

Dear data custodian,

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 dictionary is also a guideline for the transformation of your source data to the COVID-19 in MS core dataset format.

Important to keep in mind: the **variable ID** and the **label** (the value between brackets in the 3rd and 4th column) should be identical in your dataset that is going to be imported into our platform. During your data collection this is not necessary, but make sure that you do the right transformations before you import your data into the platform.

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.

Thanks again for your participation in this initiative! #DataSavesLives

COVID-19 Incidence

Title	Variable_ID	Data Type	Options Label (Value)	Do you collect this variable? Y/N	Comments Please elaborate on the original ID (=name of the variables) as well as the original format
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)			
<p>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?</p> <p>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?</p>	covid19_country	Single choice	COUNTRY NAME		
<p>Date of COVID-19 symptom onset</p> <p>When have you had the first COVID-19 symptoms?</p>	covid19_date_suspected_onset	Date (YYYY-MM-DD)			

COVID-19 Severity

Title	Variable_ID	Data Type	Options Label (Value)	Do you collect this variable? Y/N	Comments Please elaborate on the original ID (=name of the variables) as well as the original format
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	covid19_ventilation	Single choice	YES (yes) NO (no)		

(suspicious) infection?					
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) NO (no)		
Date of death	covid19_outcome_death_date	Date (YYYY-MM-DD)			

Demographics

Title	Variable_ID	Data Type	Options Label (Value)	Do you collect this variable? Y/N	Comments Please elaborate on the original ID (=name of the variables) as well as the original format
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?	is_healthcare_profession	Single choice	YES (yes) NO (no)		

Are you a healthcare professional?					
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MS history and severity

Title	Variable_ID	Data Type	Options Label (Value)	Do you collect this variable? Y/N	Comments Please elaborate on the original ID (=name of the variables) as well as the original format
MS Type	ms_type	Single choice	CIS (CIS) RRMS (RRMS) SPMS (SPMS) PPMS (PPMS) Not sure (not_sure)		
MS onset When did you have the	ms_onset_date	Date (YYYY-MM-DD)			

first signs of MS?					
MS diagnosis When were you formally diagnosed with MS?	ms_diagnosis_date	Date (YYYY-MM-DD)			
EDSS/PDSS					
Date of evaluation	edss_date_diagnosis	Date (YYYY-MM-DD)			
Value PDSS 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)	Do you collect this variable? Y/N	Comments Please elaborate on the original ID (=name of the variables) as well as the original format
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)		Comment from MSDA/QMENTA: you can change the names of the DMT's, the options the patients/clinicians have in your survey. However, the labels (values in bold between brackets) should be the same in order to be able to do the import into the platform. For example, you may offer several interferon options to the user but they all are saved as "interferons" in your import file for the platform.

			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)	Do you collect this variable? Y/N	Comments Please elaborate on the original ID (=name of the variables) as well as the original format
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			