Epidemiology

EPIDEMIOLOGICAL SCIENCE

Influence of COVID-19 pandemic on decisions for the management of people with inflammatory rheumatic and musculoskeletal diseases: a survey among EULAR countries

Christian Dejaco 1,2, Alessia Alunno 3, Johannes WJ Bijlsma 4, Annelyes Boonen 5, Bernard Combe 6, Axel Finckh 7, Pedro M Machado 8, Ivan Padjen,9 Francisca Sivera 10,11 Tanja A Stamm 12, Frank Buttgerfeit 13

ABSTRACT

Objectives To investigate how the first wave of COVID-19 pandemic influenced decisions of rheumatologists and health professionals in rheumatology regarding the management of patients with inflammatory rheumatic and musculoskeletal diseases (RMDs).

Methods An English-language questionnaire was developed by a EULAR working group and distributed via national rheumatology societies of EULAR countries, EMEUNET and individual working group members. Responses were collected using an online survey tool. Descriptive statistics were calculated.

Results We analysed 1286 responses from 35/45 EULAR countries. Due to containment measures, 82% of respondents indicated cancellation/postponement of face-to-face visits of new patients (84% of them offering remote consultation) and 91% of follow-up visits (96% with remote consultation). The majority of respondents (58%) perceived that the interval between symptom onset and first rheumatological consultations was longer during containment restrictions than before. Treatment decisions were frequently postponed (34%), and the majority (74%) of respondents stated that it was less likely to start a biological disease modifying anti-rheumatic drug (DMARD)/targeted synthetic DMARD during the pandemic, mainly because of patients’ fear, limited availability of screening procedures and decreased availability of rheumatological services. Use of (hydroxy)chloroquine (HCQ) and tocilizumab (TCZ) for the COVID-19 indication was reported by 47% and 42% of respondents, respectively, leading to a shortage of these drugs for RMDs indications according to 49% and 14% of respondents, respectively.

Conclusion Measures related to containment of COVID-19 pandemic led to a perceived delay between symptom onset and a first rheumatological visit, postponement of treatment decisions, and shortage of HCQ and TCZ, thereby negatively impacting early treatment and treat-to-target strategies.

INTRODUCTION

The novel SARS-CoV-2 and COVID-19 is a highly contagious disease that has reached Europe at the beginning of 2020 and has been causing high morbidity and mortality.1-3 Containment measures have been established in most European countries in order to prevent exponential growth of the infection.5 To what extent these measures influenced early diagnosis and treatment of patients with inflammatory rheumatic and musculoskeletal diseases (RMDs) is unknown.

While the majority of patients with COVID-19 has a favourable outcome, some of them develop severe pneumonia eventually leading to respiratory failure along with other organ manifestations and
COVID-19 appears to have at least two distinct disease phases: a phase characterised by the immune response against the virus aiming at eliminating the pathogen, and in some patients, a subsequent phase of severe ‘cytokine release syndrome’ instead of the expected phase of convalescence. Some of the most severe complications of COVID-19 seem indeed to be caused by an exaggerated response of the immune system. Immunomodulatory agents commonly prescribed in rheumatology such as hydroxychloroquine (HCQ) or tocilizumab (TCZ) have been used for treatment of patients with COVID-19. Whether the off-label use of these drugs in COVID-19 induces a shortage of supply and whether this has an impact on treatment decisions in patients with RMDs is elusive so far.

Looking at the current situation from a public health perspective, there are several questions that arise: (1) have the ‘treat to target’ and ‘early diagnosis’ paradigms for patients with inflammatory RMDs been still feasible during the COVID-19 crisis; (2) have patients been less likely to initiate TCZ or other biologicals or have they been switched from TCZ to therapies with other modes of action in order to save drugs for patients with COVID-19; (3) has a shortage of medication led to patients having to stop HCQ or TCZ?

This EULAR project was designed to clarify how and to what extent COVID-19 affected decisions of rheumatologists and health professionals in rheumatology (HPR) concerning the management of patients with RMDs from a public health perspective. The knowledge gained from this study will help to prepare for future waves of COVID-19 and other pandemics caused by highly contagious infectious agents.

**METHODS**

An English-language questionnaire was developed by a EULAR working group composed of rheumatologists, a methodologist, experts in public health, and an HPR. The questionnaire contained 37 questions organised in three broad sections: (1) professional background, (2) influence of containment measures on the organisation of care for patients with inflammatory RMDs and (3) drugs used both in rheumatology and to treat COVID-19. The majority of questions were in the multiple-choice format recognising the possibility that multiple not mutually exclusive strategies might have been applied (eg, which patient groups have been prioritised during closure for a face-to-face or remote visit). The survey also contained a few single choice (eg, for age and sex) or open-ended questions.

The survey was distributed via EULAR secretariat and EULAR scientific member societies (No.: 45), delegates of the EULAR Standing Committee on Epidemiology and Health Services Research, and EMEUNET using emails, newsletters and social media. The working group members also personally contacted physicians and HPR from different countries, requesting them to answer and disseminate the questionnaire (snow-ball principle). The questionnaire was accompanied by an explanatory letter regarding the purpose of the survey. The answers were collected via an online survey tool (SurveyMonkey) from 13 May till 17 June 2020. At least one reminder was sent by EMEUNET and individual working group members. Online supplemental file 1 provides the full questionnaire and additional details on the execution of the survey. Ethical approval was not required because the study did not involve patients; all responses were anonymous.

The target audience of the survey were rheumatologists and other physicians or HPR from EULAR countries who have been directly involved in care of patients with inflammatory RMDs, however; the survey was open to all physicians/HPR.

Descriptive and summary statistics were applied to the questionnaire responses. Absolute and relative frequencies were calculated and depicted in tabular and graphical form. Data are presented as number (nominator) and percentage of all available responses to each question (denominator) throughout the manuscript. The denominator may change from question to question for the following reasons: (1) questions and individual answers could have been skipped, (2) some questions could have been answered with ‘not applicable’ or ‘do not know’, which were detracted from the denominator as indicated, (3) specific subgroup analyses were conducted. Since the majority of questions were in the multiple-choice format, the sum of nominators from individual questions may exceed the corresponding denominator.

**RESULTS**

A total of 1428 responses were collected from 58 countries (see online supplemental table 1 for number of responses from all countries): 1286 (90%) were from 35 out of the 45 EULAR countries, 15 (1%) came from Africa, 10 (0.7%) from Asia, 8 from North-America (0.6%), 7 from South-America (0.5%), 2 (0.1%) from Australia/New Zealand, 1 (0.1%) from Andorra whereas 99 (7%) have not specified the country of practice.

In this paper, only results for EULAR countries are presented (n=1286). Ten (22%) EULAR countries provided no and 19 (56%) more than 10 responses. Demographic data of respondents are summarised in table 1. The number of responses per question ranged from 663 to 1286. To support the interpretation of results in relation to the country-specific impact of COVID-19, we summarised data on infections with SARS-CoV-2, mortality and containment measures in EULAR countries as per April 2020 in online supplemental table 2.

