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RESEARCH PAPER

The Participation Scale: Measuring a key concept in public health

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Abstract

Purpose. To develop a scale to measure (social) participation for use in rehabilitation, stigma reduction and social integration programmes.

Method. A scale development study was carried out in Nepal, India and Brazil using standard methods. The instrument was to be based on the Participation domains of the International Classification of Functioning, Disability and Health (ICF), be cross-cultural in nature and assess client-perceived participation. Respondents rated their participation in comparison with a 'peer', defined as 'someone similar to the respondent in all respects except for the disease or disability'.

Results. An 18-item instrument was developed in seven languages. Cronbach's α was 0.92, intra-tester stability 0.83 and inter-tester reliability 0.80. Discrimination between controls and clients was good at a Participation Score threshold of 12. Responsiveness after a 'life change' was according to expectation.

Conclusions. The Participation Scale is reliable and valid to measure client-perceived participation in people affected by leprosy or disability. It is expected to be valid in other (stigmatised) conditions also, but this needs confirmation. The scale allows collection of participation data and impact assessment of interventions to improve social participation. Such data may be compared between clients, interventions and programmes. The scale is suitable for use in institutions, but also at the peripheral level.

Keywords: Disability, ICF, leprosy, participation, scales, stigma

Introduction

Many diseases and health conditions not only affect the body or mind, but also daily activities and key social areas, such as relationships and employment. This is particularly true of chronic stigmatised conditions like mental illness, leprosy, HIV/AIDS, epilepsy and various (other) forms of physical disability. The International Classification of Functioning, Disability and Health (ICF) classifies problems at the level of the body or mind as 'impairments', problems in the performance of

activities as 'activity limitations' and 'problems an individual may experience in involvement in life situations' as 'participation restrictions' [1]. The latter are often referred to as 'social exclusion' or 'socio-economic problems'. 'Disability' is used as the umbrella term for problems in any of these areas. In many instances, activity limitations and restrictions in (social) participation are more important to the affected person than the underlying health condition. Therefore, these are often the targets of interventions in the field of rehabilitation [2–4]. The ICF emphasises the important role of the environment,

including society, in the process of disablement. Especially stigma and discrimination are powerful forces in society that profoundly affect the lives of millions of people affected by stigmatised health conditions [5–10]. Stigma is not the only cause of participation restrictions, but can greatly aggravate the disabling effect of impairments, activity limitations or other environmental barriers to participation.

Data on social participation are needed for programme planning, monitoring and evaluation, and for assessing the impact of interventions aimed at reducing participation restrictions (e.g., rehabilitation interventions, counselling, social integration programmes, stigma reduction programmes, health education campaigns and legislation). At the individual level, knowledge about the severity of participation restrictions is needed to select clients for rehabilitation interventions and to monitor their progress over time. While it is generally acknowledged that participation restrictions are a very widespread phenomenon, epidemiological data are scarce. People living with HIV/AIDS report ‘widespread and severe discrimination’ in many countries [11]. In a survey of over 53,000 leprosy-affected people in India, 34% were considered to have participation restrictions to the extent they might need socio-economic rehabilitation [12]. In Bangladesh, 8% of 2364 people affected by leprosy were considered to have severe enough problems to need socio-economic rehabilitation [13]. Chen et al. [14] found participation restrictions among 46% of 4240 people affected by leprosy in Shandong Province, China. In a study in south India, 57% of 150 people with deformity due to leprosy had socio-economic problems [15]. Studying people with spinal cord injury, Noreau and Fougereyrolas [16] reported ‘significant disruptions’ in home maintenance, participation in recreational and physical activities, as well as in productive activities and the achievement of sexual relations. While these figures indicate that problems in the participation area are common, the assessments on which the estimates are based differed greatly in nature and extent to which all participation domains were covered.

