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Immediate effect of the COVID-19 pandemic on patient health, health-care use, and behaviours: results from an international survey of people with rheumatic diseases

Jonathan S Hausmann, Kevin Kennedy, Julia F Simard, Jean W Liew, Jeffrey A Sparks, Tarin T Moni, Carly Harrison, Maggie J Larché, Mitchell Levine, Sebastian E Sattui, Teresa Semalulu, Gary Foster, Salman Surangiwala, Lehana Thabane, Richard P Beesley, Karen L Durrant, Elsa F Mateus, Serena Mingolla, Michal Nudel, Candace A Palmerlee, Dawn P Richards, David F L Liew, Catherine L Hill, Suleman Bhana, Wendy Costello, Rebecca Grainger, Pedro M Machado, Philip C Robinson, Paul Sufka, Zachary S Wallace, Jinoos Yazdany, Emily Sirotich, on behalf of the COVID-19 Global Rheumatology Alliance*

Summary

Background The impact and consequences of the COVID-19 pandemic on people with rheumatic disease are unclear. We developed the COVID-19 Global Rheumatology Alliance Patient Experience Survey to assess the effects of the COVID-19 pandemic on people with rheumatic disease worldwide.

Methods Survey questions were developed by key stakeholder groups and disseminated worldwide through social media, websites, and patient support organisations. Questions included demographics, rheumatic disease diagnosis, COVID-19 diagnosis, adoption of protective behaviours to mitigate COVID-19 exposure, medication access and changes, health-care access and communication with rheumatologists, and changes in employment or schooling. Adults age 18 years and older with inflammatory or autoimmune rheumatic diseases were eligible for inclusion. We included participants with and without a COVID-19 diagnosis. We excluded respondents reporting only non-inflammatory rheumatic diseases such as fibromyalgia or osteoarthritis.

Findings 12,117 responses to the survey were received between April 3 and May 8, 2020, and of these, 10,407 respondents had included appropriate age data. We included complete responses from 9300 adults with rheumatic disease (mean age 46·1 years; 8375 [90·1%] women, 893 [9·6%] men, and 32 [0·3%] participants who identified as non-binary). 6273 (67·5%) of respondents identified as White, 1565 (16·8%) as Latin American, 198 (2·1%) as Black, 190 (2·0%) as Asian, and 42 (0·5%) as Native American or Aboriginal or First Nation. The most common rheumatic disease diagnoses included rheumatoid arthritis (3636 [39·1%] of 9300), systemic lupus erythematosus (2882 [31·0%]), and Sjögren’s syndrome (1290 [13·9%]). Most respondents (6921 [82·0%] of 8441) continued their antirheumatic medications as prescribed. Almost all (9266 [99·7%] of 9297) respondents adopted protective behaviours to limit SARS-CoV-2 exposure. A change in employment status occurred in 2524 (27·1%) of 9300 of respondents, with a 13·6% decrease in the number in full-time employment (from 4066 to 3514).

Interpretation People with rheumatic disease maintained therapy and followed public health advice to mitigate the risks of COVID-19. Substantial employment status changes occurred, with potential implications for health-care access, medication affordability, mental health, and rheumatic disease activity.

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Introduction People with rheumatic disease are at increased risk of infection due to immune dysregulation and the use of immunosuppressive medications.12 Behavioural changes that could mitigate these risks are often discussed as part of the shared decision making that occurs during the management of rheumatic diseases.7 However, at the beginning of the COVID-19 pandemic, little was known to inform discussions about the risks of COVID-19 in people with these rheumatic diseases. As a result, people with rheumatic diseases faced substantial challenges in deciding how to modify their behaviour to reduce their risk of infection with the SARS-CoV-2 virus.

The pandemic also caused substantial disruptions in health-care delivery, including the delay or cancellation of clinic visits, infusions, and procedures8 and impaired access to some antirheumatic medications because these were diverted to prevent or treat COVID-19.9 These challenges also greatly affected employment and education, and consequently, access to health insurance and the ability to obtain health care.10 Understanding the effect of the pandemic on people with rheumatic disease might help rheumatologists better address their patients’ needs.
Evidence before this study
We searched PubMed for articles published up to March 1, 2020, regarding the risks of infection in patients with rheumatic disease. We included the Medical Subject Headings “rheumatology” OR “rheumatic diseases” AND “infections” AND “risk.” We did not restrict our search to a specific language or type of publication. We found multiple studies showing that people with rheumatic disease are at increased risk of infection due to immune dysregulation and the use of immunosuppression. We then did a Medical Subject Headings search with “rheumatology” OR “rheumatic diseases AND “COVID-19” AND “behavior” OR “patient reported outcome measures” to our search algorithm and no relevant articles were found. At the beginning of the COVID-19 pandemic, little was known about the risks of COVID-19 in people with rheumatic disease or how people with rheumatic disease changed their behaviours because of the pandemic. Among this population, the impact of the pandemic on health-care access, use of health-care systems, and employment had not been well-characterised.

