Table S1. **Overview of publications**

First author, publication year[ref. no.]	Topic	Country	Design	Population	N	Aims
Driedger et al, 2017[38]	CCSVI	Canada	Qualitative	PwMS and MS stakeholders	69 PwMS, 15 stakeholders	To explore the discussions between PwMS and their neurologists following the release of news of Zamboni's hypothesis.
Murray et al, 2014[39]	CCSVI	Canada	Qualitative	PwMS	15	To explore the experience of liberation procedure decision-making in PwMS.
Ploughman et al, 2014[40]	CCSVI	Canada	Qualitative	PwMS	15	To explore the liberation-procedure decision-making in PwMS.
Snyder et al, 2014[41]	CCSVI	Canada	Qualitative	PwMS	15	To assess the experiences of Canadians with MS seeking CCSVI treatment abroad.
Hynes et al, 2019[43]	CCSVI	UK	Mixed methods	PwMS	1293 videos by 54 PwMS	To determine if PwMS continue to report the benefits of CCSVI treatment on YouTube, and if perspectives have changed.
Ghahari et al, 2016[42]	CCSVI	Canada	Observational, cross-sectional study	PwMS; HCPs	621 videos by 224 PwMS	To review videos related to MS and CCSVI posted by PwMS on YouTube that describe symptoms before and after the surgical procedure, as well as videos presented by HCPs.
Bansback et al, 2019[29]	DMD decision-making; decision aid	Canada	Mixed methods	PwMS	25 (survey, N=18; FGM, N= 7)	To develop and test the efficacy of a patient decision aid for first-line DMDs for PwRRMS.
Bottomley et al, 2017[18]	DMD decision-making; attributes; discrete-choice experiment; conjoint analysis;	UK	Observational, cross-sectional study	PwMS	350	To explore PwMS preference for different DMD attributes.

First author, publication year[ref. no.]	Topic	Country	Design	Population	N	Aims
	patient preference					
Brown et al, 2018[33]	DMD decision-making	EU countries and US	Observational, cross-sectional study	PwMS	1586 (Q4 2015), 1591 (Q4 2016), 1698 (Q4 2017) and 688 (Q4 2015), 602 (Q4 2016), 663 (Q4 2017) charts of eligible PwRRMS.	To assess PwMS engagement level in treatment decision-making in Europe (UK/Germany/France/Italy/Spain), and in the US.
Bruce et al, 2016[19]	DMD decision-making; adherence; behavioral economics; probability discounting	US	Observational, cross-sectional study	PwMS	77 (38 non-adherent and 39 adherent PwMS)	To examine if the behavioral economic construct of probability discounting (i.e. weighing of relative risks and benefits when deciding to take DMDs) can be used to explain treatment decisions in chronic diseases.
Bruce et al, 2018[20]	DMD decision-making; probability discounting	US	Observational, cross-sectional study	PwMS	208	To test a probability discounting model to explain the independent influences of risks and benefits when patients make hypothetical treatment decisions.
Ceuninck van Capelle et al, 2017[37]	DMD decision-making; use of DMDs	Netherlands	Qualitative	PwMS	10	To explore the perspective of PwMS on using DMDs.

First author, publication year[ref. no.]	Topic	Country	Design	Population	N	Aims
Cofield et al, 2017[30]	DMD decision-making; patient preference (CPS)	US, Canada and over 50 other countries (Countries for this survey were not reported)	Observational, cross-sectional study	PwMS	7009	To assess the role preferences of a large cohort of PwMS (NARCOMS Registry).
Col et al, 2018[14]	DMD decision-making; patient preference	US	Observational, cross-sectional study	PwMS	135	To evaluate the accuracy, completeness, and representativeness of a preference assessment tool in a national sample of PwMS.
D'Amico et al, 2016[31]	DMD decision-making; patient preference	Italy	Observational, cross-sectional study	PwMS	100	To examine factors associated with PwMS role preferences in the therapeutic decision-making process.
Eskyte et al, 2019[10]	DMD decision-making; critical interpretative synthesis	UK	Qualitative	PwMS	83 studies	To explore the experience of PwRRMS and their perspectives in choosing DMDs.
Fox et al, 2015[21]	DMD decision-making; risk tolerance; standard gamble	US	Observational, cross-sectional study	PwMS	5446	To determine PwMS tolerance to risky therapies and identify associated characteristics.
Heesen et al, 2017a[32]	DMD decision-making; natalizumab; patient	Germany (n=73 centres)	Observational, cross-sectional study	PwMS	801 PwMS, 99 neurologists	To assess the role preferences, perception of severity of MS, PML risk, and efficacy of natalizumab, knowledge about results of pivotal natalizumab trials and PML risk

