Measures of Participation in Persons With Musculoskeletal Conditions

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INTRODUCTION

To be able to participate in society is important for many persons with musculoskeletal conditions (MSCs) (1). It is also an important part of rehabilitation in goal formulation as well as an outcome (2). Although the term participation has gained worldwide acceptance and is also included as important in standards of care for persons with MSCs (1), the concept of participation is difficult to define. This also makes it difficult to find the best approach to assess it. The World Health Organization defines participation in the International Classification of Functioning, Disability and Health (ICF) as “involvement in a life situation” (3). In the ICF, participation is defined as a rather neutral term to describe social health and functioning in everyday roles. This broad definition further enhances the challenge of assessing participation, and there is a wide selection of aspects to be included. Consequently, there are numerous measures meant to assess participation, comprising different aspects and domains, both generic and disease specific.

The purpose of this article was to assist the selection of measures to use when assessing participation in research and clinical practice in persons with MSCs. The selected measures have their basis in an earlier article by Wilkie et al (4), which recommended various instruments for assessing participation and social function in MSCs. In a literature search, we reviewed which of these had been used as outcome measures for participation in individuals with MSCs during the last decade. In addition, in a broad literature search of participation in individuals with MSCs as an outcome in research studies during the last 10 years, additional instruments assessing participation were identified. A manual search was also done in reference lists of relevant articles. We selected from among instruments, both generic and disease specific, those that 1) were of relevance for people with MSCs, 2) assessed participation as defined by the ICF, 3) had been widely used during the last 10 years, and 4) had been evaluated in relation to psychometric properties. There are many instruments that assess participation of people with MSCs that fit our criteria. We have selected a variety of both generic and disease-specific instruments that, from our perspective, have been well used in research and/or clinical follow-ups over the past decade. However, this means that measures that were identified in the previous review (4) that were not used to the same extent in individuals with MSCs during the last 10 years, such as the Keele Assessment of Participation (KAP) or Participation Objective, Participation Subjective, can still be valuable instruments to assess participation. During the last years, the Patient-Reported Outcomes Measurement Information System (PROMIS) has been undertaken to improve and standardize assessment of patient-reported outcomes (PROs) (5); consequently, a PROMIS scale focused on participation that has been evaluated in relation to MSCs was also included. The following instruments have been selected and reviewed concerning their content, use, strengths, and weaknesses (Tables 1 and 2).

- Impact on Participation and Autonomy (IPA)
- PROMIS-29: satisfaction with participation in social roles
- Patient-Specific Functional Scale (PSFS)
- Social Role Participation Questionnaire (SRPQ)
- Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation)
- Valued Life Activity Scale (VLA)

IMPACT ON PARTICIPATION AND AUTONOMY

Description

Purpose. The IPA was developed as a generic measure used to assess autonomy and participation of people with chronic disorders. The scale was developed for use as a profile for disease severity assessment, needs assessment, and outcome assessment (evaluation) (6).

Content. The items cover four domains: social relations, autonomy in self-care, mobility and leisure, and family role (6). In further development, the domains were expanded to five: auton-
omy indoors, family role, autonomy outdoors, social relations, and work and education (7).

**Number of items.** In the developed version, there are 31 items in 5 subscales, of which 8 items are related to experienced problems (7).

**Response options/scale.** The IPA includes a five-point Likert scale (very good, good, fair, poor, very poor) for each item. The items related to experienced problems are rated on a three-point Likert scale (no, minor, severe).

**Recall periods for items.** Current.

**Cost to use.** Information is not available.

**How to obtain.** The questionnaire is available in the appendixes of previously published articles (6,7).

**Practical application**

**Method of administration.** Self-completed questionnaire.

**Scoring.** Each item is scored on the five-point Likert scale and summarized within each domain: indoor autonomy (seven items, range 0-28), outdoor autonomy (five items, range 0-20), family role (seven items, range 0-28), social relations (six items, range 0-24), and work and educational opportunities (six items, range 0-24).

**Score interpretation.** A higher score denotes more restrictions in participation and/or a higher problem experience on the specific domain.

**Respondent time to complete.** Approximately 20 minutes (8).

**Administrative burden.** Minimal.

**Translations/adaptations.** The original version is in Dutch (6), but the IPA has been translated, culturally adapted, and used in other languages and contexts (9–12).

**Psychometric information**

**Floor and ceiling effect.** No information.

**Reliability.** In the original version with four domains (6), the internal consistency, measured by Cronbach’s $\alpha$, of the subscales was as follows: 0.86 (social relationships), 0.87 (autonomy in self-care), 0.84 (family role), and 0.85 (mobility and leisure). In the developed version with five domains, test-retest reliability on the domain level showed no significant difference between the mean scores of the measurements, indicating good test-retest reliability. Intraclass correlation coefficients (ICCs) ranged from 0.83 (family role) to 0.91 (autonomy outdoors) (7).