**Influence of containment measures on organisation of care for patients with inflammatory RMDs**

**General organisation of rheumatology care**

Partial closure of rheumatology services guaranteeing, for example, only emergency visits was reported by 622/1094 (57%, 192 skipped the question) of respondents, 19 (2%) indicated that rheumatology services were suspended completely at least temporarily, 263 (24%) reported both, partial and complete closure and only 188 (17%) indicated no closure. Partial closure typically lasted between 5 and 8 weeks (43% of
Epidemiology

Table 1 Demographics of respondents from EULAR countries (n=1286)

| Professional background | Number of responses | Percentage of responses |
|-------------------------|---------------------|-------------------------|
| Rheumatologist or other specialist primarily managing patients with inflammatory RMDs | 966 | 75.1 |
| Rheumatologist in training | 145 | 11.3 |
| Healthcare professional in rheumatology | 163 | 12.7 |
| Other | 12 | 0.9 |

| Primary affiliation | Number of responses | Percentage of responses |
|---------------------|---------------------|-------------------------|
| University hospital | 648 | 50.4 |
| Community based hospital | 375 | 29.2 |
| Private practice | 231 | 18.0 |
| Other | 32 | 2.5 |

| Responses according to countries | Number of respondents | Percentage of respondents |
|----------------------------------|------------------------|---------------------------|
| Romania | 143 | 11.1 |
| Italy | 121 | 9.4 |
| Netherlands | 114 | 8.9 |
| Germany | 110 | 8.6 |
| France | 109 | 8.5 |
| Spain | 80 | 6.2 |
| Denmark | 78 | 6.1 |
| Austria | 76 | 5.9 |
| UK | 70 | 5.5 |
| Greece | 69 | 5.4 |
| Switzerland | 55 | 4.3 |
| Portugal | 46 | 3.6 |
| Croatia | 36 | 2.8 |
| Turkey | 33 | 2.6 |
| Sweden | 31 | 2.4 |
| Ireland | 19 | 1.5 |
| Finland | 17 | 1.3 |
| Norway | 15 | 1.2 |
| Hungary | 13 | 1.0 |
| Slovenia | 8 | 0.6 |
| Belgium | 5 | 0.4 |
| Albania | 4 | 0.3 |
| Georgia | 4 | 0.3 |
| Israel | 4 | 0.3 |
| Lebanon | 4 | 0.3 |
| Cyprus | 3 | 0.2 |
| Czech Republic | 3 | 0.2 |
| Latvia | 3 | 0.2 |
| Montenegro | 3 | 0.2 |
| Russian Federation | 3 | 0.2 |
| Bulgaria | 2 | 0.2 |
| Serbia | 2 | 0.2 |
| Belarus | 1 | 0.1 |
| San Marino | 1 | 0.1 |
| North Macedonia | 1 | 0.1 |

| Age ranges | Number of respondents | Percentage of respondents |
|------------|------------------------|---------------------------|
| <30 | 475 | 4.7% |
| 30–39 | 249 | 24.9% |
| 40–49 | 192 | 20.5% |
| 50–59 | 262 | 29.5% |
| 60–69 | 128 | 12.8% |
| ≥70 | 84 | 2.5% |

| Gender | Number of respondents | Percentage of respondents |
|--------|------------------------|---------------------------|
| Male | 475 | 4.7% |
| Female | 807 | 62.9% |
| Other | 2 | 0.2% |

| Number of patients with inflammatory RMDs normally seen in a week by the respondent | Number of respondents | Percentage of respondents |
|---------------------------------------------------------------|------------------------|---------------------------|
| <30 | 449 | 35.2 |
| 30–59 | 552 | 43.2 |
| 60–99 | 192 | 15.0 |
| ≥100 | 84 | 6.5 |

*Specialists in rehabilitation, physicians primarily working for pharma or health insurance, specialist in nuclear medicine, dermatologist, nephrologists, internists, retired rheumatologists.
RMD, rheumatic and musculoskeletal disease.

Due to complete and/or partial closure of rheumatology services, 899/1094 (82%) physicians/HPR indicated cancellation or postponement of at least some face-to-face visits of new patients with (suspected) RMDs, 84% of those who had to cancel/postpone visits offered remote consultation at least for some of these visits (see tables 2 and 3 for details). Concerning follow-up visits, 991/1094 (91%) responded to have cancelled/postponed visits with 96% of them offering remote consultation. The frequency of postponement/cancellation of face-to-face visits of new patients and follow-up visits in relation to the duration of partial and complete closure is detailed in figure 2. Accordingly, the percentage of postponed/cancelled visits increased along with the duration of closure.

Remote consultations were conducted by different health workers: 924/1030 (90%) respondents indicated that rheumatologists and/or other specialists performed this activity, 302 (29%) and 223 (23%) stated that specialists in training and HPR, respectively, were also involved. Phone (966/1005, 96%) and/or email (n=498, 50%) were among the techniques most commonly used to consult with patients, whereas video (n=241, 24%) or mobile applications (n=44, 4%) were less frequently applied. Respondents stated that patients with suspected inflammatory RMDs (458/1029, 45%), those with previously unstable or active disease (n=563, 55%) or those with ongoing intravenous drug therapy (n=448, 44%) were prioritised for a face-to-face visit. They also indicated that patients receiving biological disease modifying anti-rheumatic drugs (bDMARDs) or targeted synthetic DMARDs (tsDMARDs) (319/1031, 31%) as well as those with unstable disease (n=234, 23%) were prioritised for a remote consultation. No specific prioritisation plan was reported by 277/1029 (27%) for face-to-face visits and by 434/1031 (42%) respondents for remote consultations.

Influence of changed care on principles of early diagnosis and treat to target
The majority of respondents had the impression that the intervals between symptom onset and first rheumatological visits were longer during COVID-19 related closure as compared with the months before (599/1031, 58%, with 26% of those 599 physicians/HPR stating that it was considerably longer). A minority of respondents (153/1030, 15%) answered that they were contacted more frequently by patients for a suspected flare as compared with before the crisis. Patients with a suspected flare were managed using multiple approaches: most physicians/HPR indicated that a face-to-face visit (723/927, 78% to whom the question was applicable) or a remote consultation (n=553, 60%) were offered. Day-care or in-patient care, referral to the emergency department or consultation with another specialist were rare options (each<10%). The majority of respondents (678/1029, 66%) felt that disease activity of patients with inflammatory RMDs they consulted during closure was not different from that in the preceding period.

Cancellation or postponement of non-urgent tests either by the service provider or by patients themselves were reported by 699/1030 (68%) and 426 (41%) respondents, respectively. Also, 34% of physicians/HPR (298/873 to whom the question was applicable) indicated that treatment decisions were frequently postponed and 62% (n=542) stated that patients' management was mainly based on history and clinical examination without additional tests.
Drugs used in rheumatology and to treat COVID-19

The use of HCQ for COVID-19 indications was reported by 466/1003 (47%) respondents. HCQ was particularly prescribed to patients admitted to the hospital (351 of those 442 who felt knowledgeable to answer this question, 79%) or to the intensive care unit (n=234, 53%), but also to those managed on an outpatient basis (184, 42%). Only a minority of respondents used HCQ for prophylaxis in health workers and/or other individuals (38/1003, 4%) as well as in patients with RMDs (mean 2%±9% of RMDs patients, n=914 responses). A shortage of HCQ was noted by 492/999 (49%) of respondents with large differences between countries (see figure 3). Consequently, this drug had to be stopped in a mean of 10% (±18%) of RMDs patients (n=811 responses). The majority of physicians/HPR (738/996, 74%) stated that they were less likely to start a bDMARD or tsDMARD in RMDs patients during COVID-19 crisis mainly because of patient’s fear to start such a treatment (n=569, 57%), limited availability of screening procedures (n=284, 29%) and/or decreased availability of rheumatological services (n=270, 27%).

Treatment of patients with COVID-19 with TCZ was reported by 423/1005 (42%) respondents, either in the setting of a clinical trial (178 of those 423 who indicated the use of TCZ in their hospital or practice, 42%) or off-label outside a study (n=245, 58%). TCZ was mainly administered to patients admitted to the intensive care unit (64% of those reporting use of TCZ for COVID-19). A shortage of TCZ was noted by 134/980 (14%) respondents, mainly in Italy and Spain as outlined in figure 3.