First author, publication year[ref. no.]	Topic	Country	Design	Population	N	Aims
	preference; risk perception; risk knowledge					stratification, and PML risk tolerance of a large cohort of natalizumab -treated PwMS and their neurologists.
Hincapie et al, 2017[12]	DMD decision-making; attributes; conjoint analysis; patient preference	US	Observational, cross-sectional study	PwMS	129	To assess the preferences of PwMS for non-economic and economic attributes of current DMDs.
Jarmolowicz et al, 2017[22]	DMD decision-making; adherence; behavioral economics; side effect	US	Observational, cross-sectional study	PwMS	49	To investigate how side effect severity influences hypothetical medication decision-making of PwMS; to determine if these decision-making patterns relate to clinical measures of medication adherence.
Köpke et al, 2014[25]	DMD decision-making; information provision in MS; patient education program	Germany	RCT	PwMS	192 (IG, 93; CG, 99)	To evaluate the efficacy of an evidence-based patient information program aiming to increase informed choice in PwMS.
Köpke et al, 2016[26]	DMD decision-making; Patient education;	Germany	Quasi-experimental	PwMS	156 (IG, 75; CG, 81)	To investigate the effectiveness of a multi-component evidence-based education program on DMDs in PwMS.
Kremer et al, 2018[15]	DMD decision-making; attributes; neurologists and	Netherlands	Observational, cross-sectional study	Neurologists; nurses	60 (27 neurologists, 33 MS nurses)	To assess which DMD attributes are most important for the HCPs in selecting a DMD; to compare their perspectives on DMDs.

First author, publication year[ref. no.]	Topic	Country	Design	Population	N	Aims
	MS nurses					
Kremer et al, 2016[11]	DMD decision-making; attributes; Nominal group Technique	Netherlands	Mixed methods	PwMS	FGM: N=19; survey: N=185	To identify the full spectrum of DMD attributes; to quantify their relative importance in PwMS
Lowden et al, 2014[36]	DMD decision-making	Canada	Qualitative	PwRRMS	9	To explore the lived experience of making a first decision about treatment with DMDs in PwRRMS.
Lee Mortensen et al, 2017[35]	DMD decision-making; treatment preference	Denmark	Qualitative	PwMS	Five FGMs with 40 PwMS	To explore the main factors affecting PwMS preferences regarding DMD treatment and health care.
Rahn et al, 2015[28]	DMD decision-making; decision coaching, shared decision-making	Germany	RCT protocol	PwMS	-	To test the feasibility of a decision coaching program.
Rahn et al, 2018[27]	DMD decision-making; decision coaching, shared decision-making	Germany	RCT	PwMS	38/35	To test the feasibility of a decision coaching program.
Rath et al, 2017[57]	DMD decision-making; understanding of PML risk	Australia	Observational, cross-sectional study	PwMS	37	To assess PwMS understanding of their individual risk of PML, knowledge of the potential symptoms of PML, and their engagement in detecting possible symptoms of PML.