**Validity.** **Construct validity.** Factor analysis with a four-factor solution showed that the scale structure could be best interpreted according to the following dimensions of perceived handicap: social relationships, autonomy in self-care, mobility and leisure, and family role (the former subscales family role and financial independence). With this factor solution, 68% of the total variance could be explained (6).

**Convergent validity.** Convergent validity was best supported by the correlations between the IPA domains and the four aspects of the London Handicap Scale (LHS) (13): mobility, physical independence, occupation, and social integration. As expected, the correlations between social relations and autonomy outdoors (IPA) ($r = 0.51$) and social integration (LHS) ($r = 0.57$) were substantial. Autonomy indoors, autonomy outdoors, and family role (IPA) and mobility, occupation, and physical independence (LHS) were also correlated (range: $r = 0.42-0.57$), supporting convergent validity (7).

**Discriminant validity.** Discriminant validity was best supported between the IPA and two domains of the LHS: orientation and economic self-sufficiency. Correlations between all domains of the IPA and the domains economic self-sufficiency and orientation (LHS) were low (range: $r = 0.01-0.29$), demonstrating discriminant validity (7).

**Responsiveness.** Responsiveness to change was seen in three dimensions: family role, autonomy outdoors, and work and education. Results were acceptable for autonomy indoors and for social relations (14).

**Minimally important differences.** No information.

**Generalizability.** The IPA is a generic measurement that has been used and tested in several contexts and conditions (15,16).

**Use in clinical trials.** The IPA has not been used in clinical trials, but it has been used in several observational and descriptive studies.

**Critical appraisal of overall value of the rheumatology community**

The IPA is a generic participation measure covering a wide spectrum of areas of participation in everyday life, and it is useful for both the clinician and the researcher. Also, persons with MSCs have expressed the relevance of the IPA. Since the IPA was reviewed in the 2011 publication of instruments measuring participation in individuals with MSCs (4), it has been translated into
several languages and used in descriptive and observational studies with large study populations. Nevertheless, further psychometric testing is needed, particularly in relation to construct validity, responsiveness, and minimally important differences (MIDs).

**PROMIS-29: SATISFACTION WITH PARTICIPATION IN SOCIAL ROLES**

**Description**

**Purpose.** The PROMIS initiative was started to improve and standardize PROs in general. The PROMIS profiles are available in 29-, 43-, and 57-item versions that contain four, six, or eight items from each domain. Each domain can be measured separately. In this review, we have focused on the 29-item PROMIS profile, which covers seven domains. Together these domains make up the most relevant areas of self-reported health for the greatest majority of people with chronic illness and have been evaluated in individuals with MSCs (17). There is one domain that is related to participation, satisfaction with participation in social roles, which is our focus of review.

**Content.** The PROMIS-29 domain measures satisfaction with participation in social roles.

**Number of items.** There is a four-item static form for satisfaction with participation in social roles. The items are as follows: 1) I have trouble doing all of my regular leisure activities with others, 2) I have trouble doing all of the family activities that I want to do, 3) I have trouble doing all of my usual work (including work at home), and 4) I have trouble doing all of the activities with friends that I want to do.

**Response options/scale.** The questions are ranked on a five-point Likert scale, in which 5 represents never and 1 represents always. Higher scores represent better functioning.

**Recall periods for items.** In the past 7 days.

**Cost to use.** Free to use.

**How to obtain.** Available at: http://www.healthmeasures.net/explore-measurement-systems/promis.

**Practical application**

**Method of administration.** The domain can be filled in online, by mailed paper questionnaire, or by telephone interview (17).

**Scoring.** The four items are scored on the Likert scale and converted to T scores, with a population mean of 50 and an SD of 10, by using PROMIS scoring documentation (available at http://assessmentcenter.net) (17).

**Score interpretation.** For all PROMIS scales, higher scores represent more of the domain being measured (17). Norm-based scores have been calculated for each domain on the PROMIS measures so that a score of 50 represents the mean or average of the reference population. A score of 60 means that the person is 1 SD above the reference population (SD 10).

**Respondent time to complete.** Less than 5 minutes.

**Administrative burden.** Low.

**Translations/adaptations.** PROMIS has been constructed and validated rigorously, with more than 50 research protocols and more than 60,000 people contributing data, and it has been translated into several languages (18,19). Studies also report that PROMIS-29 in general is useful for specific patient populations, for example, patients with chronic musculoskeletal pain (20) and primary care patients with chronic pain (21).

**Psychometric information**

**Floor and ceiling effect.** In the satisfaction with participation in social roles domain, large ceiling effects were noted for the social roles scale for rheumatic diseases (17).

**Reliability.** The satisfaction with participation in social roles domain demonstrated excellent internal consistency, with Cronbach’s $\alpha$ greater than 0.88 (17).

**Validity.** *Convergent validity.* For the PROMIS-29 satisfaction with participation in social roles domain, correlations with similar measures were mostly moderate to high.

