Online Supplementary Table S1: Research agenda regarding patient-reported outcome measures for young people with inflammatory arthritis

| - Identification of modifications to be applied to existing PROMs based on cross-checking qualitative and quantitative findings of commonly used PROs for young people with IA. |
| - Structured process of involving young people with IA as patient research partners in the development of future PROMs, and modification of existing PROMs. |
| - Validation of functional questionnaires focusing on those aged 35 years or younger, for further adaption to cover young peoples’ issues, which have not been previously assessed. |
| - Agreement on which available PROMs should be used in clinical practice (as a core set) demonstrating value to young people with IA. |

IA: inflammatory arthritis; PRO: patient-reported outcome; PROM: patient-reported outcome measure
Online Supplementary Figure S1. Timeline of the project to develop points to consider for including the perspective of young patients with inflammatory arthritis into patient-reported outcomes measures

November 2018:
First Task Force meeting
Identification of themes & concepts
Discussion of results refinement of concepts → 6 overarching themes, 48 concepts → Structuring of the anticipated survey

May – August 2019
Survey open
The survey was online from May till August 2019 and promoted by EULAR PARE and affiliated organisations

November 2019 – January 2020
Agreement process
After the task force meeting a report and the suggested overarching principles and points to consider were circulated via email, followed by an anonymous voting process

January – August 2018
Qualitative study:
- Development of a semi-structured interview guide for focus groups in young people with inflammatory arthritis
- Conduction of focus groups and analyses and reporting

January – May 2019
Survey establishment:
- After the first task force meeting: Re-consideration of topics included in the survey. Finetuning of questions and answer options in several online-feedback loops between task force participants
- Translation into German, Italian, Spanish, Russian, Polish, French and Portuguese

October 2019
Second Task Force meeting
The results of the survey were discussed and elaborated topics were phrased into overarching principles and points to consider after standardized voting procedures