

# 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](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 complete 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](mailto:RheumCOVIDregistry@ucsf.edu)

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## 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 \_\_\_\_\_

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

- Yes
- No
- Unknown

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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 : \_\_\_\_\_

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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:

\_\_\_\_\_

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Is the patient deceased?

- Yes, deceased
- Not deceased
- Unknown

*If deceased,*

Approximate number of days from COVID19 symptom onset to death: \_\_\_\_\_

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

- Yes
- No
- Unknown

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

\_\_\_\_\_

(# days)

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

- Yes
- No
- Unknown

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

- Yes
- No
- Unknown

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*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

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

\_\_\_\_\_

(# days)

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

- Yes
- No
- Unknown

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

- Yes
- No
- Unknown

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*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

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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: \_\_\_\_\_

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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, notsystemic
- 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

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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

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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, nintedanib)
- 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?**

	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"/>
Nonsteroidal anti-inflammatory (NSAID)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Was the patient taking a Cox-2 inhibitor?	<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"/>

**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  $\geq 40$ )
- Obesity (BMI  $\geq 30$ )
- 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

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Race: other, please specify:

\_\_\_\_\_

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### Smoking Status

- Current smoker
- Former smoker
- Never smoked
- Unknown smoking status

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Does the patient currently use e-cigarettes or vape?

- Yes
- No
- Unknown

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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)

Pathogen Tests			
	Positive	Negative	Not Assessed
Influenza A	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Influenza B	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NON COVID-19 Coronavirus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
RSV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adenovirus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bacteria	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other Respiratory Infection (e.g. fungal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

	Yes	No	Not Assessed
Anemia (hemoglobin < 9.2 g/dL)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
D-dimer > upper limit of normal (ULN)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ferritin >2000 ng/mL	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IL-6 levels > ULN	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
sIL2R > ULN	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fibrinogen < 250 mg/dL	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Leukopenia (WBC < 5,000/mm <sup>3</sup> )	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
AST OR ALT (SGOT or SGPT) > ULN	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Absolute Lymphocyte Count < 1,500/mm <sup>3</sup>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Platelets < 110,000/mm <sup>3</sup>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Triglyceride >133 mg/dL	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Splenomegaly or hepatomegaly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**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