

ORIGINAL ARTICLE

Measuring participation when combining subjective and objective variables: the development of the Ghent Participation Scale (GPS)

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ABSTRACT

BACKGROUND: The ICF reflects a bio-psycho-social paradigm and is increasingly used in outpatients rehabilitation settings. The component of participation is in the ICF the manifestation of a bio-psycho-social reasoning. Different participation measures have already been developed and were operationalized through objective and/or a limited set of subjective variables, but keeping them as separate concepts. There is still need for a generic participation instrument including both objective and all relevant subjective variables resulting in one participation score.

AIM: To develop a generic participation measure based on objective and subjective aspects and leading to one final score; the Ghent Participation Scale (GPS). Additionally it was the aim to explore whether the GPS has a good internal validity by means of factorial validity and homogeneity and whether the GPS is feasible and interpretable.

DESIGN: Cross-sectional study.

SETTING: Outpatient rehabilitation centre.

POPULATION: One hundred thirty former rehabilitation outpatients with various conditions.

METHODS: Item derivation for the GPS was based on qualitative research. The participants administered the GPS in the third week after discharge from the Ghent University Hospital. An exploratory factor analysis was performed to determine underlying dimensions. Statistical coherence was expressed in both item-total correlations and in Cronbach's α coefficient.

RESULTS: An exploratory factor analysis showed 3 underlying dimensions within the GPS: 1) performing activities according to preferred choices and wishes; 2) social appreciation and acceptance by performing activities; and 3) the need to delegate activities explaining 55.8% of the total variance. The results show a good to strong homogeneity (item-total ranged from 0.58 to 0.80) and a strong internal consistency (Cronbach's α ranged from 0.76-0.92).

CONCLUSIONS: The results of this preliminary validation study suggest that the GPS appears to be a valid measure to rate participation.

CLINICAL REHABILITATION IMPACT: Further research and more and more powerful psychometric models such as Rasch Analysis or Item Response models are needed to establish a psychometrically sound instrument.

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A paradigm-shift over the past decades from a bio-medical towards a more bio-psycho-social conception of disability has led to a change in contemporary rehabilitation.¹⁻⁴ Under strong recommendation and guidance from the World Health Organization (WHO), by means of the International Classification of

Functioning Disability and Health (ICF),⁵ rehabilitation medicine nowadays strives to enable people to perform daily activities and resume participation in important life roles after being affected by injury or disease.⁶ The concept of participation, in the ICF defined as “*involvement in a life situation*”,⁵ is considered to be the embodiment of this paradigm-shift and comprises of 9 domains: 1) learning and applying knowledge; 2) general tasks and demands; 3) communication; 4) mobility; 5) self-care; 6) domestic life; 7) interpersonal interactions and relationships; 8) major life areas; and 9) community, social and civic life.⁵ Meanwhile, the concept is widely used in rehabilitation and different instruments have been developed to rate individuals level of participation. However, the way the instruments have been operationalized differ. Some instruments have operationalized participation as objective and normative variables such as frequency, duration and limitations of activities⁷ (the Keel Assessment of Participation [KAP],⁸ the Measure of Home and Community Participation [PAR-PRO],⁹ the Participation Scale [P-scale]¹⁰ and the ICF measure of Participation and Activities screener [IMPACT-s]¹¹). Other instrument operationalized participation as a combination of objective and subjective variables and include a set of variables to rate the perceived satisfaction in each performed activity (The Participation Objective, Participation Subjective [POPS],⁷ the Participation Measure for Post-Acute Care [PM-PAC]¹² and the Utrecht Participation Scale [USER-participation]¹³) or include a set of variables to rate the choice and control in performing activities (the Impact on Participation and Autonomy Questionnaire [IPA]^{14, 15} and the Participation Survey/Mobility [PARTS/M]¹⁶).

What is useful to know and what is missing?

Despite the widely used concept of participation in rehabilitation and the existence of different instruments, different authors believe it to be poorly operationalized.¹⁷⁻¹⁹ Research shows crucial subjective components in experiencing participation. Unfortunately, these determinants are not used to operationalize participation: meaningful engagement, being part of, having responsibilities, having impact on others,¹⁷ exerting influence, doing things for others, belonging,²⁰ making challenges, asking and accepting help, dealing with others²¹ and being in hands of others.²² The “missing” insider values of participation is a first issue in the operationalization of participation, questions the content validity

of the existing instruments and it impedes practitioners to rate the individuals’ level of participation in a valid way.^{11, 18, 23, 24} A second issue in the operationalization of participation is that there is no consensus on how to differentiate between activity and participation and consequently there is also no consensus on which domains of the ICF should be covered when measuring participation. Besides the IMPACT-S,¹¹ none of the measures cover all nine domains. A review showed that all the above described measures cover domains 6 to 9 (KAP, PAR-PRO, PM-PAC, POPS, PARTS/M, P-Scale), but they differ in the coverage of the other domains;²⁵ The KAP, the PAR-PRO and the POPS cover additionally domain 4; the PM-PAC and the P-scale cover additionally domains 1,3,4 and 5 and the PARTS/M covers additionally 4 and 5. The discussion as described above on how to operationalize participation impedes research and a clear definition with accompanying determinants for participation is favorable. Qualitative research with regard to conceptualizing and theorizing the concept of participation in individuals who have experienced a loss of participation led to a more comprehensible definition of the concept: “*participation is a complex and multidimensional construct that may be considered as a dyad between the individual’s social interactions and the specific activities they perform; it is not only to be quantified as an objective way of (limitations in) performing activities within a societal context or as frequencies of performed activities, but it is also to be operationalized as an internal process of negotiation that seemed to be based upon balancing subjective personal and societal values*”.²⁶ This study revealed 15 subjective determinants for participation that were directly related to self-performed or delegated activities in the individuals’ societal context. These determinants are published elsewhere and show at the same time that it is not the activity itself that is of primary interest, but rather the persons’ own choice, his autonomy, the relation with his identity and all other relevant subjective values that is of primary interest in experiencing participation.²⁶

