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## Assessing health-related stigma and social participation

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## CHAPTER 5

### Development and structural validation of a shortened version of the Participation Scale

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“I need explanations and some fitting solutions, because I’m turning in a stranger more and more” (Selah Sue).

## Development and structural validation of a shortened version of the Participation Scale

*Purpose* To validate a shortened version of the Participation Scale (P-scale) that will be quicker to use and to describe the factor structure found in the P-scale data in various study samples.

*Methods* A large multi-country and multi-cultural database was compiled consisting of 5,125 respondents. Item analysis, explanatory factor analysis, and confirmatory factor analysis were applied to identify items for deletion and investigate the factor structure of the P-scale.

*Results* The multi-country database included eleven databases from six different countries. Respondents were affected by a range of health conditions, including leprosy, HIV/AIDS and various disabilities. Of the respondents included 57% were male. The P-scale Short (PSS) contains 13 items. A two factor structure, with factors named 'work-related participation' (3 items) and 'general participation' (10 items), showed the best model fit (CFI = 0.983, TLI = 0.979, RMSEA = 0.061). The Cronbach's alphas were very good for both the whole scale and the subscales, 0.91, 0.83, and 0.90, respectively. Correlation between the two factors was high ( $r = 0.75$ ) indicating that interpreting the P-scale as measuring an overall factor 'participation' is still valid. A very high correlation ( $r = 0.99$ ) was found between the full P-scale and the PSS.

*Conclusions* The findings suggest good validity of the P-scale across a range of languages and cultures. However, field testing needs to confirm the validity of the PSS to measure the level of social participation restrictions across cultures and health conditions.

## Introduction

People are social beings. All over the world they live in social relationships. They participate in family life, relationships with friends, community life, religious activities, civil society, work, politics, and so on. The precise nature and level of this participation may vary from person to person and culture to culture, but otherwise, 'social participation' is a global phenomenon. Many people living with disabling conditions such as leprosy, HIV/AIDS, physical disabilities, mental illness or epilepsy experience restrictions in their participation in daily life situations, such as marital and domestic life, relationships, communication, mobility, education and work. Participation, defined as 'the involvement in a life situation' in the International Classification of Functioning, Disability and Health (ICF), is therefore a key concept in disability and rehabilitation (1). The above restrictions in participation are defined as 'problems an individual may experience in involvement in life situations' (1). Improving participation is often cited as an important goal of rehabilitation interventions (2-4).

To assess the level of participation (restriction), several instruments have been developed for adults as well as children (5-10). The Participation Scale (P-scale) was developed to be suitable for use in low and middle income countries, while the majority of the other participation instruments have been developed and applied in high-income countries only (11;12).

Theoretically grounded in the ICF, the P-scale was developed simultaneously in six languages in three countries namely India, Nepal and Brazil (12). The P-scale has been used widely across different study populations, languages and countries (4;12-16). As far as we know, the instrument is available in at least 25 languages, including Bahasa Indonesia, Bangla, Dutch, Hausa, Hebrew, Hindi, Khmer, Nepali, Portuguese, Tamil, Telugu, Thai and Vietnamese. The scale has been used among persons affected by leprosy, HIV/AIDS, diabetes mellitus and various disabilities such as physical, visual, mental and multiple disabilities.

The psychometric properties of the scale were found to be good. During the initial validation study, factor analysis indicated a unidimensional structure (12). The first factor, conceptualized to be 'participation', accounted for 90% of the variability ( $n = 497$ ). Additional analysis revealed a Cronbach's alpha of 0.92, intra-tester stability of 0.83 (weighted  $\kappa$ ) and inter-tester reliability of 0.80 ( $n = 296$  and  $n = 210$ , respectively) (12). The P-scale was also part of a study conducted in West Bengal and Tamil Nadu (India), aimed at validating a toolkit to measure different aspects of stigma in a community based rehabilitation setting. The analysis showed a Cronbach's alpha of 0.93 ( $n = 806$ ) and test-retest reproducibility of 0.80 (weighted  $\kappa$ ;  $n = 49$ ) (14). Recently, a further validation study in Eastern Nepal unexpectedly showed best fit for a two factor model instead of the previously found one-dimensional structure (Stevelink et al. accepted). This two-factor model consisted of a factor

‘work-related participation’ (3 items) and ‘general participation’ (15 items) (Stevelink et al. accepted). These findings may have implications for the use and statistical analysis of the P-scale.

Experiences from the field suggest that the P-scale is very useful. However, further shortening of the scale would make it more suitable for rapid assessments. For example, it would encourage public health managers and researchers to use the scale in situations where a quick assessment is important, especially in surveys. For this reason, and because of the ambiguous results found regarding the dimensionality of the P-scale, the present study aimed to investigate ways to further shorten the instrument and to re-investigate the factor structure through secondary analysis of a large multi-country and multi-culture database.

## **Methods**

### *Design*

Several large databases with P-scale data were collected from 6 countries and synthesized into one large database.

### *Sample*

With the help of one of the initial developers of the P-scale (WvB), several previous and current users of the scale were contacted and kindly requested to share their databases for the compilation of a large multi-country and multi-cultural database. The following inclusion and exclusion criteria were applied. The databases had to have:

- At least 150 respondents
- Sufficient data quality (< 25% missing values) and availability of an extended study description (e.g. study population, sampling method, methods used).

