

ORIGINAL ARTICLE

Social Role Participation Questionnaire for patients with ankylosing spondylitis: translation into Dutch, reliability and construct validity

Simon van Genderen,^{1,2} Guy Plasqui,³ Diane Lacaille,^{4,5} Suzanne Arends,^{6,7} Floris van Gaalen,⁸ Désirée van der Heijde,⁸ Liesbeth Heuft,⁹ András Keszei,¹⁰ Jolanda Luime,¹¹ Anneke Spoorenberg,^{6,7} Robert Landewé,¹² Monique Gignac,¹³ Annelies Boonen^{1,2}

To cite: van Genderen S, Plasqui G, Lacaille D, *et al.* Social Role Participation Questionnaire for patients with ankylosing spondylitis: translation into Dutch, reliability and construct validity. *RMD Open* 2016;**2**:e000177. doi:10.1136/rmdopen-2015-000177

► Prepublication history and additional material is available. To view please visit the journal (<http://dx.doi.org/10.1136/rmdopen-2015-000177>).

Received 27 August 2015

Revised 26 October 2015

Accepted 20 November 2015

ABSTRACT

Objective: The Social Role Participation Questionnaire (SRPQ) assesses the influence of health on participation in 11 specific and one general participation role across 4 participation dimensions: 'importance', 'satisfaction with time', 'satisfaction with performance' and 'physical difficulty'. This study aimed to translate the SRPQ into Dutch, and assess the clinimetric properties and aspects of its validity among patients with ankylosing spondylitis (AS).

Methods: Translation was performed using the dual panel approach. For each participation dimension, internal consistency, test-retest reliability (n=31), and construct validity were assessed in 246 patients with AS.

Results: The translation required only minor adaptations. Cronbach α s were $\alpha \geq 0.7$. A strong correlation was present between satisfaction with 'time' and 'performance' ($r=0.85$). Test-retest reliability was satisfactory ($\kappa=0.79-0.95$). Correlations with participation domains of the Short-Form Health Survey 36 (SF-36), the WHO Disease Assessment Score II, and generic as well as disease-specific health outcomes (Physical and Mental component scale of the SF-36, Satisfaction With Life Scale, Bath Ankylosing Spondylitis Disease Index (BASDAI), Bath Ankylosing Spondylitis Functioning Index (BASFI)) were at least moderate ($r=-0.41$ to 0.75) for all dimensions except for 'role importance' where correlations were weak ($r \leq 0.40$). Discriminative ability across 5 self-reported health states was good for all dimensions ($p < 0.01$). The 'general participation' role showed similar reliability and validity for each dimension, as the average of the all 11 roles.

Conclusions: The Dutch version of the SRPQ is available to help understand social role participation of patients with AS. The dimension 'role importance' measures a distinct aspect of participation. The general participation item was a good global measure of participation.

Key messages

What is already known about this subject?

► The Social Role Participation Questionnaire (SRPQ) is a promising instrument as it assesses a broad range of roles, including one 'general participation role', across various participation dimensions. The English version of the SRPQ has proven to be reliable and valid for use in patients with ankylosing spondylitis (AS) in Canada.

What does this study add?

► The Dutch translation of the SRPQ was found relevant and comprehensible by patients with AS, and showed acceptable internal consistency and test-retest reliability.
► The dimensions 'satisfaction with time spent' and 'satisfaction with performance' correlated strongly. 'Satisfaction with performance' had better construct validity, suggesting redundancy of the dimension 'satisfaction with time'.
► The dimension 'role importance' provides different information, but these are likely to be additional information.

How might this impact on clinical practice?

► The 'general participation' item had adequate reliability construct validity and can, therefore, be considered as a more feasible approach to measure social role participation.



CrossMark

For numbered affiliations see end of article.

Correspondence to

Simon van Genderen;
s.vangenderen@
maastrichtuniversity.nl

INTRODUCTION

Participation in social roles is increasingly recognised by healthcare professionals, as well as by policymakers, to be an important outcome of healthcare and healthcare services.

Ankylosing spondylitis (AS) is a chronic inflammatory rheumatic disease with a usual

onset in the third decade of life, when persons are committed to various social roles that adults fulfil.¹ While a large amount of literature is available on restrictions on worker participation, the number of studies and the knowledge about restrictions in the full spectrum of adult social roles for patients with AS is limited.^{2–3} Research is hampered by continuing discussions on the exact definition of participation and challenges to operationalising the concept.⁴

With regard to the definition, the International Classification of Functioning, Disability and Health (ICF) defines participation as ‘an involvement in a life situation’, and classifies the concept as the aspect of functioning beyond impairments in body functions and activities, which are typical and relevant in the larger setting of someone’s life.^{4–5}

