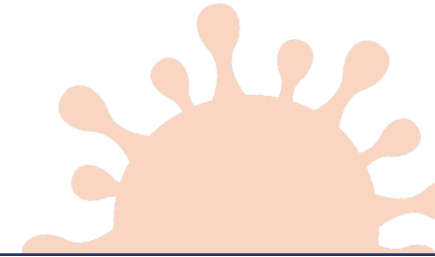




COVID-19 & MS
Global Data
Sharing Initiative

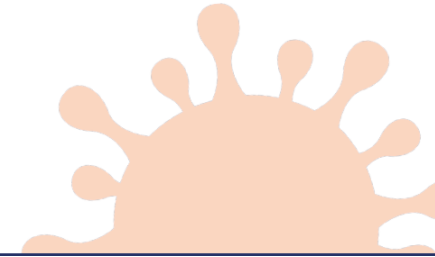


COVID-19 & MS Core Data Dictionary

In this document you can find the COVID-19 core dataset, which is a list of variables that has been agreed upon by a global task force to be the common denominator across the different data initiatives focussing on COVID-19 in people with MS.

The title of the variables/questions may differ in some cases (patient/clinicians) so both options are given in the “title” field. This is only a guideline, not a mandatory formulation.

#DataSavesLives

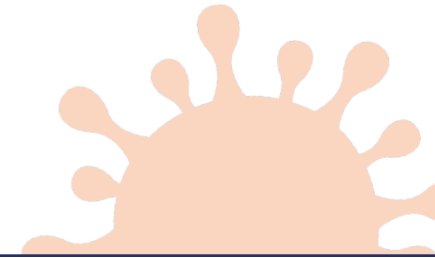


COVID-19 Incidence

Title	Variable_ID	Data Type	Options Label (Value)
Date of Visit/Reporting (This date refers to (last) date of COVID19 reporting. It serves to assess how up-to-date the COVID19 information is.)	covid19_date_reporting	Date (YYYY-MM-DD)	
COVID-19 Symptoms	covid19_has_symptoms	Single choice	YES (yes) NO (no)
What COVID19 symptoms did/does the patient/ do you have?			
Fever	covid19_sympmt_fever	Single choice	YES (yes) NO (no)
Dry Cough	covid19_sympmt_dry_cough	Single choice	YES (yes) NO (no)
Fatigue	covid19_sympmt_fatigue	Single choice	YES (yes) NO (no)
Pain (joint,bone,muscle)	covid19_sympmt_pain	Single choice	YES (yes) NO (no)



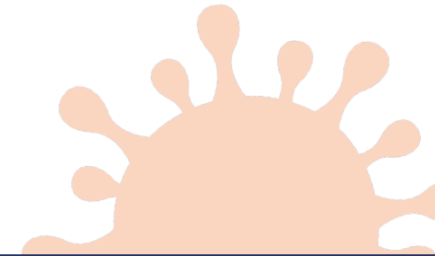
COVID-19 & MS
Global Data
Sharing Initiative



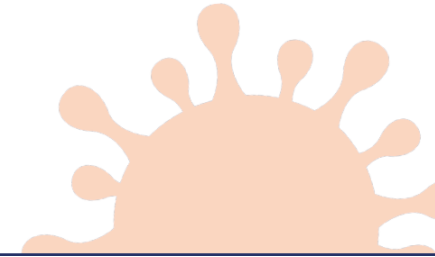
Sore Throat	covid19_symp_t_sore_throat	Single choice	YES (yes) NO (no)
Shortness of breath	covid19_symp_t_shortness_breath	Single choice	YES (yes) NO (no)
Nasal congestion	covid19_symp_t_nasal_congestion	Single choice	YES (yes) NO (no)
Chills	covid19_symp_t_chills	Single choice	YES (yes) NO (no)
Loss of smell or taste	covid19_symp_t_loss_smell_taste	Single choice	YES (yes) NO (no)
Pneumonia	covid19_symp_t_pneumonia	Single choice	YES (yes) NO (no)
Do you suspect the patient has or had COVID-19?	covid19_suspected_case	Single choice	YES (yes)
Do you suspect that you have/had COVID-19?			NO (no)
Did you recommend self-isolation for the patient?	covid19_self_isolation	Single choice	YES (yes)
Have you been recommended to self-isolate?			NO (no)