Overall, shortage or expected shortage of TCZ only rarely influenced the decision to start this drug in rheumatoid arthritis (RA).

| No closure | Complete closure | Partial closure | Complete and partial closure | Total |
|------------|------------------|----------------|----------------------------|-------|
| 67 (35.6)  | 2 (10.5)         | 102 (16.4)     | 24 (9.1)                   | 195   |
| 24 (12.8)  | 4 (21.1)         | 94 (15.1)      | 17 (6.4)                   | 139   |
| 14 (7.4)   | 2 (10.5)         | 96 (15.4)      | 33 (12.5)                  | 145   |
| 83 (44.1)  | 11 (57.9)        | 330 (53.1)     | 191 (72.1)                 | 615   |
| Total      | 188 (100)        | 19 (100)       | 622 (100)                  | 265   |

Data indicate the number (percentages) of respondents indicating cancellation/postponement of face-to-face visits of new patients with (suspected) rheumatic and musculoskeletal diseases with or without remote consultations.
Epidemiology

Table 3  Cancellation or postponement of follow-up face-to-face visits, according to the extent of closure of the rheumatology services

|                          | No closure | Complete closure | Partial closure | Complete and partial closure | Total |
|--------------------------|------------|------------------|-----------------|------------------------------|-------|
| No cancellation           | 48 (25.5)  | 2 (10.5)         | 39 (6.3)        | 14 (6.3)                     | 103 (9.4) |
| With remote visit         | 35 (18.6)  | 4 (21.1)         | 115 (18.5)      | 26 (9.8)                     | 180 (16.5) |
| Without remote visit      | 4 (2.1)    | 2 (10.5)         | 21 (3.4)        | 15 (5.7)                     | 42 (3.8)  |
| With and without remote visits | 101 (53.7) | 11 (57.9)       | 447 (71.9)      | 210 (79.2)                   | 769 (70.3) |
| Total                    | 188 (100)  | 19 (100)         | 622 (100)       | 265 (100)                    | 1094 (100) |

Data indicate the number (percentages) of respondents indicating cancellation/postponement of follow-up face-to-face visits of patients with rheumatologic and musculoskeletal diseases with or without remote consultations.

or giant cell arteritis, or to change treatment in patients with stable disease as depicted in table 4. In Italy and Spain however, preference of another bDMARD/tsDMARD, postponement of treatment with TCZ, as well as change of therapy in stable patients was commonly considered (online supplemental table 3).

Other bDMARDs/tsDMARDs used to treat patients with COVID-19 were sarilumab (58 of those 728 who felt knowledgeable to answer this question, 8%), baricitinib (n=55, 8%), canakinumab (n=20, 3%) and/or anakinra (n=103, 14%).

A recommendation for patients with RMDs to decrease or stop nonsteroidal anti-inflammatory drugs (NSAIDs) even when they did not have symptoms of COVID-19 in order to decrease the possible risk for a worse outcome of this disease was made by 151/998 (15%) and 15 (2%) of respondents, respectively. Similarly, 226/1000 (23%) and 1 (0.1%) recommended to decrease or stop glucocorticoids, respectively.

DISCUSSION

The magnitude of the impact of COVID-19 on both management decisions and quality of care of patients with RMDs has been unknown. The most worrisome findings, although not unexpected, are the fact that the lag between symptom onset to first rheumatological visits was increased during COVID-19 related closure, and that treatment decisions, particularly those to start a new b/tsDMARD were postponed mainly because of patients’ concerns to start a new treatment during the pandemic, but also due to limited availability of rheumatological services and/or screening tests. COVID-19 thus impacts heavily on two fundamental principles of rheumatology management, namely those of early diagnosis and treat to target.8 9 While we know from previous studies that long-term non-adherence to these strategies results in worse clinical and structural outcomes, the question to what extent a short-term interruption due to an infectious crisis impacts patients’ disease course is still unclear.8 10 See box 1 for the lessons learnt from this wave of the COVID-19 pandemic.

EULAR provisional recommendations for the management of RMDs in the context of SARS-CoV-2 suggest to consider withholding face-to-face visits temporarily or transforming them into a remote visit in phase of closure when the rheumatic disease is stable.11 According to the results of our survey, rheumatology service providers compensated for cancelled/postponed face-to-face visits using telemedicine, and many of them developed standard operating procedures to prioritise patients for face-to-face visits. Recent publications also indicate rapid development of telemedicine during the first wave of the pandemic,12–14 however, it seems that patients’ acceptance of telemedicine is only moderate yet.15 16 Besides, we have insufficient data on the effectiveness of telemedicine in rheumatology and need to know more about how and when telemedicine might efficaciously replace live visits.17 Given the expected increase in the prevalence of inflammatory and non-inflammatory RMDs in future due to an ageing population and other reasons, and the expected insufficient growth of workforce in rheumatology,18 19

Figure 2  Postponement/cancellation of face-to-face visits according to the duration of closure of rheumatology services. Figures indicate the cumulative percentage of respondents (Y axis) indicating the proportion of face-to-face visits (4 categories represented by the colours) of new patients and follow-up visits postponed/cancelled with or without remote consultation in relation to the duration of partial and/or complete closure of rheumatology services in weeks.
telemedicine and strategies to better prioritise visits are essential to maintain high quality of care in RMDs, irrespective of additional waves of the COVID-19 pandemic.

Another lesson we learnt from this crisis is that we need to better address patients’ concerns and fears about possible risks of immunosuppression in order not to delay treatment of new or active patients. Till today, there is no convincing evidence suggesting that patients with RMDs (regardless of whether or not they are taking DMARDs) are at an increased risk for COVID-19 infection and course as compared with the general population.20 21 Many advisories, including official government bodies nevertheless considered these patients at risk with corresponding communications to patients’ societies, which might have further increased patients’ concerns to adhere to hospital visits and immunosuppressive therapy.22–26

Another observation is that management of RMD patients during closure was mainly based on patient’s history and clinical examination, given that non-urgent tests were either not available or not desired by patients. Some of these tests such as imaging are important to inform rheumatologists who establish a diagnosis and to aid monitoring of disease status and disease activity.27–29 Similarly, laboratory tests are essential to guarantee patients’ safety in case a new DMARD is considered but also for those who are on stable drug treatment.30 Investigations performed in the office as part of the clinical visit (eg, ultrasound conducted by the rheumatologist) or on a domestic

---

**Figure 3** Shortage of (hydroxy)chloroquine (HCQ) and tocilizumab (TCZ) in EULAR countries. Figures indicate the percentage of respondents indicating a shortage of HCQ and/or TCZ according to countries. Only data for EULAR countries with >10 responses are shown.

**Table 4** Influence of shortage/expected shortage of tocilizumab on treatment decisions in rheumatoid arthritis and giant cell arteritis

| Influence on decision to start tocilizumab de novo | Rheumatoid arthritis | Giant cell arteritis |
|---------------------------------------------------|----------------------|---------------------|
| No influence | n=707*               | No influence        | n=663*              |
| Preference of another bDMARD/tsDMARD               | 599 (85%)            | Preference of MTX or another csDMARD | 614 (93%) |
| Postponement of treatment with TCZ                 | 32 (5%)              | Postponement of treatment with TCZ | 19 (3%)  |
| Sarilumab used off-label                          | 6 (1%)               |                     |         |

| Influence on decision to modify treatment with tocilizumab in patients with stable disease | Rheumatoid arthritis | Giant cell arteritis |
|-----------------------------------------------------------------------------------------------|----------------------|---------------------|
| No influence | n=925*               | No influence        | n=788*              |
| Switch of intravenous to subcutaneous TCZ | 191 (21%)            | Switch of intravenous to subcutaneous TCZ | 65 (8%) |
| Prolongation of administration interval | 28 (3%)              | Prolongation of administration interval | 10 (1%)  |
| Change of TCZ to another DMARD                   | 5 (0.6%)             | Change of TCZ to another DMARD | 2 (0.3%)  |
| Change of TCZ to sarilumab                       | 18 (2%)              | Stopped treatment with TCZ | 2 (0.3%)  |

*Total number of answers to this question.