In order to enhance practitioners’ effectiveness in using participation as an important concept and measure in rehabilitation this study aimed to develop a participation measure focusing on the above described conceptualization and definition, including both the objective and subjective aspects, and covering all domains of the ICF; the Ghent Participation Scale (GPS). The objective

of this first study was to report on the 1) development; face and content validity; and 2) the psychometric properties in terms of factorial validity, homogeneity, and the feasibility of the developed scale.

Materials and methods

Development of the scale, item derivation, face and content validity

Item derivation for the GPS was based on qualitative research as described in the introduction.²⁶ The items were compared to existing knowledge from similar research in people with disabilities in general,¹⁷ in people with an acquired brain injury,²⁰ in elderly people²² and in people with chronic pain.²⁷ Finally, whether these items appeared to be measuring true variables of participation was reviewed by experts from various fields: occupational therapy, rehabilitation medicine, sociology, social sciences, consumers of rehabilitation treatment with varying disabilities and healthy individuals.

From survey tot scale

The items were rephrased into statements and combined in a digital survey with a reference period of 1 week. Firstly, the participants were asked to report their activities they performed and delegated during this last week using the detailed ICF list of activities.⁵ In a second phase the participants were asked to prioritize the 5 most important self-performed activities and the 5 most important delegated activities. This process of prioritizing was based on similar research in rating activities.²⁸ Based on these 10 prioritized activities the participants were asked to assess the different statements by means of a Likert Scale ranging from totally disagree (1) to totally agree (5). A sample item for the self-performed activities is: "it was completely my choice to engage in this activity". A sample item for the delegated activities is "I experienced more control by asking someone else to do this activity for me" (see Appendix A for all statements). Which domains of the ICF are covered was consequently different for every respondent and depended upon the reported prioritized activities. Demographic questions (N.=12) and 4 normative questions that were already proven in other research to be important issues in the operationalization of participation^{7, 9, 13, 23} were added to the survey: 1) the number of activities per-

formed; 2) the time spent in activities; 3) the number of delegated activities; and 4) the number of delegated activities that the person wanted to perform themselves.

Study population

One hundred thirty individuals with various health related problems from an outpatient rehabilitation centre were asked to participate in the study and to fill out the digital survey. Individuals who did not understand the Flemish language and individuals with a cognitive impairment that could possibly hinder filling out the digital questionnaire were excluded. Individuals were invited for the study at the moment they were discharged from the hospital and started a multidisciplinary outpatient rehabilitation program. The questionnaire was completed in the rehabilitation centre during a follow-up meeting with a physician or another health care professional (at least two weeks after being discharged, because of the 1 week reference period). A trained researcher was present, who was informed of individuals' comments regarding the items of the survey. Individuals who didn't administer the questionnaire entirely were kindly asked to continue until all questions were filled. The trained researchers were asked to report on the initial missing values and to ask for the reason. The study was approved by the Ethics committee of Ghent University Hospital and all participants had given their informed consent.

Psychometric properties in terms of factorial validity, homogeneity, feasibility and interpretability

FACTORIAL VALIDITY

Exploratory factor analysis was conducted on the ordinal data to empirically derive the factor structure of the scale and to identify possibly underlying dimensions. Maximum likelihood was used as the extraction method and in order to maximize factor simplicity oblique rotation (promin) was used as a rotation method.²⁹ To check whether the data was appropriate to conduct the exploratory factor analysis, the Kaiser-Meyer-Olkin measure of sampling adequacy was performed and was beforehand defined to be greater than 0.70.³⁰ Additionally, the Bartlett's test of sphericity was performed and was beforehand defined to be significant ($P < 0.01$) to be sure that there are correlations in

the data set that are appropriate for factor analysis.³⁰ Due to a relatively small sample of 130 participants it was not known whether the sample size was adequate to yield distinct and reliable factors. Different authors argue that sample sizes can be relatively small (between 100 and 200) when communalities after extraction are greater than 0.60.^{31, 32} Therefore, the communalities after extraction were calculated and were used to clarify whether the sample size was acceptable.

HOMOGENEITY

The statistical coherence between the items was expressed in Cronbach's Alpha coefficient. The homogeneity is considered to be good if the Cronbach's Alpha ranges between 0.70 and 0.95.³³ Cronbach's Alpha was calculated for the three subscales. Items that did not contribute to the internal consistency or homogeneity (item-total correlations under 0.4) were considered to be unreliable and were excluded from the final measure.

FEASIBILITY

The feasibility of the GPS was assessed by recording the number of missing values and the time needed to complete the questionnaire. In cases when respondents left fields blank or wanted to stop before the last question, they were friendly asked to continue by a trained researcher who was present during the administration.