When operationalising the concept, existing instruments first vary according to the participation roles they include. In a review of instruments, relationships with family and friends, role at home, social (including political and religious life) life and work/education were recognised as unmistakable participation roles. On the other hand, discussion remains whether sexual life, hobbies or travel/transport reflect social role participation.⁶ Second, instruments differ with respect to which aspects or dimensions of social roles they measure. While the majority of instruments address restrictions or difficulty in performance of social roles,⁴ other aspects/dimensions of social role participation seem to be relevant with regard to health and/or the experience of health. From a patient-centered perspective, the level of ‘satisfaction’ can be of interest as it provides additional information on the personal appraisal of role performance independent of the difficulty or level of social participation.⁷ Moreover, ‘role importance’ seems highly relevant, as it includes the value the individual attaches to this role and can provide meaningful information that can be used as an additional qualifier for participation scores.⁴

The Social Role Participation Questionnaire (SRPQ) is a promising instrument as it assesses a broad range of roles, including one ‘general participation role’, across various dimensions.^{8–9} The English version of the SRPQ has proven to be reliable and valid for use in patients with AS and osteoarthritis in Canada.^{8–10} Since no validated Dutch patient-reported measure exists to assess participation in Dutch patients with AS, the present study aimed to translate the English version of the SRPQ into Dutch, assess reliability, and further explore the construct validity for Dutch patients with AS.

No major problems for translation and cultural adaptation were expected. With regard to internal consistency and construct validity, it was hypothesised that the ‘importance’ dimension of the SRPQ would provide dissimilar results because this dimension conceptually differs from other dimensions. Finally, we expected that the ‘general participation’ item would have a similar construct validity compared with average scores of all 11 included roles in the SRPQ.

MATERIALS AND METHODS

SRPQ, translation and cultural adaptation

The initial version of the SRPQ assesses the influence of health on 11 specific social roles and 1 ‘general participation’ item across 3 participation dimensions: ‘role importance’, ‘satisfaction with time spent in roles’ and ‘satisfaction with the role performance’.⁹ As subsequent validation showed a high correlation between the two ‘satisfaction’ dimensions and indicated that a dimension on difficulty with participation was missing, a modification was proposed to exclude ‘satisfaction with time’ and add ‘physical difficulty’.^{8–10} Given that this suggested modification for SRPQ was never validated, we decided to include all four dimensions in the current study. All roles of the SRPQ can be scored in each dimension on a five-point Likert scale (1: not at all important/not at all satisfied/unable to do to 5: extremely important/extremely satisfied/no difficulty). For the roles employment, education, intimate relationships and relationship with children/step-children/grandchildren, the patients can indicate that this role is not applicable and consequently, the ‘difficulty’ and ‘satisfaction dimensions’ will not be completed (figure 1).

For each dimension, a summary score can be calculated for presenting the average of all roles. To deal with non-applicable roles, for the dimension ‘physical difficulty’ it is assumed that no restrictions are experienced if the role is not applicable; however, for the satisfaction dimensions the average scores are only calculated if participants participate in at least 9 of the 11 roles.⁸

Translation of the SRPQ was performed following the dual panel approach.¹¹ First, four bilingual translators (native Dutch speakers) and 2 native (English) speakers worked together to produce a preliminary Dutch translation. Second, a healthy Dutch lay panel, consisting of three women and three men varying in age (range 25–64 years) and level of education, discussed the wording and comprehensiveness of the translation under the supervision of the project leader who was part of the first step. Finally, cognitive debriefing interviews with the adjusted version were conducted among five patients with AS. The final version was back-translated into English and the developer’s approval was sought.

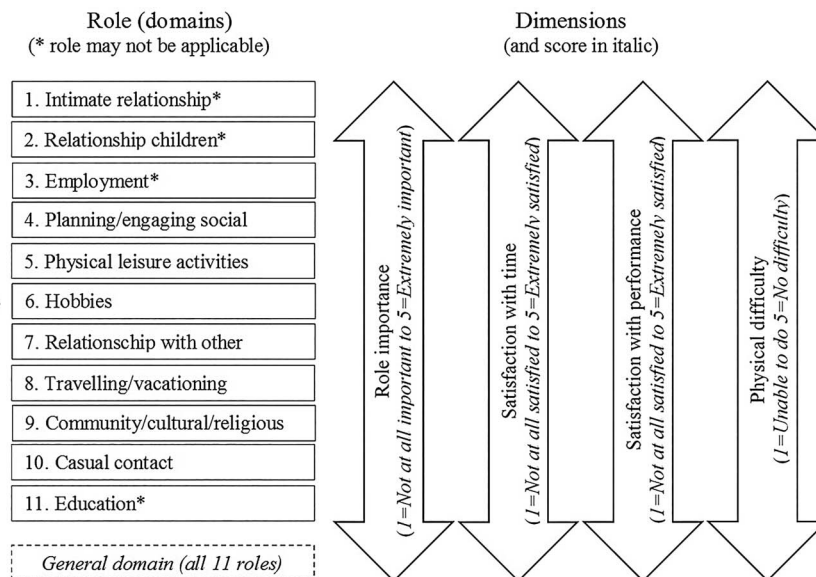
Clinimetric properties and validation

The COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidelines and checklist manual were used to ensure methodological quality of the current study.^{12–13}

