

## SHORT REPORT

# Fears and hopes of patients with rheumatic and musculoskeletal diseases during the COVID-19 pandemic across Europe. Results from the REUMAVID study (phase 1 and phase 2)

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## Funding information

Novartis Pharma AG

## KEYWORDS

COVID-19, Fears, Hopes, Patient-Reported Outcomes, Patient Perspective, Rheumatic Diseases

## 1 | INTRODUCTION

Patients with rheumatic and musculoskeletal diseases (RMDs) lived through the first wave of the COVID-19 pandemic in Europe with a great degree of uncertainty, constant changes in the confinement measures and overwhelming media coverage causing severe distress (Dong & Zheng, 2020). Many saw their regular disease management interrupted, with limited access to their clinical care team (Garrido-Cumbrera et al., 2021).

Early research suggested that some drugs commonly used in the treatment of RMDs were associated with more severe COVID-19 disease or mortality while others may have had protective effects (Putman et al., 2021). Such conflicting information together with the fear of contracting the COVID-19 virus infection, may have contributed to RMD patients adhering more strictly to the

confinement measures as compared to the general population (Hooijberg et al., 2020). Furthermore, patients had to cope on their own with the most important public health challenge of modern society, facing queries that even trusted health institutions such as the World Health Organization (WHO) or the scientific community were not yet prepared to answer, including “Am I at greater risk of contracting COVID-19 because of my rheumatic disease?” or “If I get COVID-19, will I be more vulnerable due to my immunosuppressant medication” (Landewé et al., 2020).

Given these circumstances, it became imperative to understand the true journey of RMD patients through the pandemic, as reported from their own perspective, in order to accurately identify unmet needs and inform meaningful response measures. Therefore, the present study aimed to assess COVID-19-related fears and hopes in patients with RMDs during the first stages of the pandemic in Europe.

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## 2 | METHODS

REUMAVID is a multidisciplinary international consortium assembled at the start of the COVID-19 pandemic aiming to explore its impact on RMD patients from seven European countries (Cyprus, France, Greece, Italy, Portugal, Spain, and the UK). Data were collected across two phases; phase 1 (April–July 2020) and phase 2 (February–April 2021) with recruitment conducted by patient organizations. REUMAVID was first approved by the ethical committee of University Hospital La Paz, Spain, under the code PI-4121 and was subsequently approved in all other participating countries as legally required. The seminal article describing the study is published elsewhere (Garrido-Cumbrera et al., 2021). Understanding patients' emotional response to the pandemic, including their actual fears and hopes was an important objective of REUMAVID. Together, the patient research partners and study psychologists developed a set of fears and hopes (Table 1). Participants were asked to rate these fears and hopes on a scale from zero ("no concern/hopeful at all") to five ("extremely concerned/hopeful"). Mann-Whitney test were used to analyse the differences between fears and hopes in both REUMAVID phases.

## 3 | RESULTS

### 3.1 | Sociodemographic characteristics

A total of 1800 and 2002 patients participated during the first (2020) and second (2021) phases of REUMAVID. Compared to the first

TABLE 1 Fears and hopes items of REUMAVID study.

Fears	Hopes
I am more likely to be infected because of the condition I live with.	Availability of a treatment or vaccine suitable for COVID-19.
The treatment I take means I am more likely to get severe disease if I get infected with COVID-19.	To be able to go out as before the COVID-19 pandemic.
There will be a significant impact on healthcare in the future.	Maintain and even improve my current economic situation after the COVID-19 pandemic.
That medication for my rheumatic disease may not reach my country.	To be able to travel as before the COVID-19 pandemic.
I Will lose my job.	To be able to continue my treatment as usual.
There will be a popular uprising.	That I don't get COVID-19 and my health stays the same.

TABLE 2 Fears during COVID-19 pandemic (N = 1670–1934).

	Phase 1 (2020)			Second phase 2 (2021)			p-value
	N	Mean (SD)	Median	N	Mean (SD)	Median	
That there will be a significant impact on healthcare in the future	1722	3.1 (1.6)	3.0	1931	3.2 (1.6)	4.0	0.051
That I am more likely to be infected because of the treatment I take	1719	2.8 (1.8)	3.0	1932	2.9 (1.8)	3.0	0.160
That I am more likely to be infected because of the condition I live with	1721	2.8 (1.7)	3.0	1928	2.9 (1.7)	3.0	<b>0.040</b>
That medication for my rheumatic disease may not reach my country	1722	2.4 (1.8)	2.0	1934	1.9 (1.8)	2.0	<b>&lt;0.001</b>
That there will be popular uprising	1710	2.0 (1.6)	2.0	1924	1.8 (1.7)	2.0	<b>0.001</b>
That I will lose my job	1670	1.5 (1.9)	0.0	1896	1.4 (1.9)	0.0	<b>0.003</b>

Note: p-values are shown in bold due to statistical significance ( $p < 0.05$ ).

phase in 2020, patients in 2021 had a mean age of 55.0 years (vs. 52.6 years in 2020), 83.7% were female (vs. 80.2% in 2020), 68.3% were married (vs. 69.6% in 2020) and 47.8% had university education (vs. 48.6% in 2020). In 2020 the most frequently represented RMD was axial spondyloarthritis (37.2%), while in 2021 it was rheumatoid arthritis (53.1%).

