

EULAR COVID-19 Registry

First published: 01/02/2024

Last updated: 17/10/2024

Data source

Human

Disease registry

Spontaneous reports of suspected adverse drug reactions

Administrative details

Administrative details

Data source ID

44873

Data holder

[European Alliance of Associations for Rheumatology \(EULAR\)](#)

Data source type

Disease registry

Spontaneous reports of suspected adverse drug reactions

Main financial support

Funding by own institution

Care setting

Other

Data source qualification

If the data source has successfully undergone a formal qualification process (e.g., from the EMA, ISO or other certifications), this should be described.

No

Data source website

<https://www.eular.org/eular-covid-19-registry>

Contact details

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Data source regions and languages

Data source countries

Croatia

Czechia

France

Germany

Greece

Ireland

Israel

Italy

Latvia

Portugal

Romania
Slovakia
Spain
Sweden
Switzerland
Türkiye
United Kingdom

Data source languages

English

Data source establishment

Data source established

15/02/2020

Data source time span

First collection: 15/02/2020

The date when data started to be collected or extracted.

Last collection: 15/04/2022

If data collection in the data source has ceased, the date new records last entered the data source.

Publications

Data source publications

[Gianfrancesco M, Hyrich KL, Al-Adely S, Carmona L, Danila MI, Gossec L, Izadi Z, Jacobsohn L, Katz P, Lawson-Tovey S, Mateus EF, Rush S, Schmajuk G, Simard J, Strangfeld A, Trupin L, Wysham KD, Bhana S, Costello W, Grainger R, Hausmann JS, Liew JW, Sirotich E, Sufka P, Wallace ZS, Yazdany J, Machado PM, Robinson PC. Characteristics associated with hospitalisation for COVID-19 in people with](#)

rheumatic disease: data from the COVID-19 Global Rheumatology Alliance physician-reported registry. *Ann Rheum Dis.* 2020 Jul79(7):859-866. doi: 10.1136/annrheumdis-2020-217871. Epub 2020 May 29. PubMed PMID: 32471903 PubMed Central PMCID: PMC7299648.

Strangfeld A, Schäfer M, Gianfrancesco MA, Lawson-Tovey S, Liew JW, Ljung L, Mateus EF, Richez C, Santos MJ, Schmajuk G, Scirè CA, Sirotych E, Sparks JA, Sufka P, Thomas T, Trupin L, Wallace ZS, Al-Adely S, Bachiller-Corral J, Bhana S, Cacoub P, Carmona L, Costello R, Costello W, Gossec L, Grainger R, Hachulla E, Hasseli R, Hausmann JS, Hyrich KL, Izadi Z, Jacobsohn L, Katz P, Kearsley-Fleet L, Robinson PC, Yazdany J, Machado PM. Factors associated with COVID-19-related death in people with rheumatic diseases: results from the COVID-19 Global Rheumatology Alliance physician-reported registry. *Ann Rheum Dis.* 2021 Jul80(7):930-942. doi: 10.1136/annrheumdis-2020-219498. Epub 2021 Jan 27. PubMed PMID: 33504483 PubMed Central PMCID: PMC7843211.

Sparks JA, Wallace ZS, Seet AM, Gianfrancesco MA, Izadi Z, Hyrich KL, Strangfeld A, Gossec L, Carmona L, Mateus EF, Lawson-Tovey S, Trupin L, Rush S, Katz P, Schmajuk G, Jacobsohn L, Wise L, Gilbert EL, Duarte-García A, Valenzuela-Almada MO, Pons-Estel GJ, Isnardi CA, Berbotto GA, Hsu TY, D'Silva KM, Patel NJ, Kearsley-Fleet L, Schäfer M, Ribeiro SLE, Al Emadi S, Tidblad L, Scirè CA, Raffener B, Thomas T, Flipo RM, Avouac J, Seror R, Bernardes M, Cunha MM, Hasseli R, Schulze-Koops H, Müller-Ladner U, Specker C, Souza VA, Mota LMHD, Gomides APM, Dieudé P, Nikiphorou E, Kronzer VL, Singh N, Ugarte-Gil MF, Wallace B, Akpabio A, Thomas R, Bhana S, Costello W, Grainger R, Hausmann JS, Liew JW, Sirotych E, Sufka P, Robinson PC, Machado PM, Yazdany J. Associations of baseline use of biologic or targeted synthetic DMARDs with COVID-19 severity in rheumatoid arthritis: Results from the COVID-19 Global Rheumatology Alliance physician registry. *Ann Rheum Dis.* 2021 Sep80(9):1137-1146. doi: 10.1136/annrheumdis-2021-220418. Epub 2021 May 28. PubMed PMID: 34049860 PubMed Central PMCID: PMC8172266.