We decided to include only respondents of 16 years and older based on the applicability of the work-related items in the P-scale. In addition, the P-scale was developed and validated for use in adult populations, defined by the WHO as ‘persons aged 16 years and older’ (16). Since various versions of the P-scale exist, only the databases that used versions 3 to 5 of the P-scale were included in the multi-country database. This was done to ensure the comparability of the items used.

### *Research instrument*

The P-scale, used to measure the level of participation restriction, consists of 18 items that cover most participation domains conceptualized in the ICF, namely learning and applying knowledge, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major

life areas and community, social and civic life. The scale has a two-tier question and response format. First, a respondent is asked to indicate whether they experience restriction in a particular aspect of participation. Only if this is the case, the respondent is asked how big a problem this restriction is to him or her, namely 'no problem' (1 point), 'small problem' (2 points), 'medium problem' (3 points) or 'large problem' (5 points). A unique feature of the P-scale is the peer concept, where respondents are asked to compare themselves with a peer, defined as 'someone similar to the respondent in all respects except for the disease or disability' (12). For example, 'Do you have equal opportunity as your peers to find work? Answer options, *Yes, No or Sometimes; [if sometimes or no]* How big a problem is this to you?' The overall P-score is derived by summing the individual item scores. A higher score indicates a higher level of participation restriction. As mentioned above, the scale has shown to have good psychometric properties in several studies (4;12;14;15).

#### *Data analysis*

Data were cleaned and prepared for analysis. Missing values were handled as follows: a participant was excluded when more than 2 missing items were identified in the P-scale. Otherwise the mean score of the participant was imputed. For invalid scoring, the same criteria were applied. Data were analyzed using MPlus (v. 6.11) and SPSS (v. 16.0).

The statistical procedure, based on the guidelines proposed by Floyd and Widaman, was divided in two rounds (18). A randomly selected 50% of the cases in the database was used during round one (19). The other 50% was used during round two, to cross-validate the structure found (19).

The first round consisted of the application of Explanatory Factor Analysis (EFA) because we aimed primarily to clarify the dimensions being measured with the P-scale (18). Due to the discrepancy found between the two-factor structure in the recent study in Nepal and the unidimensional factor structure in the initial development study, common factor analysis was applied without limiting the number of factors (Stevenson et al. accepted) (12). An oblique geomin rotation method (weighted least squares with adjustment for means and variances) was used, assuming correlated factors and taking into account the non-normal distribution of the data (18;19). Factors were extracted during the first round based on the break point of the successive eigenvalues identified in the Scree Plot (e.g. number of factor points before a break in the Scree Plot), item factor loadings (at least  $r = 0.30$ ) and interpretability (20;21). In addition, items were identified as eligible for deletion based on the presence of cross loadings ( $r > 0.30$ ), factor loadings ( $r < 0.30$ ), item-total correlations ( $r < 0.40$ ), endorsement levels (> 80% of the respondents answering 'no restriction' on a particular item), substantial increase in Cronbach's alpha if the item was deleted (> 0.05) and field experiences (20-22).

During the second round, Confirmatory Factor Analysis (CFA) was applied to investigate whether the scale showed the same dimensions across the different study populations and to determine the best model of the P-scale fitting the research data. Sufficient model fit was measured using the Comparative Fit Index (CFI), Tucker Lewis Index (TLI) and Rooted Mean Square Error of Approximation (RMSEA). The latter was considered adequate if below 0.08, where the first two fit indices needed to exceed the threshold of 0.95 (23;24). Furthermore, Pearson's correlation between the full and the shortened version of the P-scale (PSS) was investigated. We hypothesized a highly significant correlation of at least 0.60 between the full and shortened version of the P-scale.

These statistical procedures were applied first on the individual databases from the different study samples. Subsequently, the multi-country database was analyzed to describe the definitive structure of the P-scale.

## **Results**

A total of 11 databases, from six different countries, namely Bangladesh, Brazil, India, Indonesia, Nepal and the Netherlands, were included in the present study (Table 1). The final multi-country database consisted of 5,125 respondents with a range of health conditions, including leprosy, HIV/AIDS and various disabilities.

Table 1: Overview included databases P-scale

<b>Authors and year</b>	<b>Country</b>	<b>Language</b>	<b>Study population</b>	<b>Number of respondents</b>	<b>Mean score (SD) P-scale</b>
van Veen et al. 2011	Bangladesh	Bangla	Respondents with leprosy related disability	222	13.53 (18.30)
Nardi et al. 2011	Brazil	Portuguese	Leprosy affected respondents after treatment	220	13.53 (14.77)
Rensen et al. 2010	India	Tamil, Bengali	Respondents affected by leprosy	795	16.37 (19.13)
Stevelink et al. 2010	India	Tamil	Respondents affected by leprosy or living with HIV/AIDS	190	13.05 (15.58)
Pichaimuthu et al. 2011	India	Tamil	Respondents affected by psoriasis or vitiligo	290	8.45 (11.84)
van Brakel et al. in preparation	Indonesia	Bahasa Indonesia	Respondents with various disabilities	295	17.47 (21.14)
Sihombing et al. submitted	Indonesia	Bahasa Indonesia	Respondents affected by leprosy	1299	13.99 (14.70)
Stevelink et al. accepted	Nepal	Nepali	Respondents with various disabilities	151	36.00 (23.49)
NLR report, 2009	Nepal	Nepali	Respondents with various disabilities	1430	29.71 (20.66)
van der Zee et al. accepted	Netherlands	Dutch	Respondents with various disabilities	384	17.36 (16.28)
Van Brakel et al. 2006	Develop-ment database; Brazil India Nepal	Portuguese Nepali Tamil Hindi Telegu Bengali	Respondents with various disabilities	555	15.04 (14.75)