Added value of this study
Our study is the largest international survey of people with rheumatic disease during the COVID-19 pandemic. We found that people with rheumatic disease adhered to risk-mitigating behaviours such as physical distancing and mask-wearing and avoided potential high-risk exposures; the proportion of participants reporting a diagnosis of COVID-19 during this time period was low. Respondents largely continued their use of antirheumatic and immunosuppressive drugs. More than a quarter of respondents had changes in employment status, with decreases in the number of full-time employees while the number of those unemployed increased. Our study complements and contextualises data gathered from other sources, such as medical records, claims databases, and physician-entered registries.

Implications of all the available evidence
Understanding the behaviours and access to care among people with rheumatic disease during the early phase of the pandemic is essential to inform clinical decision making and structural changes required within health-care systems. Given the substantial changes to employment in people with rheumatic disease, policies that promote remote working might help them to continue working while avoiding potentially high-risk exposures. Future studies should investigate the long-term effects of the COVID-19 pandemic on patients, including COVID-19 vaccination, behavioral modifications, and effect on rheumatic disease activity.
study. Patient organisations disseminated the survey to their members and through social media channels. Additionally, the survey was publicly accessible from the COVID-19 Global Rheumatology Alliance website. A copy of the survey is provided in appendix (pp 1–39).

Adults age 18 years and older with inflammatory or autoimmune rheumatic diseases were eligible to participate. We included all adult respondents who completed the survey between April 3 and May 8, 2020, and provided their age, gender, country of residence, race or ethnicity (or both), rheumatic disease diagnosis, and reported their use of antiinflammatory medications. Participants with and without a COVID-19 diagnosis were included. We excluded participants reporting non-inflammatory rheumatic diseases such as fibromyalgia or osteoarthritis.

The project was deemed exempt from requiring ethics review by the Boston Children’s Hospital Institutional Review Board. The survey was anonymous and consent was implied by survey completion.

Survey data collection
As part of the survey, participants were required to provide information on demographics and clinical characteristics. Participants self-reported demographics, including age, gender (female, male, non-binary, prefer not to answer), country of residence, and race or ethnicity. Country of residence was grouped by WHO region.12 Race or ethnicity was grouped into mutually exclusive categories: Black, Asian (including East Asian, South Asian, and West Asian), Latin American, White, Native American or Aboriginal or First Nations, Arab, Pacific Islander, and multiple identities (participants with more than one race or ethnicity).

Participants reported tobacco smoking status (current, past, never) and selected from 22 common comorbidities, including those that had been associated with poorer outcomes from COVID-19 (appendix p 40). Individual comorbidity burden was defined by the number of comorbid conditions reported, and categorised as: none, one, two, and three or more comorbidities.

Participants were also required to report their COVID-19 status, and if believed to have the SARS-CoV-2 virus, how it was diagnosed (self-diagnosed on the basis of symptoms, diagnosed by a health-care provider on the basis of symptoms, or via laboratory testing).

The survey additionally included questions on rheumatic disease diagnoses and rheumatic disease activity. Respondents could indicate multiple rheumatic diseases. Rheumatic diseases were categorised as: rheumatoid arthritis, systemic lupus erythematosus, Sjögren’s syndrome, psoriatic arthritis, antiphospholipid syndrome, spondyloarthritis, vasculitis, other connective tissue disease, autoinflammatory disease, other arthritis, and other rheumatic disease (appendix p 40). Rheumatic disease activity was adapted from a patient global assessment of disease activity on a visual analogue scale.10 Participants were asked “considering all the ways your rheumatic disease affects you, rate how well you are doing today on the following scale,” in which 0 indicated “very well” and 10 indicated “very poor”.