SCORING AND INTERPRETABILITY

For every statement 5 scores were given by the respondent by means of a Likert scale; 1 for each prioritized activity. These ordinal data were, based on similar research in participation measures^{11, 13, 34} and other health-related measures,^{35, 36} recalculated into mean scores to get one single score for each statement. A total score was calculated by summarizing the mean scores of all the statements for both the performed and the delegated activities, divided by the number of items. Consequently an overall score was given from 1 to 5. This total-score was labeled as the Purely Subjective Participation Score (PSPS). Rather, because of the conceptualization of participation as a multidimensional concept combining subjective and objective variables²³ it was hypothesized that there is a relation between this PSPS

and the above described objective variables defined as: 1) the number of activities performed; 2) the time spent in activities; 3) the number of delegated activities; and 4) the number of delegated activities that the person wanted to perform themselves. Therefore, an index was proposed depending on correlations between these objective items and the PSPS. Thus, a weighted score composing objective and subjective variables was calculated for every participant (PSPS x index of objective index) and is based on Wilde and colleagues in which the subjective reality is multiplied by an index indicating the objective reality.³⁷ To check whether the weighted score was a valid and reliable indication of the individuals level of participation a transition index based on Deyo and Inui³⁸ was used as a reference; it was hypothesized that totally being prepared to be discharged resulted in a higher level of participation. Therefore, the participants were asked to rate their preparedness to go home; ranging from (1) completely ready to be discharged to (5) not at all ready to be discharged. The final GPS score is a weighted score multiplied by 20 to get an indication of participation in terms of a percentage. At this time the survey was considered to be a scale. A higher percentage indicated a higher perceived participation level and a lower percentage indicated a lower perceived participation level. To be able to interpret the result of every individual, an overview of the scores and the alphanumeric ICF codes denoting the prioritized activities is proposed (See Appendix C).

Statistical analysis

The exploratory factor analysis was conducted using Factor.³⁹ All other statistics were administered with SPSS 22,⁴⁰ the level of significance was predefined on 0.01.

Results

Study population

The population was heterogeneous regarding the diagnosis. We included 59 men and 71 women in the sample (N.=130). The mean age of the participants was 52,3. At the time of inclusion only 6,7% (N.=9) of them reported to be totally prepared for discharge and to live independently, 93.3% reported to be prepared but feeling slightly insecure (23.5%, N.=30), moderately in-

TABLE I.—*Characteristics of the participants (N.=130).*

Age: mean (SD)	52.3 (13.9)
Gender M/W	59/71
Diagnosis n (%)	
Stroke	29 (22.3)
Spinal cord injury	11 (8.4)
Polytrauma	27 (20.8)
Parkinson	21 (16.2)
Multiple sclerosis	20 (15.3)
Rheumatic disorder	13 (10)
Neuromuscular disorder	9 (7)
Highest level of education N. (%)	
General Secondary education (12 to 18 years)	8 (6.2)
Technical and vocational secondary education (12 to 18 years)	62 (47.7)
University College (18 plus)	32 (24.6)
University (18 plus)	28 (21.5)
Readiness to be discharged and go home N. (%)*	
Completely ready to be discharged	9 (6.7)
Ready to be discharged. but feeling slightly insecure	30 (23.5)
Ready to be discharged. but feelings moderately insecure	48 (38.7)
Ready to be discharged. but feeling severely insecure	39 (31.1)
Not at all ready to be discharged	0 (0)

*4 missing.

secure (38.7%, N.=48) or severely insecure (31.1%, N.=39) about their discharge. None of them reported to be totally unprepared. All the persons lived before and after admission at home, 117 with a partner and 13 without a partner. All other characteristics of the study population are presented in Table I. The total amount of self-performed activities for all respondents together was 962, with a mean amount of 7.4 (range from 5 to 21), and for the delegated activities 728 with a mean amount of 5.6 (range from 5 to 9). There were 1300 prioritized activities (650 self-performed and 650 delegated). Because the detailed ICF list of activities, including the detailed subcategories, was used to prioritize the activities, the alphanumeric system (including a letter and a numeric code) was used to denote the different activities and were automatically categorized into the 9 domains of the ICF. An overview of which domains of the ICF are covered is given in Table II.

Items in the scale

The rephrasing of the subjective determinants resulted in 11 statements for the self-performed activities and 6 statements for the delegated activities (Table III). These statements were listed in a survey and were rated by means of a Likert scale ranging from 1 to 5.

TABLE II.—*Amount of self-performed/delegated activities and the coverage of the ICF domains.*

	Total amount (N.=130)	Mean amount per respondent	Range
Self-performed activities	963	7.4	(5-21)
Delegated activities	728	5.6	(5-12)
Domains of the ICF covered for the prioritized activities N. (%)			
1. Learning and applying knowledge			152 (11.7)
2. General tasks and demands			42 (3.2)
3. Communication			125 (9.6)
4. Mobility			98 (7.5)
5. Self-care			203 (15.6)
6. Domestic life			197 (15.2)
7. Interpersonal interactions and relationships			76 (5.8)
8. Major life areas			212 (16.3)
9. Community and civic life			195 (15)

Factorial validity

The Kaiser-Meyer-Olkin measure of adequacy was 0.85, and Bartlett's test of sphericity was statistically significant ($\chi^2=939.5$, $df=120$, $P<0.01$), which meant that the data were appropriate to conduct an exploratory factor analysis. Because communalities after extraction were between 0.61 and 0.74 our sample size of 130 could be considered adequate. The factor analysis was performed multiple times with a restricted number of factors (2, 3, 4 and 5 factors) and the factor structures were compared to each other. The factor analysis with a 3 factor solution was chosen to achieve the ideal model fit. The first factor, "activities according to preferred choices and wishes" had 5 items and accounted for 28.42% of the total variance. The second factor, "activities leading to social appreciation and acceptance" had 6 items and accounted for 24.24% of the total variance and finally the third factor, "delegated activities", had 6 items and accounted for 19.54% of the total variance. That means that the dimension of the self-performed activities could be divided in two separate factors: 1) social appreciation and acceptance; and 2) preferred choice and wishes. With this factor solution 72.2% of the total variance could be explained (Table IV).