The lack of information about social participation is partly due to the fact that participation is a relatively new construct, introduced during the revision process of the ICF [17]. The most closely related construct to ‘participation restriction’ is that of ‘handicap’, as defined in the former International Classification of Impairments, Disabilities and Handicaps [18]. Cardol et al. [3] reviewed instruments assessing the ICF concept of ‘handicap’. They concluded that ‘a generic person-perceived handicap questionnaire could not be identified’ [19,20]. Perenboom and Chorus [21] conducted a thorough review to evaluate to what extent instruments assess participation according to the conceptual framework of the ICF. They

concluded that the ‘two instruments closest to solely involve items on participation level are the Perceived Handicap Questionnaire (PHQ) and the London Handicap Scale (LHS)’. The PHQ measures perceived handicap across five of the six life domains that make up the construct [21,22]. The instrument contains one item per domain. The self-administered London Handicap Scale assesses the impact of chronic disease on all six handicap ‘dimensions’ (orientation, physical independence, mobility, occupation, social integration and economic self-sufficiency) [21,23,24]. The instrument is attractive because it is short (only six items). However, the authors state that the scale is not intended for assessment of individual subjects’ handicap, but is ‘meant for comparisons between groups of subjects’ [24]. The way questions and response levels are formulated assumes a particular frame of reference that may apply to affluent countries, but may be less valid in low and middle-income countries.

Walker et al. [25] examined the validity of the Craig Handicap Assessment Reporting Technique (CHART) for measuring participation in different disability groups in the United States and concluded, ‘CHART may be an appropriate measure of handicap for a range of physical or cognitive impairments’. The CHART exists in a 32-item Long Form and a 19-item Short Form. The items cover assistance needed, mobility, transportation, the way time is spent, relationships and financial resources. The scoring system is complicated, but the results have been shown to be valid in rehabilitation settings in the US and a number of other developed countries. Anandaraj [26] developed a scale to measure debilitation among people affected by leprosy, a concept closely related to participation restriction. While this scale covers several participation domains, it is not comprehensive enough to be called a participation scale. It also contained items that measured self-esteem, which is a relevant concept, but not part of the ICF participation component. To date, only the Impact on Participation and Autonomy Questionnaire (IPAQ) specifically measures participation as conceptualised in the framework of the ICF, [19,20]. The scale has 31 items covering six of the nine Participation domains of the ICF. In addition, eight items probe ‘problem experience’. More recently, the Assessment of Life Habits (LIFE-H) was developed, based on the conceptual framework of the Disability Creation Process, which is close to that of the ICF [27,28]. The LIFE-H exists in two formats, the General Short Form v.3.1 consists of 77 items covering 12 categories of activities of daily living and social participation, and the Long Form, consisting of 240 items [29]. The response scales assess level of accomplishment, level of assistance and level of satisfaction.

In 1999, a large rehabilitation field programme in Nepal identified the need for an instrument to evaluate the impact of rehabilitation interventions in rural conditions. The above instruments do not meet this need. Therefore, work was started to develop such an instrument (Anderson et al., in preparation). The preliminary results of the work done in Nepal were used as the basis for the development of the instrument presented here, the Participation Scale.

Methods

'Terms of reference'

It was decided the scale should adhere to the following terms of reference:

Be based on the Participation domains of the ICF. These nine domains are Learning and applying knowledge, General tasks and demands, Communication, Mobility, Self-care, Domestic life, Interpersonal interactions and relationships, Major life areas and Community, Social and Civic life.

Be cross-cultural nature. To facilitate cross-cultural and cross-border comparisons in participation, the scale was developed simultaneously in six languages

in three countries. The master scale was in English. The scale development built on extensive qualitative research by a team in Nepal. The Brazil and India teams conducted a round of qualitative research to see if any further items would need to be added (Phase I, see Table I). The resulting questionnaire was translated and field-tested in Nepal, Brazil and in four major language areas in India (Hindi, Bengali, Telugu and Tamil). The results were analysed and only items endorsed in all areas were retained.

Be client-perceived. A client perception perspective is important because people with similar health conditions may experience very different levels of participation restriction [30]. In addition, perceived restrictions would include those resulting from perceived stigma, which would not be obvious to an observer.

