

New: Young perspectives in inflammatory arthritis

This is the lay version of the EULAR points to consider for including the perspective of young people with inflammatory arthritis inpatient-reported outcomes measures. The original publication can be downloaded from the EULAR website: www.eular.org.

[Studenic P, Stamm TA, Mosor E, 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. doi: 10.1136/rmdopen-2022-002576](#)

Introduction

EULAR gives advice to doctors, nurses, and patients about the best way to treat and manage diseases. Health professionals and patients, worked together to develop these *points to consider* on including the perspectives of young people with inflammatory arthritis in patient-reported outcomes measures. The patients in the team ensured that the patient point of view was included.

What do we already know?

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 young people (18–35 years) regarding PROMs and their administration have not previously been examined, and there is not much information available.

EULAR approved this project and set up a task force of 14 members from 8 European countries, with strong representation from patient research partners. Because there is limited evidence on this topic, a focus group and online survey was used to collect information, rather than a traditional literature search.

What do the points say?

In total, there are four overarching principles and eight points to consider. The principles say that inflammatory arthritis has a considerable impact on young people's lives, and that PROMs are useful to measure this – but that these tools are also useful to support communication and shared decision-making between young people and their healthcare team. Overall, it emphasizes that the value of PROMs is maximized when young people are informed and empowered

Each point is based on the best current knowledge from studies of scientific evidence or expert opinion. The more stars a point has the stronger the evidence is. However, points to consider with limited scientific evidence may be important, because the experts can have a strong opinion even when the published evidence may be lacking.

One star (*) means it is a point with limited scientific evidence.

Two stars (**) means it is a point with some scientific evidence.

Three stars (***) means it is a point with quite a lot of scientific evidence.

Four stars (****) means it is a point supported with a lot of scientific evidence.

Points to consider

- **People should be informed about the purpose and relevance of PROMs.***
If you have an inflammatory arthritis, you may be asked to complete a PROM to monitor and assess your disease. This could take a variety of forms, and may be done online or in person. Your healthcare

provider should explain to you what the PROM is designed to measure, and how it might help you better understand or manage your disease.

- **You should have access to your personal PROM data.***

Where possible, your healthcare provider should give you access to the results from your completed PROMs.

- **Your healthcare provider should discuss your results and include them in shared decision-making.***

The results of your PROM will be helpful for your healthcare team to better understand the impact your inflammatory arthritis has on various elements of your disease. This information should be discussed with you, and included as part of the shared decision-making process around treatments and management of your disease.

- **You may need to complete more than one PROM.***

Different PROMs assess various domains and should therefore be used to cover a broad spectrum of the disease.

- **Healthcare providers should check your willingness to talk about issues such as body image and life plans, and respect your preferences when talking about certain areas.***

Some PROMs will ask your questions about personal aspects, such as your body image, or what your life plans might be. Your team should check with you if you are comfortable answering these sort of questions, and respect your preferences.

- **Your assessment should encompass items daily life such as psychosocial issues, participation in social activities, education/work, sports, and using technologic devices.****

If you are a young person with an inflammatory arthritis, your PROMs should also measure the impact of your disease on your wider everyday life. This could include your work and education, or ability to take part in social activities.

- **The schedule of PROMs assessment should be agreed with your team to balance frequency versus inconvenience.***

Your team should give you a good idea of how often you will need to complete PROM questionnaires.

- **Online and e-solutions for PROMs should be used when possible and convenient.***

Wherever possible, you should be offered online PROM tools to make sure completing them is convenient and easy for you.

Summary

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

Points with just one or two stars are based mainly on expert opinion and not backed up by studies, but these may be as important as those with three or four stars.

If you have any questions or concerns about your disease or your medication, you should speak to a health professional involved in your care.