Participants were required to answer questions regarding medication use and availability. Participants identified all antiinflammatory medications they took within 3 months of completing the survey from a list of 23 classes of medications, with an option to report medications not listed (appendix p 40). Respondents indicated whether there were any changes to their medication use specifying: “yes, I continue to take this drug”; “no, pharmacy did not have supply”; “no, it was not effective”; or “no, I want to avoid immunsuppression.”

The survey also included questions on adaptive behaviours during the pandemic. Participants were asked whether they contacted their rheumatologist, adopted protective behaviours, and engaged in activities that could increase their risk of COVID-19. Modes of communicating with their rheumatologist included phone call, email or patient portal, telemedicine or video conference, in person visit, unable to communicate, and unnecessary to communicate. The protective behaviours included physical distancing (avoiding crowds and large groups of people), quarantining (staying home and avoiding others as much as possible), using gloves or masks, or both during social interactions, or none. Those reporting quarantining also specified whether it was self-imposed or imposed by their government. We also asked about travel to an area with many COVID-19 cases, close contact with a person with confirmed or probable COVID-19, and presence in a health-care facility where COVID-19 is managed.

Finally, the survey included questions about employment and educational status. Participants indicated their employment or student status as of Jan 1, 2020 (employed full-time, part-time, not employed looking for work, not employed not looking for work, retired, disabled, or full-time student) and whether this had changed at the time of survey completion. Full-time students specified how they were participating in classes at the time of survey completion (in the classroom, virtually on a computer, classes were cancelled, or other).

Statistical analysis
Descriptive statistics, including means and SDs, proportions and 95% CIs, were summarised. Missing data for each question were omitted. A sensitivity analysis was done to determine the effect of including respondents with missing demographics information.

Role of the funding source
The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report.

Results
Between April 3 and May 8, 2020, 12 117 responses were received. Of these, 1710 were missing age data, and
10 407 respondents had included adequate age data. 623 responses were excluded on the basis of age, which showed that 9784 responses were received from adults. 484 responses were further excluded and 9300 responses were included in survey data analysis (figure 1). A sensitivity analysis showed no effect when including respondents with missing demographics information. Demographics and clinical characteristics of adult participants are outlined in the table. Additional characteristics, stratified by gender, are presented in the appendix (pp 41–42).

Responses were collected from more than 90 countries, with most respondents from the Americas (6113 [65·7%] of 9300) or Europe (2697 [29·0%]). 8375 (90·1%) respondents were women, 893 (9·6%) were men, and 32 (0·3%) identified as non-binary. The mean age of respondents was 46·1 years (SD 12·8). 6273 (67·5%) respondents identified themselves as White, 1565 (16·8%) as Asian, 42 (0·5%) as Native American or Aboriginal or First Nations. The remaining 1032 (11·1%) respondents indicated that they identified as other races or ethnicities (table). The most common rheumatic disease diagnoses were rheumatoid arthritis (3636 [39·1%]), systemic lupus erythematosus (2882 [31·0%]), and Sjögren’s syndrome (1290 [13·9%]). The mean score of the patient global assessment of disease activity was 4·5 (SD 2·5). The most commonly reported antirheumatic medications taken within the previous 3 months were conventional synthetic disease modifying antirheumatic drugs (DMARDs; 6637 [71·4%]), systemic glucocorticoids (3248 [34·9%]), and biologic DMARDs (2888 [31·1%]).

At least one comorbidity was reported by 5665 (63·5%) of 8923 respondents (table). Two or more comorbidities were reported by 2833 (31·7%) respondents. The most common comorbidities were cardiovascular disease (2241 [25·1%]), pain syndromes (1901 [21·3%]), and pulmonary disease (1819 [20·4%]; appendix p 41). Current smoking was reported by 943 (10·1%) of 9300 respondents and past tobacco smoking was reported by 2875 (30·9%) respondents (table). Additionally, 348 (3·8%) of 9266 respondents reported current use of vaping or e-cigarettes, whereas 512 (5·5%) reported past use (appendix p 41).

Of the 9300 participants, 510 (5·5%) reported a COVID-19 diagnosis. Of these, 223 (43·7%) were self-diagnosed on the basis of symptoms, 179 (35·1%) were diagnosed by a health-care provider on the basis of symptoms, and 91 (17·8%) were confirmed by laboratory testing. The remaining 17 (3·3%) respondents indicated that they were unsure of how they were diagnosed or did not complete the question (table).