Be generic in nature. Because participation restriction is a widespread phenomenon experienced by people with a variety of conditions, it was decided to develop a generic scale. Therefore, any disease-specific items were eliminated.

Be suitable for non-professional interviewers. Professionals such as social workers, rehabilitation workers

Table I. Overview of the scale development steps used in the Participation Scale Development Programme.

Scale development steps

Phase I

1. Item collection through field observation, key informant interviews and focus group discussions
2. Item reduction, eliminating items addressing similar issues and those that cannot be assessed through an interview-based scale
3. Converting the items into questions
4. Translation of the questionnaire into the regional languages, followed by back-translation into English
5. Piloting of the questionnaire in each language region and adjustment of the wording of the questions and of the translation, where necessary

Phase II

6. Interviews to collect data for the item reduction analysis
7. Item reduction analysis (endorsement, item-to-total correlation, split-half reliability, Cronbach's alpha, factor analysis, criterion validity, association with age, sex, condition)
8. Discussion of the results in an international workshop, followed by selection of items for the draft scale
9. Checking of face validity and content validity of the draft scale

Phase III

10. Data collection for psychometric testing
11. Psychometric analysis
  - Inter-interviewer reliability (within 1 month)
  - Stability (intra-interviewer; 1–3 months)
  - Discrimination between clients and controls
  - Criterion validity
  - Content validity
  - Dynamicity (responsiveness to change (9–12 months))
12. Discussion of the results in an international workshop, followed by finalisation of the scale

Phase IV

13. Data collection for dynamicity
14. Beta-testing of the scale in institutions and departments that had not taken part in the scale development process
15. Dynamicity and scaling analysis. Determination of potential cutoffs for abnormal
16. Discussion of the results in an international workshop. Review of the Beta-testing feedback and dynamicity results. Decision on the cutoff for abnormal, the optimal weighting of the response scales and the setting of grading categories for severity of participation restrictions

or counsellors are few in number, particularly in low-income countries. Therefore, the scale was designed for use by non-specialist staff at the peripheral level.

Use the 'peer comparison' concept. To allow the scale to be used in a variety of settings, respondents were asked to compare themselves with a 'peer', defined as 'those who are similar to the respondent in all respects (socio-cultural, economic and demographic) except for the disease or disability'. For example, 'Do you get invited to social functions as often as your peers?'

The scale development process

The Participation Scale was developed using standard scale development procedures [31]. An overview of the methods used is given in Table I.

Subjects and sample size

Subjects were selected according to a standard selection grid used in each centre. The grid determined the distribution of cases according to age group, sex, condition (leprosy or other disability) and severity of impairment. Each centre was to aim to enrol 90 subjects. Thirty were re-interviewed to test inter-interviewer reliability, 30 to test intra-interviewer stability over a period of 1 month. The remaining 30 were interviewed by the expert and also had a Participation Scale interview. Fifteen of these were to be re-assessed after 9–12 months to evaluate the dynamicity of the scale. Of these, 10 were to be subjects expected to experience a major life change in this period (e.g., clients who were to receive major rehabilitation assistance) and five were to be controls. In addition, each centre interviewed 10 control subjects without leprosy, disability or other significant health condition.

External validity

Since no other participation assessment tool validated under the prevailing conditions was available, we decided to validate the results against the opinion of an expert—someone considered able to assess the severity of participation restrictions based on an interview. The experts rated the severity of participation restrictions on a 1–5 scale (1 = none, 5 = complete restriction). The scores of the draft scale were correlated against the expert scores. Similarly, the participation scores were correlated with the Eyes Hands Feet (EHF) score (subjects with leprosy only), a measure of extent of impairment. Third, subjects were asked to grade their own current situation ('how life is now?') on a 0–10 visual analogue scale. The results of this self-assessment were also correlated

with the participations scores. For all three comparisons, a significant positive correlation was considered to be support of the validity of the scale.

