Ean NEuro-covid ReGistrY (ENERGY)

Patient Number	________________ (automatically generated patientcounter)
Data entry is	◯ prospective ◯ retrospective

Identification

Username	________________ (automatically filled out user ID)
Site of visit	◯ Hospital (Ward/ICU) ◯ Emergency Room ◯ Outpatient service ◯ Other, specify (Where is the patient seen by neurologist)
If site of visit is other, please specify	________________
Reason for neurological assessment	◯ Consulation ◯ Other, specify
If reason is other, please specify	________________
Date of registration	________________ (Date in which the patient was first seen by neurologist (MM/DD/YYYY))
Date of admission	________________ (If hospitalized, date of patient admission (MM/DD/YYYY))

Demographics & History

Year of birth	________________ ((YYYY, 4-digits))
Biological sex	◯ Male ◯ Female ◯ Intersex ◯ Unknown
Patient's height	________________ ((in cm, 3-digits))

Patient's weight	______________________ ((in kg, 3-digits))
Current smoker	◯ Yes ◯ No ◯ Unknown
Source of COVID-19 contact	◯ Occupation ◯ Family member ◯ Social ◯ Travel ◯ Unkown ◯ Other, specify (Where was the most probable exposure)
If source is other, please specify	______________________
Date of COVID-19 symptom onset (If the exact day is unkown, enter 01 as day and check the next question!)	______________________ (Date when the patient started noticing first symptoms (MM/DD/YYYY))
	☐ I don't know the exact day
Final COVID-19 status (final diagnosis)	☐ Suspected ☐ Confirmed ☐ PCR negative ☐ PCR positive (oropharyngeal AND/OR serum AND/OR CSF) ☐ Antibodies positive ☐ Other, specify (If patient first tested negative and then turned positive, please code as positive. (Multiselect))
If final status is other, please specify	______________________

Comorbidities in history

Any comorbidity with impact on patients perceived health? If yes, specify in the next questions	◯ Yes ◯ No ◯ Unkown
Arterial hypertension	◯ Yes ◯ No ◯ Unknown (History of hypertension or taking anti-hypertensive medications prior to admission)
Diabetes	◯ Type 1 ◯ Type 2 ◯ Unkown ◯ No ◯ Other, specify (History of diabetes (types 1 or 2) or taking antidiabetic medications)
If diabetes is other, please specify	______________________

	Yes	No	Unknown
Cardiovascular Disease	◯	◯	◯
Chronic kidney disease	◯	◯	◯
Chronic liver disease	◯	◯	◯
Chronic pulmonary disease	◯	◯	◯
Anemia	◯	◯	◯
Cancer	◯	◯	◯
Immunosuppressed state	◯	◯	◯

Cardiovascular Disease: History of cardiovascular disease (myocardial infarction; chronic heart failure, coronary artery disease, peripheral artery disease or taking cardiovascular drugs) Chronic kidney disease: History of any disease affecting renal function (includes undergoing dialysis) Chronic liver disease: History of any disease affecting liver function Chronic pulmonary disease: History of any disease affecting lung function (includes chronic obstructive pulmonary disease, asthma) Anemia: History of decrease in whole-blood Hb concentration requiring treatment Cancer: Any neoplasm with impact on patient's health Immunosuppressed state: Pre-existing immunosuppressed state (taking immunosuppresants/chemotherapy, chronic steroids, hematologic malignancy, HIV, other immunodeficiency syndrome)

Other non-neurological comorbidities

◯ Yes, specify ◯ No
◯ Unknown
(Any other non-neurological disease with impact on patient's health)

If any other non-neurological comorbidities is yes, please specify

____

Premorbid modified Rankin Scale score (mRS)

____
(mRS score (0 - 5, 1-digit))

Another complication

◯ Yes, specify ◯ No
◯ Unknown
(Did the patient develop another complication)

Any neurological disease with impact on patient's health

☐ Dementia
☐ Parkinson's disease
☐ Stroke: ICH, ischemic stroke, TIA
☐ Multiple sclerosis
☐ Motor neuron disease
☐ Neuromuscular disorder
☐ Neuropathy
☐ Other, specify
☐ No
☐ Unkown
((Check all that apply, multiselect))

