

**Supplementary table 3.** Overview about similarities and differences of concepts on a focus group level; the last row shows that no ‘new’ lower-level concepts came up in the last three subsequent focus groups (columns marked in grey), indicating that thematic saturation was reached.

Higher-level concept	Lower-level concept	Lower-level concept addressed in the respective focus group												
		RA AT	PsA AT	SpA AT	RA HR	PsA HR	SpA HR	RA NL	PsA NL	SpA NL	RA IT	PsA IT	SpA IT	
6	48													
1. Information, transparency and clarity regarding the purpose of PROMs are often missing	Reasons for using PROMs are often not known			new	+				+	+	+	+	+	+
	Need for definition/explanation of terms	new	+	+	+	+	+	+	+	+	+	+	+	+
	Uncertainty what to tick		new	+	+	+	+	+	+	+				+
	Questions are incorrectly or not answered			new										+
	Questions incite anxiety and/or fear									new				+
	Feedback on PROM results is appreciated	new	+	+		+		+	+	+			+	+
2. PROMs on daily functioning were seen as outdated	Information about PROM results are available for members of the healthcare team								new		+	+		
	PROMs not up-to-date	new			+			+	+	+	+	+		
	Inappropriate questions for young people	new	+		+			+	+	+		+	+	
	Items relevant to young people need to be added	new	+		+	+	+	+			+		+	+
	Questions (wording) need to be reformulated	new							+	+	+	+	+	+
3. Relevant issues are often not sufficiently addressed when assessing PROs in young people	PROMs should be developed for different age groups								new					
	Future plans for life			new		+	+	+						
	Education					new	+	+	+	+				
	Work and career goals			new			+	+						
	Intimate relationships		new				+					+		
	Sexuality		new									+		
	Body image and appearance		new	+										
	Family planning			new	+		+							
	Self-management		new							+				
	Use and outcomes of non-pharmacological treatments		new	+	+	+	+		+					+
	Use of technological/assistive devices	new			+							+		
	Diet and food intake	new			+					+				
	Psychosocial aspects of being chronically ill		new	+		+	+		+		+		+	+
Social life, including hobbies and sports	new	+		+			+	+	+	+	+	+	+	
Mobility – commuting on public transport and driving		new		+			+							
Changing/holding a certain position						new	+							

Higher-level concept	Lower-level concept	LLC addressed in the respective focus group											
6	48	RA AT	PsA AT	SpA AT	RA HR	PsA HR	SpA HR	RA NL	PsA NL	SpA NL	RA IT	PsA IT	SpA IT
4. The scoring on a rating scale sometimes differs from the current health situation	Scoring differently than the situation was experienced (on purpose to achieve something)	new		+		+	+			+			+
	Wish for getting in touch/being recognized		new										
	Changes in disease management	new		+									
	To show a flare in between visits (lack of continuous monitoring)		new			+							
5. The individual life situation of young people adds essential importance to the results of PROMs	PROMs should not only be used for data gathering, but as a mediator for discussions with HCPs	new		+									
	<b>Individualization of outcome assessment would be appreciated</b>	new	+	+		+	+	+	+	+	+	+	+
	<b>Using comprehensive PROMs</b>		new				+	+	+		+	+	+
	<b>Using single scales only is insufficient</b>	new	+	+		+	+	+	+	+	+		
	Clear reference points are often missing (with and without medication, compared to someone without a disease or another patient in remission)		new	+		+					+		
	<b>Time frame is not adequate, e.g. a longer time frame for scoring pain to include flares</b>	new	+	+		+	+	+	+		+	+	+
	Substantial fluctuation of pain levels is difficult to score									new			
	<b>Forgetting the extent of pain over time</b>		new	+		+				+		+	
	Interpreting results is difficult from the patients' perspective	new	+	+		+				+			
	<b>Loosing important information (if PROs are quantified only, qualitative information, e.g. in a discussion with the healthcare professional, is missing)</b>	new	+			+		+	+	+		+	+
	Missing overview about disease course (patient would appreciate an overview regarding their scores over time)	new	+			+		+	+	+			
Patients prefer NRS to VAS		new	+	+	+	+			+	+			
<b>Patients were confronted with differently formulated PGA questions</b>	new	+	+		+	+	+					+	
6. The use of technology for data acquisition was suggested by some young people	New formats for collecting PROs are needed			new				+	+	+	+		
	Continuous monitoring supports self-management		new	+		+				+			
	Use of a symptom diary/log could be facilitated by digital technologies		new	+		+				+			
	Time saving for patients and HCPs							new					
Number of LLCs addressed in a FG for the first time		<b>+19</b>	<b>+16</b>	<b>+6</b>	<b>+0</b>	<b>+2</b>	<b>+0</b>	<b>+2</b>	<b>+2</b>	<b>+1</b>	<b>+0</b>	<b>+0</b>	<b>+0</b>

Note. RA/AT = rheumatoid arthritis focus group (RA-FG) in Austria, including patients with JIA (juvenile idiopathic arthritis) and Still's disease; SpA/AT = spondyloarthritis focus group (SpA-FG) in Austria; PsA/AT = psoriatic arthritis focus group (PsA-FG) in Austria; RA/HR = RA-FG in Croatia, SpA/HR = SpA-FG in Croatia; PsA/HR = PsA-FG in Croatia; RA/NL = RA-FG in the Netherlands; SpA/NL = SpA-FG in the Netherlands; PsA/NL = PsA-FG in the Netherlands; RA/IT = RA-FG in Italy; SpA/IT = SpA-FG in Italy; PsA/IT = PsA-FG in Italy; lower level concepts (LLC) in bold were mentioned in all three disease areas and four countries; new = LLC addressed in a FG for the very first time, + = LLC which had already been addressed in a FG