Participants

Patients were recruited as part of a multicentre cross-sectional study, the Social Role Participation in Ankylosing Spondylitis Study (SPASS). Patients from six hospitals in the Netherlands who were at least 18 years of age, registered with AS according to Dutch ‘diagnosis related groups’ or similar patient lists, and in whom the diagnosis, according to the modified New York criteria,

Figure 1 Graphical representation of the content of the Social Role Participation Questionnaire (SRPQ), which assesses several dimensions of role participation across 11 specific roles and general role participation item.



was confirmed by the treating rheumatologist were invited to participate by a letter. Patients were excluded if they indicated they had no access to the internet or were not familiar with the Dutch language. A random subsample of patients was invited to complete the SRPQ again after 2 weeks to evaluate test-retest reliability. The ethics committee of the academic hospital Maastricht and Maastricht University approved the study, and informed consent was obtained from all participating patients.

Assessments

Patients completed an online survey. Questions on socioeconomic background comprised age, gender, highest completed educational degree and work status. Social participation was assessed using the SRPQ, and by social role domains of the *WHO Disease Assessment Score II* (WHODASII) and the *Short Form Health Survey 36* (SF-36). The WHODASII contains 36 items across six subdomains assessing difficulties in understanding and communicating, getting around, self-care, getting along with people, life activities, and participation in society. The latter three subdomains are considered to represent participation. Domain scores range from 0 to 100, lower scores reflecting fewer limitations.¹⁴ The SF-36 contains 36 items assessing difficulties due to mental or physical health across eight domains: social function, physical function, bodily pain, role-physical, general health, vitality, role-emotional and mental health. The domains social functioning, role-physical and role-emotional represent participation roles. Domain scores range from 0 to 100 (higher scores reflecting less difficulties/health problems). In addition, two summary scores, the Physical Component Summary (PCS) and Mental Component Summary (MCS) scores (range 0–100) can be calculated to present overall health-related quality of life (HR-QoL).¹⁵

To assess disease-specific aspects of health, patients indicated their disease duration, current use of tumour necrosis factor- α inhibitors, and completed the *Bath Ankylosing Spondylitis Disease Index* (BASDAI) and the *Bath Ankylosing Spondylitis Functioning Index* (BASFI). The BASDAI is a composite score of six questions assessing different aspects of disease activity with AS. Scores for each item and the total index range from 0 to 10 (10 reflecting highest disease activity).¹⁶ The BASFI determines the level of normal daily functioning of people with AS across 10 items. Scores for each item and total index range from 0 to 10 (10 reflecting most impairments in functioning).¹⁷ Finally, the Satisfaction With Life Scale (SWLS) was added to assess the overall satisfaction with the respondent's life. The questionnaire has five items that can be rated on a Likert scale (1 not at all agree to 7 totally agree). Total scores range from 5 to 35, higher scores indicating more life satisfaction.^{18 19}

Statistical analyses

Statistical analyses were performed using PASW Statistics V.20 (SPSS, Chicago, Illinois, USA). Analyses are performed for each dimension of the SRPQ by first using the averaged 11 specific role score and next the score on the single 'general participation' item.

Internal consistency was assessed by Cronbach's α coefficients (adequate: ≥ 0.70).²⁰ Item deletion analyses were performed to reveal any outstanding items influencing the Cronbach's α . Spearman correlations between dimensions were computed (correlation weak: ≤ 0.40 ; moderate: >0.41 but ≤ 0.75 ; strong: >0.75).²¹

Floor and ceiling effects were defined as $>15\%$ of patients scoring not at all important/not at all satisfied/unable to do (floor effect) or $>15\%$ of patients scoring very important/very satisfied/no difficulty (ceiling effect), in the dimensions score or single item score.²²

Test-retest reliability was assessed assuming stable health over the 2 weeks' assessment interval, first by weighted κ s with quadratic weights (agreement slight (≤ 0.2), fair (>0.2 but <0.4), moderate (≥ 0.41 but <0.6), substantial (≥ 0.6 but <0.8) and almost perfect (≥ 0.81)),²³ and second by the smallest detectable difference (SDD).

Construct validity with other participation measures was tested by Spearman correlations with the participation domains of the WHODASII⁶ and the SF-36. Construct validity with other health outcomes was tested using Spearman correlations with PCS and MCS of the SF-36, BASDAI, BASFI and SWLS.

