

International Neuromuscular COVID-19 Database

The International Neuromuscular COVID-19 Database is a paediatric and adult database to monitor and report on outcomes of “Coronavirus Disease 2019” (COVID-19) occurring in patients with Neuromuscular Diseases. There is an urgent need to understand outcomes of patients who acquire “severe acute respiratory syndrome coronavirus 2” (SARS-CoV-2) infection and are receiving immunosuppressants and/or have disease features (e.g. cardiac or respiratory involvement) that may affect the outcome of COVID-19. This will help guide neuromuscular specialists and other health care professionals in advising and caring for their patients.

Please note, this survey is for health care professionals caring for paediatric or adult neuromuscular patients. Reporting a case to this registry should take 10-15 minutes. Please also report if you have a high suspicion of COVID-19 infection in your patients and indicate that this is unconfirmed. Patients’ identifiers such as name or date of birth are NOT collected.

After submitting a case you will receive a link allowing you to return to the same case to update/complete data.

Please report after a minimum of 7 days and sufficient time has passed to observe the disease course through resolution of acute illness and/or death although we appreciate your time is pressured and precious currently. You may not have access to information to answer all questions. Do your best.

Please note that if you are reporting a case of Mitochondrial Disease or a case of Guillain-Barré Syndrome (GBS) associated with COVID-19 you will be asked to submit a second short disease specific-form that will pop-up after the first form is completed.

Please contact Smaragda Agathou (s.agathou@ucl.ac.uk) if you have any questions about the database. Please note that this email address is for technological clarifications about the database and NOT for patient data and queries.

Reporting provider details

Family name/last name of reporting provider

* must provide value

Given name/first name of reporting provider

* must provide value

Email address

* must provide value

Institutional email preferred

Role of reporting provider (e.g., physician, nurse, etc.)

Specialty of reporting provider

Hospital or clinic name

* must provide value

City of hospital/clinic

* must provide value

Country of hospital/clinic

* must provide value

Neuromuscular COVID-19 patient information

Please do not enter any patient identifiable information in open textboxes in this form.

Local ID for case (optional)

Patient age

* must provide value

0-120 years

Patient sex at birth

* must provide value

reset

Race/ethnic origin

Check all that apply

Smoking Status

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Does the patient currently use e-cigarettes or vape?

Current smoker

Former smoker

Never smoked

Unknown smoking status

reset

Has the patient had the seasonal flu vaccination this season?

Yes

No

Unknown

reset

COVID-19 information

COVID-19 Diagnosis: How was the COVID-19 diagnosis made?

+ Presumptive diagnosis based on symptoms only

+ PCR swabs

+ Antibody/Serology

+ Metagenomic testing

+ Chest radiograph (X-ray)

+ CT scan

+ Laboratory assay, type unknown

+ CSF

+ Unknown

✓ Other

+ Option available for new GBS cases only: Presented during pandemic but without COVID-19 specific symptoms or confirmatory tests (if choosing this option please use date of onset of GBS symptoms in date of COVID-19 diagnosis)

Check all that apply

COVID-19 Diagnosis: other diagnostic testing, please specify:

Date of COVID-19 diagnosis (or presumptive diagnosis): Day

* must provide value

Date of COVID-19 diagnosis (or presumptive diagnosis): Month

* must provide value

Date of COVID-19 diagnosis (or presumptive diagnosis): Year

* must provide value

2019

2020

2021

[reset](#)**How did you become aware of this neuromuscular patient with COVID-19 (or presumptive COVID-19)?**

I am/was one of the patient's primary COVID-19 carers

This patient is under the care of my team/department and I became aware that the patient has/had COVID-19

1 + 2 above

I was consulted about this patient but I am/was not one of the patient's primary COVID-19 carers and the patient is not under the care of my team/department

Other

[reset](#)**Other type of awareness of neuromuscular patient with COVID-19 (or presumptive COVID-19), please specify:****Infection Acquisition: In the 14 days before onset of illness did the patient have any of the following?**

