya; Jogulu, Uma; Allotey, Pascale (2020) Chronic illness and sustainable careers: How individuals with multiple sclerosis negotiate work transitions in a middle-income country. Social Science & Medicine 245: 112699	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Visser, L. A.; De Mul, M.; Redekop, W. K. (202p) Innovative medical technology and the treatment decision-making Process in multiple sclerosis: A focus group study to examine patient perspectives. Patient Preference & Adherence 15: 927-937	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Visser, L. A., Louapre, C., Uyl-de Groot, C. A. et al. (2020) Patient needs and preferences in relapsing-remitting multiple sclerosis: A systematic review. Multiple sclerosis and related disorders 39: 101929	- Systematic review used as source of primary studies
W.H., Smithson; D., Hukins; Jones, L. (2006) How general practice can help improve care of people with neurological conditions: a qualitative study. Primary Health Care Research & Development 7(3): 201-210	- Population not relevant to this review protocol

Study	Code [Reason]
Wawrziczny, Emilie; Corrairie, Aubane; Antoine, Pascal (2021) Relapsing-remitting multiple sclerosis: An interpretative phenomenological analysis of dyadic dynamics. Disability and Rehabilitation 43(1): 76-84	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Webb, E. J. D., Meads, D., Eskyte, I. et al. (2020) The impact of reproductive issues on preferences of women with relapsing multiple sclerosis for disease-modifying treatments. Patient 13(5): 583-597	- Study design not relevant to this review protocol
Wendebourg, M. J., Feddersen, L. K., Lau, S. et al. (2016) Development and feasibility of an evidence-based patient education program for managing fatigue in multiple sclerosis: The "Fatigue Management in MS" Program (FatiMa). International Journal of Ms Care 18(3): 129-37	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Wendrich, K., van Oirschot, P., Martens, M. B. et al. (2019) Toward digital self-monitoring of multiple sclerosis: Investigating first experiences, needs, and wishes of people with MS. International Journal of MS Care 21(6): 282-291	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Wilhite, B., Keller, M. J., Hodges, J. S. et al. (2004) Enhancing human development and optimizing health and well-being in persons with multiple sclerosis. Therapeutic Recreation Journal 38(2): 167-187	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Wilkinson, Hannah Rose and das Nair, Roshan (2013) The psychological impact of the unpredictability of multiple sclerosis: a qualitative literature meta-synthesis. British Journal of Neuroscience Nursing 9(4): 172-178	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Willson, Catherine Louise, Tetley, Josie, Lloyd, Cathy et al. (2018) The impact of multiple sclerosis on the identity of mothers in Italy. Disability & Rehabilitation 40(12): 1456-1467	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Wingfield, N. P. (1997) Midlife development and disability onset in a family context: A qualitative integration. PhD.	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Wood, V. and Kasser, S. L. (2020) Spousal support and self-determined physical activity in individuals with multiple sclerosis: A theory-informed qualitative exploration. Disability & Health Journal 13(1): 100835	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Wright-St Clair, V. (2003) Storymaking and storytelling: making sense of living with multiple sclerosis. Journal of Occupational Science 10(1): 46-51	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Yazdannik, A., Abolhassani, S., Taleghani, F. et al. (2015) The challenges of healthcare delivery to people with multiple sclerosis in Iran. Journal of Education & Health Promotion 4: 83	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Yorkston, Kathryn M.; Klasner, Estelle R.; Swanson, Kristen M. (2001) Communication in context: a qualitative study of the experiences in individuals with multiple sclerosis. American Journal of Speech-Language Pathology 10(2): 126-137	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Ytterberg, C., Chruzander, C., Backenroth, G. et al. (2017) A qualitative study of cognitive behavioural therapy in multiple sclerosis: experiences of psychotherapists. International journal of qualitative studies on health and well-being 12(1): 1325673	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Ytterberg, C., Johansson, S., Gottberg, K. et al. (2008) Perceived needs and satisfaction with care in people with multiple sclerosis: a two-year prospective study. BMC Neurol 8: 36	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Study	Code [Reason]
Yılmaz, Sema D., Gumus, Haluk, Odabas, Faruk O. et al. (2017) Sexual life of women with multiple sclerosis: A qualitative study. International Journal of Sexual Health 29(2): 147-154	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Ziemssen, T., Tolley, C., Bennett, B. et al. (2020) A mixed methods approach towards understanding key disease characteristics associated with the progression from RRMS to SPMS: Physicians' and patients' views. Multiple Sclerosis and Related Disorders 38: 101861	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population
Žiaková, Katarína, Čáp, Juraj, Miertová, Michaela et al. (2020) An interpretative phenomenological analysis of dignity in people with multiple sclerosis. Nursing Ethics 27(3): 686-700	- Does not cover one of the specific population subgroups focused on in protocol or report on coordination of care in general MS population

