



EULAR COVID-19 registry: Lessons learnt and future considerations

DOI:

[10.1136/annrheumdis-2021-220319](https://doi.org/10.1136/annrheumdis-2021-220319)

Document Version

Final published version

[Link to publication record in Manchester Research Explorer](#)

Citation for published version (APA):

Lawson-Tovey, S., Strangfeld, A., Hyrich, K. L., Carmona, L., Rodrigues, D., Gossec, L., Mateus, E. F., & Machado, P. M. (2021). EULAR COVID-19 registry: Lessons learnt and future considerations: Lessons learnt and future considerations. *Annals of the rheumatic diseases*, 80(9), 1110-1115. <https://doi.org/10.1136/annrheumdis-2021-220319>

Published in:

Annals of the rheumatic diseases

Citing this paper

Please note that where the full-text provided on Manchester Research Explorer is the Author Accepted Manuscript or Proof version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version.

General rights






Copyright and moral rights for the publications made accessible in the Research Explorer are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

Takedown policy

If you believe that this document breaches copyright please refer to the University of Manchester's Takedown Procedures [<http://man.ac.uk/04Y6Bo>] or contact uml.scholarlycommunications@manchester.ac.uk providing relevant details, so we can investigate your claim.



EULAR COVID-19 registry: lessons learnt and future considerations

Saskia Lawson-Tovey ^{1,2}, Anja Strangfeld ³, Kimme L Hyrich ^{2,4},
Loreto Carmona ⁵, Diana Rodrigues,⁶ Laure Gossec,^{7,8} Elsa F Mateus,^{9,10}
Pedro M Machado ^{11,12,13}

Handling editor Josef S Smolen

For numbered affiliations see end of article.

Correspondence to

Dr Pedro M Machado, Centre for Rheumatology & Department of Neuromuscular Diseases, University College London, London WC1 B5E, UK; p.machado@ucl.ac.uk

Received 9 March 2021
Revised 16 April 2021
Accepted 17 April 2021
Published Online First 27 April 2021

INTRODUCTION

Future disease outbreaks of epidemic proportion are inevitable. Advance planning and preparation is essential to mitigate future public health risks; the WHO emphasises the importance of in-depth evaluation of response to and lessons learnt from a national/international pandemic.¹ Research is critical to an informed, evidence-based response, therefore establishing pandemic research study protocols, systems to manage and report data, and rapid response teams are considered key to well-prepared, accelerated research in public health emergencies.²

Establishing international data collection registries poses many challenges, which are only amplified in the urgent nature of a global pandemic. The aim of this manuscript is to reflect on the successes and challenges of the European Alliance of Associations for Rheumatology (EULAR) COVID-19 registry³ to better understand how the rheumatology community (and other disease-specific communities) can be better prepared for rapid response research in the future. In particular, we consider the successes and challenges of the registry, what can be learnt from this experience, and what procedures and resources should be established and strengthened now in preparation for future pandemics.

HISTORY OF THE EULAR COVID-19 REGISTRY

In the early stages of the SARS-CoV-2 pandemic, a need was identified for data to address the lack of information on the relationship between COVID-19 outcomes and rheumatic and musculoskeletal diseases (RMDs) and their associated treatments. Generally, immunomodulatory/immunosuppressive treatments and comorbidities are associated with an increased risk of serious infection in people with rheumatic diseases,⁴ which indicated that these patients may be at a higher risk of more severe COVID-19 infection. Conversely, some rheumatic disease treatments are being studied for the prevention or treatment of COVID-19 and its associated complications.⁵

To rapidly collect data on and learn about COVID-19 outcomes in this population, the COVID-19 Global Rheumatology Alliance (GRA)⁶ set up a global provider-entered registry, 13 days after initial Twitter discussions prompted by COVID-19 initiatives in other diseases. Further details on the initial development of GRA core data variables are described elsewhere,^{7,8} and similar initiatives are listed in [table 1](#).

Due to General Data Protection Regulations⁹ in the European Union, Europe needed a separate, parallel registry. As EULAR represents patients and health professionals in rheumatology, a COVID-19 taskforce, comprising members of the executive and different committees, patients and epidemiologists, was swiftly created to address the challenges of the pandemic and its impact on patients with RMDs. It was decided that this registry should fall under the EULAR COVID-19 taskforce; the EULAR COVID-19 registry was launched via a REDCap platform 3 days later, and a partnership established with the GRA. A registry steering committee was created, composed of clinical epidemiologists involved in other registries and/or EULAR taskforces or committees, two data scientists, a People with Arthritis/Rheumatism in Europe representative, and EULAR communications staff.