Finally, to assess whether the SRPQ is discriminative between groups that differ in overall health (the five health states of the SF-36 general health item (1=poor to 5=excellent health)), differences between provided scores within each dimension were calculated by using Kruskal-Wallis test.

RESULTS

Translation and cultural adaptation

The translator and lay panel identified issues concerning the wording of the roles representing work and education. The original English version asks about the type of paid work or education that 'you are able to have' and not 'you are able to do' as for all other roles. The panels considered this difference as liable to misinterpretation. Moreover, in the Dutch situation, 'able to have' would be less applicable and ambiguous, as society focuses on maintaining work and less on considering other types of work. Hence, formulation was changed in accordance with the questioning in the other roles. Results of the cognitive debriefing showed that the translated version of the questionnaire was correctly understood, and no roles or dimensions were missing or unimportant. The average time to complete the SRPQ was 12 ± 7 min. The back-translated final version was approved by the developer.

Clinimetric properties of the SRPQ

Samples

Of the 740 patients invited, 296 (40%) agreed to participate of which 246 (83%) completed the questionnaire. Of these patients, 31 participated in the test-retest reliability substudy. The characteristics of the study population are given in table 1. Most patients were male (62%), average age 51 ± 12 years and diagnosis duration of 17 ± 12 years. For roles that might not be applicable, the table also presents the number and proportions of persons for whom roles were applicable. This resulted in $n=235$ (96%) patients who had participated in at least nine roles (and therefore contribute to the satisfaction dimension).

Internal consistency

Cronbach's α was adequate for all dimensions but, as hypothesised, this was lower for 'role importance'

Table 1 Characteristics of 246 patients with ankylosing spondylitis

	n, Per cent or mean (SD) [minimum–maximum]
Gender (males)	153 (62%)
Age (years)	51 (12) [24–79]
Diagnosis duration (years)	16.8 (11.8) [5–44]
BASDAI	4.4 (2.3) [0–10]
BASFI	4.2 (2.5) [0–10]
Current use of TNF- α inhibitors (n, %)	123 (50%)
Higher professional education or university (n, %)	81 (33%)
SF-36 PCS	38.7 (10.1) [5.2–61.9]
SF-36 MCS	49.2 (12.8) [10.9–70.5]
SWLS	22.2 (7.2) [5–35]
SRPQ roles that are optional	
Has a partner, intimate relationship (n, %)	187 (79%)
Has (step/grand) children	184 (75%)
Has other family	239 (98%)
Employment (n, %)	140 (57%)
Work disabled (n, %)	59 (24%)
Following some form of education (n, %)	40 (16%)

BASDAI, Bath Ankylosing Spondylitis Disease Index; BASFI, Bath Ankylosing Spondylitis Functioning Index; MCS, Mental Component Score; PCS, Physical Component Score; SF-36, 36-item Short Form Health Survey; SRPQ, Social Role Participation Questionnaire; SWLS, Satisfaction With Life Scale; TNF, tumour necrosis factor.

($\alpha=0.74$) compared with the 'satisfaction with time' ($\alpha=0.83$), 'satisfaction with performance' ($\alpha=0.89$) and 'physical difficulty' ($\alpha=0.86$). Item deletion did not indicate any outstanding items influencing Cronbach's α . The correlations between the dimension 'role importance' and each other dimension were weak ('satisfaction with time' ($r=0.20$), 'satisfaction with performance' ($r=0.21$) and 'physical difficulty' ($r=0.10$)). Strong correlations were observed between both 'satisfaction' dimensions ($r=0.85$), and moderate correlations between 'physical difficulty' and either 'satisfaction with performance' ($r=0.69$) or 'satisfaction with time' ($r=0.52$). The correlations between the single general participation item and the averages role scores were moderate for the dimension 'role importance' ($r=0.59$), and strong for the other dimensions ($r \geq 0.80$).

Floor and ceiling effects

In none of the dimensions were floor or ceiling effects found. The general participation item showed a ceiling effect in 43% of patients in the dimension 'role importance' (participation very important).

