

EULAR
28.10.2022
Kilchberg,
Switzerland

NEW: INCLUDING YOUTH PERSPECTIVES

EULAR ‘points to consider’ published in the *Annals of the Rheumatic Diseases*

A range of patient-reported outcome measures (PROMs) with different features is available for people with inflammatory arthritis. However, the specific needs and priorities of younger patients have not been explored. EULAR – the European Alliance of Rheumatology Associations – set out to develop a new framework to include the perspectives of young patients with inflammatory arthritis.

PROMs aim to collect information on how a disease impacts key areas of a person’s life, such as their quality of life, ability to do everyday activities, and their social or sexual health. This information is useful in addition to disease activity scales and clinical measures to give a good picture of a person’s whole experience and the impact of their disease.

The new EULAR points-to-consider were developed by a multidisciplinary task force from 8 European countries. The group included health professionals and patient research partners. The work was completed in line with EULAR standardized operating procedures.

The paper developed by EULAR and published in the month 2022 issue of *RMD Open* includes four overarching principles and eight points to consider in people aged 18–35 with inflammatory arthritis. The principles emphasize that inflammatory arthritis has a considerable impact on all aspects of the life of young people, and that PROMs are useful to measure part of this, as well as to support communication and inform shared decision-making. The value of PROMs is optimized when young people are informed and empowered.

The points to consider highlight the need to keep young people informed about their PROMs, and to give them access to their data. They also look at how healthcare professionals can use PROMs to engage young patients in their care, whilst noting the need to respect patient preferences and willingness to talk about their body image and life plans. Online solutions should be used whenever possible and convenient for young patients with inflammatory arthritis.

These EULAR points to consider provide the first guidance to optimize the use of available PROMs for young people with inflammatory arthritis. They should serve as a companion for clinicians and researchers in rheumatology practice, and when developing new PROMs or modifying existing tools.

Source

[Studenic P, et al. EULAR points to consider for including the perspective of young patients with inflammatory arthritis into patient-reported outcomes measures. *RMD Open* 2022;8:e002576.](#)

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 burden of RMDs on individuals and society and to improve the treatment, prevention and rehabilitation of RMDs. To this end, EULAR fosters excellence in education and research in the field of rheumatology. It promotes the translation of research advances into daily care and fights for the recognition of the needs of people with RMDs by the EU institutions through advocacy action.

Contact

EULAR Communications, communications@eular.org, Tel. +41 44 716 30 30

Notes to Editors

[EULAR Recommendations](#)

[EULAR Strategy](#)

[EULAR School of Rheumatology](#)

[EULAR Press Releases](#)

[EULAR COVID-19 Registry](#)