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The EULAR COVID-19 Registry: lessons learned and future considerations

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Introduction

Future disease outbreaks of epidemic proportion are inevitable. Advance planning and preparation is essential to mitigate future public health risks; the World Health Organisation (WHO) emphasises the importance of in-depth evaluation of response to and lessons learnt from a national/international pandemic¹. 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 emergencies².

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) Coronavirus disease 2019 (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 severe acute respiratory syndrome coronavirus 2 (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 diseases⁴, 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 complications⁵.

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 of 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 PARE representative, and EULAR communications staff.

The 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 re-creation 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 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 Group (EUSTAR) to facilitate a combined analysis specific to systemic sclerosis (SSc) patients 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 whilst 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 prioritization 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 6126 cases in the registry, including 225 paediatric cases (as of 01/Mar/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 2560 (42%) cases reported directly into the database and 3566 (58%) 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 minute 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 pre-specified 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 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 pre-defined ranges (e.g. minimum/maximum age of 0-120) 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 was suspicious (e.g. a pregnant 80-year old). 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 whilst 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 01/Mar/2021, multiple papers^{11,12,13} 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 (CARRA) COVID-19 Global Paediatric Rheumatology Database, European Scleroderma Trials and Research group (EUSTAR), the Surveillance Epidemiology of Coronavirus Under Research Exclusion (SECURE)-Inflammatory Bowel Disease (IBD), and the Psoriasis Registry for Outcomes, Therapy and Epidemiology of COVID-19 (PsoProtect) 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 community hoping it would help alleviate patient anxiety around COVID-19 risk for RMD patients.

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. Whilst 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 to 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 minutes 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 (e.g. age could be <0), increasing the need for second-line data quality measures.

Additionally, not all data was 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

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. Whilst 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 whilst 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, whilst 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 Centre¹⁴, 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.

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Patient and public involvement: One patient sits on the EULAR COVID-19 Registry steering committee and contributed to the design of the registry, the questions being asked and the analysis of the results. No public were involved in the design or analysis of this project.

Patient consent for publication: Not required.

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.

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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	Hematology
COVID-19 and Cancer Consortium	Cancer
PRIORITY	Pregnancy Outcomes
Global Hidradenitis Suppurative COVID-19 Registry	Hidradenitis Suppurativa
<p>COVID-19, Coronavirus Disease 2019; GRA, Global Rheumatology Alliance; EULAR, European Alliance of Associations for Rheumatology; SECURE-IBD, Surveillance Epidemiology of Coronavirus Under Research Exclusion-Inflammatory Bowel Disease; SECURE-SCD, Surveillance Epidemiology of Coronavirus Under Research Exclusion-Sickle Cell Disease; COVID-HEP, COVID-19 in Patients with Liver Disease or Transplantation; SECURE-LIVER, Surveillance Epidemiology of Coronavirus Under Research Exclusion-Liver Disease; PsoProtect, Psoriasis Registry for Outcomes, Therapy and Epidemiology of COVID-19 Infection; T1D Exchange, Type 1 Diabetes Exchange; SECURE-AD, Surveillance Epidemiology of Coronavirus Under Research Exclusion-Atopic Dermatitis; CURE-HIV, Coronavirus Under Research Exclusion-Human Immunodeficiency Virus ; ASH RC COVID-19, American Society of Hematology Research Collaborative COVID-19 Registry for Hematology; PRIORITY, Pregnancy Coronavirus Outcomes Registry</p>	