The percentage missing values per item was acceptable (< 1% per item) and invalid scoring that was not detected by the original researcher occurred only occasionally. The multi-country database comprised 2,917 males and 2,203 females (5 missing items) with a mean age (SD) of 44.1 (16.1). The mean total score of the 18-item P-scale was 18.8 (19.2) and the median was 12.0 (interquartile range: 24). Figure 1 and Figure 2 provide an overview of the median P-scale total score stratified by gender, health condition and country.

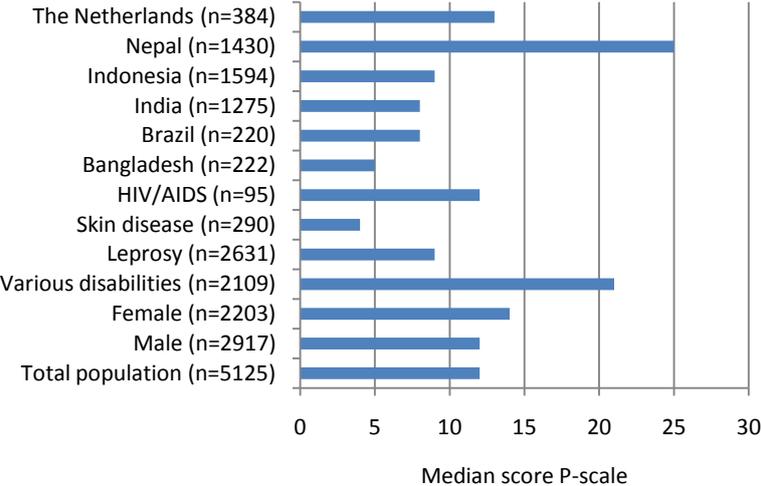


Figure 1: Overview median scores total score 18-item P-scale

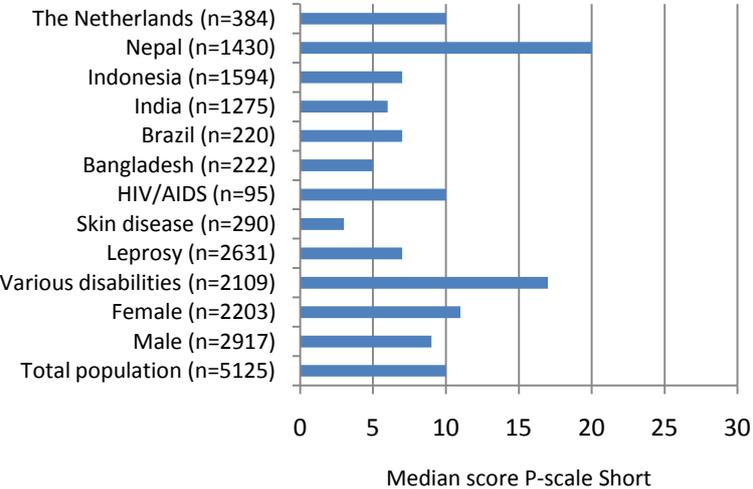


Figure 2: Overview median scores 13-item P-scale Short

### *Explanatory Factor Analysis and Confirmatory Factor Analysis per database*

The EFA results suggested two different factor structure patterns across the study samples (Table 2). A one factor structure, named 'participation' was found in four databases (Bangladesh, India and Indonesia). Four databases showed a two factor solution, that consisted of 'work-related participation' (N1-N3) and 'general participation' (N4-N18) (Nepal, the Netherlands and Indonesia). Both one (4 databases) and two-factor structure (4) models were found across the different health conditions included in the studies. The cumulative variance explained by the best EFA fitting models, ranged from 44.4% to 70.2%. The majority of the items showed sufficient factor loadings. However, inadequate item-total correlations of some items ( $<0.4$ ) were identified in different study samples (Table 2).

The CFI, TLI and RMSEA showed adequate fit across the different factor structures and all the Cronbach's alphas were found to be above the threshold of 0.70. The explained variance for the best possible fit models identified with CFA, ranged from 38.6% to 88.9% (Table 2). Two databases (Brazil and India) showed insufficient fit indices for both the one and two factor solutions.

Table 2: Results Explanatory Factor Analysis and Confirmatory Factor Analysis for the different databases from Bangladesh, Brazil, India, Indonesia, Nepal and the Netherlands.