*Known-groups validity.* PROMIS-29 scores were examined according to satisfaction with health and self-rated health. For each PROMIS-29 scale in each condition, there was a consistent pattern of declining scores with declining satisfaction and declining self-rated health (17).

**Responsiveness.** The PROMIS-29 satisfaction with participation in social roles domain showed adequate responsiveness to changes in relation to other PROs (Katz P, et al: unpublished observations).

**Minimally important differences.** MID estimates were less than 1 point for improvement 1 to 2 points for worsening for the participation in social roles scale (Katz P, et al: unpublished observations).

**Generalizability.** PROMIS-29 is generic, with related norm values.
Use in clinical trials. PROMIS-29 has been used, for example, to assess the effectiveness of providing PROMIS symptom scores to clinicians on symptom outcomes in a randomized clinical trial study (22).

Critical appraisal of overall value of the rheumatology community

PROMIS has been constructed and validated rigorously, with more than 50 research protocols and more than 60,000 people contributing data. Development included a comprehensive literature review, focus group and psychometric testing, cognitive interviews, and expert review. It is a rather complex system that allows for a lot of different versions and computer-adaptive testing. One large benefit is the ability to compare scores both to the general population and between conditions. In relation to MSCs, the PROMIS-29 satisfaction with participation in social roles domain has proven to have good psychometric properties but also high ceiling effects, indicating that the scale may not be sensitive enough to the participation restrictions of persons with rheumatic diseases. A skewed distribution was also seen earlier (23). In relation to the specific participation domain in PROMIS-29 and its psychometric performance in persons with rheumatic diseases, future work is needed to evaluate the specific participation more as well as the meaning of the ceiling effects in relation to responsiveness.

PATIENT-SPECIFIC FUNCTIONAL SCALE

Description

Purpose. The PSFS is a generic measure that is aimed at specifically eliciting and recording activity problems of relevance to the patient before and after treatment (24).

Content. Activities that are of relevance for the individual.

Number of items. Three to five self-selected activities of importance by the patient (24).

Response options/scale. The respondent names the activity, and each activity is accompanied by a 0 to 10 score related to difficulty (24).

Recall periods for items. At baseline: “Today, are there any activities that you are unable to do or have difficulty with because of your problem?” At follow-up: “Today, do you still have difficulty with 1…2…3…?” (24).

Cost to use. Free to use.

How to obtain. The PSFS is available in the appendix of the original publication (25).

Practical application

Method of administration. The PSFS is administered through an interview in which the clinician reads and asks from a questionnaire (24). It can also be used as a telephone interview (26).

Scoring. The respondent names three to five activities that are of relevance to be able to do. The respondent is then asked to rate their current level of difficulty on an 11-point scale. Scores can vary from 0 to 10 (24).

Score interpretation. A higher score indicates better function (24).

Respondent time to complete. Two to four minutes.

Administrative burden. Low.

Translations/adaptations. The PSFS has been translated to other languages, for example, Nepali (27). It has also been tested in several conditions, including musculoskeletal disorders (28).

Psychometric information

Floor and ceiling effect. There are no floor effects, but there are ceiling effects after treatment (29).

Reliability. The test-retest reliability of the PSFS has been assessed in different studies on MSCs, resulting in ICCs between 0.71 (30) and 0.97 (31).

Validity. Construct validity. Paired-samples t-tests demonstrated that the mean change score was consistent, with 0 in the stable group, and significantly different from 0 (in the appropriate direction) in the improved group. Independent-samples t-tests demonstrated a significant difference in mean change between the stable and improved groups. Differences for all outcome measures were highly significant (P < 0.001), providing evidence of the construct validity of the PSFS.

Concurrent validity. The concurrent validity of the PSFS was supported by moderate correlation with the Upper Extremity Functional Scale (0.59; 95% confidence interval [CI] 0.48-0.67) and the Numeric Pain Rating Scale (0.51; 95% CI 0.39-0.61) (30).
Responsiveness. The group-level responsiveness statistics (Cohen’s d) for PROs were compared with those for the PSFS. The responsiveness of the PSFS exceeded that of the PRO in each comparison except for the Neck Disability Index (32).

Minimally important differences. The minimal detectable change (MDC) has been shown to be 3.0 (95% CI 1.7-4.2). The MID for the PSFS was a change in score of 1.2 points (sensitivity 0.88, specificity 0.79) (30). The MID for the PSFS (on a scale from 0-10) ranged from 1.3 (small change) to 2.3 (medium change) to 2.7 (large change) (29).

Generalizability. The PSFS is a generic measurement.

Use in clinical trials. The PSFS has not been used in clinical trials, but it has been used in several other studies in different conditions.