Variable Description	Total N = 6162	
	Unknown	Missing
General		
Date of case report	N/A	73 (1.19)
Age	N/A	0
Biological sex	N/A	0
Race/ethnic origin	209 (3.39)	2086 (33.85)
Comorbidities	95 (1.54)	262 (4.25)
Smoking status	1435 (23.29)	718 (11.65)
E-cigarette/Vaping status	1649 (26.76)	2043 (33.15)
Seasonal flu vaccination	1552 (25.19)	2734 (44.37)
Availability of lab tests	353 (5.73)	2701 (43.83)
COVID-19 Measures		
Date of COVID-19 diagnosis	0	2 (0.03)
Method of COVID-19 diagnosis	168 (2.73)	37 (0.60)
COVID-19 diagnosis location	844 (13.70)	1971 (31.99)
COVID-19 infection acquisition	1395 (22.64)	2051 (33.28)
COVID-19 clinical symptoms (*)	53 (0.97)	61 (1.12)
COVID-19 treatment	139 (2.26)	1539 (24.98)
COVID-19 complications	188 (3.05)	2704 (43.88)
COVID-19 Outcome		
COVID-19 outcome	203 (3.29)	2 (0.03)
Hospitalised	19 (0.31)	148 (2.40)
Interventions in hospital (*)	52 (2.38)	738 (33.74)
Approximate number of days from COVID-19 symptom onset to death (*)	N/A	117 (24.53)
Approximate number of days from COVID-19 symptom onset to resolution (*)	N/A	1580 (31.27)
Rheumatic disease		
Rheumatic disease diagnosis	0	0
Rheumatic disease activity	218 (3.54)	1927 (31.27)
Medication		
Immunomodulatory medication for rheumatic disease	22 (0.36)	345 (5.60)
Glucocorticoids at time of COVID-19 diagnosis	50 (0.81)	40 (0.65)
Glucocorticoid dose (*)	N/A	75 (3.93)
PD5 inhibitors	153 (2.48)	2329 (37.80)
ACE inhibitors	198 (3.21)	2222 (36.06)
Angiotensin receptor blockers	202 (3.28)	2260 (36.68)
Selective NSAIDs	212 (3.44)	2195 (35.62)
Non-selective NSAIDs	227 (3.68)	1676 (27.20)
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.		

FIGURES

Figure 1: EULAR COVID-19 registry timeline. This figure shows key milestones reached by the EULAR COVID-19 registry from its inception until the present.

EULAR COVID-19 Registry Timeline

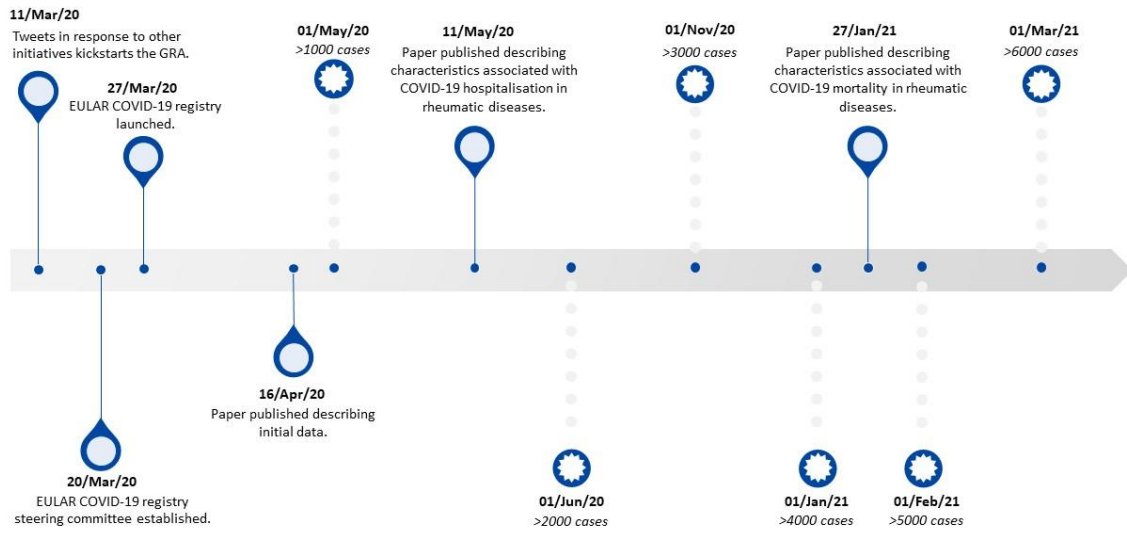


Figure 2: Cases reported to the EULAR COVID-19 registry as of 01/Mar/2021. Panel (A) shows the cumulative number of cases over time and panel (B) shows the distribution of cases across Europe.

