



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

- Consultation
 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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chronic kidney disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chronic liver disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chronic pulmonary disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anemia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Immunosuppressed state	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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 immunosuppressants/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
 Unknown
 ((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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Coagulation disorder /Disseminated intravascular coagulation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Refractory shock	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Extra-Corporeal Membrane Oxygenation (ECMO)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mechanical ventilation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

New Neurological Findings

Neurological findings at visit

Yes No

(Did the patient have any neurological complaint)

Neurological findings date

(If the exact day is unknown, 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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hyposmia/Hypogeusia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dysautonomia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vertigo	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Myalgia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep disturbances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleepiness/Hypersomnia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cognitive impairment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dysexecutive syndrome	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hyperactive delirium	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hypoactive delirium/acute encephalopathy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Stupor/coma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Syncope	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seizures/status epilepticus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Meningitis/encephalitis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stroke	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chorea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dystonia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Myoclonus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dyskinesia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parkinsonism	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Yes, not COVID assoc	Yes, likely COVID assoc	No	Unknown
Ataxia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spinal cord disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Peripheral neuropathy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Was the patient admitted to the ICU?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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 treatment(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)

Corticosteroids

Yes No
 (Did the patient take nonsteroidal or corticosteroids 30 days prior to admission)

Other immunosuppressives

Yes No
 (Did the patient receive other immunosuppressive 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 Mechanical Ventilation

((0 - 60))

WBC on presentation

 ((0.00 - 50.00) (unit: 10⁹/L))

Lymph on presentation

 ((0.00 - 50.00) (unit: 10⁹/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 discharge disposition type is other, please specify

 (Discharge disposition (other))

Finally

Any comment
