## 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.

In order to get more insight into the variables of the core dataset that you will actually be collecting, its format and possible transformations that would influence the analyses, could you please **complete the last two columns of this dictionary** and send it afterwards to [lotte.geys@uhasselt.be](mailto:lotte.geys@uhasselt.be)? Thanks!

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

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| **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**) |  |  |  |
| 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  When have you had the first COVID-19 symptoms? | **covid19\_date\_suspected\_onset** | Date  (**YYYY-MM-DD**) |  |  |  |

## COVID-19 Severity

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| **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 (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**)  NO (**no**) |  |  |
| Date of death | **covid19\_outcome\_death\_date** | Date  (**YYYY-MM-DD**) |  |  |  |

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## Demographics

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| **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?  Are you a healthcare professional? | **is\_healthcare\_profession** | Single choice | YES (**yes**)  NO (**no**) |  |  |

## MS history and severity

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| **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 first signs of MS? | **ms\_onset\_date** | Date  (**YYYY-MM-DD**) |  |  |  |
| 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**)  Dimethyl fumarate (**dimethyl\_fumarate**)  Teriflunomide (**teriflunomide**)  Alemtuzumab (**alemtuzumab**)  Ocrelizumab (**ocrelizumab**)  Cladribine (**cladribine**)  Siponimod (**siponimod**)  Rituximab (**rituximab**) |  | **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. |
| 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 |  |  |  |