If another complication is yes, please specify

____

If any other neurological disease, please specify

____

Complications: Any complications requiring medical intervention and/or hospitalization
Dyspnea: Shortness of breath not explained by an overt pulmonary disease (e.g. pneumonia, ARDS)
Pneumonia: Did the patient develop clinical or radiographic evidence of pneumonia
Cardiovascular: Did the patient develop cardiovascular complications (including myocardial infarction)
Renal insufficiency/dialysis: Did the patient develop acute kidney injury requiring dialysis/continuous renal replacement therapy (CRRT)
Coagulation disorder/disseminated intravascular coagulation: Did the patient develop any coagulation disorder/disseminated intravascular coagulation
Refractory shock: Did the patient experience refractory shock while hospitalized
Extra-Corporeal Membrane Oxygenation (ECMO): Did the patient require ECMO therapy while hospitalized
Mechanical ventilation: Did the patient receive mechanical ventilation

	Yes	No	Unknown
Renal insufficiency/dialysis	○	○	○
Coagulation disorder /Disseminated intravascular coagulation	○	○	○
Refractory shock	○	○	○
Extra-Corporeal Membrane Oxygenation (ECMO)	○	○	○
Mechanical ventilation	○	○	○

New Neurological Findings

Neurological findings at visit ○ Yes ○ No
(Did the patient have any neurological complaint)

Neurological findings date

(If the exact day is unkown, enter 01 as day and check the next question!)

____
(Date of patient developed the first neurological signs and symptoms (DD/MM/YYYY))

☐ I don't know the exact day

	Yes, not COVID assoc	Yes, likely COVID assoc	No	Unknown
Headache	○	○	○	○
Hyposmia/Hypogeusia	○	○	○	○
Dysautonomia	○	○	○	○
Vertigo	○	○	○	○
Myalgia	○	○	○	○
Sleep disturbances	○	○	○	○
Sleepiness/Hypersomnia	○	○	○	○
Cognitive impairment	○	○	○	○
Dysexecutive syndrome	○	○	○	○
Hyperactive delirium	○	○	○	○
Hypoactive delirium/acute encephalopathy	○	○	○	○

Stupor/coma	◯	◯	◯	◯
Syncope	◯	◯	◯	◯
Seizures/status epilepticus	◯	◯	◯	◯
Meningitis/encephalitis	◯	◯	◯	◯
Stroke	◯	◯	◯	◯

Headache: Did the patient develop new on set headache before or or during hospitalization for COVID 19 (self report or family report)
Hyposmia/Hypogeusia: Did patient have abnormal smell or taste before or during hospitalization/clinical visit for COVID-19 (self-reported or family reported)
Dysautonomia: Did the patient exhibit signs/symptoms of dysautonomia
Vertigo: Did the patient report about dizziness with the feeling that (s)he or the objects around are moving when they are not
Myalgia: Did patient develop/complain about myalgia
Sleep disturbances: Did the patient complain/exhibit a disturbance of sleep or a non-restorative sleep
Sleepiness/Hypersomnia: Did patient develop excessive daytime sleepiness (involuntary napping, daily) and/or hypersomnia (>10 hours sleep/24h)
Cognitive impairment: Did the patient develop any symptoms of higher functions impairment (amnesia, aphasia, apraxia, agnosia, etc)
Dysexecutive syndrome: Does the patient present inattention, disorientation, poorly organized movements in response to command in off-sedation
Hyperactive delirium: Did the patient develop delirium (acute mental disturbance characterized by confused thinking and disrupted attention often accompanied by impaired speech or hallucinations)
Hypoactive delirium/acute encephalopathy: Did patient develop new onset altered mental status before or during hospitalization for COVID 19, EXCLUDING direct medication effect or hypotension (MAP < 60 mmHg)
Stupor/coma: Did patient develop stupor or coma (no speech, absent purposeful movements/reaction to painful stimuli, no eye opening or only for a short time even after painful stimuli)
Syncope: Did the patient exhibit transient loss of consciousness due to an insufficient blood flow to the brain
Seizures/status epilepticus: Did the patient present with transient or prolonged disruption of the brain's electrical activity accompanied by altered consciousness and/or other neurological and behavioural manifestations
Meningitis/encephalitis: Did patient have meningitis or encephalitis (confirmed by CSF findings)
Stroke: Is the patient exhibiting signs of acute stroke (confirmed by neuroimaging)