First author, publication year[ref. no.]	Topic	Country	Design	Population	N	Aims
Tintore et al, 2017[16]	DMD decision-making; satisfaction; treatment expectations	Italy, Germany, Spain, UK, US	Observational, cross-sectional study	PwMS; neurologists	900 neurologists, 982 PwMS	To assess the current state of MS care from both PwMS and neurologists; to gain insight into perceptions of treatment expectations, treatment decisions, treatment challenges, and satisfaction with care.
Sempere et al, 2017[13]	DMD decision-making; attributes; patient preference	Spain	Observational, cross-sectional study	PwMS	37	To evaluate PwMS preferences toward key DMDs attributes.
Utz et al, 2014[17]	DMD decision-making; attributes; conjoint analysis; patient preference	Germany	Observational, cross-sectional study	PwMS	156	To assess patients' implicit preferences for oral vs. parenteral DMDs, and influences on preferences.
Wicks et al, 2015[23]	DMD decision-making; attributes; discrete-choice experiment; conjoint analysis; patient preference	US	Observational, cross-sectional study	PwMS	319	To explore the preferences of oral-naïve PwMS regards to oral DMD attributes.
Wilkie et al, 2019[34]	DMD decision-making, decisional conflict	UK	Observational, cross-sectional study	PwMS	254	To determine if decisional conflict and decisional regret reflect different stages of the decision-making process when initiating DMDs.

First author, publication year[ref. no.]	Topic	Country	Design	Population	N	Aims
Wilson et al, 2014[24]	DMD decision-making; attributes; conjoint analysis; patient preference	US	Observational, cross-sectional study	PwMS	291	To calculate patient preferences for risk/benefit trade-offs for hypothetical DMDs.
Dehghani et al, 2018[64]	Health literacy; questionnaire	Iran	Mixed methods	PwMS; experts	Face validity: N=12 PwMS; content validity: N=15 experts; construct validity: N= 210 PwMS	To develop and validate a questionnaire for the assessment of health literacy in PwMS.
Gaissmaier et al, 2018[62]	Health literacy; numeracy	Germany	Observational, cross-sectional study	PwMS	725	To investigate whether MS patients' numeracy was impaired compared to a probabilistic national sample.
Kasper et al, 2017[60]	Health literacy; understanding of absolute risk reduction	Germany	RCT	PwMS	682	To evaluate newly developed bar graphs for PwMS risk communication in comparison to standard pictographs.
Rahn et al, 2016[63]	Health literacy; comprehension of confidence intervals	Germany	Mixed methods	PwMS	Qualitative study: N=16; RCT: N=64 (IG: 36; CG: 28)	To develop and pilot-test different written patient information materials explaining confidence intervals to PwRRMS.
Reen et al, 2018[61]	Health literacy; understanding of risks and benefits	UK	Observational, cross-sectional study	PwMS	45	To identify the best methods of communicating clinical trial data; to examine the relationship between patients' understanding with decisional

First author, publication year[ref. no.]	Topic	Country	Design	Population	N	Aims
						conflict, individual traits, and MS symptoms.
Borreani et al, 2014[46]	Information provision/patient education; Information aid	Italy	Qualitative	PwMS; physicians; neurologists	Interviews with 9 PwMS; FGM with 4 physicians; FGM with 6 caring neurologists	To scrutinize the experience of SIMS-Trial participants in order to gain better understanding of the effectiveness of the information aid and its components.
Brand et al, 2014[48]	Information provision/patient education; MRI knowledge	Germany	Mixed methods	PwMS	Interviews: N=5; survey: N=104; pilot testing: N=26	To investigate patients' experiences, knowledge and interest concerning MRI using mixed-methods. To develop and pilot-test an evidence-based patient education program on MRI in MS.
Colombo et al, 2014[51]	Information provision/patient education; web (search behavior)	Italy	Qualitative	PwMS; family members	FGMs: 40 PwMS, 20 family members	To analyze PwMS and their family members' experience about the Web-based health information, to evaluate how they asses this information, and how they integrate health information with personal values.
Colombo et al, 2016[53]	Information provision/patient education; web (website development); DMDs	Italy	Observational, cross-sectional study	PwMS	276 PwMS, 68 family members, and 89 others	To describe the development of the Italian IN-DEEP website and its assessment through an online survey.