Country (authors, year, n=)*	Factors	Results EFA				Results CFA				
		<i>Eigenvalues</i>	<i>Cumulative variance (%)</i>	<i>Item factor loadings below 0.30</i>	<i>Item-total correlations below 0.40</i>	<i>CFI</i>	<i>TLI</i>	<i>RMSEA</i>	<i>Explained variance (%)</i>	<i>Internal consistency</i>
<b>Bangladesh</b> (van Veen et al. 2011, n = 222)	F1: participation (N1-18)	10.47	58.2	None	NLearn (0.377)	0.981	0.978	0.046	52.9	0.91
<b>Brazil</b> (Nardi et al. 2011, n = 220)	F1: participation (N1 – N18)	6.88	38.2	NEat (0.260) NDiscuss (0.298)	NDiscuss (0.192) NEat (0.224) NMeet (0.267)	0.879	0.863	0.073	49.0	0.87
	F1: N1-N13, N15 (NEat) F2: N14 (NDiscuss), N16 - 18 (NHelp, NMeet, NLearn)	F1: 6.88 F2: 1.89	48.7	None	“same “	0.895	0.880	0.068	F1: 49.3 F2: 34.9	F1: 0.87 F2: 0.48
<b>India</b> (Rensen et al. 2010, n = 795)	F1: participation (N1 – N18)	11.21	62.3	None	None	0.972	0.969	0.066	46.0	0.93
<b>India</b> (Pichaimuthu et al. 2011, n = 290)	F1: participation (N1-N18)	7.86	43.7	None	NOpwork (0.334) NDiscuss (0.232) NCare (0.323) NMove (0.375) NRespect (0.311)	0.767	0.736	0.093	54.1	0.85

Country (authors, year, n=)*	Factors	Results EFA				Results CFA				
					NMeet (0.399)					
	F1: work-related participation & learning (N1 – N3 & N18) (NOpWork, NEconomic, NWorkHard, NLearn) F2: general participation (N4- N17)	F1: 7.86 F2: 2.24	56.1	F1: None F2: None	“same”	0.912	0.900	0.058	F1: 67.7 F2: 54.1	F1: 0.74 F2: 0.86
<b>Indonesia</b> <i>(van Brakel et al. in preparation, n = 295)</i>	F1: participation (N1-N18)	11.94	66.3	None	NMeet (0.344) NRespect (0.207) NEat (0.344)	0.989	0.987	0.062	60.7	0.94
<b>Indonesia</b> <i>(Sihombing et al. 2011, n = 1,299)</i>	F1: participation (N1 – N18)	8.27	45.9	None	NDiscuss (0.361) Neat (0.246)	0.942	0.934	0.077	50.7	0.91
	F1: work-related participation (N1 – N3) (NOpWork, NEconomic, NWorkHard) F2: general participation (N4 – N18)	F1: 8.27 F2: 1.321	53.3	F1: None F2: None	“same”	0.968	0.964	0.057	F1: 70.2 F2: 60.1	F1: 0.78 F2: 0.89
<b>Nepal</b>	F1: participation	10.87	60.4	None	NOpWork	0.979	0.976	0.114	34.6	0.93

Country (authors, year, n=)*	Factors	Results EFA				Results CFA				
<i>(Stevellink et al. accepted, n = 151)</i>	(N1 – N18)				(0.359) NRelation (0.304) NMeet (0.322)					
	F1: work-related participation (N1 – N3) F2: general participation (N4 – N18)	F1: 10.87 F2: 1.76	70.2	F1: None F2: None	“same”	0.992	0.991	0.069	F1: 63.8 F2: 88.9	F1: 0.78 F2: 0.93
<i>Nepal (NLR report 2009, n = 1,430)</i>	F1: participation (N1-18)	9.77	54.3	None	NHelp (0.272)	0.934	0.925	0.127	48.3	0.93
	F1: work-related participation (N1 – N3) F2: general participation (N4 – N18)	F1: 9.77 F2: 1.38	61.9	F1: None F2: NVisit (0.275) Cross-loading with Factor 1 (0.297)	“ same”	0.959	0.954	0.101	F1: 68.8 F2: 80.3	F1: 0.81 F2: 0.92
<i>The Netherlands (van der Zee et al. accepted, n = 384)</i>	F1: N1 – N18	8.90	49.4	None	NLearn (0.381) NEat (0.222)	0.938	0.930	0.093	54.6	0.91
	F1: work-related participation (N1 – N3) F2: general participation (N4 – N18)	F1: 8.90 F2: 1.39	57.2	F1: None F2: None	“same”	0.979	0.976	0.055	F1: 74.6 F2: 81.0	F1: 0.82 F2: 0.90

Country (authors, year, n=)*	Factors	Results EFA				Results CFA				
<i>Development; Brazil, India, Nepal (van Brakel et al. 2006, n = 555)</i>	F1: participation (N1-13 N15 - N18)	7.99	44.4	None	NDiscuss (0.224) NEat (0.220) NCare (0.311) NMeet (0.233)	0.974	0.970	0.051	38.6	0.86

\*The database from India was included in the multi-country database but excluded for the analyses per database due to 'one or more zero cells in the bivariate table'.

After the analysis by database, a multi-country database was compiled consisting of 5,125 respondents. This database was randomly divided in two subsets. The first subset for EFA (n = 2,562) and the second subset for CFA (n = 2,563) were comparable with respect to gender, health condition and country (Table 3).

