

Last update: 9 July 2024

Doc. by	name	variable_name	Collection time	data format	SNOMED term	SNOMED code	value(s)	value_name	SNOMED term	SNOMED code
B	Date of Visit / Reporting date (for PRO)	date_visit	FV, FU	YYYY-MM-DD	Date of visit (observable entity)	406543005				
Demographic Data										
B	Date of Birth	date_birth	FV	YYYY-MM-DD	Date of birth (observable entity)	184099003	(if dd or MM is not allowed, 15 is used for dd or 06 MM respectively)	-	-	-
B	(Biological) Sex	sex	FV	radio/select	Biological sex (property) (qualifier value)	734000001	Female	female	Female (finding)	248152002
							Male	male	Male (finding)	248153007
B	Country of Residence	residence	FV, FU	list	Country of residence (observable entity)	416647007	ISO 3166-1 (alpha-2)	residence_xx (xx = country per ISO standard)	-	-
B	Race / Ethnicity	race_ethnicity	FV	list	Race (observable entity) Ethnic group finding (finding)	103579009 397731000	(there are no value recommendations given because of the global differences in race/ethnicity as well as the corresponding legislation on data collection; a collection of local ethnic/racial data where possible is strongly encouraged though)			
B	Educational level	education	FV	list	Educational achievement (observable entity)	105421008	ISCED 0 = Early childhood education ISCED 1 = Primary Education ISCED 2 = Lower Secondary Education ISCED 3 = Upper Secondary Education ISCED 4 = Post-secondary non-Tertiary Education ISCED 5 = Short-cycle tertiary education ISCED 6 = Bachelors degree or equivalent tertiary education level ISCED 7 = Masters degree or equivalent tertiary education level ISCED 8 = Doctoral degree or equivalent tertiary education level	iscd_0 iscd_1 iscd_2 iscd_3 iscd_4 iscd_5 iscd_6 iscd_7 iscd_8		
B	Employment Status	employment	FV, FU	list	Employment status (observable entity)	224362002	Employed with unknown status (full/part-time)	employed	Employed (finding)	224363007
							Full-time employed	ft_employed	Full-time employment (finding)	160903007
							Part-time employed	pt_employed	Part-time employment (finding)	160904001
							Student	student	Student in full time education (occupation)	413327003
							Retired	retired	Retired, life event (finding)	105493001
							Medically retired (due to MS)	med_retired_ms	Medically retired, life event (finding)	160898008

							Medically retired (due to other diseases)	med_retired_other	Medically retired, life event (finding)	160898008
							Unemployed	unemployed	Unemployed (finding)	73438004
							Maternal/ parental leave	parental_leave	On maternity leave (finding) / On parental leave (finding)	224457004 / 700149001
							Homemaker (housewife/houseman)	homemaker	Homemaker (person)	444168002
B	Smoking status	smoking	FV, FU	radio/select			Never smoked	never_smoked	Never smoked tobacco (finding)	266919005
							Current smoker	current_smoker	Smoker (finding)	77176002
							Former smoker	former_smoker	Ex-smoker (finding)	8517006
							Unknown	smoking_unknown	Tobacco smoking consumption unknown (finding)	266927001
							If current_smoker: number of cigarettes (daily)	smoking_count	Cigarette consumption (observable entity)	230056004
B	Family History of MS	ms_family	FV	boolean	Family history: Multiple sclerosis (situation)	160337009	Yes No Unknown / Not sure	yes no unknown / not_sure	Yes (qualifier value) No (qualifier value) Unknown (qualifier value)	373066001 373067005 261665006