Critical appraisal of overall value of the rheumatology community

The PSFS is valid, reliable, and responsive for measuring change over time in persons with MSCs, including limitations related to knee, low back, and neck dysfunction (31). The PSFS is easy to administer and free to use, which is an advantage. In relation to the concept of participation, it could be debated whether PSFS assesses participation or functional limitations in persons with MSCs. In relation to the ICF’s definition of participation as involvement in a life situation, it can be argued that whether the PSFS assesses participation or not depends on the complexity of the activities that the person is mentioning. In current literature, the PSFS is found as an example of a measure for participation and is used in several groups with MSCs. Still, there is a need for further psychometric development.

SOCIAL ROLE PARTICIPATION QUESTIONNAIRE

Description

Purpose. The SRPQ was developed for rheumatic diseases to assess social role participation in reference to activities an individual undertakes in the larger social context.

Content. The SRPQ includes three-dimension scores that assess 1) role importance, 2) satisfaction with time spent in roles, and 3) satisfaction with role performance (33,34). The satisfaction with role performance dimension has been changed to difficulties to performing role. Respondents are asked to rate the importance, satisfaction, and difficulty they experience in the following 11 social roles: 1) intimate relationships; 2) relationships with (step/ grand) children; 3) employment; 4) social events; 5) physical leisure; 6) travel or vacation; 7) hobbies; 8) relationships with other family; 9) community, religious, cultural involvement; 10) casual or informal contact with others; and 11) education. The SRPQ also includes one general role that is rated in the three dimensions (33).

Number of items. Eleven plus one social roles rated in three dimensions (n = 36).

Response options/scale. The PSFS is rated on a five-point Likert scale from 1 (not at all important/not at all satisfied/extremely difficult) to 5 (extremely important/extremely satisfied/not at all difficult). The option “nonapplicable” is also available.

Recall periods for items. Current.

Cost to use. Not stated.

How to obtain. Not stated.

Practical application

Method of administration. Self-completed questionnaire.

Scoring. Normative data are available from 510 population controls (35).

Score interpretation. Scores for each dimension are obtained by the average value of the individual social role scores. The total score can be averaged if the respondent completed at least 9 of the 12 roles.

Respondent time to complete. Information is not available.

Administrative burden. Information is not available.

Translations/adaptations. Except for an English version, there are translated and culturally adapted versions in Chinese (36) and Dutch (35). There is also a short form, the s-SRPQ, in which six items are rated in the three dimensions. The s-SRPQ has, for example, been translated into Dutch (37) and Turkish (38).

 Psychometric information

Floor and ceiling effect. No floor or ceiling effects were found in any of the dimensions in the Dutch translation, but the general participation item showed a ceiling effect in 43% of patients in the role importance dimension (39), whereas no floor
or ceiling effects (less than 15% was cut off) were found in the Chinese version (36).

**Reliability.** Cronbach’s $\alpha$ (internal consistency) was adequate for all dimensions: salience, 0.74; satisfaction with time spent in role, 0.83; and satisfaction with role performance, 0.85 (33) (in the Dutch version: 0.74, 0.83, and 0.89, respectively; physical disability dimension: 0.86) (39). Inter-item correlation (scalability) in ankylosing spondylitis (AS) was as follows: role importance, 0.09 to 0.53; satisfaction with time spent in role, 0.51 to 0.85; and satisfaction with role performance, 0.43 to 0.88. Inter-item correlation in psoriatic arthritis (PsA) was as follows: role importance, 0.02 to 0.75; satisfaction with time spent in role, 0.35 to 0.77; and satisfaction with role performance, 0.36 to 0.89 (34). Scale homogeneity by Cronbach’s $\alpha$ in AS was as follows: role importance, 0.69; satisfaction with time spent in role, 0.96; and satisfaction with role performance, 0.95. Scale homogeneity in PsA was as follows: role importance, 0.82; satisfaction with time spent in role, 0.93; and satisfaction with role performance, 0.93 (34).

Reliability by test-retest ICC in AS was as follows: role importance, 0.93 (95% CI 0.70-0.98); satisfaction with time spent in role, 0.98 (95% CI 0.93-0.99); and satisfaction with role performance, 0.99 (95% CI 0.94-0.99). Reliability by test-retest ICC in PsA was as follows: role importance, 0.79 (95% CI 0.60-0.90); satisfaction with time spent in role, 0.94 (95% CI 0.88-0.97); and satisfaction with role performance, 0.96 (95% CI 0.92-0.98) (3). Reliability (Dutch version) was as follows: role importance, $\kappa = 0.79$ (substantial); satisfaction with time spent in role, $\kappa = 0.84$ (very high); satisfaction with role performance, $\kappa = 0.85$ (very high); and physical difficulties, $\kappa = 0.95$ (very high). In the Chinese version, test-retest reliability by ICC was almost perfect for the dimensions role importance (0.84), satisfaction with time spent in role (0.83), satisfaction with role performance (0.89), and physical difficulty (0.865) as well as for the general participation item for each dimension (0.857, 0.857, 0.885, and 0.885, respectively) (36).

**Validity.** Content validity. Cognitive debriefing did not identify any items that were missing or unimportant, and the questionnaire was easily understood (34).