Table 3: Respondent characteristics Multi-country 1 (n=2,562) and Multi-country 2 (n=2,563) subsets

<b>Variable</b>	<b>Multi-country 1</b> N (%) (EFA)	<b>Multi-country 2</b> N (%) (CFA)	<b><math>\chi^2</math></b> <b>p-value</b>
<i>Total</i>	2562 (50)	2563 (50)	
<i>Sex</i>			0.508
Male	1457 (49.6)	1481 (50.4)	
Female	1103 (50.5)	1080 (49.5)	
<i>Health Condition</i>			0.593
Various disabilities	1077 (50.8)	1042 (49.2)	
Skin disease	141 (50.5)	138 (49.5)	
Leprosy	1306 (49.4)	1336 (50.6)	
HIV/AIDS	38 (44.7)	47 (55.3)	
<i>Country</i>			0.558
Bangladesh	104 (48.6)	110 (51.4)	
Brazil	119 (52.0)	110 (48.0)	
India	618 (49.8)	624 (50.2)	
Indonesia	786 (48.6)	830 (51.4)	
Nepal	746 (51.9)	692 (48.1)	
Netherlands	189 (49.0)	197 (51.0)	

#### *Explanatory Factor Analysis multi-country database*

The Scree Plot suggested a one factor model, however the magnitude of the eigenvalues (>1.0) suggested a two factor structure model (Figure 3).

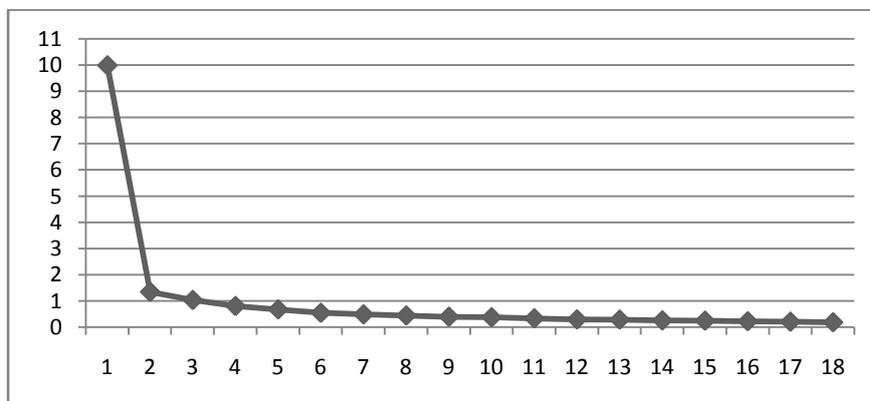


Figure 3: Scree Plot Explanatory Factor Analysis multi-country datababase (n = 2,562)

Four items were identified for deletion based on a combination of substantial cross-loadings ( $r > 0.30$ ), low item-total correlations ( $r < 0.40$ ), endorsement levels (<20%; data not shown) and no or minimal reduction in the Cronbach's alpha after item deletion (Table 4). These were 'Caring for oneself' (N9), 'Using separate eating utensils' (N15), 'Helping other people' (N16) and 'Learning new things' (N18). After several rounds of analyses, where several item deletion combinations were tested, the decision was made to select these four items for deletion. In addition item 7, 'being socially active', was deleted based on our own experiences in the field research, as well as those from other researchers (personal communications, Beise, 2010 and Sermittirong, 2011).

Respondents were confused because of the overlap with items 5 and 6 and the abstract wording of this particular item. Removal of this item had no substantial implications for the Cronbach's alpha and fit indices. After deletion, a two-factor model consisting of 'work-related participation' (3 items) and 'general participation' (10 items) best fitted the data (Table 4).

Table 4: Results Explanatory Factor Analysis Multi-Country subset N=2,562

Database	Factors	Results EFA						
		<i>Eigenvalues</i>	<i>Cumulative variance (%)</i>	<i>Item factor loadings below 0.30</i>	<i>Cross-loadings (&gt;0.30)</i>	<i>Internal consistency</i>	<i>Item-total correlations below 0.40</i>	<i>Cronbach's alpha if item deleted</i>
<b>Multi-country subset 1 (N=2,562)</b>	F1: participation (N1-N18)	9.98	55.4	None	NA	0.92	NHelp (0.370)	NLearn: 0.92 NEat: 0.92 NCare: 0.92 NHelp: 0.93
	F1: work- related participation (N1 – N3) (NOpWork, NEconomic, NWorkHard) F2: general participation (N4 – N18)	F1: 9.98 F2: 1.34	62.9	F1:None F2: None	NLearn (F1: 0.399 & F2: 0.341) NEat (F1: 0.371 & F2: 0.389) NCare (F1: 0.276 & F2: 0.462)	F1: 0.83 F2: 0.92	F1: None F2: NHelp (0.387)	F1: - F2: NHelp: 0.92 NLearn: 0.91 NEat: 0.91 NCare: 0.91

Database	Factors	Results EFA						
		<i>Eigenvalues</i>	<i>Cumulative variance (%)</i>	<i>Item factor loadings below 0.30</i>	<i>Cross-loadings (&gt;0.30)</i>	<i>Internal consistency</i>	<i>Item-total correlations below 0.40</i>	<i>Cronbach's alpha if item deleted</i>
<b>Multi-country subset 1 (N=2,562)</b> <i>(Exclusion N7, N9, N15, N16, N18)</i> <i>(NSocActiv, NCare, NEat, NHelp NLearn)</i>	F1: N1 – N6 N8 N10 – N14 N17	F1: 7.80	60.0	None	NA	F1: 0.91	None	-
	F1: work-related participation (N1 – N3) F2: general participation N4 – N6 N8 N10 – N14 N17	F1: 7.80 F2: 1.17	69.0	None	None	F1: 0.83 F2: 0.90	None	F1: - F2: -

### *CFA multi-country database*

The one factor models suggested inadequate model fit, whereas the two factor structure models indicated good fit for the 18-item P-scale (CFI = 0.970, TLI = 0.966, RMSEA = 0.065) (Table 5). The 13-item P-scale showed even better overall fit indices (CFI = 0.983, TLI = 0.979 and RMSEA = 0.061). For the latter, factor one, 'work-related participation', explained 73.4% of the variance, whereas 69.8% of the variance was explained by factor two, 'general participation'. The correlation between the two factors was high, specifically  $r = 0.75$  (Table 5).