MTX; methotrexate; b, biological; cs, conventional synthetic; DMARD, disease modifying anti-rheumatic drug; TCZ, tocilizumab; ts, targeted synthetic.
Epidemiology

Box 1 Lessons learnt from this wave of COVID-19 pandemic

► Patient communication needs to be improved in order to address patients’ concerns about the risk of infection and course of new viral epidemics such as COVID-19, particularly if a new disease modifying anti-rheumatic drug therapy is planned.

► Telemedicine and other models of care should be regularly assessed and researched more intensively in order to maintain high-quality of care even when face-to-face visits are not feasible.

► Off-label use of drugs for COVID-19 indication outside a clinical trial might lead to shortage of the respective substance for patients with rheumatic and musculoskeletal diseases (RMDs) and should be discouraged.

► Prioritising strategies for face-to-face visits and investigations such as laboratory testing, imaging and others should be developed in order not to delay diagnosis and treatment, and to guarantee adequate monitoring of disease activity and safety of patients with RMDs.

basis (eg, blood tests) might be preferable over those requested from another department or hospital service, in order to reduce (patients’ concerns about) the contact to other patients and hospital-based structures.

HCQ was used for the COVID-19 indication according to almost half of respondents for inpatients and outpatients and occasionally for prophylaxis. The common use of this drug in this off-label indication led to a shortage in several countries and consequently, about 10% of patients with RMDs had to stop it at least temporarily. A shortage of TCZ occurred mainly in Italy and Spain, two countries who were heavily affected by the COVID-19. Clinicians might have been pressured to try every drug with possible efficacy in critically ill patients, however, the use of HCQ and TCZ for COVID-19 was not based on solid data rather than on theories about the mode of action, case series and small observational studies. Recent studies indicate that HCQ is not recommended for COVID-19, and some evidence suggests that it might perhaps increase mortality when combined with azithromycin. Patients with inflammatory RMDs, particularly those with connective tissue disease, might be at a considerable risk of flare when they run out of HCQ. A comparable problem arises for TCZ: while a change to another bDMARD/ tsDMARD (at least in RA) might be considered in case of drug shortage, this is definitely not desirable due to the risks of intolerance and lack of efficacy. Our survey indicates that in fact, this has been performed only occasionally in clinical practice. While there is some evidence from observational studies and non-randomised trials that TCZ helps to reduce the mortality of patients with COVID-19 who develop severe (autoinflammatory) pneumonia, the randomised phase III (COVACTA) trial comparing TCZ with placebo in patients with severe COVID-19 associated pneumonia failed its primary endpoint of improved clinical status, as well as the key secondary endpoint of reduced mortality. Almost 60% of those 423 physicians/HPR who stated that TCZ had been used in their hospital/practice for patients with COVID-19 indicated off-label use of this drug outside a clinical trial, an ethically questionable approach that is discouraged by EULAR.11

NSAIDs, which have been concerned to upregulate ACE 2 receptors and to increase the susceptibility to the virus, and glucocorticoids, which might negatively affect virus clearance, should not automatically be stopped in patients with RMDs according to the EULAR task force.11 Even patients with symptoms of COVID-19 who are chronically treated with glucocorticoids should continue this treatment. Interestingly, 23% of respondents advised their patients to reduce the glucocorticoid dose and 15% that of NSAIDs, presumably not to expose patients to unnecessary risk during the pandemic. Discontinuation of these drugs, however, was the exception.

Our study is limited by the descriptive nature and by a potential responder bias. There were more responses from Romania and the Netherlands, countries with a relatively small population, than from the UK, Spain, France or Germany. We followed the same dissemination strategy of the survey in every country, so any imbalance in the number of responses compared with the expected target population may be due to factors beyond our control (eg, different communication strategies of national societies). Furthermore, owing to its anonymous nature, the survey could have been completed by different healthcare providers within the same centre, and we were unable to contact respondents to solve any data inconsistency. Two respondents, for example, indicated no cancellation of first or follow-up visits despite complete closure of their rheumatology service. While there might be a plausible explanation for this answer (eg, patients were sent to another rheumatologist), we were unable to clarify it. We did not ask to stratify the responses on prioritisation strategies according to diagnosis, acknowledging that the diagnosis (eg, inflammatory arthritis vs systemic RMDs) might have had an impact on these strategies.

Our study reflects experiences and opinions of physicians and HPR from EULAR countries and despite its limitations, this survey provides important insights into management decisions concerning patients with inflammatory RMDs during the COVID-19 outbreak. Retrieval of empirical data to respond to the questions raised was certainly not feasible during this wave of the pandemic.

In conclusion, measures related to containment of the COVID-19 pandemic led to a perceived delay between symptom onset and a first rheumatological visit, a postponement of treatment decisions, and a shortage of drugs used to treat RMDs patients and those with COVID-19 such as HCQ and TCZ. Important lessons we have learnt are the need to better address patients’ concerns about the risk of infection and course of COVID-19, particularly in case a new DMARD is planned. Telemedicine and prioritising strategies should be researched more extensively in order to maintain high quality of care even when face-to-face visits and other investigations, such as laboratory testing or imaging, are not feasible, for example, during a future wave of the COVID-19 pandemic.

Author affiliations

1Rheumatology, Medical University of Graz, Graz, Austria
2Rheumatology, Hospital of Brunico (SABES-ASDAA), Brunico, Italy
3Department of Medicine, Rheumatology Unit, University of Perugia, Perugia, Italy
4Rheumatology & Clinical Immunology, UMC Utrecht, Utrecht, The Netherlands
5Internal Medicine, Division of Rheumatology, and School for Public Health and Primary Care (CAPHRI), Maastricht University Medical Centre, Maastricht, The Netherlands
6Department of Rheumatology, CHU Montpellier, Montpellier University, Montpellier, France
7Department of Medicine, Division of Rheumatology, University Hospital of Geneva, Geneva, Switzerland
8Department of Rheumatology, University College London & University College London Hospitals & Northwick Park Hospital, London, UK
Epidemiology

Dejaco C, et al. Ann Rheum Dis 2021;80:518–526. doi:10.1136/annrheumdis-2020-218697

Tanja A Stamm http://orcid.org/0000-0003-3073-7284
Frank Buttgerie http://orcid.org/0000-0003-2534-550X