Construct validity. The SRPQ satisfaction subscales were moderately correlated (range: 0.64-0.78) with other measures of participation: KAP and Late Life Disability Index (LLDI). For participants with AS, the correlations of the SRPQ satisfaction subscales with the LLDI limitations subscale were slightly higher than anticipated at 0.76 and 0.78 (34). The Chinese version has appropriate construct validity (36).

Responsiveness. Further longitudinal studies of responsiveness are needed (37).

Minimally important differences. MDC at the 95% confidence level in AS was as follows: role importance, 0.44; satisfaction with time spent in role, 0.57; and satisfaction with role performance, 0.43. Standard error of measurement (SEM) in AS was as follows: importance, 0.23; satisfaction with time spent in role, 0.29; and satisfaction with role performance, 0.22. MDC in PsA was as follows: importance, 0.86; satisfaction with time spent in role, 0.75; and satisfaction with role performance, 0.68. SEM in PsA was as follows: importance, 0.43; satisfaction with time spent in role, 0.38; and satisfaction with role performance, 0.35 (34). Smallest detectable difference (SDD) for averaged scores was as follows: role importance, 0.74; satisfaction with time spent in role, 0.69; satisfaction with role performance, 0.83; and physical difficulty, 0.38. The SDD for the general participation score in each domain was 1.60, 1.23, 1.35, and 1.29, respectively (39).

**Generalizability.** Although the SRPQ has been developed and validated for use in specific groups, its items represent general roles.

**Use in clinical trials.** No.

**Critical appraisal of overall value of the rheumatology community**

The SRPQ is well related to the ICF’s definition of participation and has been developed to assess participation in individuals with MSCs. It has been evaluated to have good psychometric properties but still needs further testing related to, for example, responsiveness. The SRPQ has been mentioned to be rather long, hampering its application in trials and observational studies. Therefore a short version (s-SRPQ) has been developed to facilitate feasibility for use in research settings and for clinical use. The s-SRPQ has also showed good psychometric properties.

**UTRECHT SCALE FOR EVALUATION OF REHABILITATION-PARTICIPATION**

**Description**

**Purpose.** The USER-Participation is a generic participation instrument that is aimed at assessing both objective and subjective participation (40). The USER-Participation covers chapters six through nine in the ICF and has been considered as the most characteristic for participation (41). The USER-Participation has been developed as a complement to the Utrecht Scale for Evaluation of Rehabilitation (USER), which is a measure of functional independence in the domains of cognition, mobility, and self-care.
Content. The USER-Participation covers three aspects of participation: frequency, restrictions, and satisfaction.

Number of items. The USER-Participation comprises 31 items in 3 separate aspects: frequency, restrictions, and satisfaction. In the frequency aspect, there are two parts. The first part includes four items on frequency of vocational activity that measure the amount of time the respondent spends on paid work, unpaid work, study, and housekeeping. The second part contains eight items on frequency of leisure and social activity that measure the frequency of performing activities such as visiting family or friends. In the restrictions aspect, the respondent rates the experienced restrictions as a result of his or her health condition in 10 activities, such as making day trips and other outdoor activities. In the satisfaction with participation aspect, the respondent rates their satisfaction with nine aspects of life, such as contacts with family members.

Response options/scale. Frequency of participation is rated as follows: part 1, 0 (not at all) to 5 (36 hours or more); part 2, 0 (not at all) to 5 (19 times or more). “Not applicable” is available for the restrictions scale.

Recall periods for items. For frequency of participation, the recall period is a typical week in part 1 and the past 4 weeks in part 2. For participation restrictions, no recall period is stated. For satisfaction with participation, no recall period is stated.

Cost to use. No information.

How to obtain. No information.

Practical application

Method of administration. Questionnaire (40) or online questionnaire (42).

Scoring. The sum scores for the frequency, restrictions, and satisfaction scales are all converted to scores on a 0 to 100 scale. There is no USER-Participation total score.

Score interpretation. Frequency of participation is scored in hours in part 1 and in times in part 2. For participation restrictions, a higher score indicates less participation restrictions. For satisfaction with participation, a higher score indicates more satisfaction.

Respondent time to complete. No information.

Administrative burden. No information.

Translations/adaptations. The original version is in Dutch (42), and there is also a Korean version (43).

Psychometric information

Floor and ceiling effect. The USER-Participation has acceptable skewness and no floor or ceiling effects (40). There were no floor effects, and only the restrictions scale showed a ceiling effect (42).

Reliability. The weighted $\kappa$ values of the individual items ranged from 0.30 to 0.95 and were fair for 2 items, moderate for 9 items, substantial for 13 items, and almost perfect for 7 items (40). The differences between mean scores on the first and second measurements were very small. The restrictions and the satisfaction scales showed satisfying reliability, but the frequency scale showed less than satisfying ICC values. Agreement expressed by the SEM was well below 10% of the score range. Internal consistency of the USER-Participation scales was satisfactory (frequency: $\alpha = 0.70$; restrictions: $\alpha = 0.91$; satisfaction: $\alpha = 0.88$) (42).