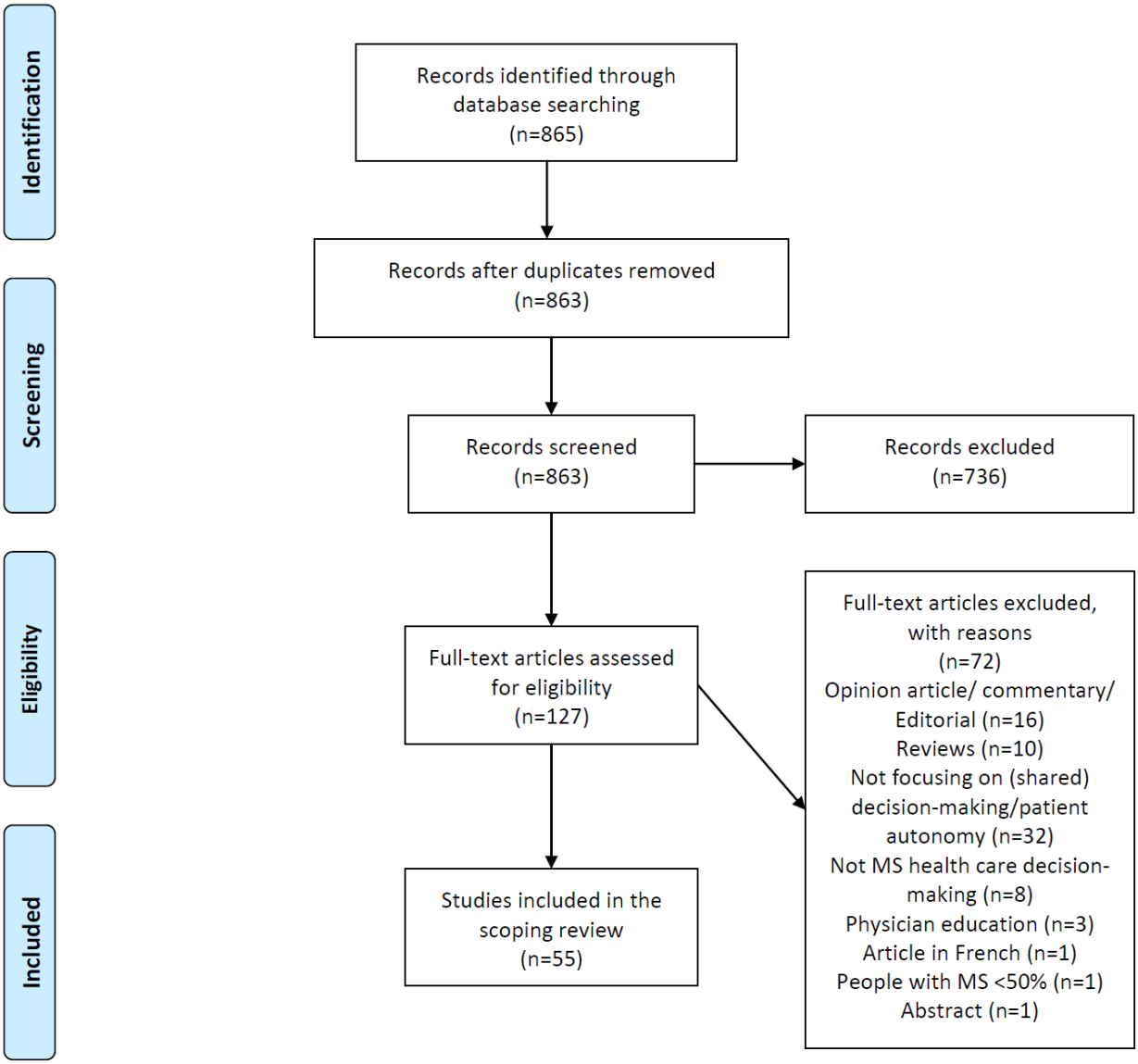
First author, publication year[ref. no.]	Topic	Country	Design	Population	N	Aims
Della Rosa et al, 2019[54]	Information provision/patient education; Social network	US	Observational, cross-sectional study	PwMS	24,915 members	To investigate the potential role of social network sites in health care.
Dennison et al, 2018[49]	Information provision/patient education; patient preference	UK	Observational, cross-sectional study	PwMS	3175	To investigate the prognosis communication experiences and preferences of PwMS.
Giordano et al, 2014[44]	Information provision/patient education; Information aid	Italy	Controlled trial	PwMS	159 (whole information aid: N=77; take-home materials: N=82)	To assess the effectiveness of an information aid in clinical practice and to compare the whole information aid with the take-home booklet/website component alone.
Giunti et al, 2018[58]	Information provision/patient education; Apps	Spain	Review-scoping	PwMS		To assess how the features present in MS apps meet the reported needs of PwMS.
Lavorgna et al, 2017[55]	Information provision in MS; social media; quality of information	Italy	Other	PwMS	-	
Lavorgna et al, 2018[56]	Information provision/patient education; social media	Italy	Observational, cross-sectional study	PwMS		To assess the role of appointed influencers in a medically supervised Italian web community (SMsocialnetwotk.com) for PwMS.
Mazanderani et al, 2019[50]	Information provision/patient education;	UK	Qualitative	PwMS, partners, family	77	To explore the intra-familial dynamics of managing health information in the context of chronic illness.