EULAR COVID-19 REGISTRY TODAY

The EULAR COVID-19 registry is an observational registry capturing physician-entered data on both adult and paediatric patients with a pre-existing RMD and SARS-CoV-2 infection. A timeline of key milestones for the EULAR COVID-19 registry is shown in [figure 1](#). Data are entered voluntarily directly into the European data entry portal. In addition, as some countries were already collecting COVID-19 data, either within existing registries or in new COVID-19 registries (France, Germany, Italy, Portugal, Sweden and Switzerland), they were invited to share their data with the EULAR COVID-19 registry. Once formal data sharing agreements were complete, data import pipelines were set up between these national registries and EULAR. REDCap automatically created a bespoke data dictionary and data import template for the registry, which could be shared with the national societies to enable recreation of the same variables and data mapping. Some registries opted to do the mapping themselves, whereas others sent their data directly to the database management team at The University of Manchester for mapping.

Successes

Database development

In response to updated data and information on COVID-19, the steering committee regularly reviewed the database using feedback and existing EULAR guidelines on registry establishment¹⁰ where appropriate. Changes were made if there was a clear need (i.e., adding new COVID-19 treatments or a new variable to capture cause of



© Author(s) (or their employer(s)) 2021. No commercial re-use. See rights and permissions. Published by BMJ.

To cite: Lawson-Tovey S, Strangfeld A, Hyrich KL, et al. *Ann Rheum Dis* 2021;**80**:1110–1115.

EULAR COVID-19 Registry Timeline

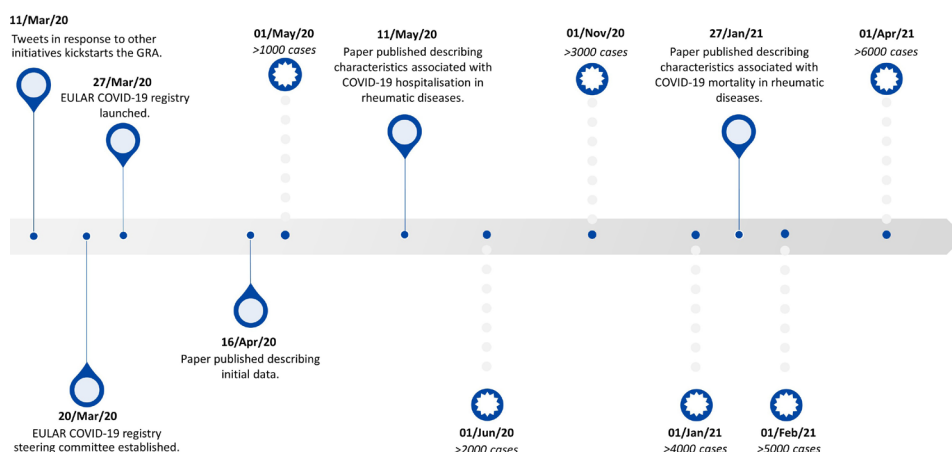


Figure 1 European Alliance of Associations for Rheumatology (EULAR) COVID-19 registry timeline. This figure shows key milestones reached by the EULAR COVID-19 registry from its inception until the present.

non-COVID-19-related death), which were then communicated to all national societies and the GRA. Additional data variables were also added after connecting with the European Scleroderma Trials and Research (EUSTAR) group to facilitate a combined analysis specific to patients with systemic sclerosis with COVID-19. COVID-19 vaccination questions were added once vaccines became available.

Having a steering committee made up of practicing clinicians, epidemiologists, data scientists, a communications expert and a patient partner ensured that we captured data and carried out analysis reflecting the needs of a broad spectrum of society. We met on a weekly basis for the first 6 months while we gained confidence with the challenges of running a European-wide registry and analysis effort in a rapidly changing situation. Subsequently, these meetings were reduced to a monthly basis supported by regular email communication.

Data acquisition

The prioritisation of COVID-19 by research ethics committees expedited the ethical review process of this registry in many jurisdictions. As the registry collects anonymous data, the UK Health Research Authority (and many others) considered it exempt from patient consent, making it easy to submit data. Furthermore, when submitting data, all providers accept that their own personal data are processed in accordance with the EULAR privacy notice.

There are currently 5824 cases in the registry, including 211 paediatric cases (as of 1 March 2021). The distribution of cases across Europe and the cumulative number of cases reported since the registry's inception are shown in [figure 2](#). This includes 2519 (43%) cases reported directly into the database and 3305 (57%) cases imported from national registries. Rates of data acquisition fluctuated with the waves of SARS-CoV-2 infection seen across Europe, but the rate remains high with >500 cases directly reported in January 2021. Anonymous data collection in the form of a 5–10 min smartphone-compatible survey allowed clinicians to fit in data submission around their day-to-day work.