Statistical methods

Initial item reduction was based on endorsement, the percentage of people scoring positive on a given option in the response scale of an item in the questionnaire. Item-to-total correlation and criterion validity was examined using Spearman rank correlation. All remaining items were checked for association with gender, age, deformity and type of disability (leprosy versus other disability). Items with a particularly strong association with one variable were excluded, to avoid measuring a particular characteristic rather than participation restriction due to leprosy or disability.

After initial item reduction the remaining list of items was subjected to factor analysis to confirm the existence of a primary general factor and identify items not included in that factor. The internal consistency or reliability of the draft scales was checked with Cronbach's α . We aimed for a combination of items with an alpha coefficient of > 0.80 . Ability of the draft scale to discriminate was checked by comparing scores between clients (people affected by leprosy and/or disability) and controls. Items for which no statistically significant difference was found at the 10% level were excluded.

Inter- and intra-interviewer reliability was evaluated using Intra-Class Correlation coefficients (ICC), based on a two-way analysis of variation without replication [32]. ICCs may be interpreted as the proportion of agreement between two interviewers. ICCs were classified as 'excellent', 'good', etc., according to Altman's reliability classification [33]. Items with poor reliability were omitted from the scale. The scale was considered responsive to change if a statistically significant difference (at the 5% level) could be demonstrated between the initial scores and the results of the post-life-change assessment (paired t -test), if the minimum difference was at least 10 scale points and if the majority of the score changes went in the expected direction. Details of the scale development process and the analyses will be reported separately (Anderson et al., in preparation).

Ethical issues

The Participation Scale Development Programme was approved by the ethics committee of The Leprosy Mission India. Each interviewee gave verbal informed consent before enrolment into the study. No incentives were paid. Appropriate arrangements were made for referral of interviewee in case of severe distress due to the emotional nature of the interviews.

Results

The initial 166 items were reduced to around 30. The results of this analysis were discussed in depth at a workshop of all principal investigators and agreement was reached on a 22-item draft Participation Scale (P-scale). The coverage of ICF Participation domains is given in Table II. The Phase III field-testing results showed that validity, reliability and dynamicity of the final P-scale were very satisfactory (see Table III). The final scale was reduced to 18 items (see Annex). Arbitrary severity categories of participation restriction were chosen based on the distribution of scale scores in the control and client populations (see Table IV).

Beta-testing

Beta-testing of the P-scale was carried out in centres and departments that had not taken part in the development work ($n = 14$). Participating centres

Table II. Content validity: participation domains from the ICF (2001) covered by items in the Participation Scale.

Participation domain	Number of items in Participation Scale
Learning and applying knowledge	1 item
Communication	1 item
Mobility	3 items
Self care	1 item
Domestic life	3 items
Interpersonal interactions and relationships	3 items
Major life areas	3 items
Community, social and civic life	3 items
General tasks and demands	None

reported feedback on the scale use on a structured questionnaire providing details on user friendliness of the scale and the Users Manual, the ease of use and the utility of the scale. Suggestions for improvement of the manual were invited. Feedback was very positive. Users found the manual easy to understand and the scale easy to use (respondents rated ease of use as 'easy' or 'very easy'). Utility of the scale was rated as 'useful' or 'very useful' and all but one centre planned to continue using the scale.

Discussion

The Participation Scale is a new 18-item interview-based instrument to measure perceived problems in major, mainly socio-economic areas of life. The scale is based on the terminology and conceptual framework of the ICF [1] and provides a quantitative measure of the severity of participation restrictions as defined in the ICF. The content represents all key domains of the ICF Participation component. However, it was not designed to provide a comprehensive overview of problems in all areas of life. An in-depth interview will be needed to make a comprehensive assessment of all problems that may need to be addressed.