Test-retest reliability

The weighted κ was substantial in the 'role importance' dimension ($\kappa=0.79$), and almost perfect for the

Table 2 Spearman correlation coefficients of the SRPQ dimensions and other domains of questionnaire assessing participation

	SF-36 social functioning	SF-36 role emotional	SF-36 role physical	WHODASII getting along with people	WHODASII life activities	WHODASII overall participation
SRPQ dimension (average of all roles)						
Role importance	0.063	0.003	0.255	-0.181	-0.009	-0.058
Satisfaction time*	0.586	0.378	0.335	-0.399	-0.435	-0.562
Satisfaction performance*	0.720	0.390	0.560	-0.461	-0.546	-0.646
Physical difficulty	0.735	0.384	0.713	-0.471	-0.714	-0.665
SRPQ general participation item						
Role importance	0.075	0.018	0.164	-0.094	0.133	-0.040
Satisfaction time	0.603	0.377	0.392	-0.412	-0.444	-0.566
Satisfaction performance	0.582	0.323	0.464	-0.402	-0.453	-0.575
Physical difficulty	0.693	0.390	0.611	-0.461	-0.640	-0.625

*Average scores of the 'satisfaction' dimensions could only be calculated for 235 of the 246 patients.

SF-36, 36-item Short Form Health Survey; SRPQ, Social Role Participation Questionnaire; WHODAS, WHO Disease Assessment Score.

dimensions 'satisfaction with time' ($\kappa=0.84$), 'satisfaction with performance' ($\kappa=0.85$) and 'physical difficulties' ($\kappa=0.95$). The reliability of the general participation item was lower, with a κ that was fair for 'role importance' ($\kappa=0.30$) and substantial ($\kappa \geq 0.7$) for the other dimensions. The SDDs for averaged scores and general participation score [in square brackets] were 0.74 [1.60], 0.69 [1.23], 0.83 [1.35] and 0.38 [1.29] for the dimensions 'role importance', 'satisfaction time', 'performance' and 'physical difficulty', respectively.

Construct validity

As expected, the dimension 'role importance' correlated weakly with the six participation domains of WHODAS or SF-36 (table 2). 'Satisfaction' with time or performance correlated moderately with three or five external measures of participation, respectively. 'Physical difficulty' correlated moderately with five participation measures. Correlations of the general participation item with external measures were comparable to the correlations based on the averages of specific roles. The weak

correlations for the satisfaction and difficulty dimensions were always seen with the 'emotional role' of the SF-36.

The dimension 'role importance' correlated weakly with all five measures representing aspects of HR-QoL (table 3). 'Satisfaction with time' correlated moderately with two, and weakly with three HR-QoL measures. 'Satisfaction with role performance' and 'physical difficulty' correlated moderately with all available HR-QoL measures, except for a weak correlation between the dimension 'physical difficulty' and the SF-36 MCS. Finally, the general participation item showed moderate correlations for all dimensions with the exception of 'role importance', which showed a weak correlation. Overall, the best correlations were seen between the 'satisfaction' dimensions and SWLS, and between the 'physical difficulty' dimension and SF-36 physical role, BASDAI and BASFI.

Discriminative ability

Finally, all dimensions as well as the general participation item were discriminative between the five health states of

Table 3 Spearman correlation coefficients of the SRPQ and other instruments assessing generic or disease-specific (aspects of) health in AS

	SF-36 PCS	SF-36 MCS	SWLS	BASDAI	BASFI
SRPQ dimension (average all roles)					
Role importance	0.146	0.004	0.166	-0.040	-0.260
Satisfaction time*	0.335	0.528	0.656	-0.339	-0.359
Satisfaction performance*	0.504	0.490	0.653	-0.483	-0.546
Physical difficulty	0.691	0.350	0.468	-0.636	-0.723
SRPQ general participation item					
Role importance	0.108	-0.004	0.168	0.002	-0.157
Satisfaction time	0.383	0.503	0.649	-0.370	-0.380
Satisfaction performance	0.439	0.422	0.652	-0.415	-0.426
Physical difficulty	0.634	0.379	0.457	-0.583	-0.585

*Average scores of the 'satisfaction' dimensions could only be calculated for 235 of the 246 patients.

AS, ankylosing spondylitis; BASDAI, Bath Ankylosing Spondylitis Disease Index; BASFI, Bath Ankylosing Spondylitis Functioning Index; MCS, Mental Component Score; PCS, Physical Component Score; SF-36, 36-item Short Form Health Survey; SRPQ, Social Role Participation Questionnaire; SWLS, Satisfaction With Life Scale.

Table 4 Average SRPQ scores across SF-36 rated health states for 246 patients with AS

	Poor N=20 8.1%	Fair N=109 (44.3%)	Good N=93 37.8%	Very good N=22 8.9%	Excellent N=2 0.8%	p Value
SF-36 current health state						
SRPQ dimensions (average all roles)						
Importance (1–5)	3.59	3.65	3.85	3.96	4.15	0.024
Satisfaction time* (1–5)	2.47	2.99	3.47	3.82	3.90	<0.001
Satisfaction performance* (1–5)	2.36	2.85	3.54	4.04	4.01	<0.001
Physical difficulty (1–5)	3.45	3.82	4.33	4.67	5.00	<0.001
SRPQ general participation item						
Importance	4.25	4.18	4.25	4.64	5.00	0.062
Satisfaction time	2.45	2.97	3.55	4.18	4.00	<0.001
Satisfaction performance	2.15	2.59	3.41	4.14	3.50	<0.001
Physical difficulty	2.45	3.18	3.85	4.36	5.00	<0.001