☐ History of travel to an area with documented cases of COVID-19 infection

☐ Close contact with a confirmed or probable case of COVID-19 infection

☐ Presence in a healthcare facility where COVID-19 infections have been managed

☐ Direct contact with an health care professional (in the community)

☐ None of the above (community acquired - but no known direct contact with an health care professional)

☐ Unknown

☒ Other

Check all that apply

COVID-19 other infection acquisition, please specify:

COVID-19 Diagnosis: location

Home or standalone testing (e.g. mobile testing site)

Nursing home or assisted living facility

Outpatient facility

Emergency department

Inpatient/hospital

Unknown

Other

reset

COVID-19 Diagnosis: other location, please specify:

Has this patient ever had symptoms of COVID-19 infection?

Yes

No

Unknown

reset

COVID-19: Treatment (only include medications given as treatment for this infection; treatment for underlying neuromuscular disease listed in next section)

- ☐ No treatment except supportive care
- ☐ Remdesivir
- ☐ Lopinavir/ritonavir
- ☐ Oseltamivir
- ☐ Favipiravir
- ☐ Darunavir
- ☐ Azithromycin
- ☐ Anti-malarials (e.g. chloroquine, hydroxychloroquine)
- ☐ IL-1b inhibitors (e.g., anakinra, canakinumab)
- ☐ IL-6 inhibitors (e.g. tocilizumab, sarilumab, siltuximab)
- ☐ Colchicine
- ☐ Bevacizumab
- ☐ JAK inhibitors (e.g. tofacitinib, baricitinib, upadacitinib, ruxolitinib)
- ☐ Serpin inhibitors
- ☐ Ciclesonide
- ☐ Glucocorticoids
- ☐ IVIG
- ☐ Plasma from recovered patients
- ☐ Antibiotics (either prophylactic or to treat secondary infection)
- ☐ Heparin (prophylactic doses)
- ☐ Heparin (high doses)

☒ Other

Check all that apply

COVID-19: Treatment, additional notes/other:

Outcome of COVID-19 disease

* must provide value

Full recovery

Resolved, with sequelae

Deceased, due COVID-19

Deceased, due to another reason (reason needs to be clearly not COVID-19 related)

Vital status not known at this time

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Please confirm that the patient is dead

* must provide value

Yes, the patient has died

No, the patient has not died

reset

Approximate number of days from COVID-19 symptom onset to death:**Outcome of COVID-19 is "Deceased, due to another reason (reason needs to be clearly not COVID-19 related)", please specify cause of death:**

* must provide value

Was the patient hospitalised during the illness?

Yes

No

Unknown

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What was the maximum level of care required during the patient's illness (so far)?

Did not require supplemental oxygen

Required supplemental oxygen

Required non-invasive ventilation (NIV) or high flow oxygen devices

Required invasive mechanical ventilation

Required extracorporeal membrane oxygenation (ECMO)

Ventilation required, but type unknown

Interventions unknown

reset

COVID-19: Complications (except neurological)

- ☐ No known complications
- ☐ Acute Respiratory Distress Syndrome (ARDS)
- ☐ Sepsis
- ☐ Myocarditis or new heart failure
- ☐ Concomitant or secondary infection (e.g. bacterial pneumonia, Influenza)
- ☐ Cytokine storm or similar condition (e.g. macrophage activation syndrome/reactive hemophagocytic lymphohistiocytosis)
- ☐ Venous tromboembolism (VTE) - deep vein thrombosis (DVT)
- ☐ Venous tromboembolism (VTE) - pulmonary embolism (PE)
- ☐ Acute kidney injury (AKI) / Acute kidney failure
- ☒ Other serious complication

check all that apply

COVID-19 complications: please specify other serious complications

COVID-19: Neurological Complications

- ☐ No known neurological complications
- ☐ Acute disseminated encephalomyelitis (ADEM)
- ☐ Acute flaccid paralysis
- ☐ Aseptic meningitis
- ☐ Ataxia
- ☐ Cranial neuropathy
- ☐ Encephalopathy-Encephalitis
- ☐ Epilepsy-Epilepsia Partialis Continua
- ☐ Guillain-Barré syndrome
- ☐ Haemorrhagic stroke
- ☐ Ischaemic stroke
- ☐ Hyperkinetic movement disorder
- ☐ Neuralgia
- ☐ Vasculitis
- ☐ Venous sinus thrombosis