Validity. Concurrent validity was shown by strong correlations between the frequency scale and the Frenchay Activities Index (0.59), the restrictions scale and the participation subscale of ICF Measure of Participation and Activities Screener (IMPACT-SP) (0.75), and the satisfaction scale and the Participation Scale (−0.73). Discriminant validity was shown by significant differences in USER-Participation scores between participants with different levels of independence and between participants with different health conditions (42).

Responsiveness. No information.

Minimally important differences. The MID has been calculated as follows: SDD (individual) = 15.2 and SDD (group) = 2.2. The SDD (individual) reflects the smallest change in score of an individual that can be interpreted as real change (ie, change above measurement error at an $\alpha$ level of 0.05) (40).

Generalizability. The USER-Participation is a generic measure. More than half of the respondents considered all three measures to be a relevant measure for their participation. Respondents who preferred one of the measures judged the USER-Participation to be the best and the Participation Scale to be the least favorable (40).

Use in clinical trials. Until today, the USER-Participation has not been used in any clinical trials but has been used in observational studies. A study on metric properties of the USER-
Participation in patients with spinal cord injury showed that the restrictions and satisfaction scales of the USER-Participation showed satisfactory metric properties (41).

**Critical appraisal of overall value of the rheumatology community**

The USER-Participation is a generic participation measure. Its advantages are the construction of measuring objective and subjective participation covering the most important domains of the ICF and the link to the broader USER measurement. Although it has not yet been widely cited, there is some evidence that it is both valid and potentially useful for adults with rheumatic diseases. Limitations are that it has not been published in other languages, and it is unclear how the USER-Participation is obtained.

**VALUED LIFE ACTIVITY SCALE**

**Description**

**Purpose.** The original version of the VLA was developed and validated in the United States. The aim was to assess participation in valued life activities. Valued life activities were defined as activities that the person actually does and that are important (44).

**Content.** The questionnaire includes 33 activities for which one can report difficulty performing an activity, whether an activity is relevant or not, and how important the activity is to the individual. The 33 activities represent a wide spectrum of participation and were derived theoretically from the disableness process model and from interviews with patients with rheumatoid arthritis who stated that activities were often affected by the disease. They have also been linked to the activities covered in ICF chapters two through nine (45). The activities could be clustered in three different types of activities: obligatory (eg, self-care), committed, or discretionary activities (eg, recreation and social participation) (44). Obligatory activities are those required for survival and self-sufficiency, including activities of daily living, such as hygiene and self-care, walking inside, walking outside, and using transportation or driving. Committed activities are those associated with one’s principal productive social roles, such as paid work, household responsibilities, and child and family care. Discretionary activities are activities such as socializing, exercise, engaging in leisure-time activities and pastimes, participating in religious or spiritual activities, pursuing volunteer work or hobbies, or other activities that individuals engage in for relaxation and pleasure.

**Number of items.** Thirty-three valued life activities are rated as applicable or not, as important or not, and regarding performance and use of help from another person or any adaptations when performing the activity.

**Response options/scale.** Activities that are scored as applicable and important are rated according to difficulty by using a four-point Likert scale in which 0 represents no difficulty and 3 represents inability to perform. Both help from another person and use of accommodation is scored as “yes” or “no” in each performance-rated activity.

**Recall periods for items.** Current.

**Cost to use.** No cost.

**How to obtain.** Available on request to the authors.

**Practical application**

**Method of administration.** Questionnaire on paper or by telephone interview.

**Scoring.** Three types of VLA summary scores can be calculated: the number of activities that individuals are completely unable to do because of their condition (unable), the number of activities that are affected by the condition (unable to do or any level of difficulty; affected), and the average difficulty score (difficulty). All scores are calculated for the total VLA and for the obligatory, committed, and discretionary subscales. Activities that participants deem unimportant to them or that they did not do for reasons unrelated to rheumatoid arthritis are not rated and are not included in scoring (44). Use of help from another person or use of accommodations are not included in the score.

**Score interpretation.** A higher score indicates more participation restrictions (44).

**Respondent time to complete.** Fifteen minutes.

**Administrative burden.** Low.

**Translations/adaptations.** There is a short version of the VLA, the S-VLA. The S-VLA includes 14 activities related to obligatory, committed, or discretionary activities and has good psychometric properties (46). There is also a Swedish version, which has been tested in a large and well-characterized sample and has been found to be a linguistically valid and culturally adapted self-report measure of participation (45).