Lawson-Tovey S, Hyrich KL, Gossec L, Strangfeld A, Carmona L, Raffener B, Yardımcı GK, Trefond L, Roux N, Rodrigues A, Papagoras C, Mateus EF, Mariette X, Machado PM. SARS-CoV-2 infection after vaccination in patients with inflammatory rheumatic and musculoskeletal diseases. *Ann Rheum Dis*. 2021 Sep 6. doi: 10.1136/annrheumdis-2021-221217. [Epub ahead of print] PubMed PMID: 34489305.

Sattui SE, Liew JW, Kennedy K, Sirotich E, Putman M, Moni TT, Akpabio A, Alpízar-Rodríguez D, Berenbaum F, Bulina I, Conway R, Singh AD, Duff E, Durrant KL, Gheita TA, Hill CL, Howard RA, Hoyer BF, Hsieh E, El Kibbi L, Kilian A, Kim AH, Liew DFL, Lo C, Miller B, Mingolla S, Nudel M, Palmerlee CA, Singh JA, Singh N, Ugarte-Gil MF, Wallace J, Young KJ, Bhana S, Costello W, Grainger R, Machado PM, Robinson PC, Sufka P, Wallace ZS, Yazdany J, Harrison C, Larché M, Levine M, Foster G, Thabane L, Rider LG, Hausmann JS, Simard JF, Sparks JA. Early experience of COVID-19 vaccination in adults with systemic rheumatic diseases: results from the COVID-19 Global Rheumatology Alliance Vaccine Survey. *RMD Open*. 2021 Sep7(3). doi: 10.1136/rmdopen-2021-001814. PubMed PMID: 34493645 PubMed Central PMCID: PMC8424419.

Data elements collected

The data source contains the following information

Disease information

Does the data source collect information with a focus on a specific disease? This might be a patient registry or other similar initiatives.

Yes

Disease details (other)

Rheumatic and musculoskeletal diseases

Rare diseases

Are rare diseases captured? In the European Union a rare disease is one that affects no more than 5 people in 10,000.

Yes

Pregnancy and/or neonates

Does the data source collect information on pregnant women and/or neonatal subpopulation (under 28 days of age)?

Yes

Hospital admission and/or discharge

Yes

ICU admission

Is information on intensive care unit admission available?

Yes

Cause of death

Captured

Cause of death vocabulary

Other

Cause of death vocabulary, other

Reporting doctor confirms whether the patient has died due to COVID-19 or another cause

Prescriptions of medicines

Captured

Prescriptions vocabulary

other

Prescriptions vocabulary, other

Own vocabulary for medication names

Dispensing of medicines

Not Captured

Advanced therapy medicinal products (ATMP)

Is information on advanced therapy medicinal products included? A medicinal product for human use that is either a gene therapy medicinal product, a somatic cell therapy product or a tissue engineered products as defined in Regulation (EC) No 1394/2007 [Reg (EC) No 1394/2007 Art 1(1)].

No

Contraception

Is information on the use of any type of contraception (oral, injectable, devices etc.) available?

No

Indication for use

Does the data source capture information on the therapeutic indication for the use of medicinal products?

Not Captured

Medical devices

Is information on medicinal devices (e.g., pens, syringes, inhalers) available?

No

Administration of vaccines

No

Procedures

Does the data source capture information on procedures (e.g., diagnostic tests, therapeutic, surgical interventions)?

Captured

Procedures vocabulary

Other

Procedures vocabulary, other

Own vocabulary for procedures

Healthcare provider

Is information on the person providing healthcare (e.g., physician, pharmacist, specialist) available?
The healthcare provider refers to individual health professionals or a health facility organisation licensed to provide health care diagnosis and treatment services including medication, surgery and medical devices.

