

Title: Exploring the Role of Rheumatic and Musculoskeletal Disease Patient Organisations during the COVID-19 Pandemic. Results from the REUMAVID Study (Phase 1)

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During the initial phase of the COVID-19 pandemic, essential health provision was significantly disrupted (1), with rheumatology services throughout Europe closing partially or completely, cancelling face-to-face visits, and postponing important treatment decisions and diagnostic tests (2). As most European countries imposed lockdown measures, patients with rheumatic and musculoskeletal diseases (RMDs) adhered to stricter isolation measures (3) and had limited access to healthcare resources (4). Many struggled with questions regarding the possible interaction of the SARS-CoV-2 virus with their underlying RMD and existing immunosuppressant treatment that the scientific community were unable to answer due to limited evidence (5,6).

Under these circumstances, RMD patient organisations (POs) were faced with a challenge of their own; ensuring their patients received reliable information and supportive services, preventing the detrimental effects of isolation, and promoting healthy lifestyles during an unprecedented pandemic. Therefore, this study aims to assess the role of RMD POs during the COVID-19 pandemic.

REUMAVID is an international collaboration led by Health & Territory Research (HTR) from the University of Seville, together with a multidisciplinary working group comprising rheumatologists, health care professionals and researchers, and PO representatives from seven European countries: Cyprus, France, Greece, Italy, Portugal, Spain, and the United Kingdom. Further details about the study design and overall results can be found in REUMAVID's seminal article (7).

The first phase of the REUMAVID survey involved 1,800 RMD patients, of whom an average of 41.6% (748/1,798) were member of POs (Figure 1). During the first wave of the pandemic, among PO members, the proportion of those who reported receiving information on how COVID-19 might affect their disease was high (73.1% compared 40.5% of non-members), with POs being credited as the most common source of information for members (54.8%), followed by rheumatologists (28.8%), and GPs (14.3%). By contrast, among non-members, the most common source of COVID-19 related information were rheumatologists (21.1%), followed by GPs (15.4%), and their Rheumatology Society (9.1%), and only 7.6% from POs. Compared to non-members, a higher proportion of members received disease-related information from POs (58.7% vs 19.0% of non-member), help with managing their disease or lifestyle through advice or digital approaches (25.5% vs. 23.8% of non-member), as well as emotional or psychological support (21.6% vs. 9.5% of non-member; $p=0.003$).

A higher proportion of PO members were able to consult with their rheumatologist on the possible effects that their medication could have on COVID-19 (70.9% vs. 58.5% of non-members, $p=0.009$). Compared to non-members, members reported slightly better (from good to very good) self-perceived health (40.2% vs 33.0% of non-members, $p=0.017$), lower disease activity (5.0 vs 5.4 of non-members, $p=0.005$) measured by a Visual Analogue Scale (VAS), better well-being (42.5% vs 53.7% of non-members, $p<0.001$) measured by The WHO Five Well-Being Index (WHO-5), and lower risk of anxiety (54.5% vs 59.2% of non-members, $p=0.047$) measured by the Hospital Anxiety and Depression Scale (HADS). Furthermore, a higher proportion of non-members gained weight (43.6% vs 37.0%, $p=0.010$). 27.1% of members smoked more than before the COVID-19 pandemic (vs. 23.3% of non-members, $p=0.305$), while non-members increased their alcohol consumption (19.8% vs. 15.8% of members, $p=0.246$).

In conclusion, POs have played an important role in the healthcare ecosystem, filling the gap caused by the COVID-19 pandemic and related lockdowns. Members were better informed about the SARS-CoV-2 and the possible effects on their disease, while more often receiving emotional support, reporting better connection with healthcare professionals, and better health status and outcomes during these difficult moments. As members of the extended healthcare team, POs provided critical information and access to supportive resources to all RMD patients. Efforts should be made to better foster, formalise, and institutionalise collaboration between POs and healthcare systems, to improve patient care and quality of life for those affected with RMDs.

Conflicts of interest

MG-C has a research collaboration with and provides services to Novartis Pharma AG. 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.

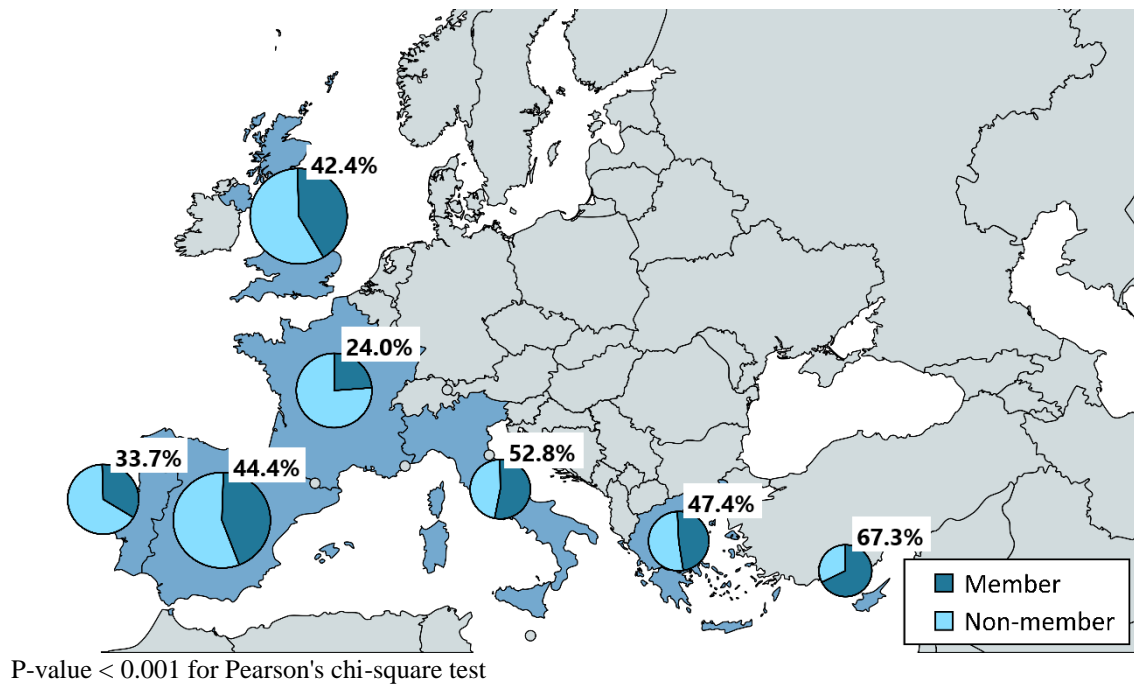
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Figures

Figure 1. Distribution of patient organisation membership by country (n = 1,798)



Supplementary material

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