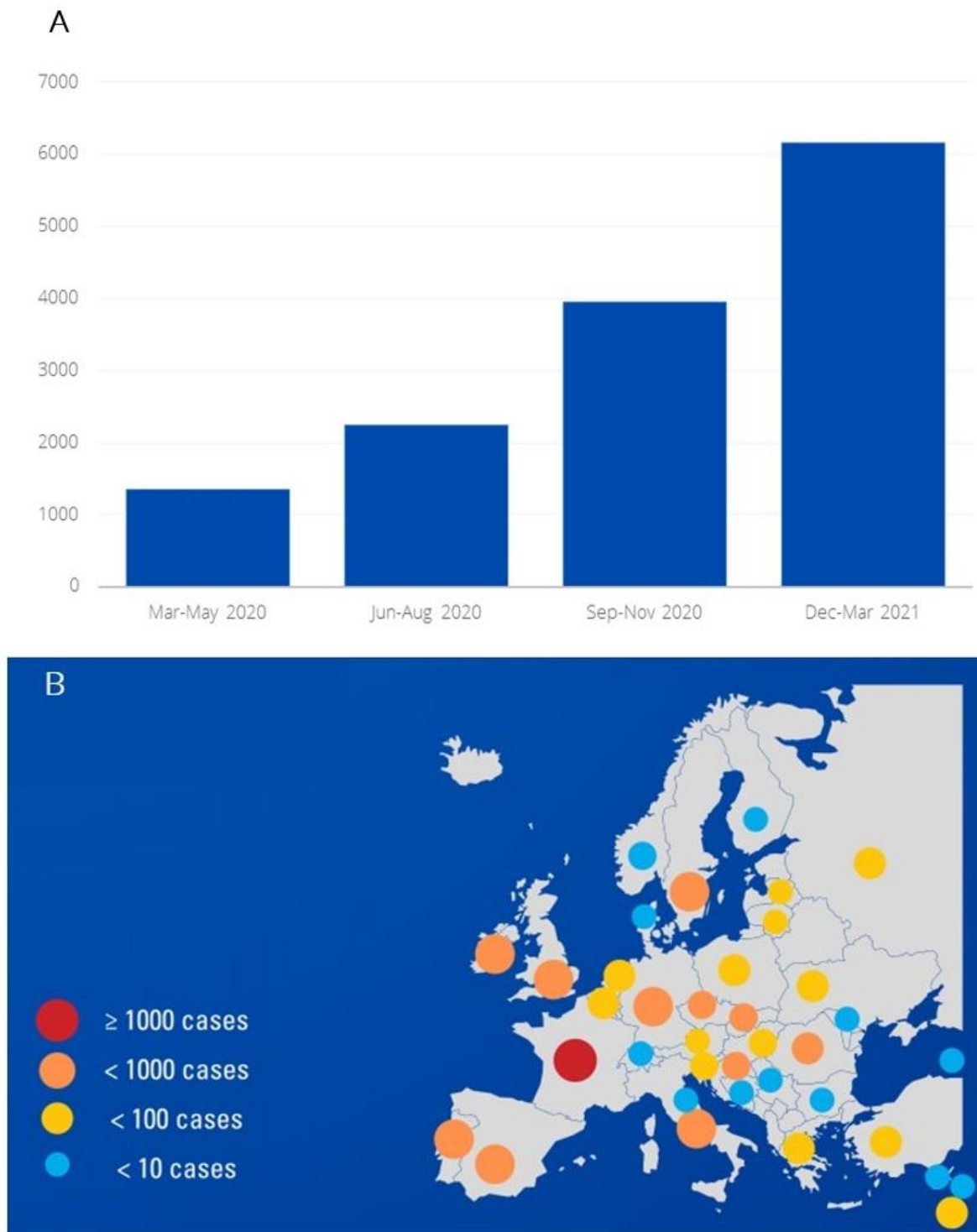


Figure 3: Web and social media analytics the EULAR COVID-19 registry as of 21/Feb/2021. Panel (A) shows the number of EULAR COVID-19 registry webpage views and unique visitors over time, panel (B) shows the cumulative EULAR COVID-19 social media impressions and engagement levels, and panel (C) shows the EULAR COVID-19 registry social media engagement over time.