The psychometric properties of the Participation Scale have been extensively field-tested in six major languages in Nepal, India and Brazil according to a rigorous scientific protocol. The results have been excellent. The participation score was shown to be responsive to changes in participation following important events in people's lives. In line with what may be expected in real life, these changes did not always conform to expectation—a positive event in someone's life did not always result in improved participation and an apparently negative event did

Table III. Summary of results of the Participation Scale development process.

Characteristic	Result
Number of scale items	18
Response scale weighting	0 = no restriction, 1 = some restriction, but no problem, 2 = small problem, 3 = medium problem and 5 = large problem
<i>Internal consistency</i>	
Item to total correlation	Range of R : 0.32–0.73
Cronbach's α	0.92
Factor analysis	First factor = 90% of variability ($n = 497$)
<i>External validity</i>	
Expert score	$R = 0.44$ ($n = 227$, $P = 0.005$, Spearman)
EHF score	$R = 0.39$ ($n = 724$, $P < 0.001$, Spearman)
Self-assessment	($n = 496$, $P < 0.001$, Kruskal–Wallis test)
Inter-interviewer reliability	0.80 ($n = 296$)
Intra-interviewer reliability (stability)	0.83 ($n = 210$)
<i>Discrimination (median score (range))</i>	Matched pairs ($n = 171$)
Clients	13 (0–72; 95th percentile 50)
Controls	2 (0–44; 95th percentile 12)

Table IV. Arbitrary severity categories chosen to classify Participation Scale results.

Score categories	Description	Distribution of scores from client data
Less than 13	No significant participation restriction	Close to 40% of data below 12
13–22	Mild restriction	Close to 55% of data below 22
23–33	Moderate restriction	Close to 70% of data below 32
34–53	Severe restriction	Close to 85% of data below 52
More than 53	Extreme restriction	Less than 15% of data

not always reduce participation. The scale can be administered, on average, in less than 20 minutes. Beta-testing of the utility of the scale under routine work conditions was performed in a number of institutions and departments not involved in the development work. The feedback was very encouraging and indicated that the scale could fulfil a useful role in the rehabilitation of people with a variety of health conditions.

The scale has been validated for use with people affected by leprosy, spinal cord injuries, polio and other disabilities. We are confident that the instrument would be suitable to assess participation restrictions in people with other chronic conditions associated with stigma and discrimination, such as in HIV/AIDS, Buruli ulcer and lymphatic filariasis. However, additional validation studies will need to demonstrate this.

Only few instruments are available to assess social participation and related constructs. Most of these assess handicap as defined in the ICIDH, which is close to the construct of 'participation restriction'. The most recently developed instruments are the IPAQ [19,20] and the LIFE-H [27,28]. As the name indicates, many items of the IPAQ emphasise autonomy in doing what one wants to do and the way one wants to do it. For example, 'my chances of fulfilling my role at home as I would like are ...'. This feature makes the IPAQ less suitable for use in societies where autonomy is not the cultural norm. Many people live in situations where they have no choice in what role they fulfil at home, even if they have no disability. The same would be true for their chances of living life the way they want, for deciding the way their money is spent, etc. The response scales of the LIFE-H assess level of accomplishment, level of assistance and level of satisfaction. This level of complexity makes the scale less suitable for use with people who have had little of no education. In addition, the scale items were designed with a developed country population in view; at least 12 of the items in the Short Form have no or limited relevance under resource-poor conditions. The new Participation Scale was specifically designed for use in middle and low-income countries.

Cross-cultural assessment

The scale items were selected and worded in such a way as to maximise cross-cultural applicability. This attempt has been successful as the scale proved applicable in rural village settings in Nepal and South India, as well as in urban neighbourhoods of metropolises like Calcutta and Sao Paulo. Beta-testing in centres and programmes that did not take part in the development process confirmed that the User's Manual was easy to understand and that the scale could be used by non-specialist staff.