Does the patient present any of new observed movement disorders

	Yes, not COVID assoc	Yes, likely COVID assoc	No	Unknown
Tremor	◯	◯	◯	◯
Chorea	◯	◯	◯	◯
Dystonia	◯	◯	◯	◯
Myoclonus	◯	◯	◯	◯
Dyskinesia	◯	◯	◯	◯
Parkinsonism	◯	◯	◯	◯

	Yes, not COVID assoc	Yes, likely COVID assoc	No	Unknown
Ataxia	◯	◯	◯	◯
Spinal cord disorder	◯	◯	◯	◯
Peripheral neuropathy	◯	◯	◯	◯

Ataxia: Did patient have ataxia (lack of voluntary coordination of muscle movements that can include gait abnormality, speech changes, and abnormalities in eye movements)
Spinal cord disorder: Did patient show signs of myelopathy or evidence of myelitis (confirmed by CSF)
Peripheral neuropathy: Any type of impairment of peripheral nervous system

Other new neurological findings

◯ Yes - not COVID assoc
◯ No
◯ Yes - likely COVID assoc
◯ Unknown
(Did the patient develop other new neurological symptoms or signs)

If other findings is yes, please specify

____

Additional Diagnostic Tools

CSF performed

◯ Yes ◯ No ◯ Unknown
(Did the patient undergo a lumbar puncture)

If abnormal, please specify

◯ Yes - not COVID assoc
◯ No ◯ Yes - likely COVID assoc
◯ Unknown

CT/MRI

◯ Yes
◯ No
◯ Findings assoc. with neuro disease
◯ Unknown
(Did the patient undergo neuroimaging)

If abnormal, please specify

◯ Yes - not COVID assoc
◯ No ◯ Yes - likely COVID assoc
◯ Unknown

Outcome

	Yes	No	Unknown
Was the patient admitted to the hospital?	◯	◯	◯
Was the patient admitted to the ICU?	◯	◯	◯

Status at discharge/visit

Modified Rankin Scale score (mRS) (Discharge/visit)

____
(mRS score at discharge (0 - 6, 1-digit))

If (mRS=6): Date of death

____
((MM/DD/YYYY))

If (mRS=6): Autopsy performed

◯ Yes ◯ No ◯ Unknown

If (mRS=0-5): Date of discharge

____
((MM/DD/YYYY))

NCC Questionnaire Supplementary

NCC additional values	◯ Yes ◯ No (Optionally you have the possibility to fill out the NCC CRF)
Patient's ethnicity	◯ Hispanic or Latino ◯ Not Hispanic or Latino ◯ Unknown ◯ Not reported ◯ Other, specify (self-reported)
If patient's self-reported ethnicity is other, define	__________________________________
Empiric COVID 19 treatment	◯ None ◯ Hydroxychloroquine ◯ Zithromax ◯ H+Z combo ◯ IVIG ◯ Remdesivir ◯ lopinavir/ritonavir ◯ Other, specify (What empiric COVID 19 treatemt(s) was given)
If empiric COVID 19 treatment is other, which?	__________________________________ (Empiric COVID 19 tx (other))
Pre-Existing Code Status	◯ Full ◯ DNR ◯ DNI ◯ CMO ◯ Other (Pre-existing code status prior to presentation to hospital)
ATII-RA	◯ Yes ◯ No (Did the patient receive angiotension -II-receptor antagonists within last 30 days before admission)
Corticosteriods	◯ Yes ◯ No (Did the patient take nonsteriodal or corticosteriods 30 days prior to admission)
Other immunosuppressives	◯ Yes ◯ No (Did the patient receive other immunosuppresive medications)
Plegia/paralysis	◯ Yes, specify ◯ No (Did patient develop new plegia/paresis, including single limb plegia/paresis, hemiplegia/paresis, and quadriplegia/paresis)
If plegia/paralysis is yes, please specify	__________________________________ (Describe new plegia or paralysis including limb, location)
Aphasia	◯ Yes ◯ No (Did patient present with new aphasia or develop aphasia during hospitalization)