REFERENCES

1 Wang L, Wang Y, Ye D, et al. A review of the 2019 novel coronavirus (COVID-19) based on current evidence. Int J Antimicrob Agents. 2020;56:105948.
2 Tuve AR, Ng V, Rees E, et al. Estimation of COVID-19 outbreak size in Italy. Lancet Infect Dis 2020;20:537.
3 Remuzzi A, Remuzzi G. COVID-19 and Italy: what next? The Lancet 2020;395:1225–8.
4 Ye Q, Wang B, Mao J. Cytokine storm in COVID-19 and treatment. J Infect 2020;80:607–13.
5 Smolen JS, Landewé RBM, Bijlsma JWJ, et al. EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs. Ann Rheum Dis 2020;79:685–99.
6 Mehta R, McAuley DF, Brown M, et al. COVID-19: consider cytokine storm syndromes and immunosuppression. Lancet 2020;395:1033–4.
7 Sanders JM, Monogue ML, Jodkowski TZ, et al. Pharmacologic treatments for coronavirus disease 2019 (COVID-19); a review. AMA J 2020;323:1824–36.
8 Smolen JS, Breedveld FC, Burmester GR, et al. Treating rheumatoid arthritis to target: 2014 update of the recommendations of an international Task force. Ann Rheum Dis 2015;74:3–15.
9 Combe B, Landewe R, Daenel CI, et al. Update of the EULAR recommendations for the management of early arthritis. Ann Rheum Dis 2016;75:948–59.
10 Monti S, Montecucco C, Bugatti S, et al. Rheumatoid arthritis treatment: the earlier the better to prevent joint damage. RMD Open 2015;1:e000057.
11 Landewé RBM, Machado PH, Kroon F, et al. EULAR provisional recommendations for the management of rheumatoid arthritis and mucocutaneous skeletal diseases in the context of SARS-CoV-2. Ann Rheum Dis 2020;79:851–8.
12 Pienolka S, Aliveranini S, Vianini V, et al. Telemedicine will not keep us apart in COVID-19 pandemic. Ann Rheum Dis 2021;80:648.
13 Santos-Moreno P, Chavez-Chavez J, Hernández-Zambrano SM, et al. Experience of telemedicine use in a big cohort of patients with rheumatoid arthritis during COVID-19 pandemic. Ann Rheum Dis 2020;doi:10.1136/annrheumdis-2020-218165. [Epub ahead of print: 25 June 2020].
14 Bozza C, Cassione E, Zanframundo G, Biglia A, et al. COVID-19 infection in a northern-Italian cohort of systemic lupus erythematosus assessed by telemedicine. Ann Rheum Dis 2020;79:1382–3.
15 So H, Sesto C-C, Tam L-S. Patient acceptance of using telemedicine for follow-up of lupus nephritis in the COVID-19 outbreak. Ann Rheum Dis 2020;doi:10.1136/annrheumdis-2020-218282. [Epub ahead of print: 24 Jun 2020].
16 López-Medina C, Escudero A, Collantes-Esteve E. COVID-19 pandemic: an opportunity to assess the utility of telemedicine in patients with rheumatic diseases. Ann Rheum Dis 2021;80:e50.
17 Najm A, Gossec L, Weill C, et al. Mobile health apps for self-management of rheumatic and mucosal skeletal diseases: systematic literature review. JMIR Mhealth Uhealth 2019;7:e14370.
18 Dejaco C, Lackner A, Buttgeri F, et al. Rheumatology workforce planning in Western countries: a systematic literature review. Arthritis Care Res 2016;68:1874–82.
19 Battafarano DF, Ditmyer M, Bolster MB, et al. American College of rheumatology workforce study: supply and demand projections of adult rheumatology workforce (2015-2030). Arthritis Care Res 2015;2018:617–26.
20 Gianfrancesco M, Hynich 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.
21 Pablo JS, Abasolo L, Alvaro-Gracia JM, et al. Prevalence of hospital PCR-confirmed COVID-19 cases in patients with chronic inflammatory and autoimmune rheumatic diseases. Ann Rheum Dis 2020;80:1–6.
22 National Health Service. Clinical guide for the management of rheumatology patients during the coronavirus pandemic. Available: https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/clinical-guide-rheumatology-patients-v1-19-march-2020.pdf.
23 Robert Koch Institut. Informationen und Hilfestellungen für Personen mit einem höheren Risiko für einen schweren COVID-19-Krankheitsverlauf. Available: https://www.bsp.quit.admin.ch/bsp/en/home/krankheiten/ausbreche-epidemien-pandemien/aktuelle-ausbreche-epidemien/novel-cov/massnahmen-des-bundes.html.
24 European Centre for Disease Prevention and Control. Fact sheet for health professionals on coronaviruses. Available: http://ecdc.europa.eu/en/covid-19/latest-evidence.
25 Reuten PA, Rauchfuss E, Belers S, et al. Between fear and courage: attitudes, beliefs, and behavior of liver transplantation recipients and waiting list candidates during the COVID-19 pandemic. Transplantation 2020;104:328–34.
COVID-19 pandemic. *Am J Transplant* 2020. doi:10.1111/ajt.16118. [Epub ahead of print: 08 Jun 2020].

27 Colebatch AN, Edwards CJ, Østergaard M, et al. EULAR recommendations for the use of imaging of the joints in the clinical management of rheumatoid arthritis. *Ann Rheum Dis* 2013;72:804–14.

28 Dejaco C, Ramiro S, Duftner C, et al. EULAR recommendations for the use of imaging in large vessel vasculitis in clinical practice. *Ann Rheum Dis* 2018;77:636–43.

29 Mandl P, Aletaha D. The role of ultrasound and magnetic resonance imaging for treat to target in rheumatoid arthritis and psoriatic arthritis. *Rheumatology* 2019;58:2091–8.

30 Singh JA, Saag KG, Bridges SL, et al. American College of rheumatology guideline for the treatment of rheumatoid arthritis. *Arthritis Rheumatol* 2015;61:1–26.

31 Sturrock BR, Chloroquine CTL. and COVID-19 - a potential game changer? *Clin Med* 2020;20:278–81.

32 Gautret P, Lagier J-C, Parola P, et al. Hydroxychloroquine and azithromycin as a treatment of COVID-19: results of an open-label non-randomized clinical trial. *Int J Antimicrob Agents* 2020;56:105949.

33 Gautret P, Lagier J-C, Parola P, et al. Clinical and microbiological effect of a combination of hydroxychloroquine and azithromycin in 80 COVID-19 patients with at least a six-day follow up: a pilot observational study. *Travel Med Infect Dis* 2020;34:101663.

34 Bouliware DR, Pullen MF, Bangdvala AS, et al. A randomized trial of hydroxychloroquine as postexposure prophylaxis for Covid-19. *N Engl J Med* 2020;383:517–25.

35 Geleris J, Sun Y, Platt J, et al. Observational study of hydroxychloroquine in hospitalized patients with Covid-19. *N Engl J Med Overseas Ed* 2020;382:2411–8.

36 Patel TK, Banalviya M, Kevadiya BD, et al. Does adding of hydroxychloroquine to the standard care provide any benefit in reducing the mortality among COVID-19 patients?: a systematic review. *J Neuroimmune Pharmacol* 2020;15:350–8.

37 Jakkhar D, Kaur I. Potential of chloroquine and hydroxychloroquine to treat COVID-19 causes fears of shortages among people with systemic lupus erythematosus. *Nat Med* 2020;26:632.

38 Aiz M, Haghbin H, Abu Sitta E, et al. Efficacy of tocilizumab in COVID-19: a systematic review and meta-analysis. *J Med Virol* 2020;33.

39 Roche. Roche provides an update on the phase III COVACTA trial of Actemra/ RoActemra in hospitalised patients with severe COVID-19 associated pneumonia. Available: https://www.roche.com/investors/updates/inv-update-2020-07-29.htm

40 Pergolizzi JV. COVID-19 and NSAIDs: a narrative review of knowns and unknowns. *Pain Ther* 2020;1:1—6.

41 Lee N, Allen Chan KC, Hui DS, et al. Effects of early corticosteroid treatment on plasma SARS-associated coronavirus RNA concentrations in adult patients. *J Clin Virol* 2004;31:304–9.
Suppl. File 1. The Survey

We used SurveyMonkey® to conduct the survey. The survey was designed as an open survey, the link to the questionnaire was distributed via e-mails, newsletters and social media. The survey was piloted for usability and technical functionality by the EULAR working group and by a group of 28 rheumatologists invited personally by the EULAR working group members. No incentive was provided to the recipients of the survey; however, national EULAR societies was offered to receive country-specific data on request.