Homogeneity

The analysis showed that the reliability of the first subscale of the activities according to preferred choices and wishes could be improved by removing 1 item and that the second subscale of activities leading to appre-

TABLE III.—*Subjective determinants of participation and the corresponding statements for the survey study.*

Determinants for participation ²⁶	Statements in the survey for the self- performed activities	Mean* (SD)	Statements in the survey for the delegated activities	Mean* (SD)
1 The possibility to choose activities oneself	1SPA It was completely my choice to engage in this activity	4.7 (0.47)		
2 The possibility to perform activities as one wishes	2SPA I performed this activity (or I was part of it) completely as I wished	4.6 (0.56)		
3 The possibility to delegate activities to others			1DA It was completely my choice to let someone else perform this activity	3.9 (0.97)
4 Experiencing that performed activities are consistent with previous experiences	3SPA In history, I found this activity equally important**	4.2 (0.71)		
5 Experiencing that performed activities are consistent with one's own identity	4SPA During this activity I was completely able to be myself	4.4 (0.64)		
6 The opportunity to work on personal growth and thus experiencing a personal challenge	5SPA This activity was completely self-fulfilling	3.99 (0.82)		
7 Experiencing trust in important others by delegating activities	/		2DA I completely trusted the person(s) who performed this activity for me	4.4 (0.64)
8 Experiencing that activities are spontaneously and unconditionally taken over by others	/		3DA I felt that the others loved to perform this activity for me	3.9 (0.78)
9 Experiencing a sense of reassurance by delegating activities	/		4DA Because others performed this activity, I didn't worry about it anymore	4.02 (0.94)
10 Experiencing security by performing or delegating activities	6SPA During this activity, I felt very safe	4.02 (0.76)	5DA I felt more safe by asking someone else to do this activity for me	3.5 (1.08)
11 Experiencing control by performing or delegating activities	7SPA During this activity, I experienced a feeling of complete control	4.13 (0.74)	6DA I experienced more control by asking someone else to do this activity for me	3.38 (1.14)
12 Experiencing being validated by performing activities	8SPA During this activity, I felt a strong appreciation	3.91 (0.80)		
13 Experiencing being important by performing activities	9SPA During this activity, it felt as if I am an important person	3.5 (0.90)		
14 Experiencing an appeal to one's capacities	10SPA I have performed this activity because they have asked me to do it**	2.29 (1.09)		
15 The possibility to share common ideas and experiencing equal identities	11SPA During this activity, I had a strong feeling to belong there (being part of)	3.73(0.96)		

SPA: questions from the subscale of self-performed activities; DA: questions from the subscale of delegated activities.
 *Mean score on the Likert scale; 1 I totally disagree, 2: I agree, 3 I doubt, 4 I agree, 5 I totally agree; **deleted statements in the final GPS because (a) the items did not load in the factor analysis and (b) because of a weak item-total correlation (<0.30).

ciation and social acceptance also could be improved by removing 1 item (See Table IV, indicated with **). Removing these items resulted in an increase of Cronbach's α of 0.152: from 0.677 to 0.829 for the subscales of the self-performed activities. The third subscale of the delegated activities showed an acceptable Cronbach's α of 0.786. The item-total correlation after re-

duction of the items ranged between 0.574 to 0.801 and is considered strong (Table V).

Feasibility

The percentage of missing values per item ranged from 0% to 4%. The missing values were all in the sec-

TABLE IV.—Exploratory factor analysis: rotated loading matrix* (N.=130).

	Social appreciation and acceptance	Preferred choice and wishes	Delegation of activities
	19.34%	18.77%	17.52%
It was completely my choice to engage in this activity.	-	0.852	-
I performed this activity (or I was part of it) completely as I wished	-	0.887	-
In history, I found this activity equally important**	-	-	-
During this activity I was completely able to be myself	-	0.683	-
This activity was completely self-fulfilling	0.459	0.658	-
During this activity, I experienced a feeling of complete control	-	0.397	-
During this activity, I felt very safe	0.443	0.343	-
During this activity, I felt a strong appreciation	0.705	-	-
During this activity, it felt as if I was an important person	0.915	-	-
I have performed this activity because they have asked me to do it**	-	-	-
During this activity, I had a strong feeling to belong there (being part of the group)	0.751	-	-
It was completely my choice to let someone else perform this activity	-	-	0.852
I completely trusted the person(s) who performed this activity for me	-	-	0.455
Because others performed this activity, I didn't worry about it anymore	-	-	0.510
I felt that the others loved to perform this activity for me	-	-	0.438
I felt more safe by asking someone else to do this activity for me	-	-	0.966
I experienced more control by asking someone else to do this activity for me	-	-	0.751

*Scores beneath absolute 0.300 omitted to increase the interpretability; **these items did not load on one of the three factors.

tion of the delegated activities at the end of the survey. The reason why participants stopped answering the questions was because the participants found that it took too long to administer the survey. All participants

TABLE V.—Homogeneity as indicated by Cronbach's α and item-total correlation before and after reduction of the items.