First author, publication year[ref. no.]	Topic	Country	Design	Population	N	Aims
	management within the family			members and close friends		
Mohamadirizi et al, 2017[45]	Information provision/patient education; (CD; booklet)	Iran	Quasi-experimental	PwMS	120 (IG: 60; CG: 60)	To compare the effect of electronic education and illustrated booklet on knowledge of PwMS.
Riemann-Lorenz et al, 2016[59]	Information provision/patient education; diet	Germany	Mixed methods	PwMS	Survey: N=337; pilot test: N=13	To design and pilot-test an evidence based patient education program on the influence of diet on MS.
Synnot et al, 2014[52]	Information provision/patient education; Internet	Australia	Qualitative	PwMS; family members	51 PwMS, 9 family members	To explore needs, experiences and preferences of PwMS for integrating treatment information into decision-making, in the context of searching on the Internet.
Solari et al, 2010[47]	Information provision/patient education; Information aid	Italy	RCT	PwMS	120 PwMS	To assess the effectiveness of an add-on information aid for newly diagnosed MS patients.
Heesen et al, 2015[65]	Risk knowledge; questionnaire	Germany	Mixed methods	Experts		To develop the RIKNO 1.0 questionnaire.
Heesen et al, 2017b[66]	Risk knowledge; questionnaire	Europe (FGM), survey Germany	Mixed methods	PwMS	FGM: 35; survey: 708	To produce a revised RIKNO 2.0 questionnaire using mixed methodology in a European setting.

First author, publication year[ref. no.]	Topic	Country	Design	Population	N	Aims
Giordano et al, 2018[3]	Risk knowledge; survey	Germany, Italy, The Netherlands, Serbia, Spain, Turkey	Observational, cross-sectional study	PwMS	1939	To investigate the level of risk knowledge and role preferences in eight countries and assess putative variables associated with risk knowledge.

CCSVI, chronic cerebrospinal venous insufficiency; CG, control group; DMD, disease-modifying drug; FGM, Focus Group Meeting. HCPs, health care professionals; IG, intervention group; MRI, magnetic resonance imaging; PwMS, people with multiple sclerosis; PML, progressive multifocal leukoencephalopathy); RCT, randomized controlled trial; RRMS, relapsing-remitting multiple sclerosis; UK, United Kingdom; US, United States.

