**Rheumatology COVID-19 Provider-Entered Registry**

Introduction

Thank you for agreeing to take part in this important effort on behalf of the global rheumatology community. Our hope is that information you and others provide will help us understand how the novel COVID-19 virus impacts patients with rheumatologic conditions or those taking immunosuppressive drugs. We hope to better understand their risk of infection, track outcomes, and use this data to inform treatment.

Please note, this survey is for health care professionals caring for adult rheumatology patients.

For providers who wish to enter reports on **pediatric patients**, please open the COVID-19 Global Pediatric Registry: <https://carragroup.org/research-registry/projects/covid-19-global-pediatric-rheumatology-database>.

**For patients** wishing to report their own symptoms, please use this link to the Patient Experiences Survey: https://rheum-covid.org/patient-survey/

In addition, if your country is part of **EULAR** (European League Against Rheumatism), please do not use this registry. Here is the link to the EULAR (GDPR-compliant) registry for both pediatric and adult rheumatology: <https://www.eular.org/eular_covid19_database.cfm>.

The case report form should take about 7-10 minutes to complete. You can enter all the data at one time, or come back to the registry later to update or compete the entry. Patients identifiers such as name or date of birth will not be collected. All information will be kept strictly confidential and will only be shared with researchers compiling information. Information and updates will be shared via the COVID-19 Global Rheumatology Alliance website: <https://rheum-covid.org>.

The success of this collaborative effort depends on active participation by our rheumatology community to obtain accurate and reliable information. We ask that you share this site with your colleagues and encourage them to report any cases of COVID-19 in rheumatology patients.

*As a final reminder, please do NOT use this registry to enter 'test' data, data about yourself (as a patient), data from pediatric patients, or from EULAR countries.*

The COVID-19 Global Rheumatology Alliance

If you have questions about the survey, you may send them to: RheumCOVIDregistry@ucsf.edu

## **Rheum COVID-19 Provider Information**

Family name/last name of reporting provider

Given name/first name of reporting provider

Email address:

(Institutional email preferred)

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

Specialty of reporting provider

Hospital or clinic name

City of hospital/clinic

State or province of hospital/clinic

Country of hospital/clinic

(EULAR countries are NOT included in this list. There is a separate registry for them.)

**This form is for reference only, please do not use it to provide data to the registry**

**Rheum COVID-19 Patient Information**

Unique Patient Identifier: (automated)

Patient age (19-99 years)

This registry is for adult patients only. For the pediatric registry please go to the pediatric registry link here: https://carragroup.org/research-registry/projects/covid-19-global-pediatric-rheumatology-database

Patient sex at birth

Female

Male

Other or not known

# COVID-19 information

COVID-19 Diagnosis: Date

(If day is unknown, enter 15. )

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

COVID-19 Diagnosis: How was the COVID-19 diagnosis made? (Check all that apply)

* + Presumptive diagnosis based on symptoms only
  + PCR
  + Antibody
  + Metagenomic testing
  + CT scan
  + Laboratory assay, type unknown
  + Unknown
  + Other

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

Yes No



Unknown

COVID-19: If yes, Clinical symptoms during course of infection (Check all that apply)

Fever

Headache

Sore throat

Cough

Shortness of breath

Arthralgia

Myalgia

Chest pain

Abdominal pain

Diarrhea, vomiting or nausea

Rhinorrhea

Irritability/confusion

Malaise

Anosmia

Dysgeusia

Other : \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

COVID-19: Treatment (Only include medications given as treatment for this infection. Treatment for underlying rheumatic disease listed in next section).

(Check all that apply)

No treatment except supportive care



Remdesivir

Lopinavir/ritonavir

Oseltamivir

Favipiravir

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

Other

COVID-19: Treatment, additional notes/other:

Is the patient deceased?

Yes, deceased



Not deceased

Unknown

*If deceased,*

Approximate number of days from COVID19 symptom onset to death:

*If not deceased,* Have the patient's COVID19 symptoms resolved at the time of this report?

Yes No



Unknown

*If yes, patient's symptoms resolved*: Approximate number of days from COVID19 symptom onset to resolution.