Communication with a rheumatologist was most commonly occurred by telephone (2252 [24·3%] of 9270), followed by email or patient portal (1611 [17·4%]), office visit (ie, in person appointment; 919 [9·9%]), and telemedicine (552 [6·0%]). Other communication methods, including social media and texting, were used by 773 (8·3%) of respondents. More than a third (3291 [35·5%]) of respondents engaged in activities that could increase their risk of SARS-CoV-2 exposure (appendix pp 41–42).

Nearby all respondents (9266 [99·7%] of 9297) adopted at least one protective behaviour (appendix p 41). Protective measures included quarantining (staying home as much as possible; 7952 [85·5%]), physical distancing (7206 [77·5%]), and using gloves or masks, or both (4631 [49·8%]). All the listed protective measures were used by 3620 (38·9%) participants. More than half of those who quarantined were instructed to do so by their local or national governments (4056 [51·1%] of 7935). Most respondents (6921 [82·0%]) identified as non-binary. The mean age of respondents was 46·1 years (SD 12·8). 6273 (67·5%) respondents identified themselves as White, 1565 (16·8%) as Asian, 42 (0·5%) as Native American or Aboriginal or First Nations. The remaining 1032 (11·1%) respondents indicated that they identified as other races or ethnicities (table). The most common rheumatic disease diagnoses were rheumatoid arthritis (3636 [39·1%]), systemic lupus erythematosus (2882 [31·0%]), and

![Figure 1: Survey respondent inclusion and exclusion criteria](https://www.thelancet.com/rheumatology)
9179 respondents, 1228 (13·4%) visited a health-care facility where COVID-19 had been managed, 394 (4·3%) had close contact with a confirmed or probable case of COVID-19, and 365 (4·0%) travelled to an area with a high prevalence of COVID-19. Other potential exposures were reported by 477 (5·2%) participants, including close interactions in the workplace, shopping, taking public transport, and secondary transmission from their children attending school or relatives and friends travelling. Of 2104 respondents who engaged in activities that might have increased SARS-CoV-2 exposure, 1781 (84·6%) reported one activity, while 290 (13·8%) reported two activities, and 33 (1·6%) reported three or more activities that could increase their risk of exposure.

As of Jan 1, 2020, almost half of the respondents reported that they were employed full-time (4066 [43·7%] of 9300), 1434 (15·4%) were employed part-time, while 1058 (11·4%) were not employed (including those not looking and those looking for work). 1321 (14·2%) were disabled and unable to work, 301 (3·2%) were full-time students, and 1120 (12·0%) were retired (appendix p 43).

A change in employment status was reported by 27·1% (2524 of 9300) of respondents, and these transitions are depicted in figure 2. The most common transition was from full-time employment to another category,
Discussion

Our study shows that almost all respondents with rheumatic disease adopted protective behaviours during the early phase of the pandemic, with most practicing physical distancing or self-isolation strategies, using masks and gloves, and avoiding activities that could increase their risk of SARS-CoV-2 exposure. Most respondents also continued their antirheumatic medications. Moreover, the pandemic had severe effects on participants’ employment and education, with an increase in unemployment and most students transitioning to virtual classes.

The COVID-19 Global Rheumatology Alliance Patient Experience Survey was unique due to the international involvement of multiple stakeholders in developing questions to ensure patient-important outcomes were collected. This survey fills a gap and complements results from physician-reported registries, medical records, and claims databases by collecting data regarding patient perceptions and behavioural adaptations. Dissemination of the survey through social media and patient organisations enabled participation from people who did not access health care and would not have been captured in medical records-based studies.

In our study, most participants continued their antirheumatic medications, including immunosuppressants. This practice conforms to current recommendations for people with rheumatic conditions during the pandemic, which were not yet available at the time of the survey. The presence of rheumatic disease and the decision to continue immunosuppression might have created an increased perceived risk of infection, which perhaps explains the frequent use of protective behaviours and avoidance of potential exposures to COVID-19 in this population. Other studies have found that those with rheumatic disease are more likely to isolate than are matched friends or family controls, and that people taking biologic drugs are more likely to practice shielding (ie, to quarantine) than are those not taking biologics. Whether or not people with rheumatic disease are at increased risk of infection or complications than the general population remains unclear. People with rheumatic diseases might be more likely to be tested for COVID-19 because of their underlying diagnoses, thus creating biases in the outcomes of many studies. Additionally, those with rheumatic disease might have increased prevalence of comorbidities such as chronic lung disease, a known risk factor for poor COVID-19 outcomes, which has been associated with increased risk of death among this patient population.