	Item-total correlation	Cronbach's α before reduction	Cronbach's α after reduction
Self-performed activities		0.677	0.829
Self-performed activities: activities according to preferred choices and wishes		0.745	0.814
It was completely my choice to engage in this activity.	0.776		
I performed this activity (or I was part of it) completely as I wished	0.711		
In history, I found this activity equally important**	0.206		
During this activity I was completely able to be myself	0.766		
This activity was completely self-fulfilling	0.782		
During this activity, I experienced a feeling of complete control	0.776		
Self-performed activities: activities leading to appreciation and social acceptance		0.685	0.765
During this activity, I felt very safe	0.768		
During this activity, I felt a strong appreciation	0.797		
During this activity, it felt as if I am an important person	0.801		
I have performed this activity because they have asked me to do it**	0.360		
During this activity, I had a strong feeling to belong there (being part of)	0.733		
Delegated activities			0.786
It was completely my choice to let someone else perform this activity	0.735		
I completely trusted the person(s) who performed this activity for me	0.574		
Because others performed this activity, I didn't worry about it anymore	0.698		
I felt that the others loved to perform this activity for me	0.781		
I felt more safe by asking someone else to do this activity for me	0.781		
I experienced more control by asking someone else to do this activity for me	0.751		

**deleted statements in the final GPS because of a weak item-total correlation (<0.30).

TABLE VI.—Scores on the GPS and the underlying subscales (N.=130).

	Mean (SD)		Range (min – max)		% Floor		%Ceiling		Median (IQR)		Skewness	
	Before weighing	After weighing	Before weighing	After weighing	Before weighing	After weighing	Before weighing	After weighing	Before weighing	After weighing	Before weighing	After weighing
GPS total score*	4.02 (0.48)	2.60 (0.86)	2.43 (2.57-5)	3.82 (1.1-4.92)	0	0	3.1	0	4 (0.61)	2.66 (1.40)	-0.02	0.23
Self-performed activities*	4.11 (0.52)	2.73 (0.81)	2.50 (2.5-5)	3.98 (1.02-5)	0	0	6.9	0.8	4.11 (0.62)	3.01 (1.41)	-0.34	0.07
Social appreciation and acceptance*	3.78 (0.66)	2.53 (0.86)	3.05 (1.95-5)	4.23 (0.78-5)	0	0	7.7	0.8	3.85 (0.81)	2.7 (1.40)	-0.61	0.20
Preferred choice and wishes*	4.4 (0.50)	2.9 (0.81)	2.30 (2.7-5)	3.8 (1.2-5)	0	0	13.8	1.6	4.5 (0.75)	3.81 (1.47)	-0.98	-0.76
Delegated activities*	3.9 (0.62)	2.4 (1.21)	2.60 (2.4-5.0)	4.36 (0.64-5)	0	0	6.9	0.6	3.8 (0.87)	1.95 (2.10)	0.13	0.70

*All scores were from 0 to 5; higher scores indicate better perceived participation.

TABLE VII.—Correlation between the purely subjective participation score and the preparedness to be discharged.

	GPS score before correction: PSPS		GPS score after Correction	
	Pearson's coefficient	P-value	Pearson's coefficient	P-value
Preparedness to be discharged	-0.251	0.137	-0.597	<0.001

TABLE VIII.—Objective factors of participation and their correlation with the purely subjective participation score (PSPS).

	Mean (Range)	Pearson Correlation with the PSPS	P-value, significance
The total number of activities performed	7.4 (5-21)	0.106	0.244
The amount of time spent in the activities**	2.1 (1-4)	0.896	<0.001*
The total number of activities delegated	5.6 (5-12)	-0.071	0.377
The number of delegated activities that the person wanted to perform himself	2.8 (0-5)	-0.678	<0.001*

*Only the five most important activities were considered here; **mean amount of time spent in the 5 most important activities ranging from: 1=maximum 1 hour, 2=more than 1 hour and less than half a day, 3=half a day, 4=a full day and 5=more than 1 day.

could be encouraged by the trained researcher to continue. Eventually all participants administered the entire survey and analysis was performed without missing values. The average administration time of the entire survey (including the demographic questions) was 32 minutes (SD 12 minutes), without the demographic questions, the average administration time was 19 minutes (SD 8 minutes).