Appendix F – GRADE CERQual tables

Pregnancy and future pregnancy

Table 6: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Content of information – possible effect of MS on pregnancy and becoming a parent					

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
6 studies[5, 12, 21, 24, 31, 37]	Interviews (n=6)	Concerns about the effect of MS on a pregnancy were commonly raised and included the effect the condition itself and any treatments associated with it might negatively affect a pregnancy. The risk of passing on MS to a child and the impact on labour and delivery options and the ability to breastfeed were also frequently mentioned.	Limitations	Moderate concerns about methodological limitations[a]	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	
Content of information – possible effect of pregnancy on MS					
7studies[5, 12, 21, 23, 24, 31, 37]	Interviews (n=7)	Participants were concerned about the effect of discontinuing treatments on MS in terms of relapse and long-term progression and wanted increased information about the risk of relapse pre-conception, during pregnancy and after pregnancy. The need for help distinguishing normal changes of pregnancy with MS symptoms and the possible effect of reproductive assistive technologies on MS was also mentioned.	Limitations	Moderate concerns about methodological limitations[a]	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	
Content of information – self-management advice and planning before birth					
3 studies[21, 31, 37]	Interviews (n=3)	Participants were aware that the management of symptoms,	Limitations	Moderate concerns about methodological limitations[a]	LOW

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
		particularly fatigue, could become more difficult after a pregnancy and some suggested self-management advice would be beneficial.	Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy[b]	
Content of information – effect of MS and treatments on fertility					
6 studies[5, 12, 21, 24, 31, 37]	Interviews (n=6)	People with MS were concerned about the effect of MS treatments on fertility and wanted more information about when they should be stopped and what the risks of stopping were. Women described how their MS diagnosis meant they planned their pregnancy due to the risk of relapse and their understanding that it might increase over the years. Currently, fertility may not be discussed as often with males as it is with females.	Limitations	Moderate concerns about methodological limitations[a]	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	
Content of information – increased information about fertility/pregnancy required in consultations					
4 studies[5, 12, 21, 24]	Interviews (n=3)	Limited information and difficulty finding reliable information about MS and pregnancy was described. Although some did have a discussion with healthcare professionals, participants wanted to be provided with sources for further information such as	Limitations	Moderate concerns about methodological limitations[a]	LOW
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Moderate concerns about adequacy[b]	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
		voluntary organisations. Women described the need for pregnancy to be actively brought up by healthcare professionals so this can be considered when planning treatments. Fertility did not appear to be discussed with male participants.			
Content of information – ability to cope with parenthood and support available					
5 studies[5, 12, 21, 31, 37]	Interviews (n=5)	Concerns about coping with MS alongside being a parent were common and the need for social support was highlighted. Many were worried about 'failing' as a parent and some wanted help with what economic support would be available to them. Some described negative experiences of the pathway involving antenatal, childbirth and post-natal care, as well as highlighting the need for integrated multi-disciplinary care.	Limitations	Moderate concerns about methodological limitations[a]	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	
Delivery of support and information – supportive and open discussions					
5 studies[5, 21, 23, 31, 37]	Interviews (n=5)	Support from healthcare professionals in making decisions about pregnancy were considered key. Participants wanted	Limitations	Moderate concerns about methodological limitations[a]	MODERATE
			Coherence	No or very minor concerns about coherence	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
		discussions to be sensitive and supportive, without focusing solely on the possible negatives.	Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	
Delivery of support and information – having the discussion as soon as possible					
2 studies[5, 21]	Interviews (n=1)	People with MS highlighted the need to have discussions with healthcare professionals as soon as possible after diagnosis. The importance of understanding whether the person with MS may wish to become pregnant in the future after diagnosis was highlighted as important in planning treatments and therapies.	Limitations	Moderate concerns about methodological limitations[a]	LOW
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Moderate concerns about adequacy[c]	
Delivery of support and information – coordinated place to get information from					
1 study[21]	Interviews (n=1)	Participants expressed frustration at having to look for information in various places and would appreciate a coordinated place to obtain information on pregnancy in MS from.	Limitations	Moderate concerns about methodological limitations[a]	LOW
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Moderate concerns about adequacy[c]	