We leveraged the strength of existing EULAR connections to promote the EULAR COVID-19 registry. Where COVID-19 data collection was already established, new collaborations were formed with great success. Once data sharing was agreed with a national registry, the respective country was hidden from our live database and providers were redirected to the national

society to submit data, thus supporting both local and international data collection, and preventing the upload of duplicate cases. National societies are also able to request an extract of their country's data without having to complete an application.

In recognition of participation, authorship was offered to national society leads and collaborator acknowledgements to clinicians who submitted a prespecified minimum number of cases depending on the analysis.

Data management/quality control

Simple measures were put in place to improve data quality from the outset. The majority of our fields were checkboxes

Table 1 List of initiatives collecting disease-specific data on COVID-19

Initiative	Medical area of interest
GRA	Rheumatic and musculoskeletal diseases
EULAR COVID-19	Rheumatic and musculoskeletal diseases
SECURE-IBD	Inflammatory bowel disease
SECURE-SCD	Sickle cell disease
COVID-HEP	Hepatology (liver disease or transplantation)
SECURE-LIVER	Liver disease
PsoProtect	Psoriasis
T1D Exchange	Type 1 diabetes
SECURE-AD	Atopic dermatitis
COVID-19 Dermatology Registry	Dermatology
CURE HIV-COVID	HIV
ASH RC COVID-19	Haematology
COVID-19 and Cancer Consortium	Cancer
PRIORITY	Pregnancy outcomes
Global Hidradenitis Suppurative COVID-19 Registry	Hidradenitis suppurativa

ASH RC COVID-19, American Society of Hematology Research Collaborative COVID-19 Registry for Hematology; COVID-HEP, COVID-19 in Patients with Liver Disease or Transplantation; CURE HIV, Coronavirus Under Research Exclusion HIV; EULAR, European Alliance of Associations for Rheumatology; GRA, Global Rheumatology Alliance; PRIORITY, Pregnancy Coronavirus Outcomes Registry; PsoProtect, Psoriasis Registry for Outcomes, Therapy and Epidemiology of COVID-19 Infection; SECURE-AD, Surveillance Epidemiology of Coronavirus Under Research Exclusion-Atopic Dermatitis; SECURE-IBD, Surveillance Epidemiology of Coronavirus Under Research Exclusion-Inflammatory Bowel Disease; SECURE-LIVER, Surveillance Epidemiology of Coronavirus Under Research Exclusion-Liver Disease; SECURE-SCD, Surveillance Epidemiology of Coronavirus Under Research Exclusion-Sickle Cell Disease; T1D Exchange, Type 1 Diabetes Exchange.

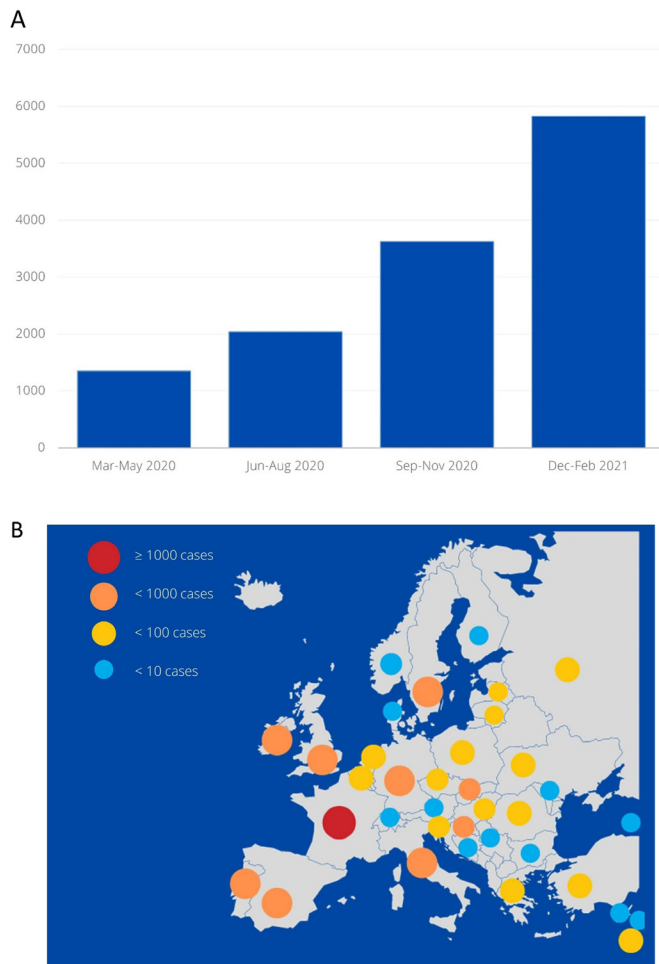


Figure 2 Cases reported to the European Alliance of Associations for Rheumatology COVID-19 registry as of 1 March 2021. (A) The cumulative number of cases over time. (B) The distribution of cases across Europe.