Health-care systems adapted quickly to the COVID-19 pandemic, even during the early stages, with participants engaging in telemedicine as early as April, 2020. Concerningly, a portion of respondents indicated that they could not communicate with their rheumatologist, perhaps because of the closures of many clinics and delays in adapting to new types of health-care delivery. How this could magnify existing disparities in rheumatology care related to access to technology and the ability to use telemedicine remains to be elucidated.

We found a shift in employment in nearly a third of respondents, with a rise in unemployment and a decrease in full-time employment. Increases in unemployment and underemployment occurred in the USA and UK during the early months of the pandemic. The impact of the COVID-19 pandemic on employment in people with rheumatic disease is further complicated by work limitations and lower workforce participation already present in this population, including for younger people.

The loss of employer-sponsored health insurance could be particularly catastrophic for those living in countries without universal health care, who might not be able to afford out-of-pocket medical costs. Policies that promote remote working might help people with rheumatic disease and the decision to continue immunosuppression. This practice conforms to current recommendations for people with rheumatic conditions during the pandemic, which were not yet available at the time of the survey. The presence of rheumatic disease and the decision to continue immunosuppression might have created an increased perceived risk of infection, which perhaps explains the frequent use of protective behaviours and avoidance of potential exposures to COVID-19 in this population. Other studies have found that those with rheumatic disease are more likely to isolate than are matched friends or family controls, and that people taking biologic drugs are more likely to practice shielding (ie, to quarantine) than are those not taking biologics. Whether or not people with rheumatic disease are at increased risk of infection or complications than the general population remains unclear. People with rheumatic diseases might be more likely to be tested for COVID-19 because of their underlying diagnoses, thus creating biases in the outcomes of many studies. Additionally, those with rheumatic disease might have increased prevalence of comorbidities such as chronic lung disease, a known risk factor for poor COVID-19 outcomes, which has been associated with increased risk of death among this patient population.

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diseases continue working while avoiding potentially high-risk exposures.

Strengths of our study include the strong engagement of stakeholders through all phases of the research, international scope and reach, and responses from more than 9000 people with rheumatic disease. Several limitations must be acknowledged. Given the online nature of our survey, there could be limited generalisability to the general rheumatic disease patient population, although our study probably gives voice to groups that would not be included in more traditional medical studies. Individuals who had severe symptoms from COVID-19 are probably underrepresented because they were not able to take the survey. Few patients with reports of COVID-19 had confirmatory laboratory tests, and the accuracy of self-reported COVID-19 is unknown. Although these details might have increased the risk of misclassification in this study, they might also reflect the limited availability of testing early in the pandemic. There was limited male and racial and ethnic diversity within the cohort, which has been shown to affect the risk and severity of COVID-19, although challenges to minority recruitment for research are not limited to this study. Barriers to enrollment of non-white participants in research studies include structural racism and distrust of research given the history of mistreatment of vulnerable individuals. The female predominance in this study probably reflects the increased prevalence of rheumatic diseases in women, as well as the increased participation of women in online studies. Relying on self-reported data, we cannot rule out misclassification of diagnosis or other relevant clinical or demographic data. Finally, we lacked a control population of people without rheumatic disease, so some of the findings of this study might not necessarily be attributable to the presence of rheumatic disease, but rather might reflect changes that occurred in the general population.

In summary, we describe adaptations employed by people with rheumatic disease early in the pandemic, including those aimed to reduce their perceived risk of COVID-19, as well as the disruptions in health care that occurred. The results of this international survey complement and provide a context for data gathered from other sources, such as medical records, claims databases, and physician-entered registries. The engagement of patients, physicians, and researchers to develop, disseminate, and analyse the results of this survey provides a model of collaboration among the rheumatology community. Understanding the early behaviours of people with inflammatory and autoimmune conditions is necessary to assess the effects of the pandemic on this population, and not only those who became infected with SARS-CoV-2. A far-reaching consequence of the pandemic at the time of data collection was the abrupt change to employment, and many people with rheumatic disease were faced with delayed or reduced income. Unique within the field of rheumatology, our study illustrates the direction and magnitude of employment change from Jan 1, 2020, to May 8, 2020. Further work should address the consequences of employment status changes for health-care access, medication affordability, mental health, and rheumatic disease activity. With an improved understanding of COVID-19 and the existence of patient recommendations from professional organisations, future studies should address changes in behaviours, perceptions, and concerns in this population, including COVID-19 vaccination, COVID-19 sequelae, and the long-term effect of the pandemic on patient outcomes.