**Psychometric information**

**Floor and ceiling effect.** No information.

**Reliability.** The S-VLA is reliable according to expected a posteriori prediction reliability (0.949) and has an excellent internal consistency (Cronbach’s α = 0.97) (46). Test-retest has not been reported.
Validity. The S-VLA demonstrated excellent construct validity. Significant correlations with all other measures in hypothesized directions were found (46). The S-VLA accurately represents results obtained with the longer version of the VLA scale (46). All of the items were strongly correlated with the S-VLA total score. S-VLA scores were highly positively correlated with the Health Assessment Questionnaire ($r = 0.81; P < 0.001$), patient-reported disease activity ($r = 0.71; P < 0.001$), satisfaction with abilities ($r = 0.82; P < 0.001$), and number of days with activity limitations ($r = 0.65; P < 0.001$). In addition, as hypothesized, the S-VLA was inversely correlated with the 36-item Short Form Health Survey (SF-36) physical component summary score ($r = 0.78; P < 0.001$) and the physical functioning ($r = 0.80; P < 0.001$), role physical ($r = 0.67; P < 0.001$), and social functioning ($r = 0.72; P < 0.001$) subscales.

Responsiveness. Not reported.

Minimally important differences. Not reported.

Generalizability. The VLA has been psychometrically tested and used in conditions other than rheumatic diseases.

Use in clinical trials. The VLA has not been used in any clinical trial but has been used in a variety of longitudinal and descriptive studies (47,48).

Critical appraisal of overall value of the rheumatology community

The original VLA was developed for persons with rheumatoid arthritis but has been used in different conditions. The development from the original version to the version used today (with 33 activities) is not really transparent, and the most psychometric testing has been done on the S-VLA and the Swedish version of the VLA. Information about test-retest reliability, responsiveness, and MIDs is still missing and needs more testing. An advantage is that the VLA is developed based on a theoretical framework in disability, is likened to the ICF, and is also based on patients’ own experiences of participation restrictions.

CONCLUSIONS

This article provides a detailed review of six participation measures, including information of their practical applications and psychometric properties, to help researchers and clinicians within the field of MSCs to select the most appropriate participation measure for their work. These six measures are chosen because they all assess participation as defined by the ICF (3), they are relevant for MSCs, and they have been widely used to assess participation during the last 10 years. There are also other measures or scales that are mentioned as measuring participation, for example, the social functioning subscale in the SF-36 (49); however, the social functioning subscale in the SF-36 is in a context of health-related quality of life rather than participation. Also, the the Canadian Occupational Performance Measure (COPM) (50) is often mentioned in relation to participation. Nevertheless, the COPM, in accordance to the PSFS, is focused a lot on performance but is, however, an excellent tool for evaluation of activities chosen by the individual. Because participation is an important but complex concept to define and therefore assess, these six measures were also chosen to capture different aspects and the complexity of participation to give researchers or clinicians different measures to choose from. These measures provide different domains of participation to assess, depending on the need of the clinician or researcher. Included are both generic (IPA, PROMIS-29 satisfaction with participation social roles domain, PSFS, and USER-Participation) measures and measures developed within the field of MSCs (SRPQ and VLA). The included measures are short and easy to administer, such as the PSFS and PROMIS-29 as well as the VLA and IPA, which also capture the complexity of participation.

As seen from the review of the instruments, all instruments need more psychometric testing and have different strengths and weaknesses. We therefore recommend that clinicians and researchers carefully consider in what way they would like to assess participation when choosing a measure: Is it in clinical practice or research? How much time is available? What domains do you want to capture? In that way, they can ensure that they select the measure that best suits their intentions. Assessment of participation is important both in clinical work and in research for persons with MSCs. It informs us of the participation restrictions and gives possibility to evaluating the efficacy of interventions aimed at increasing participation in society for persons with MSCs.

AUTHOR CONTRIBUTIONS

All authors drafted the article, revised it critically for important intellectual content, and approved the final version to be published.

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| Measure | Numbers of Items | Content/Domains | Methods of Administration | Recall Period | Response Format | Range of Scores | Score Interpretation | Availability of Normative Data | Cross-Cultural Validation |
|---------|------------------|----------------|---------------------------|---------------|----------------|------------------|-----------------------|-------------------------------|---------------------------|
| IPA     | 31 items         | Five domains: autonomy indoors, family role, autonomy outdoors, social relations, work and education | Self-complete questionnaire | Current       | Each item scored on a five-point Likert scale | Sum scores within each domain | Higher scores denote more restrictions in participation and/or a higher problem experience on the specific domain | No information | IPA is available in several languages |
| PROMIS-29 participation domain | Four-item static form | Capturing satisfaction with participation in social roles | Online or paper | 7 d | Five-point Likert scale | Recalculated to T scores of 0-100 | Higher score represents better functioning | Yes | PROMIS-29 is available in several languages |
| PSFS    | Three to five activities selected by the patient | Activities that are of relevance for the patient | Interview from a questionnaire | Current | 0-10 scale | 0-10 for each activity | Higher score indicates better function | No information | PSFS is available in several languages |
| SRPQ    | 36 items         | Eleven social roles and one general role rated in three dimensions (role importance, satisfaction with time spent in roles and difficulties to performing role) | Self-complete questionnaire | Current | Five-point Likert scale | Average score within each dimension | A high score means important/satisfied/no difficulties | Yes from 510 population controls | SRPQ is available in several languages |
| USER-Participation | 31 items | Three aspects of participation: frequency, restrictions, and satisfaction | Questionnaire online or on paper | Differs in different aspects | Hours and frequency; “not applicable” option is available | The sum scores for each aspect are converted to 0-100; no USER-Participation total score | Higher score indicates less participation restrictions or more satisfaction | No information | Limited information |
| VLA     | 33 items         | 33 valued life activities in the domains obligatory, committed, and discretionary | Questionnaire by telephone or self-completed on paper | Current | Four-point Likert scale: 0 = no difficulty, and 3 = unable to do | Average score within each domain and total score based on average on all of the 33 activities filled in; range: 0-3 | A higher score means more participation restrictions | No information | In Swedish |

