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_sympt_fever**	Single choice	YES (**yes**) NO (**no**)
Dry Cough	**covid19_sympt_dry_cough**	Single choice	YES (**yes**) NO (**no**)
Fatigue	**covid19_sympt_fatigue**	Single choice	YES (**yes**) NO (**no**)
Pain (joint,bone,muscle)	**covid19_sympt_pain**	Single choice	YES (**yes**) NO (**no**)

Sore Throat	**covid19_sympt_sore_throat**	Single choice	YES (**yes**) NO (**no**)
Shortness of breath	**covid19_sympt_shortness_breath**	Single choice	YES (**yes**) NO (**no**)
Nasal congestion	**covid19_sympt_nasal_congestion**	Single choice	YES (**yes**) NO (**no**)
Chills	**covid19_sympt_chills**	Single choice	YES (**yes**) NO (**no**)
Loss of smell or taste	**covid19_sympt_loss_smell_taste**	Single choice	YES (**yes**) NO (**no**)
Pneumonia	**covid19_sympt_pneumonia**	Single choice	YES (**yes**) NO (**no**)
Do you suspect the patient has or had COVID-19? Do you suspect that you have/had COVID-19?	**covid19_suspected_case**	Single choice	YES (**yes**) NO (**no**)
Did you recommend self-isolation for the patient? Have you been recommended to self-isolate?	**covid19_self_isolation**	Single choice	YES (**yes**) NO (**no**)

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**)

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_deat**	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**)	

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**)

			Alemtuzumab (**alemtuzumab**) Ocrelizumab (**ocrelizumab**) Cladribine (**cladribine**) Siponimod (**siponimod**) Rituximab (**rituximab**)
Other/Comment Any comments concerning the question above about your current/last disease modifying therapy	**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**)

			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**)

			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	