COVID-19 & MS Global Data Sharing Initiative



I'm self-isolated anyways:	covid19_self_isolation_by_self_patient	Single choice	YES (yes) NO (no)
Isolation start date	covid19_self_isolation_date	Date (YYYY-MM-DD)	
Duration of self-isolation (in days)	covid19_self_isolation_duration	Number	
Was the COVID-19 case confirmed by a lab test? Have you been tested positive for COVID-19?	covid19_confirmed_case	Single choice	YES (yes) NO (no)
Date of lab test confirmation	covid19_date_lab_test	Date (YYYY-MM-DD)	
What is the country in which the patients' first COVID-19 (suspicious) symptoms occurred? If the patient does not have or had any (suspicious symptoms), please select the country of residence? What is the country in which your first COVID-19 (suspicious) symptoms occurred? If you do not have or had any (suspicious symptoms), please select your country of residence?	covid19_country	Single choice	COUNTRY NAME
Date of COVID-19 symptom onset	covid19_date_suspected_onset	Date (YYYY-MM-DD)	



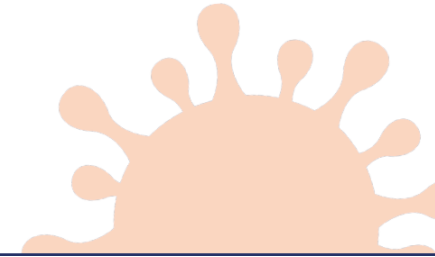
When have you had the first COVID-19 symptoms?			
--	--	--	--

COVID-19 Severity

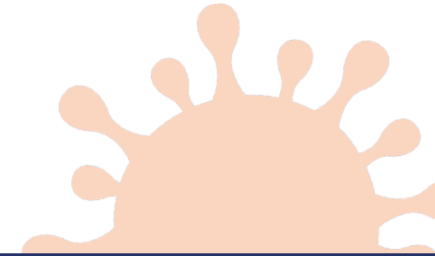
Title	Variable_ID	Data Type	Options Label (Value)
Admission in Hospital because of COVID-19 (suspicious) infection?	covid19_admission_hospital	Single choice	YES (yes) NO (no)
Admission date	covid19_admission_hospital_date	Date (YYYY-MM-DD)	
Discharge date	covid19_admission_hospital_release	Date (YYYY-MM-DD)	
Stay in ICU because of COVID-19 (suspicious) infection?	covid19_icu_stay	Single choice	YES (yes) NO (no)
Still in ICU?	covid19_still_icu_stay	Single choice	YES (yes) NO (no)



COVID-19 & MS Global Data Sharing Initiative



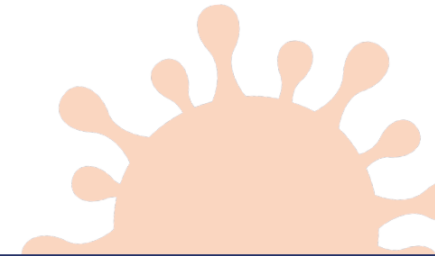
Current number of days in ICU (in days)	covid19_icu_current_duration	Number	
Total number of days in ICU (in days)	covid19_icu_total_duration	Number	
Ventilation needed during hospital stay? Have you been given assistance to breath because of COVID-19 (suspicious) infection?	covid19_ventilation	Single choice	YES (yes) NO (no)
Non-invasive? (clinicians only)	covid19_ventilation_non_invasive	Single choice	YES (yes) NO (no)
Invasive? (clinicians only)	covid19_ventilation_invasive	Single choice	YES (yes) NO (no)
Did the patient receive ECMO because of COVID-19 (suspicious) infection? (clinicians only)	covid19_ecmo	Single choice	YES (yes) NO (no)
Has the patient recovered from the (suspected) COVID-19 infection? Have you recovered yet from the COVID-19?	covid19_outcome_recovered	Single choice	YES (yes) NO (no) NOT APPLICABLE (not_applicable)
Did the patient die because of the (suspected) COVID-19 infection?	covid19_outcome_death	Single choice	YES (yes)



	h		NO (no)
Date of death	covid19_outcome_death_date	Date (YYYY-MM-DD)	