Three factors contributed to the conviction that it should be possible to develop a cross-cultural instrument. First, the extensive experience of the team members in working with people affected by stigmatised conditions in several countries indicated that the areas of life affected by participation restrictions were very similar. Second, a team from India and Brazil reviewed the potential scale items collected in Nepal and considered most of these items relevant to India and Brazil as well. Third, development of the ICF was based on extensive cross-cultural research [34]. The investigators concluded that, despite substantial cultural differences, clear common themes had emerged. They found that across the world, disability was stigmatised, though the degree and quality varied. Similar observations were reported by investigators using the LHS in non-western cultural settings. Lo and colleagues [23] concluded that 'The concept of handicap applies across cultures' and that the LHS and the scale weights developed from UK population could be used to estimate severity of handicap among Hong Kong Chinese. Our experiences have confirmed these findings. Though many potential scale items had to be discarded because of lack applicability in one or more of the participating regions, a sufficient number remained to construct a valid scale, with excellent psychometric properties across the countries and languages.

The 'peer comparison concept'

A special feature of the current scale is the concept of 'peer comparison' in assessing participation.

To assess client-perceived participation, people can be asked to compare their present situation with that before their health condition began. For example, 'Do you get invited to social functions less often than before you developed leprosy?' However, for chronic conditions this is problematic. People may not remember (accurately) what life was like many years ago. For a significant group of people the condition may have started in childhood or even from birth, so that they do not know what it was like to live without the condition. The other approach is to ask people to compare themselves with 'other people'. For Example, 'Do you get invited to social functions as often as other people?' However, 'other people' is a very wide concept. In addition, in many situations, patterns of social behaviour are culturally determined; e.g., certain people get invited, while others don't and would not even expect to be invited. Roles and expectations regarding participation may be very different for the same category of people in different settings, for example for unmarried women in rural India and in a metropolis in Brazil. To overcome these problems, the concept of 'peer comparison' was introduced. Respondents are asked to compare themselves with a 'peer', defined as 'someone similar to the respondent in all respects (socio-cultural, economic and demographic) except for the disease or disability'. Thus, the above question would be phrased as, 'Do you get invited to social functions as often as your peers?'

Generally, this approach worked well. In environments where people lived by themselves and had little interaction with neighbours, comparison with 'abstract' peers was found to be difficult. This problem was overcome by asking respondents to think of a particular (named) peer and compare him or herself with that person. This person may differ for different items on the scale. The 'peer comparison concept' goes a long way towards solving the issue of widespread 'background' problems in a given community, such as poverty or unemployment. When using non-comparative approaches or 'comparison with oneself before the condition', one easily overestimates rehabilitation needs. For example, it appears from the assessment that a person needs rehabilitation because he has a disability and is unemployed. The unemployment may be a genuine problem, but if 50% of the adult population in that community is unemployed, the solution is not likely to be an individual rehabilitation intervention, but an income generation project for the whole community. To our knowledge, the Perceived Handicap Questionnaire is the only other instrument asking respondents to compare themselves to others [22]. However, in the case of the PHQ, these 'other

persons' are only defined in terms of 'person without the handicap' or 'persons with the disease/disorder', who may or may not be peers.

Potential applications of the Participation Scale

Information on severity of participation restrictions as can be collected with the P-scale can be used for a number of specific purposes.

Needs assessment for rehabilitation or other social interventions. The scale can be used to assess whether a given person needs (socio-economic) rehabilitation, to assess the baseline needs of groups of people, for example for resource or programme planning, and for cross-sectional surveys.

Assessment of risk of socio-economic problems. In analytical studies to determine risk factors for participation restrictions, the scale can be used as an outcome measure. A further study has shown the scale to be suitable for this purpose (Nicholls et al., in preparation).

Monitoring of rehabilitation work. A key task in managing rehabilitation of individual clients and of rehabilitation programmes is monitoring progress towards the set goals. If these goals have been defined in terms of participation, as is commonly the case in socio-economic rehabilitation, the Participation Scale may be used to assess whether progress is being made.

Evaluation of rehabilitation, social inclusion and stigma reduction programmes and success of interventions in individual clients. The scale can be used to assess the impact of interventions at the programme or individual level or to determine whether certain interventions are more effective in achieving a desired outcome.