or dropdowns to limit inaccuracies frequently seen in free text. All other checkboxes in a field were disabled for selection if the provider had already selected a response of 'None' or 'Unknown'. Fields marked as required or with predefined ranges (e.g. minimum/maximum age of 0–120 years) would prompt the provider to fill/correct these fields before submission.

There were second level data quality control measures in place when cleaning the data for analysis. Dates were compared and sense checked and all free text entries were assessed to ascertain whether they could be recoded or if a reporter had clicked the correct checkboxes. If possible, cases were queried with the provider if a key variable was missing (e.g., age, COVID-19 outcome) and if the data were suspicious (e.g., a pregnant 80-year-old woman). Any fields potentially containing personal data were not shared with the GRA; this included details of the reporting clinician (except country) and any free text.

Outputs

One of our primary aims was to quickly disseminate our data and findings to the rheumatology community, hence, we committed to releasing regular summary reports on the EULAR COVID-19 registry website³ while working on more substantial and complex analyses. These reports were weekly for the first 6 months of the pandemic and were subsequently reduced to monthly due to a reduction in cases over the summer of 2020.

By integrating our data with that of the GRA, we were able to produce a larger, more robust dataset. Stored on a secure platform at the University of California, San Francisco with accompanying statistical software, the ease of access to this combined global dataset and analysis platform facilitated stronger analyses by statisticians globally.

As of 1 March 2021, multiple papers^{11–13} and abstracts have been produced using EULAR COVID-19 data, alongside numerous reviews and opinion pieces. Ongoing research includes combined analyses with the GRA, Childhood Arthritis Research and Rheumatology Alliance COVID-19 Global Paediatric Rheumatology Database, EUSTAR group, the Surveillance Epidemiology of Coronavirus Under Research Exclusion-Inflammatory Bowel Disease and the Psoriasis Registry for Outcomes, Therapy and Epidemiology of COVID-19 registries. Seven ancillary projects are also active after an open call for projects.

Our data, website and results have received high engagement from the rheumatology community, although social media engagement has declined throughout the pandemic (figure 3). We produced infographics and lay versions of our reports and papers to provide easily accessible information to the patient

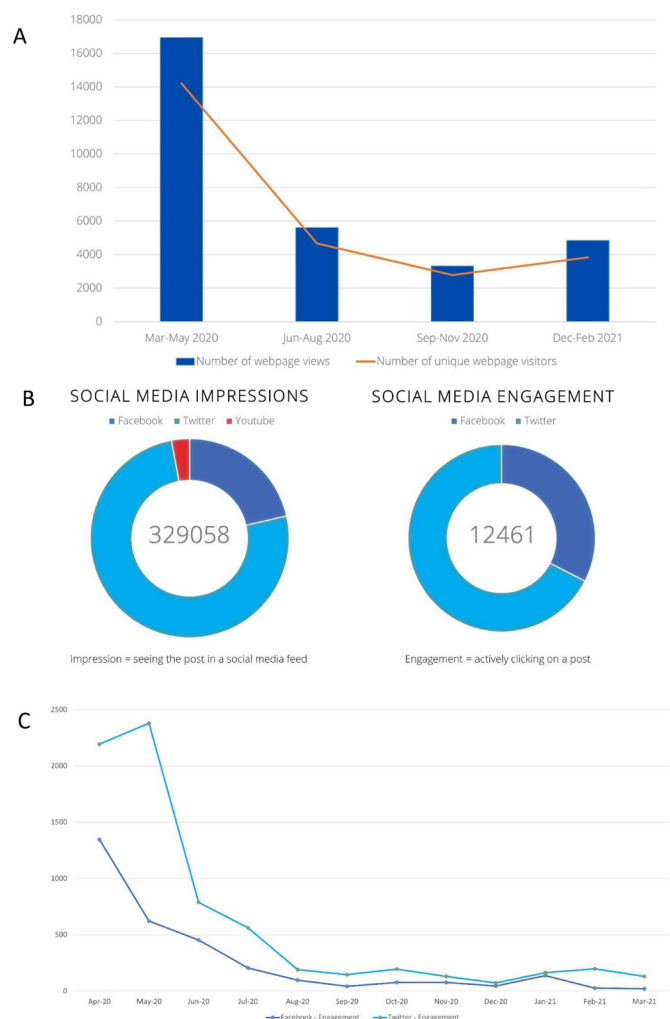


Figure 3 Web and social media analytics the European Alliance of Associations for Rheumatology (EULAR) COVID-19 registry as of 21 February 2021. (A) The number of EULAR COVID-19 registry webpage views and unique visitors over time. (B) The cumulative EULAR COVID-19 social media impressions and engagement levels. (C) The EULAR COVID-19 registry social media engagement over time.