### 3.2 | Fears about the pandemic

During the first stage of the pandemic in 2020 patients were more afraid of the potential lack of access to medications and availability of these in their own country ( $p < 0.001$ ), increased fears of possible popular uprising ( $p = 0.001$ ) and risk of job loss ( $p = 0.003$ ). However, patient's fears during 2021 were around their risk of infection associated to their illness ( $p = 0.04$ ; Table 2).

### 3.3 | Hopes for the future

Compared to 2020, patients in 2021 were more hopeful of the prospect of successful vaccination against COVID-19 ( $p < 0.001$ ); of going out ( $p < 0.001$ ) and travelling as before the COVID-19 pandemic ( $p < 0.001$ ); of maintaining and even improving their current economic situation after the COVID-19 pandemic ( $p < 0.001$ ) and of continuing their treatment as usual ( $p = 0.049$ ; Table 3).

TABLE 3 Hopes during COVID-19 pandemic (N = 1368–1391).

	N	Mean (SD)	Median	N	Mean (SD)	Median	p-value
	Phase 1 (2020)			Phase 2 (2021)			
Availability of a treatment or vaccine suitable for COVID-19	1391	3.2 (1.5)	3.0	1927	3.9 (1.3)	4.0	<b>&lt;0.001</b>
To be able to continue my treatment as usual	1383	3.7 (1.4)	4.0	1923	3.8 (1.3)	4.0	<b>0.049</b>
To be able to go out as before the COVID-19 pandemic	1390	3.1 (1.5)	3.0	1928	3.5 (1.4)	4.0	<b>&lt;0.001</b>
I don't get COVID-19 and my health remains the same	1368	3.5 (1.5)	4.0	1912	3.5 (1.5)	4.0	0.696
To be able to travel as before the COVID-19 pandemic	1386	2.8 (1.6)	3.0	1925	3.3 (1.5)	3.0	<b>&lt;0.001</b>
Maintain and even improve my current economic situation after the COVID-19 pandemic	1386	2.6 (1.7)	3.0	1924	3.0 (1.7)	3.0	<b>&lt;0.001</b>

Note: p-values are shown in bold due to statistical significance ( $p < 0.05$ ).

## 4 | DISCUSSION

These data comprising the early phases of the COVID-19 pandemic show that the greatest fear for people affected by RMDs was the significant impact that the pandemic could have in their future healthcare. While in 2020 the greatest hope was to be able to continue treatment, in 2021 it was the availability of a COVID-19 treatment or vaccine. Reassuringly, whilst patients were more fearful in 2020, they appeared to be more hopeful during 2021.

Fear is a powerful emotion with a strong impact in mind and body that can occur in any situation of stress, especially in people with chronic diseases (Tzur Bitan et al., 2020). The mass fear of COVID-19, characterized by its novelty, uncertainty and magnitude, has been termed as “coronaphobia.” A recent qualitative study highlighted how the main fears of the general population were the risk of infection and impact on healthcare, in that order (Mertens et al., 2020). In our study, however, RMD patients feared healthcare impact over the risk of contracting the infection. RMDs are chronic diseases and patients depend on their long term treatments in order to maintain their normal social and physical functioning (Garrido-Cumbrera et al., 2020), thus, it is understandable that as the pandemic negatively affected their routine management, their fear would consequently increase.

Nevertheless, RMD patients' fear of increased risk of infection due to their immunosuppressant medication is of relevance. To understand it, it is important to remember that during 2020 of the pandemic, research on the effects of anti-rheumatic treatments on COVID-19 outcomes was sometimes contradictory, and limited to observational studies with low sample size (Ladani et al., 2020). Lack of information turned into misinformation when patients encountered barriers contacting their healthcare professionals, which led to patients seeking answers in other sources which were at times sub-optimal (Reuter et al., 2021). This so called “infodemic” led the WHO to issue a series of considerations to be taken into account in communications relating to the COVID-19 pandemic also recommending minimizing news and promoting only information from trusted sources (World Health Organization, 2020). Among the latter, patient organizations fulfilled a critical role, being

ideally placed and having the potential to obtain and provide credible information to patients quickly and effectively.