☒ Other serious neurological complication

check all that apply

COVID-19 complications: please specify other serious complications

Time frame (number of days) of neurological complication(s) post primary infection:

Neuromuscular disease and treatment

Neuromuscular diagnosis

* must provide value

Motor neurone disease

Dermatomyositis

Anti-synthetase syndrome

Immune mediated necrotising myopathy

Inclusion Body Myositis (IBM)

Other idiopathic inflammatory myopathy

X-linked muscular dystrophy (Duchenne/Becker)

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Neuromuscular diagnosis other, please specify:

Is this a pre-existing or new (triggered by SARS-CoV-2) neuromuscular diagnosis?

* must provide value

Pre-existing neuromuscular diagnosis

New neuromuscular diagnosis (triggered by SARS-CoV-2)

Unknown

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Were any of the following neuromuscular disease-related features present at the time of COVID-19 symptom onset (or at COVID-19 diagnosis if asymptomatic)?

+ Ventilated - tracheostomy

+ Non invasive ventilation (BiPAP, CPAP)

+ Forced Vital Capacity (FVC) less than 60%

+ Dysphagia

+ Enteral nutrition (e.g. PEG, RIG)

+ Cardiac involvement of neuromuscular disease (e.g. cardiomyopathy)

+ Severely impaired cardiac function (LVEF < 30%)

+ Pacemaker

+ ICD

+ Able to walk with aids or part-time wheelchair user

+ Full-time wheelchair user

+ None present

+ Unknown

Check all that apply

Modified Rankin Scale *BEFORE* onset of COVID-19

No symptoms

No significant disability. Able to carry out all usual activities, despite some symptoms

Slight disability. Able to look after own affairs without assistance, but unable to carry out all previous activities

Moderate disability. Requires some help, but able to walk unassisted

Moderately severe disability. Unable to attend to own bodily needs without assistance, and unable to walk unassisted

Severe disability. Requires constant nursing care and attention, bedridden, incontinent

Unknown

reset

Modified Rankin Scale *AFTER* COVID-19 (last functional status known post-infection)

No symptoms

No significant disability. Able to carry out all usual activities, despite some symptoms

Slight disability. Able to look after own affairs without assistance, but unable to carry out all previous activities

Moderate disability. Requires some help, but able to walk unassisted

Moderately severe disability. Unable to attend to own bodily needs without assistance, and unable to walk unassisted

Severe disability. Requires constant nursing care and attention, bedridden, incontinent

Unknown

Not applicable (outcome was death)

reset

Neuromuscular disease activity/control (if applicable to the disease) at the time of COVID-19 symptom onset (or at COVID-19 diagnosis if asymptomatic)

Inactive diseases / remission / controlled

Active disease / not controlled

Not applicable

Unknown

reset

Treatments for underlying neuromuscular disease

Glucocorticoids (including prednisone, methylprednisolone) at time of COVID-19 symptom onset (or at COVID-19 diagnosis if asymptomatic):

☒ Yes

☐ No

☐ Unknown

[reset](#)

If taking glucocorticoids, then dose ([prednisone equivalent](#)) at the time of COVID-19 symptom onset (or at COVID-19 diagnosis if asymptomatic):

mg/day (enter number only)

Was the glucocorticoid stopped or continued after COVID-19 diagnosis?