In both versions of the P-scale the factor loadings were adequate (Table 6). The internal consistency (Cronbach's alpha  $\geq 0.70$ ) was very good for both item versions. An alpha of 0.93 was found for the 18-item version of the P-scale. The subscales 'work-related participation' and 'general participation' showed an alpha of 0.83 and 0.92, respectively. The shortened version of the P-scale showed an alpha of 0.91 for the total scale and 0.83 and 0.90 for the subscales. Furthermore, the full P-scale total score was highly correlated with the score of the PSS ( $r = 0.99$ ,  $p < 0.001$ ).

Extended results of the EFA and CFA can be obtained via the corresponding author. Please refer to Appendix 1 of this chapter for the PSS.

Table 5: Results Confirmatory Factor Analysis Multi-country subset 2 (n = 2,563)

Database	Factors	Results CFA				
		<i>CFI</i>	<i>TLI</i>	<i>RMSEA</i>	<i>Variance explained (%)</i>	<i>Correlation between factors</i>
<b>Multi-country subset 2 (N=2,563)</b>	F1: participation (N1 - N18)	0.935	0.927	0.096	F1: 57.6	-
	F1: work-related participation (N1- N3) F2: general participation (N4 – N18)	0.970	0.966	0.065	F1: 74.6 F2: 67.6	<i>r</i> = 0.762
<b>Multi-country subset 2 (N=2,563) (Exclusion N7, N9, N15, N16, N18) (NSocActiv, NCare, NEat, NHelp NLearn)</b>	F1: participation (N1 – N6 N8 N10 – N14 N17)	0.937	0.924	0.118	F1: 59.0	-
	F1: work-related participation (N1 – N3) F2: general participation (N4 – N6 N8 N10 – N14 N17)	0.983	0.979	0.061	F1: 73.4 F2: 69.8	<i>r</i> = 0.751

Table 6: Factor loadings for the 18 and 13-item version of the Participation Scale (n = 2,563)

<i>Item</i>	<b>18-item version</b>		<b>13-item version</b>	
	<b>P-scale</b>		<b>P-scale</b>	
	<i>Factor</i>	<i>Factor</i>	<i>Factor</i>	<i>Factor</i>
	<i>1</i>	<i>2</i>	<i>1</i>	<i>2</i>
N1 Opportunity to find work	0.864		0.857	
N2 Work as hard	0.859		0.871	
N3 Contribute economically to household	0.822		0.814	
N4 Visit places outside village/neighbourhood		0.822		0.835
N5 Take part in festivals and rituals		0.862		0.862
N6 Take part in casual social and recreational activities		0.838		0.830
N7 Socially active		0.831		
N8 Same respect in community		0.790		0.791
N9 Opportunity to take care of yourself		0.664		
N10 Visit other people in community		0.759		0.740
N11 Move around inside and outside house and village/neighbourhood		0.788		0.802
N12 Visit public places in village/neighbourhood		0.856		0.864
N13 Household work		0.618		0.620
N14 Opinion count family discussions		0.720		0.732
N15 Eating utensils kept with those used by the rest of the household		0.675		
N16 Help other people		0.486		
N17 Comfortable meeting new people		0.722		0.724
N18 Confident to learn new things		0.671		

## Discussion

The purpose of the present study was to develop a shortened version of the P-scale and describe the factor structure with the best possible fit.

We performed item analysis, and exploratory and confirmatory factor analyses. In combination with the results of the EFA, the item analysis helped to identify possible items for deletion. In addition, EFA determined the structure of the item set that would make up the PSS. CFA then validated the hypothesized factor structure by determining the goodness of fit in a random 50% of our database. We excluded five items with poor properties in this process, resulting in a 13-item scale with good goodness-of-fit indices and excellent Cronbach's alphas.

All 11 study samples showed good internal consistency, indicating that the P-scale can be used to measure participation restrictions in a reliable manner across countries and different study populations. Two different factor structures were identified in the samples, a unidimensional structure (measuring 'general participation') and a two-dimensional structure (measuring 'work-

related participation and 'general participation'). The variance in factor structure may be explained due to local cultural differences in the experience of participation restriction, including the social composition of communities, economic differences, environment, traditional roles and family life as well as the effect of translation into a particular language (25;26). In the samples where a two-dimensional structure was found, both factors were highly correlated, suggesting that, together, they measured a higher-level factor which may be interpreted as 'participation'.

For two study samples, namely Brazil (27) and India (28), the one and two-factor model showed inadequate model fit. This may be due to the fact that several items showed inadequate item-total correlations or factor loadings, which may account for the factor instability (21). In addition, the P-scale median for both studies was low, 7 and 4, respectively. This indicates that the variability in the study sample was less than in the other databases, resulting in difficulties to establish a sufficient factor model. Despite this finding, we decided to include both studies in the multi-country database, to establish an as large as possible sample size. Additional analysis revealed that exclusion of the studies from the multi-country database showed no remarkable differences in fit indices or variance explained (data not shown).