Disease-specific Information: Disease History

B	Date of Diagnosis	date_diagnosis	FV	YYYY-MM-DD	Date of diagnosis (observable entity)	432213005	(if dd or MM is not available, 01 is used for dd or MM respectively)			
B	Date of Onset	date_onset	FV	YYYY-MM-DD	Date of onset (observable entity)	298059007	(if dd or MM is not available, 01 is used for dd or MM respectively) or Unknown / Unsure		- Unknown (qualifier value)	261665006
C	Cerebrospinal Fluid: Oligoclonal IgG Bands present (for diagnosis)	csf_olib	FV	boolean	Cerebrospinal fluid oligoclonal bands (procedure)	113073005	Yes No Unknown	yes no unknown	Yes (qualifier value) No (qualifier value) Unknown (qualifier value)	373066001 373067005 261665006
B	MS Course	ms_course	FV, FU	list	Multiple sclerosis (disorder)	24700007	Radiologically isolated syndrome	ris	Radiologically isolated syndrome (disorder)	16415361000119105
							Clinically isolated syndrome	cis	Clinically isolated syndrome (disorder)	445967004
							Relapsing remitting	rrms	Relapsing remitting multiple sclerosis (disorder)	426373005
							Secondary progressive	spms	Secondary progressive multiple sclerosis (disorder)	425500002
							Primary progressive	ppms	Primary progressive multiple sclerosis (disorder)	428700003

Disease-specific Information: Disease Status

C	MS current status (clinician)	ms_status_clin	FV, FU	list	Chronic disease - follow-up assessment (finding)	170558000	Not active and without progression (stable disease)	statusC_stable	Patient's condition stable (finding)	359746009
							Active (MRI activity or relapses) and with progression	statusC_act_progr	Active (qualifier value) / Progressive (qualifier value)	55561003 / 255314001
							Active but without progression	statusC_act_noprogr	Active (qualifier value) / Non-progressive (qualifier value)	55561003 / 702322003
							Not active but with progression	statusC_inact_progr	Inactive (qualifier value) / Progressive (qualifier value)	73425007 / 255314001
P	MS current status (patient), e.g. "Compare your overall MS status now with what you experienced since last visit: Is your MS..."	ms_status_pat	FV, FU	list	Chronic disease - follow-up assessment (finding)	170558000	Much worse	statusP_worse2	Patient status determination, much worse (finding)	45112000
							Worse	statusP_worse1	Patient's condition deteriorating (finding)	275723000
							A little worse	statusP_worse	Patient status determination, slightly worse (finding)	6718007
							No change	statusP_stable	Patient's condition stable (finding)	359746009
							A little better	statusP_better	Patient status determination, slightly improved (finding)	67405006
							Better	statusP_better1	Patient's condition improved (finding)	268910001
							Much better	statusP_better2	Patient status determination, greatly improved (finding)	3286006
B	Current symptoms	current_symp	FV, FU, RI	checkboxes/list	Symptom checklist (assessment scale)	273859002	Walking/Mobility	symp_walking	Ability to walk (observable entity)	282097004
							Fatigue	symp_fatigue	Fatigue (finding)	84229001
							Pain	symp_pain	Pain (finding)	22253000
							Anxiety	symp_anxiety	Anxiety (finding)	48694002
							Depression	symp_depression	Depressive disorder (disorder)	35489007
							Vision	symp_vision	Disorder of vision (disorder)	95677002
							Dizziness	symp_dizziness	Dizziness (finding)	404640003