Table 2 Proportion of missing and unknown data (N (%)) in the EULAR COVID-19 registry as of 1 March 2021

Variable description	Total N=5824	
	Unknown	Missing
General		
Date of case report	N/A	2 (0.03)
Age	N/A	0
Biological sex	N/A	0
Race/ethnic origin	209 (3.59)	1751 (30.07)
Comorbidities	92 (1.58)	250 (4.29)
Smoking status	1435 (24.64)	709 (12.17)
E-cigarette/vaping status	1649 (28.31)	1708 (29.33)
Seasonal influenza vaccination	1552 (26.65)	2399 (41.19)
Availability of lab tests	353 (6.06)	2366 (40.63)
COVID-19 measures		
Date of COVID-19 diagnosis	0	2 (0.03)
Method of COVID-19 diagnosis	168 (2.88)	27 (0.46)
COVID-19 diagnosis location	844 (14.49)	1636 (28.09)
COVID-19 infection acquisition	1394 (23.94)	1716 (29.46)
COVID-19 clinical symptoms *	53 (1.03)	61 (1.18)
COVID-19 treatment	139 (2.39)	1315 (22.58)
COVID-19 complications	188 (3.23)	2368 (40.66)
COVID-19 outcome		
COVID-19 outcome	203 (3.49)	2 (0.03)
Hospitalised	19 (0.33)	144 (2.47)
Interventions in hospital *	52 (2.63)	532 (26.90)
Approximate number of days from COVID-19 symptom onset to death*	N/A	111 (25.52)
Approximate number of days from COVID-19 symptom onset to resolution*	N/A	1506 (31.12)
Rheumatic disease		
Rheumatic disease diagnosis	0	0
Rheumatic disease activity	218 (3.74)	1592 (27.34)
Medication		
Immunomodulatory medication for rheumatic disease	21 (0.36)	307 (5.27)
Glucocorticoids at time of COVID-19 diagnosis	50 (0.86)	40 (0.69)
Glucocorticoid dose*	N/A	75 (4.23)
PD5 inhibitors	153 (2.63)	1994 (34.24)
ACE inhibitors	198 (3.40)	1887 (32.40)
Angiotensin receptor blockers	202 (3.47)	1925 (33.05)
Selective NSAIDs	212 (3.64)	1879 (32.26)
Non-selective NSAIDs	227 (3.90)	1412 (24.24)

Data are N (%) for all variables.

*Variable adjusted for database logic.

ACE, Angiotensin-converting enzyme; COVID-19, Coronavirus Disease 2019; EULAR, European Alliance of Associations of Rheumatology; NSAIDs, non-steroidal anti-inflammatory drugs; PD5, phosphodiesterase 5.

community hoping it would help alleviate patient anxiety around COVID-19 risk for patients with RMD.

Challenges

Database development

As our data needed to easily integrate into a global dataset, at times we were limited in the changes we could make to the database. The core data variables were put together very quickly at the start of the pandemic; had we had prior experience in a pandemic and more time and knowledge of what was required, we would have done some things differently. It became clear during analysis that fields such as date of last medication administration and further specific rheumatic disease measures would

have been very useful and pertinent to the outcomes we were assessing, although we considered these against reporter time, data availability and the challenges of capturing outcomes across the entire spectrum of rheumatology.

Providers had an option to report any further relevant information in free text boxes—this led to some large paragraphs of text and full copies of patient case notes and correspondence. While we used some of this information to clean the data or evaluate the database, we rarely used this information in the analyses.

Data acquisition

Reporting bias towards more serious COVID-19 cases was evident from the start as we have a substantially higher proportion of hospitalised and deceased cases compared with the general population. Delays in mass testing availability in many European countries and cancellation of routine outpatient medical appointments would mean that some mild (or asymptomatic) SARS-CoV-2 infections may not have been detected or brought to the attention of the rheumatologist. Therefore, estimated rates of hospitalisation and death within the RMD population cannot be generated and the results cannot be used to infer any direct causal associations between the variables studied and outcome.