(a) majority of studies had moderate limitations, with common actors including lack of discussion of the role of the researcher and concerns about generalisability
(b) only four studies touched on this area and it is unclear whether additional studies may change the conclusions
(c) only two studies touched on this area and it is unclear whether additional studies may change the conclusions

Palliative care

Table 7: Summary of evidence

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Increased access to services and support – physiotherapy and rehabilitation					
2 studies[3, 13]	Interviews (n=1) or mixture of interviews and focus groups (n=1)	People with MS and their carers shared the opinion that more physiotherapy for the person with MS would be beneficial. Some people with MS commented that existing rehabilitation services are not well suited to those with severe MS.	Limitations	Minor concerns about methodological limitations[a]	LOW
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Moderate concerns about adequacy[b]	
Increased access to services and support – social isolation and psychological support					
8 studies[3, 8, 9, 11, 13, 16, 17, 27]	Interviews (n=7) or mixture of interviews and focus groups (n=1)	Social isolation and feelings of depression were common for people with MS and their carers and participants highlighted the need for increase social interaction and psychological support. Some that had attended group support sessions found these beneficial. Some participants saw neurologists as having an important role in psychological support by providing reassurance about their condition, meaning they felt supported and understood.	Limitations	Moderate concerns about methodological limitations[c]	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Increased access to services and support – <u>support with personal care and other services - home adaptations and mobility aids</u>					
5 studies[3, 7, 9, 13, 17]	Interviews (n=4) or mixture of interviews and focus groups (n=1)	Home adaptations and mobility aids were seen as important for maintaining the independence of the person with MS and participants wanted increased information and support about accessing these and support about accessing these and the suitability of them. Some noted that neurologists had provided them with information about aids which had improved their quality of life.	Limitations	Moderate concerns about methodological limitations[c]	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	
Increased access to services and support – <u>support with personal care and other services – reducing carer burden</u>					
7 studies[3, 7, 8, 11, 13, 17, 27]	Interviews (n=6) or mixture of interviews and focus groups (n=1)	Caregiver burden was an important topic raised by both people with MS and their carers. Increased support at home was desired and previous experiences arranging this were difficult. Both groups appreciated the need for carers to have time out to look after themselves and carers often felt ignored by doctors and health policy makers.	Limitations	Moderate concerns about methodological limitations[c]	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	
Content of information – <u>information about and navigation of services</u>					
6 studies[3, 7, 11, 13, 17, 27]	Interviews (n=5)	People with MS and those that cared for them shared the opinion	Limitations	Moderate concerns about methodological limitations[c]	MODERATE