(# days)

*If deceased or symptoms resolved*: Was the patient hospitalized during the illness?

Yes No



Unknown

*If not hospitalized*: Did the patient require any medical interventions? (e.g., supplemental oxygen)

Yes No



Unknown

*If hospitalized:* What was the maximum level of care required during the illness?

Did not require supplemental oxygen Required supplemental oxygen



Required non-invasive ventilation or high flow oxygen devices Required invasive mechanical ventilation or ECMO

Ventilation required, but type unknown Interventions unknown

*If symptoms not resolved*: Approximate number of days since COVID19 symptom onset (until today).

(# days)

*If symptoms not resolved*: Has the patient been hospitalized during the illness?

Yes No



Unknown

*If symptoms not resolved & not hospitalized:* Has the patient required any medical interventions so far? (e.g., supplemental oxygen)

Yes No



Unknown

*If symptoms not resolved & hospitalized:*

What is 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 or high flow oxygen devices Required invasive mechanical ventilation or ECMO Ventilation required, but type unknown

Interventions unknown

COVID-19: Complications (check all that apply)

No known complications

Acute Respiratory Distress Syndrome or ARDS Sepsis

Myocarditis or new heart failure

Concomitant or secondary infection (e.g. Influenza)

Cytokine storm or similar condition (e.g. macrophage activation syndrome)



Other serious complication

Please specify secondary or concomitant infection: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Infection Acquisition: In the 14 days before onset of illness did the patient have any of the following? (Check all that apply)

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 None of the above (community acquired)

Unknown

Other : \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Rheumatic or Autoimmune Disease and Treatment**

Primary rheumatic/autoimmune diagnosis(es) (Please check only primary diagnosis.)

ANCA-associated vasculitis (e.g., GPA, EGPA) Other vasculitis including Kawasaki disease Anti-phospholipid antibody syndrome

Autoinflammatory syndrome (including TRAPS, CAPS, FMF) Axial spondyloarthritis (including ankylosing spondylitis) Other spondyloarthritis (including reactive arthritis) Behcet's

Chronic recurrent multifocal osteomyelitis Giant cell arteritis

IgG4-related disease

Inflammatory myopathy (e.g. dermatomyositis, polymyositis) Juvenile idiopathic arthritis, not systemic

Systemic juvenile idiopathic arthritis Mixed connective tissue disease Ocular inflammation

Polymyalgia rheumatica Psoriatic arthritis Rheumatoid arthritis

Other inflammatory arthritis Sarcoidosis

Sjogren's syndrome

Systemic lupus erythematosus Systemic sclerosis

Undifferentiated connective tissue disease

Gout

Other, \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Inflammatory ocular diagnosis, please specify:

Uveitis, Anterior Uveitis, Intermediate Uveitis, Posterior Panuveitis

Scleritis

Retinal vasculitis Other

Rheumatic/autoimmune disease activity at the time of COVID-19 symptom onset (or at COVID-19 diagnosis if asymptomatic):

Remission



Minimal or low disease activity Moderate disease activity Severe or high disease activity Unknown

**Treatments for underlying rheumatic/autoimmune disease**

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

Yes No



Unknown

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

(mg/day)

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

* + Stopped
  + Continued at same dose
  + Tapered dose
  + Increased dosage
  + Unknown

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

(up to 5 medications can be selected)

* None
* Abatacept
* Antifibrotics (pirfenidone, nintedinib)
* Antimalarials (including hydroxychloroquine, chloroquine)
* Apremilast
* Azathioprine / 6-MP
* Belimumab
* CD-20 inhibitors (including rituximab within last 12 months, ofatumumab)
* Cyclophosphamide
* Cyclosporine
* Denosumab
* IL-1 inhibitors (including anakinra, canakinumab, rilonacept)
* IL-6 inhibitors (including tocilizumab, sarilumab)
* IL-12/23 inhibitors (ustekinumab)
* IL-23 inhibitors (guselkumab, risankizumab, tildrakizumab)
* IL-17 inhibitors (including secukinumab, ixekizumab)
* IVIG
* JAK inhibitors (including tofacitinib, baricitinib, upadacitinib)
* Leflunomide
* Methotrexate
* Mycophenolate mofetil / mycophenolic acid
* Sulfasalazine
* Tacrolimus
* Thalidomide / lenalidomide
* TNF-inhibitors (including infliximab, etanercept, adalimumab, golimumab, certolizumab, and biosimilars)
* Steroid eye drops
* Colchicine
* Unknown
* Other