Fatigue among reporters was also evident; during the second European wave of SARS-CoV-2 infections, less clinicians directly reported cases than during the first. Some clinicians reported the survey was taking >10 min to complete as they had to trawl through the patient's case notes for the information.

Ethical approval procedures differed between countries and in some cases, the need for additional approvals delayed the ability to participate. It is also possible that national data collection efforts were missed if the relevant parties did not notice the request for collaboration with this registry.

Data management/quality control

As data collection is anonymous and cross-sectional, it is difficult to query data quality issues. We asked reporters to wait until the outcome was known and to record the auto-generated EULAR case ID, but this did not always happen or the IDs were incorrectly recorded. We decided to query only our most essential fields, as we were aware some providers might have difficulties accessing all the data we requested. Querying imported data was more complex and time-consuming, as we had to ask the national registry to query the original data provider; not all registries were able to do so. When uploading imported data, the existing plausibility checks could be bypassed (eg, age could be <0), increasing the need for second-line data quality measures.

Additionally, not all data were easily available to providers or collected by registries, either at all or in the same format. In some cases, this led to more complex data mapping or high levels of missingness in the EULAR COVID-19 dataset. One example is ethnicity—this is not regularly collected in Swedish medical data and local French data protection laws meant they were unable to provide us with this data. Another example is inflammatory rheumatic disease activity at time of COVID-19 infection. This was not recorded in the French registry who contributed ~25% of our cases—in all analyses where this variable was essential we had to either exclude these patients or impute missing data. The number of cases with unknown or missing data across most of our data items are shown in [table 2](#).

Conclusions from the EULAR COVID-19 registry

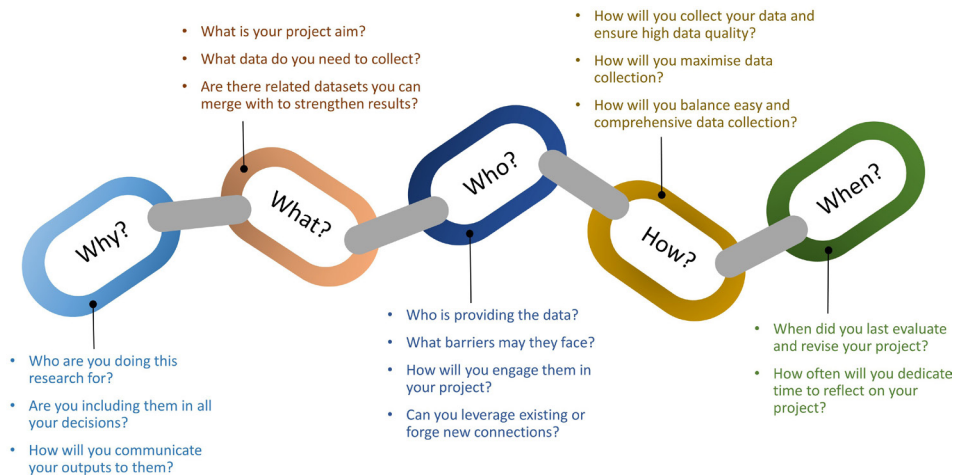


Figure 4 Key conclusions from the European Alliance of Associations of Rheumatology (EULAR) COVID-19 registry. This figure sums up our key conclusions drawn from setting up and running the EULAR COVID-19 registry.

CONCLUSIONS

The experience of setting up and managing this registry has emphasised the importance of the ‘what, who and why’ of data collection that we will all take forward to future projects. However, these considerations are not just applicable to rapid-response disease-specific research, but to all data collection projects in all specialties, regardless of region.

Arguably the most important is the why. Continuous involvement of patients and health professionals in our registry reminded us how essential it is to fully understand and address the questions and concerns of those who have a vested interest in the project’s outcome.

What data we collect and who provides these data are inevitably intertwined. While we started the registry with a clear idea of what we thought essential to collect, this quickly changed when we realised data providers faced barriers such as siloed medical care records or ethical approval processes.

The balance between easy and comprehensive data collection is delicate. We created a quick, easy, anonymous survey while knowingly sacrificing a more robust, complex longitudinal data collection process. Ensuring the data also gives enough meaningful context around the outcomes one is analysing is, while easier to state in retrospect, vital.

There was an unspoken agreement within the rheumatic disease community, like many others, that the urgency of the pandemic made COVID-19 data collection a priority. We had high levels of engagement despite voluntary involvement and additional barriers to data collection; this may not be the case outside of such unique circumstances.