Overall, the COVID-19 pandemic has created significant uncertainty for RMD patients, as reflected in their fears. Yet despite their concerns, patients with RMDs remained hopeful. Providing patients clear information targeted at addressing their fears and hopes is critical for ensuring optimal self-management, treatment adherence, mental health, and quality of life. Furthermore, implementing an evidence-based response to COVID-19 and future crisis based on real patient needs is critical for ensuring their prompt adoption and long-term success.

## 5 | CONCLUSIONS

The possible impact of the COVID-19 pandemic on future healthcare was the major fear or concern for people affected by chronic RMDs across Europe during 2020 and 2021. The greatest hope in 2020 was to be able to continue with their treatment as usual while in 2021 it was the availability of a successful treatment or vaccine against COVID-19. Based on our results, people with RMDs were more fearful during the first phase of pandemic in 2020 but became more hopeful in 2021. Providing patients with clear information targeted at addressing their fears is critical for ensuring optimal self-management and reducing stress during the ongoing COVID-19 pandemic.

### AUTHOR CONTRIBUTIONS

The authors confirm contribution to the paper as follows: study conception and design: Marco Garrido-Cumbrera, José Correa-Fernández, Helena Marzo-Ortega, Sergio Sanz-Gomez, Victoria Navarro-Compán, Laura Christen; data collection: Marco Garrido-Cumbrera, José Correa-Fernández; analysis and interpretation of results: José Correa-Fernández, Marco Garrido-Cumbrera, Sergio Sanz-Gomez, Victoria Navarro-Compán, Laura Christen, Helena Marzo-Ortega; draft manuscript preparation: Marco Garrido-Cumbrera, José Correa-Fernández, Sergio Sanz-Gomez, Victoria Navarro-Compán, Helena Marzo-Ortega, Laura Christen. All authors reviewed the results and approved the final version of the manuscript.

## ACKNOWLEDGEMENTS

We would like to thank all of the patients who completed the survey, as well as all of the patient organisations and patient representatives who participated in the REUMAVID study including: Souzi Makri from the Cyprus League for People with Rheumatism (CYLPER) from Cyprus, the Association Française de Lutte Anti-Rhumatisme (AFLAR) from France, Katy Antonopoulou from the Hellenic League Against Rheumatism (ELEANA) from Greece, the Associazione Nazionale Persone con Malattie Reumatologiche e Rare (APMAAR) from Italy, Elsa Frazão Mateus from the Portuguese League Against Rheumatic Diseases (LCPDR) from Portugal, Pedro Plazuelo-Ramos from the Spanish Federation of Spondyloarthritis Associations (CEADE), the Spanish Patients' Forum, UNiMiD, Spanish Rheumatology League (LIRE), Andalusian Rheumatology League (LIRA), Catalonia Rheumatology League and Galician Rheumatology League from Spain, and Jim Hamilton from the National Axial Spondyloarthritis Society (NASS), Clare Jacklin and Ailsa Bosworth from the National Rheumatoid Arthritis (NRAS), Shantel Irwin from Arthritis Action from the UK. We would further like to thank Patricia Pertel, Maria-Magdalena Balp, and Marina Milutinovic of Novartis Pharma AG for their contributions to the study design and execution. H Marzo-Ortega is supported by the National Institute for Health Research (NIHR) Leeds Biomedical Research Centre (LBRC). The REUMAVID study is supported by Novartis Pharma AG.

## CONFLICT OF INTEREST STATEMENT

MG-C reports grant/research support from: Novartis. HM-O reports grant/research support from: Janssen and Novartis, consultant for: AbbVie, Celgene, Janssen, Lilly, Novartis, Pfizer and UCB, speakers' bureau: AbbVie, Biogen, Celgene, Janssen, Lilly, Novartis, Pfizer, Takeda and UCB. HM-O is supported by the National Institute for Health Research (NIHR) Leeds Biomedical Research Centre. LC is an employee of Novartis Pharma AG. VN-C reports honoraria/research support from: Abbvie, BMS, Janssen, Lilly, MSD, Novartis, Pfizer, Roche and UCB.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

## ETHICS STATEMENT

REUMAVID was first approved by the ethical committee of University Hospital La Paz under the code PI-4121 and was subsequently approved in all other participating countries as legally required.