For each medication listed:

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

* Stopped
* Continued
* Unknown

**At the time of COVID-19 symptom onset (or diagnosis if asymptomatic), was the patient taking**

**any of the following medications?**

ACE inhibitor

Angiotensin receptor blocker

Nonsteroidal anti-inflammatory (NSAID)

Was the patient taking a Cox-2 inhibitor?

PD5 inhibitor (e.g., sildenafil)

Yes and medication continued







Yes and medication stopped No unknown







**Comorbidity and Pregnancy** (Check all that apply)

* + None
  + Interstitial lung disease (e.g. NSIP, UIP, IPF)
  + Obstructive lung disease (COPD/asthma)
  + Other lung disease
  + Diabetes
  + Morbid obesity (BMI >= 40)
  + Obesity (BMI >= 30)
  + Hypertension
  + Cardiovascular disease (coronary artery disease, congestive heart failure)
  + Cerebrovascular disease
  + Pulmonary hypertension
  + Chronic renal insufficiency or end stage renal disease
  + Cancer
  + Organ transplant recipient
  + Immunodeficiency
  + Inflammatory bowel disease
  + Liver disease
  + Chronic neurological or neuromuscular disease
  + Trisomy 21
  + Psychiatric condition (e.g., schizophrenia, bipolar disorder)
  + Macrophage activation syndrome (prior to COVID-19 diagnosis)
  + Psoriasis
  + Pregnancy
  + Post-partum (< 6 weeks)
  + Unknown

If ILD selected: Which choice best characterizes this patient's interstitial lung disease:(check all that apply)

* + - Idiopathic Pulmonary Fibrosis
    - Connective tissue disease , specify CTD:
    - Hypersensitivity pneumonitis
    - Sarcoidosis
    - Unknown
    - Other ILD:

**COVID-19 Patient Information**

Race/ethnic origin (Check all that apply)

Arab Black

East Asian South Asian

West Asian / Middle Eastern Pacific Islander

Latin American White

Native American / Aboriginal / 1st Nations Other

Unknown or prefer not to answer

Race: other, please specify:

Smoking Status

Current smoker Former smoker Never smoked



Unknown smoking status

Does the patient currently use e-cigarettes or vape?

Yes No

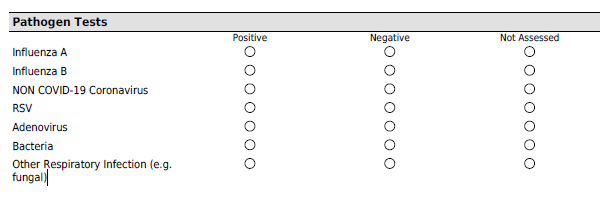


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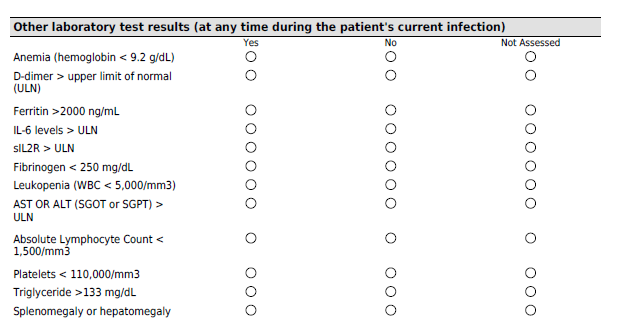
## **Laboratory Test Results**

**Optional:** Are there any laboratory test results available related to this patient's COVID-19 infection?

* Yes (see next page)
* No (go to end)



**Other laboratory test results (at any time during the patient's current infection)**



**Follow-up/Notes**

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

Yes



No

Would you like to share brief comments on any lessons from this case? (Please add anything else about the case or this registry here).

Thank you for supporting the COVID-19 Global Rheumatology Alliance Provider-Entered Registry