This registry demonstrated the strength in collaboration across Europe and we should look to strengthen these networks and pipelines further. As for the future of the EULAR COVID-19 registry, it now sits within the EULAR Virtual Research Centre,¹⁴ which will act as a catalyst to build on these collaborations, for both COVID-19 and other RMD research.

We would encourage other registries/projects to undertake similar evaluations of their own situation, regardless of the project stage and include a diagram of our key conclusions in figure 4. There is much to be learnt from the incredible research that has occurred during this pandemic; failing to reflect and prepare in advance becomes all too evident when we are in the next one.

Author affiliations

- ¹Centre for Genetics and Genomics Versus Arthritis, Centre for Musculoskeletal Research, The University of Manchester, Manchester, UK
- ²National Institute of Health Research Manchester Biomedical Research Centre, Manchester University NHS Foundation Trust, Manchester Academic Health Science Centre, Manchester, UK
- ³Epidemiology Unit, German Rheumatism Research Center (DRFZ Berlin), Berlin, Germany
- ⁴Centre for Epidemiology Versus Arthritis, The University of Manchester, Manchester Academic Health Science Centre, Manchester, UK
- ⁵Instituto de Salud Musculoesquelética, Madrid, Spain
- ⁶European Alliance of Associations for Rheumatology (EULAR), Kilchberg, Switzerland
- ⁷Sorbonne Université, INSERM, Institut Pierre Louis d’Epidémiologie et de Santé Publique, Paris, France
- ⁸Pitié-Salpêtrière hospital, AP-HP, Rheumatology department, Sorbonne Université, Paris, Île-de-France, France
- ⁹Portuguese League Against Rheumatic Diseases (LPCDR), Lisbon, Portugal
- ¹⁰European Alliance of Associations for Rheumatology (EULAR) Standing Committee of People with Arthritis/Rheumatism in Europe (PARE), Kilchberg, Switzerland
- ¹¹Centre for Rheumatology & Department of Neuromuscular Diseases, University College London, London, UK
- ¹²National Institute for Health Research (NIHR) University College London Hospitals Biomedical Research Centre, University College London Hospitals NHS Foundation Trust, London, UK
- ¹³Department of Rheumatology, Northwick Park Hospital, London North West University Healthcare NHS Trust, London, UK

Twitter Saskia Lawson-Tovey @saskiaamber, Loreto Carmona @carmona_loreto and Pedro M Machado @pedromcmachado

Acknowledgements We wish to express our gratitude to all of our colleagues who have taken time to report data, especially in the darkest moments of the pandemic—we would not be able to call this endeavour a success without the generous contribution of all these colleagues. Additionally, we wish to thank the EULAR leadership and staff, and all the National Societies for supporting the Registry, particularly the representatives of national registries who have graciously taken time to collaborate and share their data with us: Rebecca Hasseli, Sascha Eulert, Eric Hachulla, Christophe Richez, Carlo Scirè, Lotta Ljung, Maria José Santos, Fernando Martins, Almut Scherer and Javier Bachiller. We would also like to thank colleagues from the COVID-19 Global Rheumatology Alliance, with whom EULAR has established a fruitful partnership, particularly their steering committee members: Philip Robinson, Jinoos Yazdany, Paul Sufka, Rebecca Grainger, Zachary Wallace, Suleman Bhana, Emily Sirotych, Jean Liew, Jonathan Hausmann and Wendy Costello.

Contributors SL-T drafted the first version of the manuscript. All authors revised the manuscript and approved the final version.

Funding The EULAR COVID-19 Database is financially supported by European Alliance of Associations for Rheumatology (EULAR).

Disclaimer The views expressed here are those of the authors and do not necessarily represent the views of the European Alliance of Associations for Rheumatology (EULAR), the (UK) National Health Service (NHS), the National

Institute for Health Research (NIHR), or the (UK) Department of Health, or any other organisation.

Map disclaimer The depiction of boundaries on the map(s) in this article does not imply the expression of any opinion whatsoever on the part of BMJ (or any member of its group) concerning the legal status of any country, territory, jurisdiction or area or of its authorities. The map(s) are provided without any warranty of any kind, either express or implied.