Abnormal tone	◯ Yes, specify ◯ No (Did the patient have abnormal tone)
If description of abnormal is other, please specify	__________________________________ (If abnormal tone, describe (other))
Movement disorder	◯ Tremor ◯ Stiffness ◯ Change in facial expression ◯ Disturbances of dexterity ◯ Micrographia ◯ Weakness ◯ Dystonia ◯ Ambulatory/Axial Difficulties-Freezing ◯ Ambulatory/Axial Difficulties-Lack of arm swing ◯ Ambulatory/Axial Difficulties-Leg dragging ◯ Ambulatory/Axial Difficulties-Shuffling of gait ◯ Ambulatory/Axial Difficulties-Postural imbalance ◯ Ambulatory/Axial Difficulties-Falls ◯ Ambulatory/Axial Difficulties-Slowness of gait ◯ Ambulatory/Axial Difficulties-Stooped posture ◯ Ambulatory/Axial Difficulties-Other abnormality of posture or gait ◯ other, specify (Indicate the type of new movement disorder experienced)
If movement disorder is other, please specify	__________________________________
Abnormal brainstem reflexes	◯ abnormal corneal ◯ abnormal pupillary ◯ abnormal cough ◯ abnormal gag ◯ no abnormal reflexes ◯ other, specify (Specify if any of the following brainstem reflexes abnormal)
If abnormal brainstem reflexes is other, specify	__________________________________
Did patient exhibit or report new sensory symptoms	◯ Yes ◯ No (Did patient exhibit or report new sensory symptoms)
Best GCS	__________________________________ (BEST documented Glasgow Coma Score AFTER onset of severe neurological complication. For intubated patients: please use imputed GCS (1 - 15))
Baseline Oxygen Saturation (SPO2)	__________________________________ ((0.000 - 100.000))

Baseline respiratory rate

((0 - 50))

Baseline arterial blood gas Ph
(first available since acute hospital admission)

((6.00 - 8.00))

Baseline arterial blood gas PaO2
(first available since acute hospital admission)

((10.00 - 200.00))

Baseline arterial blood gas PaCO2
(first available since acute hospital admission)

((10.00 - 100.00))

Baseline arterial blood gas HCO3
(first available since acute hospital admission)

((10.00 - 40.00))

Baseline arterial blood gas O2 sat

((40 - 100))

Pre-intubation Oxygen Saturation (SPO2)

((0 - 100))

Pre-intubation Respiratory Rate

((0 - 50))

Pre-intubation arterial blood gas Ph

((6.00 - 8.00))

Pre-intubation arterial blood gas PaO2

((10.00 - 200.00))

Pre-intubation arterial blood gas PaCO2

((10.00 - 100.00))

Pre-intubation arterial blood gas HCO3

((10.00 - 40.00))

Pre-intubation arterial blood gas O2 sat

((40 - 100))

Days on Mechnical Ventilation

((0 - 60))

WBC on presentation

____
((0.00 - 50.00) (unit: 10^9/L))

Lymph on presentation

____
((0.00 - 50.00) (unit: 10^9/L))

Neuroimaging type

☐ CT scan head
☐ MRI head
☐ MRI spine
☐ none
☐ other, specify
(Describe the type of neuroimaging performed (Multiselect))

If neuroimaging type is other, please specify

____

ICU LOS

____
(Number of days patient received care in the critical care unit (0 - 100))

Hospital LOS

____
(Number of days patient received care in the hospital (0 - 100))

Discharge disposition

◯ home
◯ nursing home/SNF
◯ LTACH
◯ hospice
◯ acute rehab
◯ subacute rehab
◯ other, specify
(State the discharge location)

If dischare disposition type is other, please specify

____
(Discharge disposition (other))

Finally

Any comment

____