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## REFERENCES

Dong, M., & Zheng, J. (2020). Letter to the editor: Headline stress disorder caused by Netnews during the outbreak of COVID-19. *Health Expectations*, 23(2), 259–260. <https://doi.org/10.1111/HEX.13055>

- Garrido-Cumbrera, M., Bundy, C., Navarro-Compán, V., Makri, S., Sanz-Gómez, S., Christen, L., Mahapatra, R., Delgado-Domínguez, C. J., & Poddubnyy, D. (2020). Patient-reported impact of axial spondyloarthritis on working life: Results from the EMAS survey. *Arthritis Care & Research*. <https://doi.org/10.1002/ACR.24426>
- Garrido-Cumbrera, M., Marzo-Ortega, H., Christen, L., Plazuelo-Ramos, P., Webb, D., Jacklin, C., Irwin, S., Grange, L., Makri, S., Frazao Mateus, E., Mingolla, S., Antonopoulou, K., Sanz-Gómez, S., Correa-Fernández, J., Carmona, L., & Navarro-Compán, V. (2021). Assessment of impact of the COVID-19 pandemic from the perspective of patients with rheumatic and musculoskeletal diseases in Europe: Results from the REUMAVID study (phase 1). *RMD Open*. 7(1)e001546. <https://doi.org/10.2139/ssrn.3734278>
- Hooijberg, F., Boekel, L., Vogelzang, E. H., Leeuw, M., Boers, M., Volleghoven, R. V., Lems, W. F., Nurmohamed, M. T., & Wolbink, G. (2020). Patients with rheumatic diseases adhere to COVID-19 isolation measures more strictly than the general population. *The Lancet*, 2(20), e583–e585. [https://doi.org/10.1016/S2665-9913\(20\)30286-1](https://doi.org/10.1016/S2665-9913(20)30286-1)
- Ladani, A. P., Loganathan, M., & Danve, A. (2020). Managing rheumatic diseases during COVID-19. *Clinical Rheumatology*, 39(11), 1. <https://doi.org/10.1007/S10067-020-05387-8>
- Landewé, R. B., Machado, P. M., Kroon, F., Bijlsma, H. W., Burmester, G. R., Carmona, L., Combe, B., Galli, M., Gossec, L., Iagnocco, A., Isaacs, J. D., Mariette, X., McInnes, I., Mueller-Ladner, U., Openshaw, P., Smolen, J. S., Stamm, T. A., Wiek, D., & Schulze-Koops, H. (2020). EULAR provisional recommendations for the management of rheumatic and musculoskeletal diseases in the context of SARS-CoV-2. *Annals of the Rheumatic Diseases*, 79(7), 851–858. <https://doi.org/10.1136/ANNRHEUMDIS-2020-217877>
- Mertens, G., Gerritsen, L., Duijndam, S., Saleminck, E., & Engelhard, I. M. (2020). Fear of the coronavirus (COVID-19): Predictors in an online study conducted in March 2020. *Journal of Anxiety Disorders*, 74, 102258. <https://doi.org/10.1016/J.JANXDIS.2020.102258>
- Putman, M., Chock, Y. P. E., Tam, H., Kim, A. H. J., Sattui, S. E., Berenbaum, F., Danila, M. I., Korsten, P., Sanchez-Alvarez, C., Sparks, J. A., Coates, L. C., Palmerlee, C., Peirce, A., Jayatilleke, A., Johnson, S. R., Kilian, A., Liew, J., Prokop, L. J., Murad, M. H., ... Duarte-García, A. (2021). Antirheumatic disease therapies for the treatment of COVID-19: A systematic review and meta-analysis. *Arthritis & Rheumatology*, 73(1), 36–47. <https://doi.org/10.1002/ART.41469>
- Reuter, K., Deodhar, A., Makri, S., Zimmer, M., Berenbaum, F., & Nikiphorou, E. (2021). The impact of the COVID-19 pandemic on people with rheumatic and musculoskeletal diseases: Insights from patient-generated data on social media. *Rheumatology*. <https://doi.org/10.1093/RHEUMATOLOGY/KEAB174>
- Tzur Bitan, D., Grossman-Giron, A., Bloch, Y., Mayer, Y., Shiffman, N., & Mendlovic, S. (2020). Fear of COVID-19 scale: Psychometric characteristics, reliability and validity in the Israeli population. *Psychiatry Research*, 289. <https://doi.org/10.1016/J.PSYCHRES.2020.113100>
- World Health Organization. (2020). *Mental health and psychosocial considerations during COVID-19 outbreak* (pp. 1–6). World Health Organization.

**How to cite this article:** Garrido-Cumbrera, M., Christen, L., Marzo-Ortega, H., Correa-Fernández, J., Sanz-Gomez, S., & Navarro-Compán, V. (2023). Fears and hopes of patients with rheumatic and musculoskeletal diseases during the COVID-19 pandemic across Europe. Results from the REUMAVID study (phase 1 and phase 2). *Musculoskeletal Care*, 21(3), 932–935. <https://doi.org/10.1002/msc.1750>