

EULAR
13.06.2025
Kilchberg,
Switzerland

ONLINE INFORMATION FOR PATIENTS NEEDS GUIDANCE

How do patients search for health information online?

Rheumatic musculoskeletal diseases (RMD) have an important impact on quality of life, and represent an economic burden to society. EULAR – The European Alliance of Associations for Rheumatology – has emphasised the role of patient empowerment through education.¹

Recommendations stress that communication impacts treatment outcomes and shared decision-making between patients and physicians. Health literacy is an important aspect in this regard, and a person's understanding of their condition can impact how they are able to use health information.² There is growing evidence to suggest that internet-based information is an important tool for improving communication with healthcare professionals – and for many patients it plays a central role in their experience.³

New work presented at the 2025 annual EULAR congress in Barcelona describes a prospective study that was set up in Germany to examine the ways that people with an RMD search online for disease-related information, where they find it, and how they use it in their daily life. Overall, 705 patients with rheumatoid arthritis, axial spondyloarthritis, or psoriatic arthritis took part by completing a questionnaire.

The results showed that over three-quarters had used the internet to look for information about their RMD, while about half of the responders also used social media and health apps. Typically, an online search was performed more than once a week by 13.5% of patients and mostly without being redirected from any other sources. Symptoms, treatment efficacy or adverse events, and disease-specific nutrition were the most frequently searched topics. Free sources in search engines and patient organisation websites were the main information resources used by the responders.

While only 3.0% reported ever having actively participated in a patient forum, 62.4% did not deny using internet-based sources and said they would encourage others to use them.

Overall, the online information was considered to be easy to understand for 79.8%, and 62.3% reported that any medical terminology was well explained. However, only 42.6% of the patients subsequently discussed the information they had found online with their rheumatologist.

Additionally, 79.0% patients considered that the information they found online helped them to better understand their disease, and nearly half of the responders felt that it has helped their RMD-related anxiety or depression, while only 46.5% reported that it had helped them to better understand their therapy.

Ioana Andreica, lead author on the work, said “online disease-related information is frequently searched by patients with an RMD, but there is a lack in the guidance on where and how to look, and how to use the information that is retrieved.”

The findings suggest that there is still a large gap to close in order to achieve sufficient health literacy and support shared decision for people with RMD.

Source

Andreica I, et al. How do patients with inflammatory rheumatic musculoskeletal diseases (RMD) search, find and use online-based disease-related information in their daily life. Presented at EULAR 2025; OP0122-PARE. Ann Rheum Dis 2025; DOI: 10.1136/annrheumdis-2025-eular.D139.

References

1. Zangi HA, et al. EULAR recommendations for patient education for people with inflammatory arthritis. Ann Rheum Dis 2015;74(6):954–62. DOI: 10.1136/annrheumdis-2014-206807.
2. Elangovan S, et al. The usefulness and validity of English-language videos on YouTube as an educational resource for spondyloarthritis. Clin Rheumatol 2021;40(4):1567–73. DOI: 10.1007/s10067-020-05377-w.
3. Muir J, et al. Exploring the role of online health information and social media in the illness experience of arthritis-related fatigue: A focus group study. Musculoskeletal Care 2020;18(4):501–9. DOI: 10.1002/msc.1494.

About EULAR

EULAR is the European umbrella organisation representing scientific societies, health professional associations and organisations for people with rheumatic and musculoskeletal diseases (RMDs). EULAR aims to reduce the impact of RMDs on individuals and society, as well as improve RMD treatments, prevention, and rehabilitation. To this end, EULAR fosters excellence in rheumatology education and research, promotes the translation of research advances into daily care, and advocates for the recognition of the needs of those living with RMDs by EU institutions.

Contact

EULAR Communications, communications@eular.org

Notes to Editors

[EULAR Recommendations](#)

[EULAR School of Rheumatology](#)

[EULAR Press Releases](#)