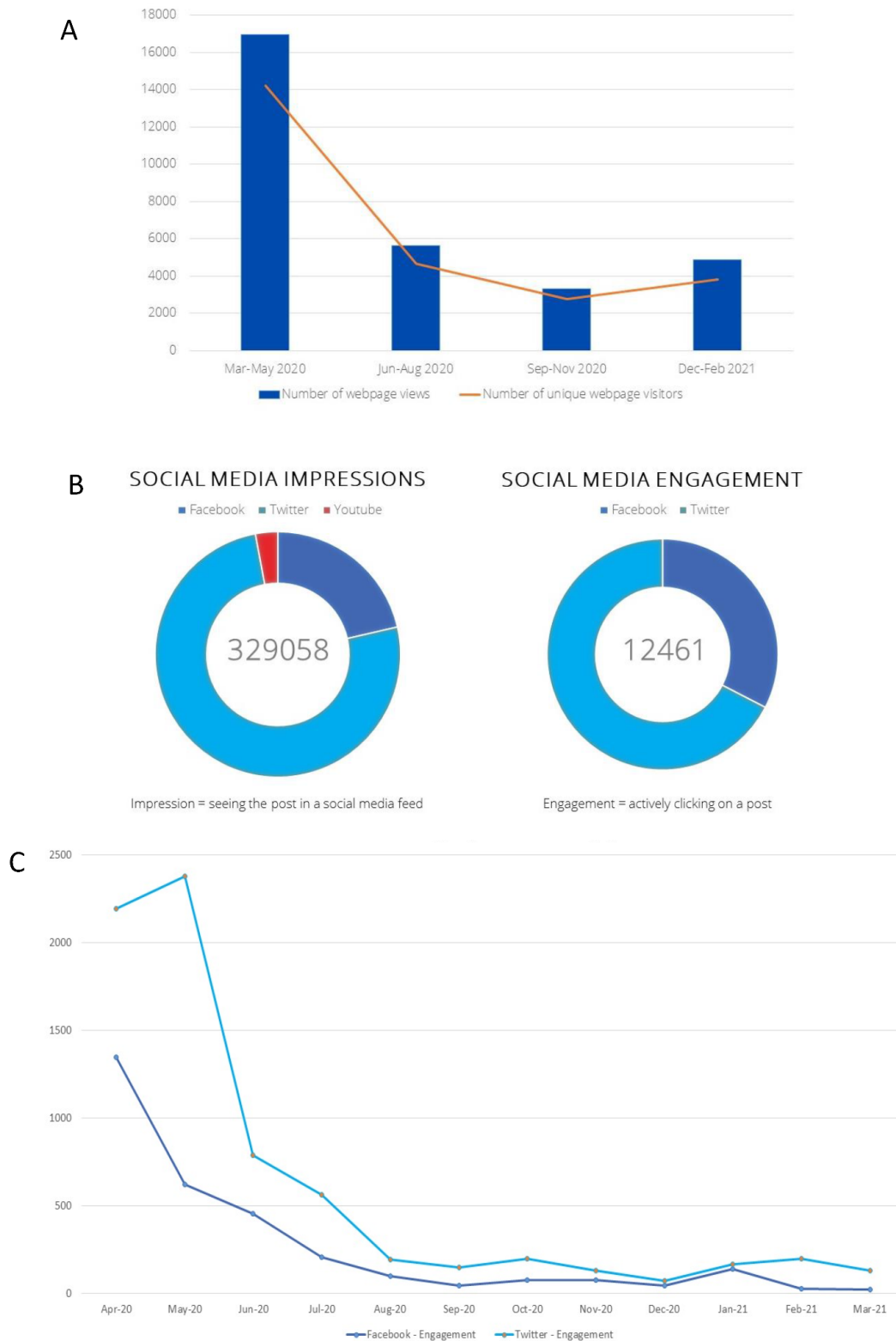


Figure 4: Key conclusions from the EULAR COVID-19 registry. This figure sums up our key conclusions drawn from setting up and running the EULAR COVID-19 registry.

Conclusions from the EULAR COVID-19 registry