No

Clinical measurements

Is information on clinical measurements (e.g., BMI, blood pressure, height) available?

Yes

Genetic data

Are data related to genotyping, genome sequencing available?

Not Captured

Biomarker data

Does the data source capture biomarker information? The term “biomarker” refers to a broad subcategory of medical signs (objective indications of medical state observed from outside the patient), which can be measured accurately and reproducibly. For example, haematological assays,

infectious disease markers or metabolomic biomarkers.

Not Captured

Patient-reported outcomes

Is information on patient-reported outcomes (e.g., quality of life) available?

No

Patient-generated data

Is patient-generated information (e.g., from wearable devices) available?

No

Units of healthcare utilisation

Are units of healthcare utilisation (e.g., number of visits to GP per year, number of hospital days) available or can they be derived? Units of healthcare utilisation refer to the quantification of the use of services for the purpose of preventing or curing health problems.

No

Unique identifier for persons

Are patients uniquely identified in the data source?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

Other

Diagnosis / medical event vocabulary, other

Own vocabulary for diagnosis/medical event

Medicinal product information

Not Captured

Quality of life measurements

Not Captured

Lifestyle factors

Captured

Lifestyle factors

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Gender

Quantitative descriptors

Population Qualitative Data

Population age groups

Paediatric Population (< 18 years)

Infants and toddlers (28 days - 23 months)

Children (2 to < 12 years)

Adolescents (12 to < 18 years)

Adults (18 to < 46 years)
Adults (46 to < 65 years)
Elderly (\geq 65 years)
Adults (65 to < 75 years)
Adults (75 to < 85 years)
Adults (85 years and over)

Estimated percentage of the population covered by the data source in the catchment area

Unsure

Description of the population covered by the data source in the catchment area whose data are not collected (e.g., people who are registered only for private care)

Regional sub-set - All cases of COVID-19 in patients with rheumatic and musculoskeletal diseases. This will include all cases from Europe and other specific countries under the EULAR and PReS umbrella.

Population

Population size

12409

Active population size

12409

Population by age group

Age group	Population size	Active population size
Paediatric Population (< 18 years)	410	410
Preterm newborn infants (0 - 27 days)	0	0
Term newborn infants (0 - 27 days)	0	0
Infants and toddlers (28 days - 23 months)	2	2
Children (2 to < 12 years)	177	177
Adolescents (12 to < 18 years)	231	231
Adults (18 to < 46 years)	3079	3079
Adults (46 to < 65 years)	5393	5393
Elderly (\geq 65 years)	3527	3527
Adults (65 to < 75 years)	2065	2065
Adults (75 to < 85 years)	1180	1180
Adults (85 years and over)	282	282

Median observation time

Median time (years) between first and last available records for unique individuals captured in the data source

0.00

Median time (years) between first and last available records for unique active individuals (alive and currently registered) capt

0.00

Governance details

Documents or webpages that describe the overall governance of the data source and processes and procedures for data capture and management, data quality check and validation results (governing data access or utilisation for research purposes).

<https://www.eular.org/eular-covid-19-registry/>

Biospecimen access

Are biospecimens available in the data source (e.g., tissue samples)?

No

Access to subject details

Can individual patients/practitioners/practices included in the data source be contacted?

No

Description of data collection

<https://www.eular.org/faq-covid-19-registry>

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

Event triggering creation of a record in the data source

Specialist encounter

Data source linkage

Linkage

Is the data source described created by the linkage of other data sources (prelinked data source) and/or can the data source be linked to other data source on an ad-hoc basis?

No

Data management specifications that apply for the data source

Informed consent for use of data for research

Other

Possibility of data validation

Can validity of the data in the data source be verified (e.g., access to original medical charts)?

No

Data source preservation

Are records preserved in the data source indefinitely?

No

Data source preservation length (years)

10 years

Approval for publication

Is an approval needed for publishing the results of a study using the data source?

Yes

Informed consent, other

There is a committee to evaluate requests for data access.

Data source last refresh

15/04/2022

Common Data Model (CDM) mapping

CDM mapping

Has the data source been converted (ETL-ed) to a common data model?

No