Scoring and interpretability

The PSPS was calculated and resulted in a high mean score of 4.02 (SD 0.48). The score distribution of the total score and the different subscales are displayed in Table VI in the column “before weighing”. The distribution of the total score and the scores on the different subscales seemed reasonable based on the skewness figures and the small difference between the mean scores

and the median score. There was however no significant correlation ($r=-0.251$, $P=0.137$) between the PSPS and the reference standard “preparedness to be discharged” (Table VII). The absence of this significant correlation, the high mean score and ceiling effects (in particular on the subscale of preferred choice and wishes 13.8%) was an extra trigger to weight the PSPS by using indices based on statistical correlations between the PSPS and the objective variables. A Pearson correlation was run to determine these relationships and is shown in Table VIII. There was a very strong, positive correlation between the PSPS and the amount of time spent in the activities ($r=0.896$, $P<0.001$) and there was a good, negative correlation between the PSPS and the number of delegated activities the individual wanted to perform himself ($r=-0.678$, $P<0.001$). There were no significant correlations between the PSPS and total number of activities performed ($r=0.106$, $P=0.244$) and the total

number of activities delegated ($r=-0.071$, $P=0.377$). It means in one hand that a higher amount of time spent in the activities has a positive impact on the perceived level of participation and on the other hand that the number of delegated activities that the individual wanted to perform himself has a negative impact on the perceived level of participation. For that reason, the score for the self-performed activities was weighted by an index for “the mean amount of time spent in the five most important activities”. The Time-Activity Index (TA): mean amount less than 1 hour: index 0.25, mean amount more than one hour but less than half a day: index 0.50, mean amount half a day: index 0.75, mean amount 1 day or more: index 1. The score for the delegated activities was weighted by an index for the number of “the five most important activities the individual wanted to perform himself”. The Performance-Delegation Index (PD): 4 or 5 activities: index 0.25, 3 activities: index 0.50, 2 activities: index 0.75 and 1 or 0 activities: index 1. The scores for the subscales were corrected by multiplying the score of the self-performed and the delegated activities with their corresponding index. This weighted score resulted in a mean score of 2.60 (SD.86); The distribution is also displayed in table 6 in the column “after weighing”. These weighted scores remained symmetric as can be seen in the skewness figures and the ceiling effects disappeared. A fair negative correlation ($r=-0.597$, $P<0.001$) between the “preparedness to be discharged” and the weighted participation score endorsed the weighing index (Table VIII). Finally, to get an indication in percentage of the perceived participation score the corrected score was multiplied by 20. To interpret the results, an overview for each individual of the prioritized activities by means of the alphanumeric system of the ICF coding system is given together with the final score and the subscores for the different subscales (Appendix C).

Discussion

The ICF reflects a bio-psycho-social paradigm and is increasingly used in outpatients rehabilitation settings. The component of participation in the ICF is the manifestation of a bio-psycho-social reasoning. Different participation measures have already been developed and were operationalized through objective variables and/or a limited set of subjective variables, but keeping them

as separate concepts. Therefore, a new measurement instrument was developed: the GPS. It is a unique instrument that includes 15 subjective components which are related to self-performed and delegated activities that are relevant and important for the individual. The instrument also includes 2 objective components: 1) the frequency, operationalized through the actual time spent in the activities; and 2) the limitations in performing activities, operationalized through the need to delegate the activities. The results of this study on internal validity are promising and are generally good to strong. Depending on the prioritized activities, this instrument covers all the domains of the ICF. Notwithstanding these promising results, this work needs to be considered as a preliminary validation study. Specifically because of these prioritized activities, every respondent started off with other activities, assuming that administering the different statements resulted in administering exactly the same items. The assumption that the item difficulties, when starting from different activities are, within an acceptable error, equal to each other cannot be tested using the a traditional psychometric approach (factorial validity and homogeneity). To test the assumption that the item difficulty is stable cross the levels of the given factor — in this case the ICF activities chosen by the respondent - more advanced methods are needed. For instance Rasch measurement or Item Response Theory are conceptually and theoretically better approaches for evaluating rating scales.⁴¹ Further research is therefore necessary to validate the GPS.

The development

The instrument has been developed based on the lived experience from individuals who have conquered a process of rehabilitation and are consequently experiencing a period of presumed less participation. Considering these experiences, it shed a new light on the operationalization of participation as a concept and formed the basis for developing this measure. The challenge to include these experiences in the instrument resulted in a high content of face validity. Checking these subjective aspect or components with rehabilitation professionals increased the credibility. This measure was also developed because it was argued that the existing measurement instruments mainly rely upon normative values to measure participation,³⁰ meaning that the in-

siders' perspective was often not or insufficiently considered.^{15, 17-23} This makes the GPS unique and fills the gap as described earlier in the literature but opens at the same time a new question. Some of the subjective determinants raised by these individuals are closely linked to the personal factors (character style, behavior patterns, psychological assets, etc.) as described within the ICF. This clearly shows the relevance of these personal factors influencing human functioning and shows the interdependency between personal factors and participation. But it shows at the same time the lack of possibilities in coding the personal factors. Furthermore, we specifically intended not to focus on the experienced problems when asking to rate their level of participation. Restrictions in activities were not specifically asked for in the GPS, but the individuals were asked to indicate which activities they had delegated and whether they had wanted to perform the activity themselves. This may be considered as an indicator of being restricted in performing these activities. We deliberately chose to focus on the positive aspects of human functioning and to ask for "what did you delegate to someone else", instead of "what was no longer possible for you", mainly because it was the goal of this measure to focus on the patients' capacities and ability to perform and their autonomy to delegate it themselves. This was also one of the main issues when the WHO rewrote the International Classification of Impairment, Disability and Handicap (ICIDH) [49] into the ICF.

