

EULAR
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RECOGNISING YOUNG PEOPLE'S PERSPECTIVES IN INFLAMMATORY ARTHRITIS

A new EULAR study shows that young people with arthritis need new ways to measure their function that take into account their age and lifestyle

Inflammatory arthritis is the name of a group of diseases that cause joint pain and swelling. This happens because the body's immune system attacks its own tissues and causes inflammation. Types of inflammatory arthritis include rheumatoid arthritis, psoriatic arthritis, and axial spondyloarthritis. Although they may be thought of as older people's conditions, these diseases can affect people at any age. Traditional patient-reported outcome measures (PROMs) record things like walking ability, which may not be relevant for young people early in their disease.

EULAR conducted a study to explore whether PROMs commonly used in inflammatory arthritis adequately cover the perspective of people aged 18 to 35 with these diseases. Using a series of 12 focus groups in four countries, information was collected to examine what these younger people knew about PROMs, and how representative they thought they were for them at their life stage. The results found that these younger people were generally positive about PROMs and could see why they were important. However, commonly assessments were seen to be outdated and not relevant for people earlier in their disease.

For example, the results suggest that traditional assessments that measure whether a person can walk or eat independently do not capture the impact that inflammatory arthritis has on younger people and may mean that healthcare teams overlook the issues that matter. Some outdated elements also asked people to record how well they could write and use a pen. New elements should be added to PROMs to take into account a person's ability to use computers and technical devices.

Young people also need PROMs that deal specifically with their life stage and measure the impact of their disease on career planning, parenting, social life, and participation in physical activities at school and University.

EULAR hopes that the results of this study will change the use of PROMs in young people in clinical practice and research. There is a need to optimise the use of PROMs in their present form and adapt PROMs to meet the current needs of young people. This study also provides the basis for further research in the field of outcomes research, since the assessment of young people's perspectives on PROMs has implications beyond rheumatology.

Source

[Mosor E, Studenic P, Alunno A, et al. Young people's perspectives on patient-reported outcome measures in inflammatory arthritis: results of a multicentre European qualitative study from a EULAR task force. RMD Open 2021;7:e001517. doi: 10.1136/rmdopen-2020-001517](#)

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.

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