During a study performed in 2000, factor stability of the General Health Questionnaire was investigated (GHQ) (29). This questionnaire can be used to assess the psychological wellbeing of respondents. A total of 15 different centres, comprising 11 different languages, were included and principal component analysis was conducted. Also in this study, the factor structure differed between the centres. According to the authors possible explanations were sampling variation and multiple cross-loadings of the items (29). Another widely used instrument, the Short Form (SF)- 36 Health Survey, was tested extensively on the generalizability of the expected two dimensional construct of health (physical and mental) (30). Findings showed that the proposed factor structure was stable across countries, supporting the construct validity of the scale (31). In addition, tests to investigate the cross-cultural equivalence of the SF-36, such as structural equation modeling and Rasch analysis were performed also and showed similar findings across countries results (32;33). The latter two methods are also interesting opportunities for future research to provide detailed evidence for the cultural equivalence of the P-Scale.

Large differences were found in the median score of the P-scale (Figure 1 and Figure 2). The persons affected by various disabilities, such as physical, multiple, hearing or vision-related disability reported a twice as high level of restrictions compared to leprosy affected persons and even four times that of people with skin diseases (vitiligo and psoriasis). This difference may be explained by the fact that

more than half of the respondents were more severely affected by a physical or multiple disability, which may increase the level of participation restriction (mobility, involvement community, social, civic life etc.) compared to the persons affected by leprosy or skin disease that had in most cases no (visible) impairments. Corresponding results were found in a study conducted in the Netherlands among persons affected by leprosy. A significant correlation was identified between the severity of the impairment with activity limitations and participation restrictions (34). In addition, activity limitations were found to be a major determinant of participation restriction (34). A study conducted in the Philippines aimed to compare the level of activity limitation and participation restriction in persons with a visible impairment due to leprosy, persons newly diagnosed with leprosy without an impairment and persons with other skin diseases symptomatic for more than one month (35). They concluded that persons with a visible impairment reported higher levels of activity limitations and participation restrictions compared to persons without a visible impairment.

The possibility may be there that the identified differences in mean P-scale score can be partly explained by improper translation procedures. However, the P-scale was simultaneously developed in Nepal, Brazil and in four languages in India, using a lengthy and extensive validation process (12). To facilitate the process of further translation of the scale into additional languages, an extensive user manual was developed, including fairly detailed translation instructions. These cover the initial meaning and key words of the items and a recommended translation procedure. Therefore, improper translation seems an unlikely cause for variation in the scale scores.

The results from the analyses of the multi-country database suggested the best model fit for a two-factor model. The first factor, named 'work-related participation' relates to the major life area 'work and employment' and represents three items related to acquiring work, performance and economic self-sufficiency (1;12). The second factor, labelled 'general participation', relates to the remaining domains of participation such as community, social and civic life, interpersonal interactions and relationships, domestic life, mobility and communication (1;12). Due to the item reduction process, the participation domains of learning and applying knowledge and self-care are no longer covered (1). For this reason, the abbreviated version will be less useful to compile a complete profile of participation restriction. An important advantage of the item reduction may be a reduced administration time of the P-scale, imposing less burden on the respondent. As a result, the short version is particularly suitable for use in surveys that use a toolkit of measurements, or in other situations where time is short in supply, to provide a quantification of the level of participation restriction in the population under study.

The item reduction may raise a question regarding the content validity of the P-scale. However, we believe that the PSS still covers the most important domains of participation. The explained variance and the internal consistency are still very high, suggesting that the deleted items only hardly contributed to the participation measurement. In addition, no definitive consensus exists about the domains that are part of the participation construct (2). We realize that 'activity' and 'participation' are part of the same component in the ICF, but in several participation instruments, such as the Participation Objective Participation Subjective and the Participation Measure Post Acute Care, self-care is not included (36;37). Self-care can be argued to be more related to activity than participation, although it contributes to fulfilling life roles (2;36;38). 'Activity' is defined as "execution of a task or action by an individual"(1). One other item, "confidence to learn new things", can also be considered to relate more to activity than participation.

Compared to other measures of participation that are widely used, such as the Impact on Participation and Autonomy (IPA) (6) and the Assessment of Life Habits (LIFE-H) (8), the full version of the P-scale was already shorter. This advantage has now been further strengthened with the PSS (4;39). However, field testing needs to confirm the time reduction achieved with the PSS compared to the full form of the P-scale. Several studies have shown that the available scales measure participation restriction in an adequate manner (and some also activity limitation) and, in general, have good psychometric properties (39;40). The LIFE-H is developed in Canada and, to the best of our knowledge, only validated for use in high-income country settings (7;8;41;42). Therefore, the use of the LIFE-H in low and middle-income countries needs further investigation. The IPA focuses on the concept of autonomy, a very important concept in many high-income countries (6). However, this may limit its applicability, because autonomy is culture dependent. In many cultures, interdependence is valued most, rather than autonomy. People have not the choice or the ability to live the way they want or to fulfill their tasks in the way they want. The P-scale uses comparison with 'peers' as a benchmark for participation. Peers are people like the respondent, but without the condition that is investigation. In this way, differences between cultures and also between groups within cultures are more easily overcome. Nevertheless, a thorough translation and contextualisation process is needed to ensure local cultural validity. This will be the same for the short version of the P-scale.