Demographics

Title	Variable_ID	Data Type	Options Label (Value)
Age (years)	age_years	Number	
Sex	Sex	Single choice	MALE (male) FEMALE (female) NON-BINARY (non-binary)
Currently pregnant	Pregnancy	Single choice	YES (yes) NO (no)
Current Smoker	current_smoker	Single choice	YES (yes) NO (no)
Former Smoker	former_smoker	Single choice	YES (yes)



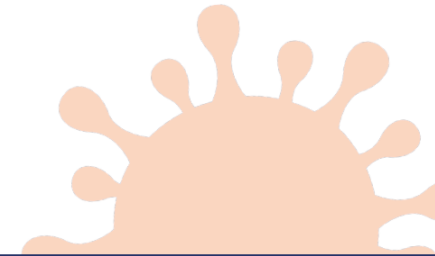
			NO (no)
Height (in cm)	Height	Number	
Weight (in kg)	Weight	Number	
Is the patient's profession in healthcare? Are you a healthcare professional?	is_healthcare_profession	Single choice	YES (yes) NO (no)

MS history and severity

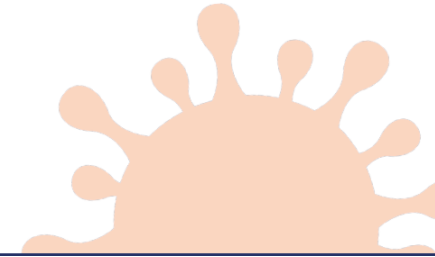
Title	Variable_ID	Data Type	Options Label (Value)
MS Type	ms_type	Single choice	CIS (CIS) RRMS (RRMS) SPMS (SPMS) PPMS (PPMS) Not sure (not_sure)
MS onset	ms_onset_date	Date (YYYY-MM-DD)	



COVID-19 & MS
Global Data
Sharing Initiative



When did you have the first signs of MS?			
MS diagnosis When were you formally diagnosed with MS?	ms_diagnosis_date	Date (YYYY-MM-DD)	
EDSS/PDDS			
Date of evaluation	edss_date_diagnosis	Date (YYYY-MM-DD)	
Value PDDS value	edss_value	Number	Values: [0.0, 10.0]
LABORATORY RESULTS (clinicians only)			
Last White Blood Cell Count before COVID-19			
value	last_white_blood_cell	Number	
unit	last_white_blood_cell_unit	Text	
Last Lymphocyte Cell Count before COVID-19			
value	last_lympho_cell	Number	
unit	last_lympho_cell_unit	Text	



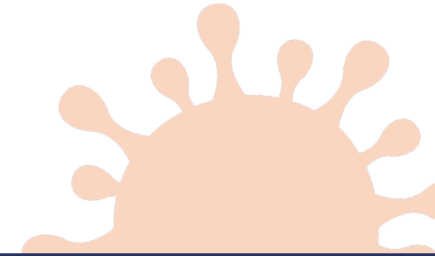
Last B Cell Count before COVID-19			
value	last_b_cell	Number	
unit	last_b_cell_unit	Text	

Disease-Modifying Therapy information

Title	Variable_ID	Data Type	Options Label (Value)
Disease-Modifying Therapy (DMT) current usage	current_dmt	Single choice	YES (yes) NO, but was in the past (no) NEVER TREATED (never_treated)
Type of last/current DMT What is the name of the current/last disease modifying therapy you are/were taking?	type_dmt	Single choice	Interferons (interferons) Glatiramer (glatiramer) Natalizumab (natalizumab) Fingolimod (fingolimod) Dimethyl fumarate (dimethyl_fumarate) Teriflunomide (teriflunomide)