Figure S1. Study flow diagram



Appendix S1. PRISMA-ScR Checklist

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	Page 1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Page 4
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	-
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	Pages 6 and 7
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	Available upon author request
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	Page 6
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	Page 6

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Appendix S2
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Page 7
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Page 7
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Page 7
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Not applicable
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	Page 6
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Page 6; Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Pages 6 and 7
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Not applicable
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Table S1
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Results

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Page 14
Limitations	20	Discuss the limitations of the scoping review process.	Page 17
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Page 14
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Available upon author request. This scoping review did not receive any funding.

Note: Page numbers refer to original manuscript.
JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.
* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.
† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).
‡ The frameworks by Arksey and O'Malley and Levac and colleagues and the JBI guidance refer to the process of data extraction in a scoping review as data charting.
§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. *Ann Intern Med.* 2018;169:467–473. doi: 10.7326/M18-0850

Appendix S2. MEDLINE search strategy

Research question: Shared decision-making in multiple sclerosis

Search dates: 2014 – 6th August 2019

Search terms

1.	"Multiple Sclerosis".mp. or Multiple Sclerosis/
2.	Multiple Sclerosis, Relapsing-Remitting/
3.	Demyelinating Diseases/
4.	"relapsing remitting multiple sclerosis".mp.
5.	"remitting-relapsing multiple sclerosis".mp.
6.	"remitting relapsing, multiple sclerosis".mp.
7.	"multiple sclerosis, relapsing-remitting".mp.
8.	"multiple sclerosis, relapsing remitting".mp
9.	"acute relapsing multiple sclerosis".mp.
10.	"relapsing multiple sclerosis".mp.
11.	"multiple sclerosis, acute relapsing".mp.
12.	"progressive relapsing multiple sclerosis".mp.
13.	"progressive relapsing, multiple sclerosis".mp.
14.	"multiple sclerosis, progressive relapsing".mp.
15.	"demyelinating disease".mp.
16.	"demyelinating diseases".mp.
17.	"demyelinating disorder".mp.
18.	"demyelinating disorders".mp.
19.	"Encephalomyelitis disseminata".mp.
20.	"encephalitis disseminata".mp.
21.	MS.mp.

22.	RRMS.mp.
23.	Myelitis, Transverse.mp. or Encephalomyelitis, Acute Disseminated/
24.	Multiple Sclerosis, Relapsing-Remitting.mp. or Demyelinating Diseases/
25.	Optic Neuritis/
26.	"relapsing remitting multiple sclerosis".mp.
27.	"optic neuritis".mp.
28.	"devic disease".mp.
29.	"clinically isolated syndromes".mp.
30.	"clinically isolated syndrome".mp.
31.	"transverse myelitis".mp.
32.	"encephalomyelitis".mp.
33.	"neuromyelitis".mp.
34.	"chronic progressive multiple sclerosis".mp.
35.	"chronic progressive, multiple sclerosis".mp.
36.	"primary progressive multiple sclerosis".mp.
37.	"secondary progressive multiple sclerosis".mp.
38.	"progressive relapsing multiple sclerosis".mp.
39.	"progressive relapsing, multiple sclerosis".mp.
40.	"multiple sclerosis, progressive relapsing".mp.
41.	"multiple sclerosis, secondary progressive".mp.
42.	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41
43.	Decision Making/
44.	"patient information".mp.
45.	"health information".mp.

46.	"patient guidance".mp.
47.	"audio-visual information".mp.
48.	"decision making".mp.
49.	"decision-making".mp.
50.	"shared decision making".mp.
51.	"shared decision-making".mp.
52.	"informed choice".mp.
53.	"decision support".mp.
54.	"informed choices".mp.
55.	"decisional support".mp.
56.	"decision coaching".mp.
57.	"decision counselling".mp.
58.	"decision counseling".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
59.	"patient education".mp.
60.	43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59
61.	42 and 60
62.	limit 61 to last 5 years