Factorial validity

The exploratory factor analysis showed 3 factors explaining the variance. At the same time it revealed that it was possible to split the subscale of self-performed activities into "Activities according to preferred choices and wishes" and "Activities leading to appreciation and social acceptance". This additional distinction is important, specifically because it shows that the concept of participation is to be operationalized as a complex concept of involvement and not solely as separate aspects. Together with the subscale of "the delegated activities" it shows that the GPS combines the different ways in which participation has been partially operationalized before in other measures: for instance: 1) choice and control: the impact on participation and autonomy (IPA),¹⁵ the Participation Scale (P-Scale),¹⁰ the

Keele Assessment of participation (KAP);⁸ 2) satisfaction and importance: the participation survey/mobility (PARTS/M);¹⁶ 3) limitations: the participation measure for post-acute care (PM-PAC).¹² Other measures include more than one aspect, such as the Utrecht Scale for evaluation of rehabilitation — Participation User-participation¹³ and the Participation Objective, Participation Subjective (POPS)⁷ but they keep the different aspects separate. We intended to combine it into one score to increase the interpretability of the scale.

Sample size

With regard to the sample size of 130 participants, the guidelines by MacMallum *et al.*³¹ and Henson *et al.*³² were followed in which a small sample is accepted, but only when the communalities after extraction are above 0.60. From this perspective, the small sample-size was considered adequate because there were next to the fact that the communalities after extraction were above 0.60, the variables loaded strongly on each factor and only one variable was cross-loading.³¹ However, another rule-of-thumb in performing factor analysis is the subject to item ratio of 10:1.⁴³ That means that the minimum sample size for an analysis should be 10 cases for each variable to be estimated and this means the need for a much larger sample size. Consequently, the sample size is considered very small and further work in a larger population is still required.

The internal consistency

The internal consistency by means of the homogeneity of the three subscales was considered to be good to strong. However, the internal consistency of the subscale on delegated activities was lower than the internal consistency of the two subscales on self-performed activities. The reason for this finding is the lower item-total relationship for the item "I completely trusted the person(s) who performed this activity for me" and the item "because others performed this activity I didn't worry about it anymore". We considered removing these items but a member check with the participants and a discussion with the expert panel made us decide not to do it, because they considered these items to be key aspects of participation. Moreover, it did not result in a substantially higher Cronbach's α .

The feasibility

The feasibility with regard to the number of missing values was satisfactory, compared with the missing values of other instruments such as the IPA (range of missing values 0% to 3%)¹⁵ and good compared with the missing values of the USER-participation (missing values 1.3%).¹³ When comparing this with the missing values of commonly used health status measures such as the SF-36 (range of missing values from 1.1% to 5.4%)⁴² the feasibility is strong. The feasibility with regard to the administration time is rather weak. However the administration time will be improved because of the reduction of two items and the reduction of a number of demographic questions that were only asked for this survey-study.

Scoring and interpretability

In contradistinction to the existing participation measures, it was the specific goal not to measure subjective and objective variables as separate concepts, as it has been argued by different authors on the topic,^{7, 44} rather to focus on the subjective experiences of performing and delegating activities and relating them to the objective variables depending on a correlation with the subjective items. Somehow there was the expectation to see a positive correlation between the amount of activities performed during the past week and the perceived level of participation, but this was not the case. Previous research by other researchers described that there is a weak correlation between the objective and the subjective aspects of participation⁷ and even broader between the objective and subjective aspects of life satisfaction in general.⁴⁵ We concluded also that there was no correlation between the amount of activities and the subjective appraisals. However, our study showed that there is a positive correlation between the amount of time they spent in the activities and the subjective appraisals of them. Additionally, there was a negative correlation between the subjective appraisal of the delegated activities and the number of activities they wanted to perform themselves. These correlations and the strong Cronbach's α justified summarizing all items in the GPS to one score.³³ It makes the GPS in that way unique. Furthermore, depending on the prioritized ICF activities, the GPS covers all domains within the ICF [12]. This finding adds to the existing knowledge of how to differentiate between activities and participation. In annex three of the ICF⁶ 4 different op-

tions are proposed for differentiating between activities and participation: 1) designating some of the domains to activities and others to participation, allowing no overlap; 2) designating some of the domains to activities and others to participation, allowing partial overlap; 3) designating all broad categories of the domains as participation and all detailed categories as activities; and 4) designating all domains to activities or participation depending on how the user considers it as activity or as participation. The GPS and its rationale is most closely linked to option number 4; every activity can contribute to the experience of individuals to participate.

Limitations of the study and future research

As described above, this study must be considered as a preliminary validation. More powerful psychometric models such as Rasch Analysis and Item Response models are needed in future studies. But next to these limitations, also other shortcomings are apparent: firstly, since this measure was meant to be pathology-independent, there was no prior expectation about possible differences in participation between the different groups. Therefore, the information about the different groups is only meant to be exploratory and needs further research. Also, it is not known how a healthy population would score. Secondly, this study has been developed in the Flemish speaking part of Belgium and only Flemish speaking persons with a physical limitation and feeling more or less prepared to go home were included. Further research is necessary to establish further applicability in persons with other (*e.g.* more severe physical and cognitive limitations) and in persons from other countries and other cultures. Third, it is a known phenomenon in scale construction that respondents have the tendency to answer to the right of the scale, resulting in a skewed distribution of the scores both on the total and on the item level.⁴⁶ A weighting is enforced by means of the objective variables on the total level. This weighting can also be performed on the item level and should be checked in future research when examining the minimal important change of the GPS. An article is in preparation specifically on the interpretability of the GPS.