*Average scores of the 'satisfaction' dimensions could only be calculated for 235 of the 246 patients. SRPQ dimension scores range from (1: not at all important/not at all satisfied/unable to do to 5: extremely important/extremely satisfied/no difficulty).
AS, ankylosing spondylitis; SF-36, 36-item Short Form Health Survey; SRPQ, Social Role Participation Questionnaire.

the general health question in the SF-36 (table 4), except for the dimension 'role importance' in the general participation item.

DISCUSSION

This study translated and culturally adapted the SRPQ into Dutch, and further tested several aspects of its validity among patients with AS. The translated questionnaire was found to be relevant and comprehensible by Dutch patients with AS; it showed overall good clinimetric characteristics and confirmed the hypothesis on construct validity.

In rheumatology, translation followed by back translation and cognitive debriefing among patients as the last step is the most common approach to translate and culturally validate questionnaires. Our study confirms that the dual panel approach provides greater efficacy due to more intense involvement of possible end users.^{11 24–28} By using the dual panel approach, we identified at an early stage (before the cognitive debriefing) the need to change the wording for the roles education and work in the dimension 'satisfaction with performance' as patients found the initially proposed translation difficult to interpret, liable to make mistakes and less applicable in Dutch society. The proposed adaptations were subsequently tested in the cognitive debriefing round and were not considered to be ambiguous anymore.

As hypothesised, the dimension 'role importance' showed lower internal consistency, weak correlations with the other dimensions of the SRPQ, and weak correlation with other instruments assessing either participation or an aspect of health. Clearly, the assessment of 'role importance' provided different information than other dimensions and can, therefore, be useful in the interpretation of the relevance of scores of the remaining dimensions. Further, it was confirmed that both dimensions for 'satisfaction' correlated strongly. As 'satisfaction with performance' had somewhat better

construct validity for all hypotheses tested (correlation with other participation measures, correlation with HR-QoL and discriminative ability across groups with different health states), 'satisfaction with time' seems less informative and redundant. On the other hand, the dimension 'physical difficulty', that was added later to the SRPQ, was found to have good correlations with external measures of participation and with HR-QoL, and discriminated particularly well across different health states. The dimension 'satisfaction with performance', as opposed to 'physical difficulty', was not found redundant as it correlated better with MCS and SWLS.

In AS, only one other study reported on participation in social roles. Davis *et al*¹⁰ previously reported on the validity of the original SRPQ in Canada and included 44 patients with AS. It is to be noted that in this version the dimension 'physical difficulty' was not tested. The authors found comparable Cronbach's α , acceptable test-retest reliability and confirmed redundancy for both satisfaction scales. Regarding comparison with other instruments measuring participation, it should be mentioned that Davis included different measures, and reported also moderate correlations of the SRPQ satisfaction scales with the Keele Assessment of Participation, which measures participation in roles 'as and when you want it',²⁹ and the Late Life Disability Instrument evaluating the frequency and limitations in performing life tasks.³⁰ This adds to the validity of the SRPQ as in our study it needs to be recognised that the instruments to assess construct validity participation (SF-36 role domains and WHODASII participation dimensions) addressed only the dimension physical restrictions of participating, therefore somewhat limiting the validation of the 'satisfaction' dimensions.

By analysing and presenting the results of the dimensions of the SRPQ as averages of all 11 roles, information on clinimetrics and validity of the specific roles could be missed. Additional analyses showed that clinimetrics and the validity of these items did not differ overall from

results based on average scores, and no clear pattern with regard to a specific role could be seen (see online supplementary file). As a first step to increase the feasibility of the SRPQ, the validity of the summary role 'general participation' was explored, and this showed that this single item had a high floor effect for role importance (very important) and somewhat lower (yet with acceptable reliability) similar correlations with external instruments, and appropriate discriminative ability across self-reported health states. Although 'global' constructs are informative as secondary end points, there is also a risk to loose information. Additional research, such as item response theory or factor analyses, could help in reducing the number of roles.