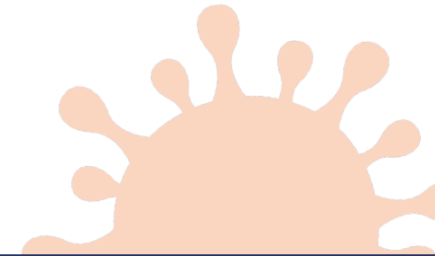
COVID-19 & MS
Global Data
Sharing Initiative



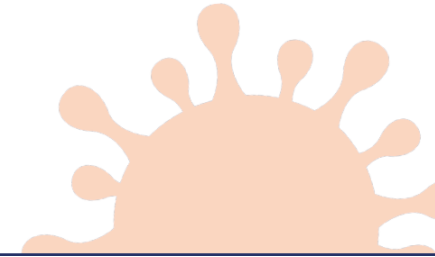
			<p>Alemtuzumab (alemtuzumab)</p> <p>Ocrelizumab (ocrelizumab)</p> <p>Cladribine (cladribine)</p> <p>Siponimod (siponimod)</p> <p>Rituximab (rituximab)</p>
<p>Other/Comment</p> <p>Any comments concerning the question above about your current/last disease modifying therapy</p>	type_dmt_other	Text	
Start Date	dmt_start_date	Date (YYYY-MM-DD)	
Date of last dose	dmt_end_date	Date (YYYY-MM-DD)	
Stop date	dmt_stop_date	Date (YYYY-MM-DD)	
Reason for stop/discontinuation	dmt_stop_reason	Multiple choice	Adverse event/side effect (adverse_event)



COVID-19 & MS
Global Data
Sharing Initiative



			Pregnancy (planning) (pregnancy) Lack of efficacy (lack_efficacy) Patient's decision (patient_decision) Onset of COVID (onset_covid)
Glucocorticoid during the past 2 months Have you received a glucocorticoid in the last 2 months?	dmt_glucocorticoid	Single choice	YES (yes) NO (no)
Start date	dmt_glucocorticoid_start_date	Date (YYYY-MM-DD)	
Stop date	dmt_glucocorticoid_stop_date	Date (YYYY-MM-DD)	
Dosage			
value	dmt_glucocorticoid_dosage_value	Number	
unit	dmt_glucocorticoid_dosage_unit	Text	

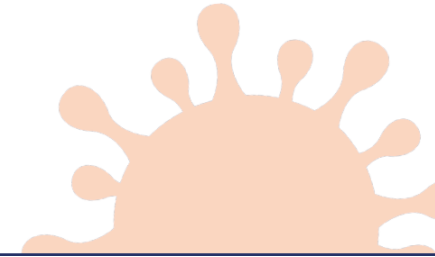


Comorbidities

Title	Variable_ID	Data Type	Options Label (Value)
Comorbidities	has_comorbidities	Single choice	YES (yes) NO (no)
Cardiovascular disease	com_cardiovascular_disease	Single choice	YES (yes) NO (no)
Hypertension	com_hypertension	Single choice	YES (yes) NO (no)
Diabetes	com_diabetes	Single choice	YES (yes) NO (no)
Chronic liver disease	com_chronic_liver_disease	Single choice	YES (yes) NO (no)
Chronic kidney disease	com_chronic_kidney_disease	Single choice	YES (yes) NO (no)
Chronic neurological and neuromuscular disease	com_neurological_neuromuscular	Single choice	YES (yes)



COVID-19 & MS Global Data Sharing Initiative



			NO (no)
Chronic lung disease	com_lung_disease	Single choice	YES (yes) NO (no)
Immunodeficiency disease	com_immunodeficiency	Single choice	YES (yes) NO (no)
Malignancy	com_malignancy	Single choice	YES (yes) NO (no)
Other	com_other	Text	