* IPA = Impact of Participation and Autonomy; PROMIS-29 = 29-item Patient-Reported Outcome Measurement Information System; PSFS = Patient-Specific Functional Scale; SRPQ = Social Role Participation Questionnaire; USER-Participation = Utrecht Scale for Evaluation of Rehabilitation-Participation; VLA = Valued Life Activity Scale.
| Measure                  | Floor, Ceiling Effects | Reliability                                                                 | Validity                                                                 | Responsiveness                                                                 | MIDs                                                                 | Generalizability      | Used in RCTs                                                                 |
|-------------------------|------------------------|------------------------------------------------------------------------------|--------------------------------------------------------------------------|--------------------------------------------------------------------------------|----------------------------------------------------------------------|-----------------------|--------------------------------------------------------------------------------|
| IPA                     | No information         | The internal consistency were between 0.84 and 0.87 for the different subscales; ICC of 0.83-0.91 and good test-retest reliability | High levels of construct validity in relation to other measures          | Good for three domains: family role, autonomy outdoor, work and education; acceptable for two domains: autonomy indoors and for social relations, the scales within each domain were responsive to change | No information         | Generic measure              | No, but in several observational and descriptive studies                      |
| PROMIS-29 participation domain | Identified ceiling effects | Excellent internal consistency                                                | High level of construct validity in relation to other measures          | Adequate responsiveness to change                                           | One point for improvement and two points for worsening               | Generic with related norm values | Yes                                                                              |
| PSFS                    | No floor effects, but ceiling effects after treatment | Excellent test-retest reliability in different studies, with ICC ranging between 0.71 and 0.97 | High level of construct validity and concurrent validity               | Good responsiveness in relation to other instruments                       | The MID ranges from 1.3 (small change) to 2.7 (large change)         | PSFS is a generic measurement              | No, but in several observational and descriptive studies                      |
| SRPQ                    | A ceiling effect has been found in the general participation item | Adequate internal consistency in the different dimensions (0.74-0.85); good test-retest reliability in different versions | A moderate correlation to other measures of participation              | Studies are needed                                                          | Minimal detectable change in different rheumatic diseases ranges between 0.22 and 0.75 in different domains | Although SRPQ is developed and validated for use in specific groups, its items represent general roles | No                                                                              |
| USER-Participation       | Acceptable skewness, no floor or ceiling effects; there were no floor effects and only the restrictions scale showed a ceiling effect | Weighted ranged from 0.30 to 0.95 and was fair for 2 items, moderate for 9 items, substantial for 13 items, and almost perfect for 7 items. The restrictions and the satisfaction scales showed satisfying reliability, but the frequency scale showed less than satisfying ICC values. | Concurrent validity was shown by strong correlations between USER-Participation and other measures. Discriminant validity was shown by significant differences in USER-Participation scores between participants with different levels of independence and different health conditions. | No information                                                      | SDD (individual) = 15.2; SDD (group) = 2.2                                  | USER-Participation is a generic measure that has been found relevant by respondents | No                                                                              |
| VLA                     | Not reported            | EAP reliability = 0.949; internal consistency (Cronbach $\alpha$) was excellent at 0.97 | The S-VLA demonstrated excellent construct validity. Significant correlations with all other measures in hypothesized directions were found as compared with the HAQ ($r = 0.81; P < 0.001$) | No information                                                                | No information                                                      | Although VLA is developed and validated for use in specific groups, its items represent general activities | No                                                                              |

* EAP = expected a posteriori prediction; HAQ = Health Assessment Questionnaire; ICC = intraclass correlation coefficient; IPA = Impact of Participation and Autonomy; MID = minimally important difference; PROMIS-29 = 29-item Patient-Reported Outcome Measurement Information System; PSFS = Patient-Specific Functional Scale; RCT = randomized clinical trial; SDD = smallest detectable difference; SRPQ = Social Role Participation Questionnaire; S-VLA = Valued Life Activity Scale (short version); USER-Participation = Utrecht Scale for Evaluation of Rehabilitation-Participation; VLA = Valued Life Activity Scale.