Some limitations need to be considered. First, the sample of patients unexpectedly included more females and the average age was higher than in most of the cross-sectional samples of patients with AS.¹ Although it is known that AS is increasingly recognised in females,³¹ it cannot be excluded that some patients might in fact have non-radiographic axial spondyloarthritis (nr-axSpA) (which is also more frequent in females). Second, when items in the SRPQ are not applicable there are theoretical different approaches to account for in the calculation of the dimension scores. In this study, it was chosen to adhere to the instruction of the original articles to allow for better comparison with the other publications on the validity of the SRPQ. Third, when evaluating test-retest reliability, erroneously no external measure to evaluate stability of health was added. Overall, it is considered that a 2-week period in a chronic disease is considered an appropriate time interval to avoid a change in health, on the one hand, and avoid a recall bias on the other hand.²⁰ More importantly, some aspects of the measurement properties have not yet been addressed. A priority is to define thresholds to enhance interpretability of the scores with regard to clinical important differences and patient acceptable participation state, and to study sensitivity to change. Finally, although the 'importance dimension' is considered relevant, a feasible approach to include this dimension in a global interpretation of social role participation is needed.

The relevance of this study is clear. The availability of a validated version of a Dutch version of the SRPQ will help researchers to gain more insight on participation as a health outcome, and the role of participation to directly or indirectly predict long-term satisfaction with life (happiness), vitality and healthy ageing, as well as resource utilisation and even mortality. Although relevant for patients, limitations in participation should not be a reason to change the pharmacological treatment, but should rather be a reason to consider non-pharmacological interventions comprising of lifestyle advice, education on coping strategies or the organisation of help from caretakers, friends or colleagues.

In summary, the Dutch SRPQ was understood well by the current sample of patients with AS. The version

addressing the dimensions 'role importance', 'satisfaction with performance' and 'physical difficulty' showed acceptable reliability and validity. The general participation item of the SRPQ seems to be a good substitute for the 11 other roles. It can, therefore, be considered to be a more feasible way to measure social role participation.

Author affiliations

¹Division of Rheumatology, Maastricht University Medical Center+, Maastricht, The Netherlands

²CAPHRI Research Institute Maastricht, Maastricht, The Netherlands

³Department of Human Biology, Maastricht University Medical Centre +, Maastricht, The Netherlands

⁴Division of Rheumatology, Department of Medicine University of British Columbia, Vancouver, British Columbia, Canada

⁵Arthritis Research Centre of Canada, Richmond, British Columbia, Canada

⁶Department of Rheumatology and Clinical Immunology, University of Groningen, University Medical Center Groningen, Groningen, The Netherlands

⁷Department of Rheumatology, Medical Center Leeuwarden, Leeuwarden, The Netherlands

⁸Department of Rheumatology, Leiden University Medical Center, Leiden, The Netherlands

⁹Department of Rheumatology, Sint Laurentius Hospital Roermond and Sint Jans Gasthuis Weert, Roermond and Weert, The Netherlands

¹⁰Department of Medical Informatics Uniklinik RWTH, Uniklinik RWTH Aachen University, Aachen, Germany

¹¹Department of Rheumatology, Erasmus Medical Center Rotterdam, Rotterdam, The Netherlands

¹²Department of Rheumatology, Amsterdam Medical Center, Amsterdam, The Netherlands

¹³Department of Rheumatology, University of Toronto, Toronto, Ontario, Canada

Acknowledgements The authors would like to thank AbbVie for their unrestricted financial support, and the patient research partners Marlou Essers (†) and Marianne Osseweijer for their contribution to this project.

Contributors SvG, GP, DL, SA, FvG, DvdH, LH, AK, JL, AS, RL, MG and AB provided substantial contributions to the conception or design of the work; the acquisition, analysis, or interpretation of data for the work; drafting of the work or revising it critically for important intellectual content; final approval of the version to be published; agreement to be accountable for all aspects of the work by ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Funding Unrestricted financial support for an investigator-initiated study by AbbVie b.v.

Competing interests None declared.

Patient consent Obtained.

Ethics approval The ethics committee of the academic hospital Maastricht and Maastricht University approved the study.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No additional data are available.

Open Access This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>

REFERENCES

1. Sieper J, Braun J, Rudwaleit M, *et al.* Ankylosing spondylitis: an overview. *Ann Rheum Dis* 2002;61(Suppl 3):iii8–18.
2. van Echteld I, Cieza A, Boonen A, *et al.* Identification of the most common problems by patients with ankylosing spondylitis using the

