

Supplementary table 2. COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

Topic	Item no.	Guide Questions/'Description	Reported in section
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	The interviews were conducted by AA (female, MD, PhD, background in rheumatology), EM (female, MSc, background in occupational health and health science), IP (male, MD, PhD, background in rheumatology) and WO (female, MSc, patient research partner), HCPs with experience in qualitative research data acquisition.
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	As the study participants were approached from the rheumatology centres; the interviewers might have known some of the participants from previous visits.
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	The researchers introduced themselves and informed the participants comprehensively about the goals and the content of the study. All participants gave oral and written consent to be included in this study. This is reported in the methods section. Reasons for undertaking the research on PROMs is reported in the background section.
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	We undertook a qualitative study using thematic analysis for analysing the qualitative interview data. This is reported in the methods section.
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	We included individuals who agreed to participate in this study. The selection criteria and are reported in the methods section.
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	All participants were contacted by phone. Those wishing to participate were asked for a suitable time for conducting the interview, which took place at the participating centre. This is reported in the methods section.
Sample size	12	How many participants were in the study?	Information about the sample and sample size is provided in the results section and in table 2. All individuals that were willing to participate in the focus group study finished the interviews.
Non-participation	13	How many people refused to participate or dropped out? Reasons?	

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Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	The interviews were conducted as focus-group interviews at the rheumatology centres of the participating countries.
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	The baseline characteristics of the sample are reported in table 1.
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	As reported in the methods section, the interview guide was developed and adapted together with HCPs and PRPs. The questions were pretested in young people with arthritis before conducting the focus groups, and were adapted according to their feedback ¹⁶ . The interview questions are depicted in supplemental table 1.
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	The focus group interviews were not repeated. This is reported in the methods section.
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	Interviews were all audiotaped and transcribed verbatim and debriefing notes were taken after each interview. This is reported in the methods section.
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	The duration of the focus group interviews were 92 minutes on average.
Data saturation	22	Was data saturation discussed?	In this study, data saturation was defined as no new qualitative codes coming up in at least three subsequent focus groups. This was reported in the methods section and the results section.
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	According to our opinion and previous negative experiences (lay study participants were concerned about their mode of expression when reviewing their transcripts), we decided not to return the transcripts to the participants for comments and/or corrections. Instead, six PRPs (IB, MK, NC, SS, TW, WO) reviewed the data analysis (reported in the methods section).
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	The data coding and analysis was primarily done by EM, Vienna, Austria, with input from the local investigators from Croatia, Italy and the Netherlands and the taskforce (including PRPs). This is reported in the methods section.
Description of the coding tree	25	Did authors provide a description of the coding tree?	An example of a coding tree is provided in the methods section.
Derivation of themes	26	Were themes identified in advance or derived from the data?	The identified themes were derived from the interview data. This inductive data analysis is described in detail in the methods section.

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Software	27	What software, if applicable, was used to manage the data?	The qualitative data analysis was facilitated by using Atlas ti data analysis software, which is described in the methods section.
Participant checking	28	Did participants provide feedback on the findings?	Several PRPs (IB, MK, NC, SS, TW, WO) provided feedback on the findings (reported in the methods section).
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Quotations are presented in the results section and in table 3. Each quotation was indexed using participant number, sex, age and information about the disease, eg: <i>I am just putting my line anywhere and think – that's fine. (female, 27, PsA, Austria)</i>
Data and findings consistent	30	Was there consistency between the data presented and the findings?	We endeavoured to ensure consistency between the data presented and the findings by using quotes to support our interpretations/findings. Please see the results section and table 3.
Clarity of major themes	31	Were major themes clearly presented in the findings?	We described our findings including original quotes from the participants in the results section and within table 3.