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
	or mixture of interviews and focus groups (n=1)	that it was difficult to access services that were scarce and that there was a general lack of information about those available to them. They wanted to be made aware of services available to them and help with navigating them.	Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	
Content of information – increased information for families and carers					
3 studies[11, 17, 27]	Interviews (n=3)	Patients felt that increased information directed at family, friends and caregivers was needed to improve their understanding of the condition and allow them to understand decisions made by the person with MS and others involved in decision making. Some caregivers expressed the need for more information and support in terms of basic caring skills.	Limitations	Moderate concerns about methodological limitations[c]	LOW
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Moderate concerns about adequacy[d]	
Content of information – end of life decisions, treatment and illness progression					
8 studies (nine analyses)[3, 7, 9, 11, 13, 15-17, 27]	Interviews (n=7) or mixture of interviews and	People with MS and their carers wanted increased information about the condition, including symptoms, progression and treatment options. Those that received this type of information valued it. It was also acknowledged that many had a	Limitations	Moderate concerns about methodological limitations[c]	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
	focus groups (n=1)	poor understanding of the possibility of palliative care in MS and what this involved, and wanted to have these discussions with professionals.			
Content of information – financial and other support					
6 studies[3, 7, 11, 13, 17, 27]	Interviews (n=5) or mixture of interviews and focus groups (n=1)	Participants highlighted uncertainty about what they may be entitled to in terms of reimbursements for costs associated with MS, such as travel expenses and purchasing mobility aids. Advice about other areas such as issues adapting the home and administrative processes such as wills and power of attorney may also be beneficial.	Limitations	Moderate concerns about methodological limitations[c]	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	
Delivery of information and support – coordination of care and a single point of contact					
1 study[13]	Interviews (n=1)	The need for increased coordination of care and a specific point of contact was highlighted by people with MS and their caregivers.	Limitations	Minor concerns about methodological limitations[e]	LOW
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Moderate concerns about adequacy[f]	
Delivery of information and support – delivered by those with increased MS knowledge					
3 studies[11, 13, 17]	Interviews (n=3)	The knowledge of MS that professionals communicating with	Limitations	Moderate concerns about methodological limitations[c]	LOW

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
		participants had was important to people with MS and their carers and they wanted to be surrounded by those that were knowledgeable and confident in dealing with MS.	Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy[d]	
Delivery of information and support – <u>honest and sensitive delivery of information with engagement</u>					
4 studies[9, 11, 13, 17]	Interviews (n=4)	People with MS and their caregivers wanted to be actively involved in discussions with healthcare professionals and wanted to be treated sensitively and with respect, with honest and early conversations also favoured. Good listening skills, good bedside manner, compassion and an open-minded approach to discussions were reported to be key for the supportive role neurologists held in one study.	Limitations	Moderate concerns about methodological limitations[c]	LOW
			Coherence	No or very minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy[d]	

(a) all studies had only minor limitations, with the role of the researcher not being discussed in both studies
(b) only two studies touched on this area and it is unclear whether additional studies may change the conclusions
(c) the majority, half or almost half of studies had moderate limitations, with common factors including lack of discussion of the role of the researcher and concerns about generalisability
(d) only three studies touched on this area and it is unclear whether additional studies may change the conclusions
(e) study had only minor limitations, with factors including lack of discussion of the role of the researcher and concerns about generalisability
(f) only a single study touched on this area and it is unclear whether additional studies may change the conclusions

Appendix G – Research recommendations – full details

G.1 Research recommendation

What information, education and support do adults with clinically isolated syndrome and their families and carers find most useful?

G.1.1 Why this is important

Clinically isolated syndrome is a symptomatic or asymptomatic acute demyelinating event of the optic nerves, brainstem or spinal cord which may be an isolated one-off event or the first clinical episode of multiple sclerosis.

There is considerable uncertainty around the risk of people with clinically isolated syndrome subsequently developing multiple sclerosis. This uncertainty may impact future monitoring, treatment decisions, life decisions and the mental and physical health of the individual and their families and carers. The information, education and support needs for this group are complex, relating both directly to the acute episode and its impact, and also to future health and care.

G.1.2 Rationale for research recommendation

Importance to 'patients' or the population	Evidence on the information and support needs of people with clinically isolated syndrome is important to improve current practice and enhance outcomes in this patient group including quality of life. This will also help to standardise care and support.
Relevance to NICE guidance	This research can improve what information and support people with clinical isolated syndrome are offered with respect to for example the future probability of developing MS
Relevance to the NHS	A clear recommendation on the provision of information and support needs of people with clinically isolated syndrome will offer clinicians clearer guidance on best care. Increased knowledge of the information and support needs would improve and standardise care.
National priorities	The national service framework for long term conditions supports the need to have information to make informed decisions about care and treatment.
Current evidence base	No evidence was identified.
Equality considerations	Trials are unlikely to impact on equality issues.

G.1.3 Modified PICO table

Population	Inclusion Adults (≥18 years) with clinically isolated syndrome
Phenomena of interest	Perceptions and experiences of adults with clinically isolated syndrome and their families and carers regarding the information, education and support they find most useful.
Outcome	Thematic analysis
Study design	Qualitative
Timeframe	Short term
Additional information	None