							Bladder control	symp_bladder	Impaired urinary system function (finding)	1156448003
							Bowel control	symp_bowel	Bowel control, function (observable entity)	129008009
							Spasticity	symp_spasticity	Spasticity (finding)	221360009
							Sensory symptoms	symp_sensory	Sensory disorder (disorder)	85972008
							Cognition	symp_cognition	Impaired cognition (finding)	386806002
							Dexterity	symp_dexterity	Poor manual dexterity (finding)	306741005
P	Symptom severity (for each symptom that was collected)	sever_symp	FV, FU, RI	scale	Symptom severity level (observable entity)	405162009	0 - 6 (0: not affected at all, 1: very mild limitation/ I make minor adjustments, 2: mild limitation/ I make frequent adjustments, 3: moderate limitation/ I reduced my daily activities, 4: severe limitation/ I gave up some activities, 5: very severe limitation/ I'm unable to do many daily activities, 6: total limitation/ I'm unable to do most daily activities)	-	-	-
B	Symptoms treated	treat_symp	FV, FU	boolean			Yes No	yes no	Yes (qualifier value) No (qualifier value)	373066001 373067005
C	Expanded Disability Status Scale (EDSS) Score	edss_score	FV, FU, RI	float	Kurtzke multiple sclerosis rating scale (assessment scale)	273554001	0, 1.0, 1.5, ..., 10	-	-	-
P	Patient determined disease steps (PDDS)	pdds_score	FV, FU	integer			0 ("Normal"), 1 ("Mild disability"), 2 ("Moderate disability"), 3 ("Gait disability"), 4 ("early cane"), 5("late cane"), 6 ("bilateral support"), 7 ("wheelchair/scooter") , 8 ("bedridden")	-	-	-
C	Timed 25 Foot Walk (T25FW)	t25fw	FV, FU	float			(time in seconds)	-	-	-
C	9-Hole Peg Test (9HPT)	9hpt_right	FV, FU, RI	float	Nine hole peg test score (observable entity)	446602000	(time in seconds, right hand)	-		
		9hpt_left	FV, FU, RI	float	Nine hole peg test score (observable entity)	446602000	(time in seconds, left hand)	-		
C	Vibratory sense	vib_sense	FV, FU, RI		Vibratory sense, function (observable entity)	397656001	Normal (right foot)	vib_normal_right	Normal vibration sensation of right foot (finding)	830005003
							Decreased (right foot)	vib_decreased_right	Impaired vibration sense of right foot (finding)	418711005
							Absent (right foot)	vib_absent_right	Absence of vibration sense of right foot (finding)	830006002

							Normal (left foot)	vib_normal_left	Normal vibration sensation of left foot (finding)	830004004
							Decreased (left foot)	vib_decreased_left	Impaired vibration sense of left foot (finding)	130980003
							Absent (left foot)	vib_absent_left	Absence of vibration sense of left foot (finding)	417892007
C	Symbol Digit Modalities Test (SDMT)	sdmt	FV, FU	int	Symbol Digit Modalities Test score (observable entity)	718387005	(number of correct answers/substitutions)	-	-	-
Disease Specific Information: Relapses										
B	Relapse Event	relapse	RI	boolean	Exacerbation of multiple sclerosis (disorder)	192929006	Yes No Unknown / Not sure	yes no unknown / not_sure	Yes (qualifier value) No (qualifier value) Unknown (qualifier value)	373066001 373067005 261665006
B	Date of Relapse	date_relapse	RI	YYYY-MM-DD			(if dd or MM is not available, 01 is used for dd or MM respectively)	-	-	-
B	Steroid treatment for relapse	relapse_treat	RI	boolean	Corticosteroid and/or corticosteroid derivative therapy (procedure)	788751009	Yes No	yes no	Yes (qualifier value) No (qualifier value)	373066001 373067005
B	Recovery	relapse_recovery	RI, FU	select/radio	Convalescence (finding)	105499002	Complete	compl_recovery		
							Partial	partial_recovery		
							No	no_recovery		
							Unknown / Not sure	unknown / not_sure	Unknown (qualifier value)	261665006
Para-clinical Investigations: MRI										
B	MRI done	mri	FU	boolean	Magnetic resonance imaging (procedure)	113091000	Yes No	yes no	Yes (qualifier value) No (qualifier value)	373066001 373067005
B	MRI region	mri_region	FU	radio/select			Brain	mri_brain	Magnetic resonance imaging of brain (procedure)	816077007
							Cervical Cord	mri_cervical	Magnetic resonance imaging of cervical spine (procedure)	241646009
							Thoracic Cord	mri_thoracic	Magnetic resonance imaging of thoracic spine (procedure)	241647000
							Whole Spinal Cord	mri_myelon	Magnetic resonance imaging of spine (procedure)	241645008
B	Date of MRI	mri_date	FU	YYYY-MM-DD				-		