Competing interests SL-T has nothing to disclose. AS reports personal fees from lectures for AbbVie, MSD, Roche, BMS, and Pfizer, all outside the submitted work. KLH reports she has received non-personal speaker's fees from AbbVie and grant income from BMS, UCB, and Pfizer, all unrelated to this manuscript, and is supported by the NIHR Manchester Biomedical Research Centre. LC has not received fees or personal grants from any laboratory, but her institute works by contract for laboratories among other institutions, such as AbbVie Spain, Eisai, Gebro Pharma, Merck Sharp & Dohme España, S.A., Novartis Farmaceutica, Pfizer, Roche Farma, Sanofi Aventis, Astellas Pharma, Actelion Pharmaceuticals España, Grünenthal GmbH, and UCB Pharma. LG reports personal consultant fees from AbbVie, Amgen, BMS, Biogen, Celgene, Gilead, Janssen, Lilly, Novartis, Pfizer, Samsung Bioepis, Sanofi-Aventis, UCB, and grants from Amgen, Lilly, Janssen, Pfizer, Sandoz, Sanofi, Galapagos, all unrelated to this manuscript. EFM reports that LPCDR received support for specific activities: grants from AbbVie, Novartis, Janssen-Cilag, Lilly Portugal, Sanofi, Grünenthal S.A., MSD, Celgene, Medac, Pharmakern, GAfPA; grants and non-financial support from Pfizer; non-financial support from Grünenthal GmbH, outside the submitted work. PMM has received consulting/speaker's fees from AbbVie, BMS, Celgene, Eli Lilly, Janssen, MSD, Novartis, Orphazyme, Pfizer, Roche and UCB, all unrelated to this manuscript, and is supported by the National Institute for Health Research (NIHR), University College London Hospitals (UCLH), Biomedical Research Centre (BRC).

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

This article is made freely available for use in accordance with BMJ's website terms and conditions for the duration of the covid-19 pandemic or until otherwise determined by BMJ. You may use, download and print the article for any lawful, non-commercial purpose (including text and data mining) provided that all copyright notices and trade marks are retained.

ORCID iDs

Saskia Lawson-Tovey <http://orcid.org/0000-0002-8611-162X>
Anja Strangfeld <http://orcid.org/0000-0002-6233-022X>

Kimme L Hyrich <http://orcid.org/0000-0001-8242-9262>
Loreto Carmona <http://orcid.org/0000-0002-4401-2551>
Pedro M Machado <http://orcid.org/0000-0002-8411-7972>

REFERENCES

- 1 World Health Organization. Pandemic influenza risk management: a who guide to inform and harmonize national and international pandemic preparedness and response, 2017. Available: <http://apps.who.int/bookorders> [Accessed 7 Jan 2021].
- 2 World Health Organization. A checklist for pandemic influenza risk and impact management; building capacity for pandemic response, 2018. Available: <http://apps.who.int/bookorders> [Accessed 7 Jan 2021].
- 3 EULAR. EULAR - COVID-19 database. Available: https://www.eular.org/eular_covid19_database.cfm [Accessed 4 Feb 2021].
- 4 Listing J, Gerhold K, Zink A. The risk of infections associated with rheumatoid arthritis, with its comorbidity and treatment. *Rheumatology* 2013;52:53–61.
- 5 Putman M, Chock YPE, Tam H, *et al*. Antirheumatic disease therapies for the treatment of COVID-19: a systematic review and meta-analysis. *Arthritis Rheumatol* 2021;73:36–47.
- 6 COVID-19 Global Rheumatology Alliance. The global rheumatology community's response to the worldwide COVID-19 pandemic. Available: <https://rheum-covid.org/> [Accessed 4 Feb 2021].
- 7 Liew JW, Bhana S, Costello W, *et al*. The COVID-19 global rheumatology alliance: evaluating the rapid design and implementation of an international registry against best practice. *Rheumatology* 2021;60:353–8.
- 8 Robinson PC, Yazdany J, Machado PM. Global research collaboration in a pandemic-challenges and opportunities: the COVID-19 global rheumatology alliance. *Curr Opin Rheumatol* 2021;33:111–6.
- 9 European Parliament and Council of the European Union. Regulation (EU) 2016/679, 2016. Available: <http://data.europa.eu/eli/reg/2016/679/oj> [Accessed 4 Feb 2021].
- 10 Dixon WG, Carmona L, Finckh A, *et al*. EULAR points to consider when establishing, analysing and reporting safety data of biologics registers in rheumatology. *Ann Rheum Dis* 2010;69:1596–602.
- 11 Gianfrancesco MA, Hyrich KL, Gossec L, *et al*. Rheumatic disease and COVID-19: initial data from the COVID-19 global rheumatology alliance provider registries. *Lancet Rheumatol* 2020;2:e250–3.
- 12 Strangfeld A, Schäfer M, Gianfrancesco MA, *et al*. 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;80:930–42.
- 13 Gianfrancesco M, Hyrich KL, Al-Adely S, *et al*. 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;79:859–66.
- 14 EULAR. EULAR virtual research centre. Available: https://www.eular.org/eular_virtual_research_centre.cfm [Accessed 9 Mar 2021].