All questions appeared in the same order to all respondents, i.e. items were not randomized. No adaptive questioning was used, mandatory items were highlighted. Respondents were able to review and change their answers by using the back button. The IP address of the client computer has been used by SurveyMonkey® to prevent potential duplicate entries from the same user.

The full questionnaire including the introduction text as displayed on SurveyMonkey® is depicted below:

Page 1 : Introduction

Title: EULAR survey on Impact of COVID-19 on care of RMD

Please help EULAR to prepare for future waves of COVID-19 pandemic!

EULAR is conducting this survey to investigate how the COVID-19 pandemic influences management decisions of rheumatologists toward patients with inflammatory rheumatic and musculoskeletal diseases (RMD). The data obtained from this project will help EULAR to prepare for future waves of COVID-19 pandemic.

Please help us by filling out the following questionnaire. It consists of 37 questions divided into 3 sections. It will take less than 10 minutes to complete the questionnaire.

Page 2 : Section 1 – Professional background:

1) What is your profession?
   a) Rheumatologist (or other specialist primarily managing patients with inflammatory rheumatic and musculoskeletal diseases (RMDs))
   b) Rheumatologist in training (or other specialist primarily managing patients with inflammatory RMDs)
   c) Health Professional in Rheumatology
   d) Patient or health professional not directly involved in care of patients with RMD
      (in survey monkey this will go directly to the end of the survey)
   e) Other
Page 3:

2) What is your main affiliation? (please complete the survey from that perspective)
   a) University hospital
   b) Community based hospital
   c) Private practice
   d) Other:

3) In which country do you practice?
   a) Drop down menu

4) What is your age?
   a) Age ranges (<30, 30-39, 40-49, 50-59, 60-69, ≥70)

5) What is your gender?
   a) Male
   b) Female
   c) Other

6) What is the number of patients with inflammatory RMD you normally see in a week?
   a) Ranges (<30, 30-59, 60-99, 100-129, ≥130)

Page 4: Section 2 – Influence of containment measures on organisation of care for patients with inflammatory rheumatic and musculoskeletal diseases (RMD):

7) How long did partial or complete closure of your rheumatology clinic/practice last due to COVID-19? (multiple responses)
   a) No closure
   b) Partial closure (e.g. open only for emergency visits) (field for a number in weeks)
   c) Complete closure (field for number in weeks)

8) How much of your working time have you been reallocated to other services (emergency department, infectious disease / COVID-19 unit or other) in the last weeks?
   a) 0-100% of the overall working time spent in that service (Slider)

9) What percentage of face-to-face visits of new patients with (suspected) inflammatory RMD did you have to postpone or cancel in the last weeks? (Several answers possible)
   a) None, conducted all face-to-face visits scheduled
   b) Yes, without remote consultation, 0-100%
   c) Yes, converted into remote consultations, 0-100%
10) What percentage of face-to-face follow-up visits of patients with inflammatory RMD did you have to postpone or cancel in the last weeks? (Several answers possible)
   a) None, conducted all face-to-face visits scheduled
   b) Yes, without remote consultation, 0-100%
   c) Yes, converted into remote consultations, 0-100%

Page 5:

11) Who conducted remote consultations? (several answers possible)
   a) Rheumatologist (or other specialist primarily managing patients with inflammatory RMDs)
   b) Rheumatologist in training (or other specialist primarily managing patients with inflammatory RMDs)
   c) Health care professional in rheumatology
   d) Other, specify
   e) Not applicable

12) Which tools did you use for remote consultation? (Several answers possible)
   a) Phone call via landline or mobile
   b) Video-consultation
   c) Email
   d) Mobile application dedicated to monitoring of RMD (e.g. with self-assessment)
   e) Other, specify
   f) Not applicable

13) Have you developed in your hospital/practice standards how to prioritize patients for face-to-face visits? (several answers possible)
   a) No specific plan
   b) Yes, patients with suspected inflammatory RMD
   c) Yes, patients with bDMARDs or tsDMARDs
   d) Yes, patients with previously instable or active disease
   e) Yes, patients with ongoing intravenous infusion therapy
   f) Yes, patients on >7.5 mg prednisone equivalent
   g) Yes, elderly people (e.g. > age of 70 years)
   h) Yes, other, please specify

14) Have you developed in your hospital/practice standards how to prioritize patients for remote consultation? (several answers possible)
   a) No specific plan
   b) Yes, patients with biological DMARDS (bDMARDs) or targeted synthetic DMARDs (tsDMARDs)
   c) Yes, patients with previously instable or active disease
   d) Yes, patients with previously stable disease
   e) Yes, patients on >7.5 mg prednisone equivalent
f) Yes, elderly people (e.g. >age of 70 years)
g) Yes, other, please specify:

15) Have you been contacted in the last weeks by patients who had a suspected flare?
a) No
b) Yes, less than usually
c) Yes, equally as usually
d) Yes, more than usually

16) If yes, how did you manage these patients? (several answers possible)
a) Invited them to a face-to-face visit
b) Sent them to hospital for day-care or in-patient treatment
c) Remote consultation using telephone/E-mail/video or similar
d) Sent them to another rheumatologist or specialist
e) Sent them to the emergency department
f) Other
g) Not applicable

17) Do you have the impression that disease activity of your patients was higher in the last weeks as compared to the period before COVID-19 crisis?
a) No, better
b) No, equal
c) Yes, somewhat higher
d) Yes, considerably higher
e) Don’t know

18) Do you have the impression that the interval between symptom onset and a first rheumatological visit was longer in the last weeks as compared to the time before COVID-19 crisis?
a) No, shorter
b) No, equal
c) Yes, somewhat longer
d) Yes, considerably longer
e) Don’t know

19) Have you had in the last weeks difficulties to arrange diagnostic tests (e.g. ultrasound, x-ray, laboratory tests) for your RMD patients? (several answers)
a) No
b) Yes, non-urgent tests were cancelled or postponed
c) Yes, patients themselves cancelled or postponed tests
d) Other:
20) **If yes**, did this influence your decisions how to manage patients with RMD? (several answers)
   a) No
   b) Yes, management was mostly based on history and clinical examination
   c) Yes, treatment decisions have been postponed
   d) Other
   e) Not applicable

Page 6: Section 3 – Role of drugs used in rheumatology and to treat COVID-19:

21) Have patients with COVID-19 in your hospital/practice been treated with (hydroxy)chloroquine for the COVID-19 indication?
   a) No
   b) Yes
   c) Don’t know

22) **If YES**, which patient groups? (several answers)
   a) Patients with suspected COVID-19 managed on an out-patient basis
   b) Patients with confirmed COVID-19 managed on an out-patient basis
   c) Patients with suspected/confirmed COVID-19 admitted to hospital
   d) Patients with suspected/confirmed COVID-19 admitted to intensive care unit
   e) Other groups (specify)
   f) Don’t know or not applicable

23) Have health workers or other groups in your hospital/practice systematically received (hydroxy)chloroquine as prophylaxis against COVID-19 infection? (several answers)
   a) No
   b) Health workers
   c) Other groups: specify
   d) Don’t know

24) Have you added to your patients with inflammatory RMD (hydroxy)chloroquine as prophylaxis against COVID-19?
   a) No
   b) Yes, 0-100%, specify which groups

25) Have you noticed in the last weeks a shortage of supply with (hydroxy)chloroquine in your hospital/practice?
   a) No
   b) Yes