Conclusions

While a bio-psycho-social rehabilitation model encourages disability to be viewed as a bio-psycho-social

construct rather than a purely personal construct of behavioral, biological and genetic factors, the goal of many rehabilitation centers is not only to focus on the medical restorative approach of individuals, but also on the long-term consequences and the individual's level of participation. This approach is only possible when a valid and reliable measure of participation is available. It was the goal of this study to develop a multi-dimensional measurement-instrument that includes both subjective and objective factors in the realm of the individuals social and environmental context. The preliminary validation study resulted in the GPS with a strong internal consistency and possibilities to rate an individual's level of participation. This unique feature creates possibilities to enhance the ability for practitioners to evaluate effectiveness of their interventions also regarding participation.

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Appendix A – The Ghent Participation Scale

Subscale 1: Self-performed activities (SPA):

1. What are the five most important activities that you have performed during the last week? (A₁-A₅)
2. How many time did you spent in these activities (one answer for each activity: TA₁-TA₅):
Response options for question 2:
1 = maximum 1 hour,
2 = more than 1 hour and less than half a day,
3 = half a day,
4 = a full day and
5 = more than 1 day
3. Subscale 1a: Activities according to preferred choices and wishes
Give an appreciation from 1 to 5 for the following statements (one answer for each activity: S₁A₁-S₅A₅):
Response options for subscale 1a:
1: I totally disagree
2: I disagree
3: I doubt
4: Agree
5: Totally agree
S₁: it was completely my choice to engage in this activity.
S₂: I performed this activity (or I was part of it) completely as I wished.
S₃: during this activity I was completely able to be myself.
S₄: this activity was completely self-fulfilling.
S₅: during this activity, I experienced a feeling of complete control.
4. Subscale 1b: Activities leading to appreciation and social acceptance
Give an appreciation from 1 to 5 for the following statements (one answer for each activity: S₆A₁-S₉A₅):

- S₆: during this activity, I felt very safe.
S₇: during this activity, I felt a strong appreciation.
S₈: during this activity, it felt as if I was an important person.
S₉: during this activity, I had a strong feeling to belong there (being part of the group).
Response option for subscale 1b: idem 1a

Subscale 2: Delegated activities (DA)

5. What are the five most important activities that you have delegated during the last week (D₁-D₅)?
6. How many of these activities would you have rather performed yourself (PD₁-PD₅)?
7. Give an appreciation from 1 to 5 for the following statements (one answer for each activity: S₁₀D₁-S₁₅D₅):
S₁₀: it was completely my choice to let someone else perform this activity.
S₁₁: I completely trusted the person(s) who performed this activity for me.
S₁₂: I felt that the others loved to perform this activity for me.
S₁₃: because others performed this activity, I didn't worry about it anymore.
S₁₄: I felt more safe by asking someone else to do this activity for me.
S₁₅: I experienced more control by asking someone else to do this activity for me.
Response options for subscale 2: idem 1a and 1b

A: Activity – TA: Time spent in activity – S: Statement – D: delegated activity – PD: Activities rather performed self.

Appendix B – Indices and algorithms to calculate the final score

1.	The index and the underlying algorithm for ‘the mean amount of time spent in the five most important activities’ (TA)		
	Algorithm	Mean amount of time spent	TA
		Less than one hour	≤ 1
		One hour, less than half a day	>1 - ≤ 3
		Half a day, less than one day	> 3 - ≤ 4
		More than half a day	> 4
	$TA = \sum_{k=1}^5 \left(\frac{TA}{k} \right) / 5$		Index TA
			0.25
			0.50
			0.75
			1
2.	The index for ‘the number of activities the individual wanted to perform himself’ (PD)		
		Number of activities:	PD
			Index PD
		≥ 4	0.25
		3	0.50
		2	0.75
		< 2	1
3.	The algorithm to calculate the score for subscale 1 (SPA, self-performed activities)		
	$SPA = \sum_{s=1}^9 \sum_{a=1}^5 \left(\frac{SPA}{sa} \right) / 45 \times \text{index TA}$		
4.	The algorithm to calculate the score for subscale 2 (DA, delegated activities)		
	$DA = \sum_{s=10}^6 \sum_{d=1}^3 \left(\frac{DA}{sd} \right) / 30 \times \text{index PD}$		
5.	The algorithm to calculate the final participation score in percentage (GPS)		
	$GPS = (SPA + DA) / 2 \times 20$		

Appendix C – Interpretation of the results, example from 1 participant

Participant:	98
Gender:	Female
Diagnosis:	Multiple Sclerosis
Age:	37
Level of Education:	University College
Experienced level of Participation:	
Total GPS score:	63.07%
Score for the Self-performed activities:	65.47%
Activities according to preferred choices and wishes:	58.80%
Activities leading to appreciation and social acceptance	72.13%
Score for the Delegated activities	60.67%
Activities on which the participation score is calculated:	
Self-performed activities:	p7601 - Child-parent relationship p4751 - Driving Motorized Vehicles p9201 - Sports p8500 - Self-Employment p5702 - Maintaining one’s health
Delegated activities:	p5404 - Choosing appropriate clothing P6102 - Furnishing a place to live P2402 - Handling crisis p6201 - Gathering daily necessities p6402 - Cleaning living area
Coverage of the ICF domains:	2 - General tasks and demands 4 - Mobility 5 - Self-care 6 - Domestic Life 7 - Interpersonal interactions and relationships 8 - Major life areas 9 - Community, social and civic life