The 13-item PSS is shorter than the original by deletion of five items. Four of these were deleted because they performed less well than the rest. These were 'Learning new things' (N18), 'Helping other people' (N16), 'Caring for oneself' (N9) and 'Using separate eating utensils' (N15). A possible explanation may be the fact that these did not include the distinctive (peer) comparison feature used in the majority of the P-scale items. The item 'Socially active'(N7) was removed because our own

field experiences with the P-scale as well as those from other researchers. These suggested that respondents were confused by the perceived overlap with the items 'Do you take part in religious festivals and rituals' (N5) and 'Do you take part in social and recreational activities' (N6) (personal communication, Beise, 2010 and Sermrittirong, 2011). Furthermore, respondents reported that the item was difficult to understand due to its abstract formulation ('being socially active'). However, we recognize the importance of the deleted item and for this reason decided to rephrase the item 'Do you take part in social and recreational activities' into 'Do you take part in social activities as much as your peers do? (e.g. sports, chat, meetings, religious or community activities)', adding the examples of the deleted item.

The study that used the latest version of the P-scale (v.6.0), which had replaced the item 'Using separate eating utensils' by 'Maintain or start a long-term relationship', was excluded from the analyses, because only one study was available that used this version and the sample size was too small to perform adequate factor analysis. At this moment, the evidence is insufficient to make an adequate decision about the inclusion of the new item in the PSS.

The question arises of the implication of the two factor structures for the use of the scale and the statistical analysis of both versions of the P-scale. For three reasons we believe that the overall P-score can still be regarded as a valid and reliable measure of the construct of participation. First, while the model fit statistics of the CFA suggest a two-factor model, strong correlation was found between the factors. This would support the existence of a 'high-order' general participation factor. Second, the factor loadings were also adequate for a unidimensional model of the P-scale (data not shown). Third, internal consistency for the unidimensional scale was found to be excellent in all databases. The variations in fit statistics found reflect both the wide variation in cultures and conditions represented in the databases and the complex nature of the underlying construct. Given these factors, the consistency found between the various databases regarding the various indices is more remarkable than the differences.

Taking these results into account, we suggest that the P-scale can be used either as one overall scale, or as two subscales of 'work-related' and 'general participation' that load on a strong general factor of 'participation'. The score calculation for the 13-item version of the P-scale will be the same, only the range of the score will change from 0-90 to 0-65. The division in several severity categories of participation restrictions, such as proposed in the initial development study, based on the 95<sup>th</sup> percentile of a control population and the distribution of the participation restriction scores in the affected populations, needs further research, before these categories can be revised. The same is

true for the possible application of the subscale 'work-related participation' as an indicator instrument. The results found during this study are promising for the validity of the PSS. Internal consistency was found to be good for the PSS and a very high correlation was found between the full P-scale and the PSS, supporting the construct validity of the PSS. However, adequate field testing is necessary to confirm these expectations. We invite researchers to use the PSS across study populations to further test its reliability, validity, reduction in administration time and usefulness.

An important strength of the study is the large sample size. As a consequence we were able to cross-validate the proposed structure resulting from the EFA by CFA with a random subset of the multi-country database. Due to the applied randomization, the groups were comparable for important variables such as gender, country and health condition that might affect the factor structures within the groups (18;19). An important limitation is the fact that only small study samples were included for certain subgroups, such as subjects from Bangladesh and Brazil, HIV/AIDS-affected respondents and respondents with skin diseases such as vitiligo or psoriasis. Secondly, in some of the studies included, no special efforts were made to test the validity of the P-scale in the particular study setting. The results from such studies should be interpreted with caution. However, the good internal consistency found across the study populations and the consistency of the factor models across the study samples plead in favour of the validity of the P-scale data used. Other culturally important and socio-demographic variables such as residency, religion, education and income were not available in the majority of the databases. They may have accounted for the differences in factor structures of the diverse study samples.

In conclusion, a 13-item version of the P-scale, the P-scale Short, was established and showed good results. Both versions of the P-scale showed optimal fit for a two-factor model comprising 'work-related participation' and 'general participation'. However, they can be applied as an unidimensional scale also. Additional field testing needs to confirm the validity of the PSS.

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**Appendix 1: Participation Scale Short**

No	Participation Scale	Not specified	Yes	Sometimes	No	Don't want to	No problem	Small	Medium	Large	SCORE
1	Do you have equal opportunity as your peers to find work?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
2	Do you work as hard as your peers do? (same hours, type of work etc)		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
3	Do you contribute to the household economically in a similar way to your peers?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
4	Do you make visits outside your village / neighbourhood as much as your peers do? (except for treatment) e.g. bazaars, markets		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
5	Do you take part in major festivals and rituals as your peers do? (e.g. weddings, funerals, religious festivals)		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
6	Do you take part in social activities as much as your peers do? (e.g. sports, chat, meetings, religious or community activities)		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
7	Do you have the same respect in the community as your peers?		0			0					

No	Participation Scale	Not specified	Yes	Sometimes	No	Don't want to	No problem	Small	Medium	Large	SCORE
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
8	Do you visit other people in the community as often as other people do?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it for you?						1	2	3	5	
9	Do you move around inside and outside the house and around the village / neighbourhood just as other people do?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
10	In your village / neighbourhood, do you visit public places as often as other people do? (e.g. schools, shops, offices, market and tea/coffee shops)		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
11	In your home, do you do household work?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
12	In family discussions, does your opinion count?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
13	Are you comfortable meeting new people?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	