26) **If YES**, in what percentage of your patients with RMD have you changed or stopped treatment with (hydroxy)chloroquine due to shortage of the drug?
Has it been less likely in the last weeks that you started a biological or targeted synthetic DMARD in your RMD patients due to COVID-19 pandemic? (several answers)

a) No
b) Yes, 0-100%, specify which groups

c) Yes, because of financial restrictions (e.g. lack of insurance coverage)

d) Yes, because of decreased availability of rheumatological services

e) Yes, because of limited availability of screening procedures (e.g. chest X-ray, tuberculosis testing)

f) Yes, because of patient’s fear to start such a treatment during COVID-19 pandemic

g) Other:

Have patients with COVID-19 in your hospital/practice been treated with tocilizumab for COVID-19 indication? (Several answers)

a) No
b) Yes, in the setting of a clinical trial
c) Yes, off-label (not in a trial)
d) Don’t know
e) Not applicable

If YES, which patient groups? (several answers)

a) Patients with suspected/confirmed COVID-19 plus hyperinflammation who are managed on an out-patient basis
b) admitted to the hospital
c) admitted to the intensive care unit
d) Other groups (specify)
e) Don’t know
f) Not applicable

Have you noticed in the last weeks a shortage with supply of tocilizumab in your hospital/practice?

a) No
b) Yes

Did the shortage/expected shortage influence your decision to start tocilizumab de novo in patients with rheumatoid arthritis?

a) No
b) Yes, therefore another biological or targeted synthetic DMARD was preferred
c) Yes, treatment start was postponed
d) Not applicable
32) Did the shortage/expected shortage influence your decision to start tocilizumab de novo in patients with giant cell arteritis?
   a) No
   b) Yes, therefore methotrexate or another DMARD was preferred
   c) Yes, therefore sarilumab was used off-label
   d) Yes, treatment start was postponed
   e) Not applicable

33) Have you in the last weeks changed current treatment with tocilizumab in patients with rheumatoid arthritis and stable disease due to drug shortage/expected shortage? (several answers)
   a) No
   b) Yes, prolonged the interval between tocilizumab administrations
   c) Yes, changed from intravenous to subcutaneous administration of tocilizumab
   d) Yes, changed from tocilizumab to sarilumab
   e) Yes, changed from tocilizumab to another DMARD
   f) Not applicable

34) Have you in the last weeks changed current treatment with tocilizumab in patients with giant cell arteritis and stable disease due to drug shortage/expected shortage? (several answers)
   a) No
   b) Yes, prolonged the interval between tocilizumab administrations
   c) Yes, changed from intravenous to subcutaneous administration of tocilizumab
   d) Yes, changed from tocilizumab to another DMARD
   e) Not applicable

35) Are other biological or targeted synthetic DMARDs used in your hospital/practice to treat patients with COVID-19? (several answers)
   a) No
   b) Yes, sarilumab
   c) Yes, baricitinib
   d) Yes, canakinumab
   e) Yes, anakinra
   f) Yes, other (specify)
   g) Don’t know

36) Do you generally recommend your patients with RMD to stop/decrease intake of NSAIDs even when they do NOT have COVID-19 symptoms in order to decrease the possible risk for a worse outcome of COVID-19?
   a) No
   b) Yes, decrease the dose / frequency of intake
   c) Yes, stop it completely
37) Do you generally recommend your patients with RMD to stop/decrease intake of glucocorticoids even when they do NOT have COVID-19 symptoms in order to decrease the possible risk for a worse outcome of COVID-19?
   a) No
   b) Yes, decrease the dose / frequency of intake
   c) Yes, stop it completely
**Supplementary Table 1.** Complete list of responses according to individual countries (n=58)

| Responses according to countries | Number of responses | Percentage of responses |
|----------------------------------|---------------------|-------------------------|
| Romania                          | 143                 | 10.7%                   |
| Italy                            | 121                 | 9.1%                    |
| Netherlands                      | 114                 | 8.6%                    |
| Germany                          | 110                 | 8.3%                    |
| France                           | 109                 | 8.2%                    |
| Spain                            | 80                  | 6.0%                    |
| Denmark                          | 78                  | 5.9%                    |
| Austria                          | 76                  | 5.7%                    |
| United Kingdom                   | 70                  | 5.3%                    |
| Greece                           | 69                  | 5.2%                    |
| Switzerland                      | 55                  | 4.1%                    |
| Portugal                         | 46                  | 3.5%                    |
| Croatia                          | 36                  | 2.7%                    |
| Turkey                           | 33                  | 2.5%                    |
| Sweden                           | 31                  | 2.3%                    |
| Ireland                          | 19                  | 1.4%                    |
| Finland                          | 17                  | 1.3%                    |
| Norway                           | 15                  | 1.1%                    |
| Hungary                          | 13                  | 1.0%                    |
| Slovenia                         | 8                   | 0.6%                    |
| Algeria                          | 7                   | 0.5%                    |
| United States of America         | 6                   | 0.5%                    |
| Belgium                          | 5                   | 0.4%                    |
| Morocco                          | 5                   | 0.4%                    |
| Albania                          | 4                   | 0.3%                    |
| Georgia                          | 4                   | 0.3%                    |
| Israel                           | 4                   | 0.3%                    |
| Lebanon                          | 4                   | 0.3%                    |
| Mexico                           | 4                   | 0.3%                    |
| Cyprus                           | 3                   | 0.2%                    |
| Czech Republic                   | 3                   | 0.2%                    |
| Latvia                           | 3                   | 0.2%                    |
| Montenegro                       | 3                   | 0.2%                    |
| Russian Federation               | 3                   | 0.2%                    |
| Argentina                        | 2                   | 0.2%                    |
| Bulgaria                         | 2                   | 0.2%                    |
| Canada                           | 2                   | 0.2%                    |
| India                            | 2                   | 0.2%                    |
| Luxembourg                       | 2                   | 0.2%                    |
| Serbia                           | 2                   | 0.2%                    |
| Andorra                          | 1                   | 0.1%                    |
| Australia                        | 1                   | 0.1%                    |
| Azerbaijan                       | 1                   | 0.1%                    |
| Belarus                          | 1                   | 0.1%                    |
| Benin                            | 1                   | 0.1%                    |
| Country                | Count | Proportion |
|-----------------------|-------|------------|
| China                 | 1     | 0.1%       |
| Colombia              | 1     | 0.1%       |
| Egypt                 | 1     | 0.1%       |
| Japan                 | 1     | 0.1%       |
| Kazakhstan            | 1     | 0.1%       |
| Kuwait                | 1     | 0.1%       |
| New Zealand           | 1     | 0.1%       |
| Pakistan              | 1     | 0.1%       |
| Qatar                 | 1     | 0.1%       |
| Republic of Korea     | 1     | 0.1%       |
| San Marino            | 1     | 0.1%       |
| North Macedonia       | 1     | 0.1%       |
| Tunisia               | 1     | 0.1%       |
**Supplementary Table 2.** People with SARS CoV2, number of deaths and COVID-19 related containment measures