Contributors
JSH, JK, JFS, JWL, JAS, TTM, CH, MJL, ML, SES, TS, GF, SS, and JF contributed to data collection, data quality control, data analysis, and interpretation. They drafted and revised the manuscript critically for important intellectual content and gave final approval of the version to be published. RPB, KLD, EFM, SM, MN, CAP, and DPR contributed to planning and data collection, reviewed the manuscript, and provided important intellectual content. DFLL and CHI critically reviewed the manuscript and provided important intellectual content. SB, WC, RG, PMM, PCR, PS, ZSW, and JY contributed to the acquisition, analysis and interpretation of the data. They drafted and revised the manuscript critically for important intellectual content and gave final approval of the version to be published. JSH, ES, and KK had full access to the study data and verify the credibility of the underlying data. All authors have read, revised, and approved this manuscript and had final responsibility for the decision to submit for publication.

Declarations of interests
JSH reports grants from Childhood Arthritis and Rheumatology Research Alliance and Rheumatology Research Alliance; and personal fees from Novartis, Pfizer, and Biogen, outside of the submitted work. JWL reports grants from Pfizer, outside of the submitted work. JAS reports grants and personal fees from Bristol-Myers Squibb; and personal fees from Gilead, Inova Diagnostics, Optum, and Pfizer, outside of the submitted work. CH reports personal fees from AstraZeneca and Aurinia Pharmaceuticals, outside of the submitted work. MJL reports grants from American College of Rheumatology during the conduct of the study and consulting fees from AbbVie, Amgen, Actelion, Boehringer Ingelheim, BMS, Celgene, Gilead, Johnson & Johnson, Mallinckrodt, Novartis, Pfizer, Roche, Sandoz, Sanofi, Sohi, and UCB, outside of the submitted work. SES is supported by the Vasculitis Clinical Research Consortium and Vasculitis Foundation outside of the submitted work. KLD reports grants from Novartis, Sohi, National Institutes of Health, and Horizon Bio, outside of the submitted work. EFM reports that the Ligue Portuguesa Contra as Doenças Reumáticas received support for specific activities; grants from Abbvie, Novartis, Janssen-Cilag, Lilly Portugal, Sanofi, Grünenthal SA, MSD, Celgene, Medac, Pharmakers, GAPA, AMGEN, A Menarini Portugal; grants and non-financial support from Pfizer; and non-financial support from Grünenthal GmbH and Tiltay, outside of the submitted work. DPR is the volunteer Vice President of the Canadian Arthritis Patient Alliance, which is primarily supported by independent grants from pharmaceutical companies. DPR reports consulting fees from NovoNordisk Canada and speaking fees and an honoraria from Eli Lilly Canada, outside of the submitted work. DFR also lives with rheumatoid arthritis. SB reports personal fees from Novartis, AbbVie, Pfizer, and Horizon Pharma, outside of the submitted work. SG reports personal fees from AbbVie New Zealand, Cornerstones, Janssen New Zealand; and personal fees and non-financial support from Pfizer New Zealand. (all <$10000) outside of the submitted work. PMM reports personal fees from Abbvie, Eli Lilly, Janssen, Novartis, Pfizer, and UCB; and grants and personal fees from Orphazyme, outside of the submitted work. PCR reports personal fees from AbbVie, Gilead, Lilly, and Roche; grants and personal fees from Novartis, UCB Pharma, Janssen, and
Pfizer; and non-financial support from BMS, outside of the submitted work. P3 reports honoraria from being a social media editor for @ACR_Journals, outside of the submitted work. ZSW reports grants from National Institutes of Health, BMS, and Sanofi; and personal fees from Vbiela Bio and Medpace, outside of the submitted work. JY reports personal fees from Pfizer and Eli Lilly, and grants and personal fees from Astra Zeneca, outside of the submitted work. ES is a Board Member of the Canadian Arthritis Patient Alliance, which is a patient-run, volunteer-based organisation whose activities are primarily supported by independent grants from pharmaceutical companies. All other authors declare no competing interests.

Data sharing
Researchers interested in performing additional analyses from survey data are invited to submit proposals through the COVID-19 Global Rheumatology Alliance at rheum-covid.org. For approved projects, we will be able to provide summary tables and data analyses as requested. We do not currently have IRB approval to make the raw data available to other researchers.

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