C	Number of Gd enhanced lesions	mri_gd_les	FU	integer			number or "Unknown"	-	- Unknown (qualifier value)	261665006
C	Number of new or enlarged T1 lesions	mri_new_les_T1	FU	integer			number or "Unknown"	-	- Unknown (qualifier value)	261665006
C	Number of new or enlarged T2 lesions	mri_new_les_T2	FU	integer			number or "Unknown"	-	- Unknown (qualifier value)	261665006
Comorbidities										
B	Comorbidities	comorbidity	FV, FU	boolean	Co-morbid conditions (finding)	398192003	Yes No Unknown / Not sure	yes no unknown / not_sure	Yes (qualifier value) No (qualifier value) Unknown (qualifier value)	373066001 373067005 261665006
B	Type of comorbidity	com_type	FV, FU	list			Alcohol abuse	com_alc_abuse	Alcohol abuse (disorder)	15167005
							Anxiety	com_anxiety	Anxiety disorder (disorder)	197480006
							Autoimmune Disorder	com_autoimmune	Autoimmune disease (disorder)	85828009
							Bipolar disorder	com_bipolar	Bipolar disorder (disorder)	13746004
							Cancer	com_cancer	Malignant neoplastic disease (disorder)	363346000
							Cardiac arrhythmia	com_arrhythmia	Cardiac arrhythmia (disorder)	698247007
							Chronic lung disease	com_chronic_lung	Chronic lung disease (disorder)	413839001
							Congestive heart disease	com_congestive_heart	Congestive heart failure (disorder)	42343007
							Depression	com_depression	Depressive disorder (disorder)	35489007
							Diabetes mellitus	com_diabetes	Diabetes mellitus (disorder)	73211009
							Drug abuse	com_drug_abuse	Drug abuse (disorder)	26416006
							Epilepsy	com_epilepsy	Epilepsy (disorder)	84757009
							Eye disease	com_eye	Disorder of eye proper (disorder)	371405004
							Fibromyalgia	com_fibromyalgia	Fibromyalgia (disorder)	203082005
							Irritable bowel syndrome	com_ibs	Irritable bowel syndrome (disorder)	10743008
							Viral hepatitis	com_hepatitis	Viral hepatitis (disorder)	3738000
							Hyperlipidemia	com_hyperlipidemia	Hyperlipidemia (disorder)	55822004
							Hypertension	com_hypertension	Hypertensive disorder, systemic arterial (disorder)	38341003

							Ischemic heart disease	com_ischemic_heart	Ischemic heart disease (disorder)	414545008
							Peripheral vascular disease	com_peripheral_vasc	Peripheral vascular disease (disorder)	400047006
							Psychosis	com_psychosis	Psychotic disorder (disorder)	69322001
							Stroke (any)	com_stroke	Cerebrovascular accident (disorder)	230690007
C	Comorbidity system (alternative to comorbidity type)	com_system	FV, FU	list	Body system structure	91689009	skeletal	sys_skel	Disorder of skeletal system (disorder)	88230002
							muscular	sys_musc	Disorder of musculoskeletal system (disorder)	928000
							nervous	sys_nerv	Disorder of nervous system (disorder)	118940003
							endocrine	sys_endo	Disorder of endocrine system (disorder)	362969004
							cardiovascular	sys_cardio	Disorder of cardiovascular system (disorder)	49601007
							lymphatic	sys_lymph	Disorder of lymphatic system (disorder)	362971004
							respiratory	sys_resp	Disorder of respiratory system (disorder)	50043002
							digestive	sys_digest	Disorder of digestive system (disorder)	53619000
							urinary	sys_urin	Disorder of the urinary system (disorder)	128606002
							reproductive	sys_reprod	Disorder of reproductive system (disorder)	362968007
Disease-modifying Treatment (DMT): for current and past treatments										
B	Current or past DMT	dmt_status	FV, FU	select/radio			Yes No (but in the past) DMT naive (Never)	yes no dmt_naive	Yes (qualifier value) No (qualifier value) Treatment naive (finding)	373066001 373067005 844585000
B	DMT type	dmt_type	FV, FU	list			Alemtuzumab	alemtuzumab	Alemtuzumab (substance)	129472003
							Cladribine	cladribine	Cladribine (substance)	386916009
							Dimethyl Fumarate	dimethyl_fumarate	Dimethyl fumarate (substance)	724035008
							Diroximel fumarate	diroximel_fumarate	Diroximel fumarate (substance)	1268407006
							Fingolimod	fingolimod	Fingolimod (substance)	449000008
							Glatiramer acetate	glatiramer_acetate	Glatiramer acetate (substance)	108755008