- international classification of functioning, disability and health. *J Rheumatol* 2006;33:2475–83.
3. Boonen A. A review of work-participation, cost-of-illness and cost-effectiveness studies in ankylosing spondylitis. *Nat Clin Pract Rheumatol* 2006;2:546–53.
 4. Dijkers MP. Issues in the conceptualization and measurement of participation: an overview. *Arch Phys Med Rehabil* 2010;91:S5–16.
 5. World Health Organisation. *International Classification of Functioning, Disability and Health*. Geneva: WHO, 2001.
 6. Eysen IC, Steultjens MP, Dekker J, et al. A systematic review of instruments assessing participation: challenges in defining participation. *Arch Phys Med Rehabil* 2011;92:983–97.
 7. Schwartz CE. Applications of response shift theory and methods to participation measurement: a brief history of a young field. *Arch Phys Med Rehabil* 2010;91:S38–43.
 8. Gignac MA, Backman CL, Davis AM, et al. Social role participation and the life course in healthy adults and individuals with osteoarthritis: are we overlooking the impact on the middle-aged? *Soc Sci Med* 2013;81:87–93.
 9. Gignac MA, Backman CL, Davis AM, et al. Understanding social role participation: what matters to people with arthritis? *J Rheumatol* 2008;35:1655–63.
 10. Davis AM, Palaganas MP, Badley EM, et al. Measuring participation in people with spondyloarthritis using the social role participation questionnaire. *Ann Rheum Dis* 2011;70:1765–9.
 11. Swaine-Verdier A, Doward LC, Hagell P, et al. Adapting quality of life instruments. *Value Health* 2004;7:S27–30.
 12. Mokkink LB, Terwee CB, Knol DL, et al. The COSMIN checklist for evaluating the methodological quality of studies on measurement properties: a clarification of its content. *BMC Med Res Methodol* 2010;10:22.
 13. Mokkink LB, Terwee CB, Patrick DL, et al. The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. *Qual Life Res* 2010;19:539–49.
 14. World Health Organization. *WHODAS II Disability Assessment Schedule*. 2001 (accessed 7 Dec 2010). <http://www.who.int/classifications/icf/whodasii/en/index.html>
 15. Ware JE Jr, Kosinski M, Bayliss MS, et al. Comparison of methods for the scoring and statistical analysis of SF-36 health profile and summary measures: summary of results from the Medical Outcomes Study. *Med Care* 1995;33:264–79.
 16. Garrett S, Jenkinson T, Kennedy LG, et al. A new approach to defining disease status in ankylosing spondylitis: the Bath Ankylosing Spondylitis Disease Activity Index. *J Rheumatol* 1994;21:2286–91.
 17. Calin A, Garrett S, Whitelock H, et al. A new approach to defining functional ability in ankylosing spondylitis: the development of the Bath Ankylosing Spondylitis Functional Index. *J Rheumatol* 1994;21:2281–5.
 18. Diener E, Emmons RA, Larsen RJ, et al. The satisfaction with life scale. *J Pers Assess* 1985;49:71–5.
 19. Arrindell WA, Meeuwesen L, Huysse FJ. The satisfaction with life scale (SWLS): psychometric properties in a non-psychiatric medical outpatients sample. *Pers Individual Differences* 1991;12:117–23.
 20. Terwee CB, Bot SD, de Boer MR, et al. Quality criteria were proposed for measurement properties of health status questionnaires. *J Clin Epidemiol* 2007;60:34–42.
 21. Fleiss JL. *Reliability of measurement. The design and analysis of clinical experiments*. New York: John Wiley & Sons, 1986:1–32.
 22. Nunnally JC, Bernstein IH. *Psychometric theory*. 3rd edn. New York: McGraw-Hill, 1994.
 23. Landis JR, Koch GG. The measurement of observer agreement for categorical data. *Biometrics* 1977;33:159–74.
 24. Epstein J, Osborne RH, Elsworth GR, et al. Cross-cultural adaptation of the Health Education Impact Questionnaire: experimental study showed expert committee, not back-translation, added value. *J Clin Epidemiol* 2015;68:360–9.
 25. Hagell P, Hedin PJ, Meads DM, et al. Effects of method of translation of patient-reported health outcome questionnaires: a randomized study of the translation of the Rheumatoid Arthritis Quality of Life (RAQoL) Instrument for Sweden. *Value Health* 2010;13:424–30.
 26. Lenderking WR. Comments on the ISPOR Task Force Report on Translation and Adaptation of Outcomes Measures: guidelines and the need for more research. *Value Health* 2005;8:92–3.
 27. McKenna SP, Doward LC. The translation and cultural adaptation of patient-reported outcome measures. *Value Health* 2005; 8:89–91.
 28. Wild D, Grove A, Martin M, et al. Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures: report of the ISPOR Task Force for Translation and Cultural Adaptation. *Value Health* 2005;8:94–104.
 29. Wilkie R, Peat G, Thomas E, et al. The Keele Assessment of Participation: a new instrument to measure participation restriction in population studies. Combined qualitative and quantitative examination of its psychometric properties. *Qual Life Res* 2005;14:1889–99.
 30. Jette AM, Haley SM, Coster WJ, et al. Late life function and disability instrument I. Development and evaluation of the disability component. *J Gerontol B Psychol* 2002;57:M209–16.
 31. Feldtkeller E, Bruckel J, Khan M. Scientific contributions of ankylosing spondylitis patient advocacy groups. *Cur Opin Rheumatol* 2000;12:239.