| EULAR countries* | Infections with SARS CoV2 | COVID-19 related deaths | Schools, nurseries, educational facilities closure | National movements restrictions | Non-essential shops closure | International movements restrictions | Flight restrictions |
|------------------|---------------------------|-------------------------|-----------------------------------------------|-------------------------------|-----------------------------|----------------------------------|---------------------|
| Romania          | 6,633                     | 331                     | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Italy            | 159,516                   | 20,465                  | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Netherlands      | 26,551                    | 2,823                   | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Germany          | 128,208                   | 3,043                   | ●                                             | ●                             | ●                           | ●                                | ●                   |
| France           | 98,076                    | 14,967                  | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Spain            | 169,628                   | 17,628                  | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Denmark          | 6,318                     | 285                     | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Austria          | 14,041                    | 368                     | ●                                             | ●                             | ●                           | ●                                | ●                   |
| United Kingdom   | 88,621                    | 13,037                  | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Greece           | 2,145                     | 99                      | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Switzerland      | 25,688                    | 1,138                   | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Portugal         | 16,934                    | 535                     | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Croatia          | 1,650                     | 25                      | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Turkey           | 61,049                    | 1,296                   | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Sweden           | 10,948                    | 919                     | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Ireland          | 10,647                    | 365                     | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Finland          | 3,064                     | 59                      | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Norway           | 6,565                     | 134                     | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Hungary          | 1,458                     | 109                     | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Slovenia         | 1,212                     | 55                      | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Belgium          | 30,589                    | 3,903                   | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Albania          | 467                       | 23                      | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Georgia          | 272                       | 3                       | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Israel           | 11,586                    | 116                     | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Lebanon          | 632                       | 20                      | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Cyprus           | 662                       | 12                      | ●                                             | ●                             | ●                           | ●                                | ●                   |
| Czech Republic   | 6,022                     | 143                     | ●                                             | ●                             | ●                           | ●                                | ●                   |
This table provides an overview of people infected with SARS CoV2, number of deaths associated with COVID-19 as well as COVID-19 related containment measures in EULAR countries who provided at least one response to the survey, as per April 13th 2020 (modified from [1-16]); * EULAR countries are listed in descending order according to the number of responses to the survey

- national measures; ● Partial/regional measures; ● no restrictions; empty cells – data not available

COVID-19, coronavirus disease 2019; SARS-CoV2, Severe Acute Respiratory Syndrome coronavirus-2

| Country            | Cases | Deaths | National Measures | Partial/Regional Measures | No Restrictions |
|--------------------|-------|--------|-------------------|---------------------------|----------------|
| Latvia             | 655   | 5      | ●                 | ●                         | ●              |
| Montenegro         | 274   | 3      | ●                 | ●                         | ●              |
| Russian Federation | 18,328| 148    | ●                 | ●                         | ●              |
| Bulgaria           | 685   | 32     | ●                 | ●                         | ●              |
| Serbia             | 4,054 | 85     | ●                 | ●                         | ●              |
| Belarus            | 2,919 | 29     | ●                 | ●                         | ●              |
| San Marino         | 356   | 35     | ●                 | ●                         | ●              |
| North Macedonia    | 854   | 38     | ●                 | ●                         | ●              |
References

1 European Union. A European roadmap to lifting coronavirus containment measures. https://ec.europa.eu/info/sites/info/files/factsheet-lifting-containment-measures_en.pdf (accessed 25 Sep 2020).

2 Berliner Morgenpost. Coronavirus Monitor. https://interaktiv.morgenpost.de/corona-virus-karte-infektionen-deutschland-weltweit/ (accessed 25 Sep 2020).

3 Dong E, Du H, Gardner L. An interactive web-based dashboard to track COVID-19 in real time. Lancet Infect. Dis. 2020;20:533–4.

4 GOV.UK. Coronavirus (COVID-19). 2020.https://www.gov.uk/coronavirus (accessed 25 Sep 2020).

5 Bundesamt für Gesundheit. Neues Coronavirus: Massnahmen und Verordnungen. 2020.https://www.bag.admin.ch/bag/de/home/krankheiten/ausbrueche-epidemien-pandemien/aktuelle-ausbrueche-epidemien/novel-cov/massnahmen-des-bundes.html (accessed 25 Sep 2020).

6 Norvegian Institute of Public Health. The Norwegian Institute of Public Health. 2020.https://www.fhi.no/en/ (accessed 26 Sep 2020).

7 Albanian Goverment. Albanian Goverment. https://qbz.gov.al/eli/vendim/2020/03/09/204/7a5d2e45-8752-4930-be38-8b55ec571ec (accessed 26 Sep 2020).

8 The Russian Goverment. The Russian Goverment. http://kremlin.ru/acts/assignments/orders/63206 (accessed 1 Oct 2020).

9 REPUBLIC OF TURKEY MINISTRY. COVID-19 INFORMATION PAGE. https://covid19.saglik.gov.tr/?_Dil=2 (accessed 1 Oct 2020).

10 Government of North Macedonia. Coronavirus. http://zdravstvo.gov.mk/korona-virus/ (accessed 2 Oct 2020).

11 A3M Mobile Personal Protection GmbH. COVID-19 pandemic - Lebanon. https://global-monitoring.com/gm/page/events/epidemic-0001946.yn4FxCb4uZYa.html?lang=en (accessed 2 Oct 2020).

12 State of Israel - The Ministry of Health. The novel Coronavirus. https://govextra.gov.il/ministry-of-health/corona/corona-virus-en/ (accessed 2 Oct 2020).
13 Official Information about coronavirus in Russia. https://стопкоронавирус.рф/info/ofdoc/ (accessed 3 Oct 2020).

14 Montenegrin government and The National Coordination Body for Infectious Diseases. Coronavirus COVID-19. https://www.coronainfocg.me/ (accessed 6 Oct 2020).

15 Ministry of Health of the Republic of Belarus. Ministry of Health of the Republic of Belarus. http://minzdrav.gov.by/ru/ (accessed 9 Oct 2020).

16 Government of Georgia. Prevention of Coronavirus spread in Georgia. https://stopcov.ge/en (accessed 10 Oct 2020).
**Supplementary Table 3.** Influence of shortage/expected shortage of tocilizumab on treatment decisions in rheumatoid arthritis (RA) and giant cell arteritis (GCA) in Italy and Spain

| Influenced decision to start tocilizumab de novo | Rheumatoid arthritis | Giant cell arteritis |
|-----------------------------------------------|----------------------|---------------------|
|                                               | Italy | Spain | Italy | Spain |
| No influence                                  | n=98* | n=72* | No influence | n=82* | n=63* |
| Preference of another bDMARD/tsDMARD          | 59 (60%) | 38 (53%) | Preference of MTX or other csDMARD | 71 (87%) | 43 (68%) |
| Postponement of treatment with TCZ            | 11 (11%) | 5 (7%) | Postponement of treatment with TCZ | 4 (5%) | 5 (8%) |
| Sarilumab used off-label                      | 0 | 6 (10%) | Sarilumab used off-label | 0 | 6 (10%) |

| Influenced decision to modify treatment with tocilizumab in patients with stable disease | Rheumatoid arthritis | Giant cell arteritis |
|------------------------------------------------------------------------------------------|----------------------|---------------------|
|                                                                                          | Italy | Spain | Italy | Spain |
| No influence                                                                              | n=121* | n=83* | No influence | n=89* | n=70* |
| Switch of i.v. to s.c. TCZ                                                                | 54 (45%) | 46 (55%) | Switch of i.v. to s.c. TCZ | 38 (54%) | 25 (36%) |
| Prolongation of administration interval                                                  | 11 (9%) | 7 (8%) | Prolongation of administration interval | 3 (3%) | 5 (7%) |
| Change of TCZ to another DMARD                                                           | 3 (3%) | 0 | Change of TCZ to another DMARD | 1 (1%) | 1 (1%) |
| Change of TCZ to sarilumab                                                               | 9 (7%) | 7 (8%) | Stopped treatment with TCZ | 0 | 1 (1%) |

* total number of answers to this question.

DMARD, disease modifying anti-rheumatic drug; b, biological; cs, conventional synthetic; i.v., intravenous; MTX; methotrexate; s.c., subcutaneous; ts, targeted synthetic TCZ, tocilizumab.