☐ Stopped

☐ Continued at same dose

☐ Tapered dose

☐ Increased dose

☐ Unknown

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Immune modulating medications immediately prior to the time of COVID-19 symptom onset (or at COVID-19 diagnosis if asymptomatic)

☒ None

☐ Abatacept

☐ Alemtuzumab (Campath)

☐ Antifibrotics (pirfenidone, nintedanib)

☐ Antimalarials (including hydroxychloroquine, chloroquine)

☐ Apheresis

☐ Apremilast

☐ Azathioprine / 6-mercaptopurine (6-MP)

☐ Belimumab

☐ CD-20 inhibitors (including rituximab within last 12 months, ofatumumab)

☐ Cyclophosphamide (IV or oral)

☐ Cyclosporine

☐ Denosumab

☐ Human stem cell transplant

☐ IL-1 inhibitors (including anakinra, canakinumab, rilonacept)

Check all that apply

☐ IL-6 inhibitors (including tocilizumab, sarilumab)

☐ IL-12/23 inhibitors (ustekinumab)

☐ IL-23 inhibitors (guselkumab, risankizumab, tildrakizumab)

☐ IL-17 inhibitors (including secukinumab, ixekizumab)

☒ Intravenous immunoglobulin (IVIG)

☐ JAK inhibitors (including tofacitinib, baricitinib, upadacitinib)

☐ Leflunomide

☐ Methotrexate

☐ Mycophenolate mofetil / mycophenolic acid (Myfortic)

☐ Sulfasalazine

☐ Tacrolimus

☐ Thalidomide / lenalidomide

☐ TNF-inhibitors (including adalimumab, certolizumab, etanercept, golimumab, infliximab, and biosimilars)

☐ Unknown

☐ Other

Was Intravenous immunoglobulin (IVIG) stopped or continued after COVID-19 diagnosis?

Stopped

Continued

Continued at lower dose or longer application interval

Unknown

[reset](#)

At the time of COVID-19 symptom onset (or diagnosis if asymptomatic), was the patient taking any of the following medications?

	Yes and medication continued	Yes and medication stopped	No	Unknown
ACE inhibitor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Angiotensin receptor blocker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Non-selective NSAIDs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Selective NSAIDs (COX-2 inhibitors)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
PD5 inhibitor (e.g. sildenafil)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Comorbidity and Pregnancy

☐ None

- ☐ Interstitial lung disease (e.g. NSIP, UIP, IPF)
- ☐ Obstructive lung disease (COPD/asthma)
- ☐ Obstructive Sleep Apnoea (OSA)
- ☐ Restrictive lung disease
- ☐ Other lung disease
- ☐ Diabetes
- ☐ Obesity (BMI ≥ 30)
- ☐ Morbid obesity (BMI ≥ 40)
- ☐ Hypertension
- ☐ Cardiovascular disease (coronary artery disease, congestive heart failure, arrhythmia)
- ☐ Cerebrovascular disease
- ☐ Pulmonary hypertension
- ☐ Chronic renal insufficiency or end stage renal disease
- ☐ Cancer
- ☐ Organ transplant recipient
- ☐ Primary immunodeficiency
- ☐ HIV
- ☐ Inflammatory bowel disease
- ☐ Liver disease
- ☐ Other chronic neurological disease (non-neuromuscular)
- ☐ Trisomy 21
- ☐ Psychiatric condition (e.g., schizophrenia, bipolar disorder)
- ☐ Rheumatological disease
- ☐ Macrophage activation syndrome (prior to COVID-19 diagnosis)
- ☐ Atopic eczema
- ☐ Congenital heart disease
- ☐ Psoriasis
- ☐ Pregnancy
- ☐ Post-partum (< 6 weeks)
- ☐ Unknown



Other

Check all that apply

Other comorbidity - please specify:

Laboratory Test results (optional)

Are there any laboratory test results available related to this patient's COVID-19 infection? (optional)

Yes

No

Unknown

reset

Follow-up/Notes

May we contact you to get more information about the outcomes of this case?

Yes

No

reset

Would you like to share any lessons or other aspects from this case?

Please do not write any patient identifiable information in this box.

Expand

Do you have any comments or feedback on the survey itself?

Expand

Information on how your personal data are processed is within this privacy notice:

Attachment:  [Neuromuscular COVID-19 Database Privacy Notice.pdf](#) (0.64 MB)

Submit

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