							Interferon-beta	interferon	Interferon beta (substance)	420710006
							Peg-Interferon-beta 1a	peg_interferone	Interferon beta (substance)	420710006
							Monomethyl fumarate	monomethyl_fumarate	Monomethyl fumarate (substance)	1010557002
							Natalizumab	natalizumab	Natalizumab (substance)	414805007
							Ocrelizumab	ocrelizumab	Ocrelizumab (substance)	733464008
							Ofatumumab	ofatumumab	Ofatumumab (substance)	444607009
							Ozanimod	ozanimod	Ozanimod (substance)	870525003
							Ponesimod	ponesimod	Ponesimod (substance)	1179253008
							Siponimod	siponimod	Siponimod (substance)	786997005
							Teriflunomide	teriflunomide	Teriflunomide (substance)	703785006
							Ublituximab	ublituximab		
							Azathioprine	azathioprine	Azathioprine (substance)	372574004
							Cyclophosphamide	cyclophosphamide	Cyclophosphamide (substance)	387420009
							Fludarabine	fludarabine	Fludarabine (substance)	386907005
							IV Immunoglobulin	immunoglobulin	Immunoglobulin (substance)	112133008
							Methotrexate	methotrexate	Methotrexate (substance)	387381009
							Minocycline	minocycline	Minocycline (substance)	372653009
							Mitoxantrone	mitoxantrone	Mitoxantrone (substance)	386913001
							Mycophenolate mofetil	mycophenolate_mofetil	Mycophenolate mofetil (substance)	386976000
							Rituximab	rituximab	Rituximab (substance)	386919002
							Corticosteroids	corticosteroids	Corticosteroid series (substance)	255877006
							aHSCT	ahsct	Transplantation of autologous hematopoietic stem cell (procedure)	709115004
B	Start date	dmt_start	FV, FU	YYYY-MM-DD	Date treatment started (observable entity)	413946009				
B	Stop date	dmt_stop	FV, FU	YYYY-MM-DD	Date treatment stopped (observable entity)	413947000				

B	Stop reason	dmt_stop_reas	FV, FU	list	Reason for (attribute) / Drug therapy discontinued (situation)	410666004 / 274512008	Developed contraindications	stop_contraindication	Medication stopped - contra-indication (situation)	395008009
							Inefficacy	stop_inefficacy	Medication stopped - ineffective (situation)	395007004
							Intolerance / Treatment-related adverse event	stop_intolerance	Medication stopped - side effect (situation)	395009001
							Non-adherence	stop_non_adherence	Non-compliance of drug therapy (finding)	702565001
							Patient Choice/Convenience	stop_patient_choice	Requested by patient (contextual qualifier) (qualifier value)	15635006
							Persistent disease activity (MRI lesions / relapses)	stop_disease_activity	Active disease following therapy (finding)	110278006
							Progression of disease / disability	stop_progression		
							Financial/insurance coverage issues	stop_financial	Finding related to health insurance issues (finding)	419808006
							Other	stop_other	Other category (qualifier value)	394841004
							Unknown	stop_unknown	Unknown (qualifier value)	261665006
Non-pharmaceutical Treatments										
B	Non-pharmaceutical treatment type	np_treat_type	FV, FU	list	Professional / ancillary services care (regime/therapy)	409023009	Occupational Therapy	occupational_therapy	Occupational therapy (regime/therapy)	84478008
							Physiotherapy	physiotherapy	Physical therapy procedure (regime/therapy)	91251008
							Psychotherapy	psychotherapy	Psychotherapy (regime/therapy)	75516001
							Rehabilitation	rehabilitation	Rehabilitation therapy (regime/therapy)	52052004
							Speech therapy	speech_therapy	Speech therapy (regime/therapy)	5154007
							Other	np_other	Other category (qualifier value)	394841004
B	Start date	np_treat_start	FV, FU	YYYY-MM-DD	Date treatment started (observable entity)	413946009	<i>date, if available/applicable</i>	-	-	-
B	Stop date	np_treat_stop	FV, FU	YYYY-MM-DD	Date treatment stopped (observable entity)	413947000	<i>date, if available/applicable</i>	-	-	-