

Recognizing young people's perspectives in inflammatory arthritis

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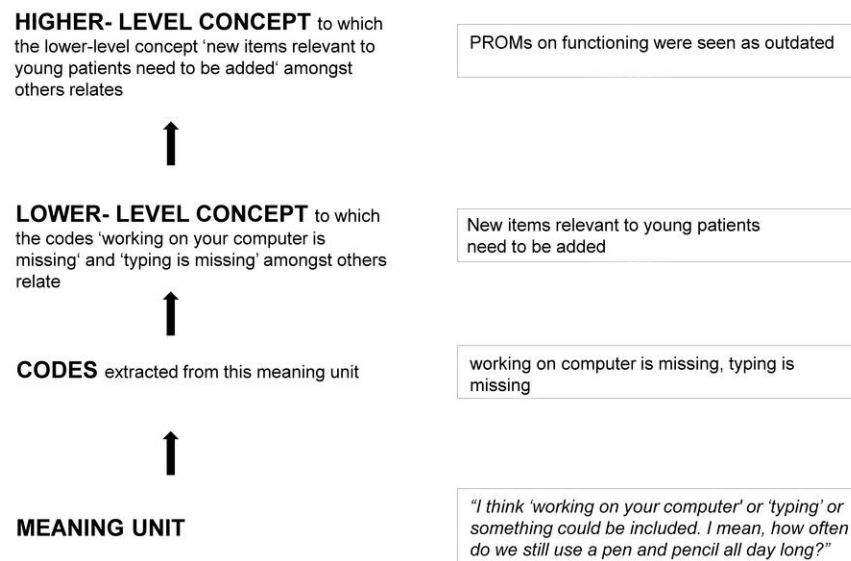


Figure 1 Example outlining the different steps of the analysis from a meaning unit to lower and higher level concepts. PROMs, patient-reported outcome measures.

Inflammatory arthritis is the name for 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. Inflammatory arthritis often affects people of working age, and can impact their employment. Work participation is often lower for people with inflammatory arthritis than the general population.

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 However, commonly assessments were seen to be outdated and not relevant for people earlier in their disease.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 Some outdated elements also asked people to record how well they could write and use a pen.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.

More information: 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*. DOI: [10.1136/rmdopen](https://doi.org/10.1136/rmdopen.2020.001517) 2020 001517

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