Advocacy. Advocacy is a key task in programmes dealing with people affected by health-related stigma and discrimination. However, effective advocacy needs information on the extent to which the lives of people are affected by the stigma. The Participation Scale can provide such information.

Disease control. Public health and disease control programmes often expect patients to adhere to treatment. If social participation is restricted because of, e.g., stigma, poverty or poor mobility, patients may default from treatment, jeopardising not only their own health, but also that of the surrounding community. This phenomenon is well known from the field of leprosy, tuberculosis and more recently HIV/AIDS. Detecting (risk of) participation

restrictions early may allow appropriate intervention before patients default from treatment. The Participation Scale may be a suitable screening instrument for this purpose.

Conclusions and recommendations

1. The Participation Scale, an interview-based instrument to measure client-perceived participation, is suitable for assessing the severity of socio-economic problems (participation restrictions).
2. The master scale is written in English and has been validated in a further six major languages.
3. The scale may be used at field level and in institutions; staff should be trained in the use of the scale, but specialist training of staff is not necessary.
4. The scale is suitable to collect baseline information for programme planning of rehabilitation and related services and to collect information for advocacy work.
5. The Participation Scale may be used as an evaluation and research tool to study participation (restrictions) and the effects of programmes to promote social inclusion. It provides a standardised measure suitable for comparison between clients, interventions and programmes.

The Participation Scale and Users Manual are available free of charge from the corresponding author on request.

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Note

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Annex

No	Participation Scale Compared to your peers . . .	Not specified, not answered	Yes 0	Sometimes	No	Irrelevant, I don't want to, don't have to	NO problem 1	Small 2	Medium 3	Large 5	SCORE
1	Do you have equal opportunity as your peers to find work? [If sometimes, no or irrelevant] How big a problem is it to you?		0				1	2	3	5	
2	Do you work as hard as your peers do? (same hours, type of work etc) [If sometimes, no or irrelevant] How big a problem is it to you?		0				1	2	3	5	
3	Do you contribute to the household economically in a similar way to your peers? [If sometimes, no or irrelevant] How big a problem is it to you?		0								
4	Do you make visits (travel) outside your village as much as your peers do? (except for treatment) e.g., Bazaars, melas, nearby villages [If sometimes, no or irrelevant] How big a problem is it to you?		0				1	2	3	5	
5	Do you help other people (e.g., neighbours, friends or relatives)? [If sometimes, no or irrelevant] How big a problem is it to you?		0				1	2	3	5	
6	Do you take as much part in casual recreational/social activities as do your peers? (e.g., sports, chat, meetings) [If sometimes, no or irrelevant] How big a problem is it to you?		0				1	2	3	5	
7	Are you as socially active as your peers are? (e.g., in religious/community affairs) [If sometimes, no or irrelevant] How big a problem is it to you?		0				1	2	3	5	
8	Do you visit other people in the community as often as other people do? [If sometimes, no or irrelevant] How big a problem is it to you?		0				1	2	3	5	
9	Are you comfortable meeting new people? [If sometimes, no or irrelevant] How big a problem is it to you?		0				1	2	3	5	

(continued)

Annex (Continued)

No	Participation Scale Compared to your peers . . .	Not specified, not answered	Yes 0	Sometimes	No	Irrelevant, I don't want to, don't have to	NO problem 1	Small 2	Medium 3	Large 5	SCORE
10	Do you have the same respect in the community as your peers? [If sometimes, no or irrelevant] How big a problem is it for you?		0								
11	Do you move around inside and outside the house and around the village/ neighbourhood just as other people do? [If sometimes, no or irrelevant] How big a problem is it to you?		0								
12	In your village, do you visit all the public places/common places? (including schools, shops, offices, market and tea/ coffee shops) [If sometimes, no or irrelevant] How big a problem is it to you?		0								
13	Do you have opportunity to take care of yourself (appearance, nutrition, health, etc.) as well as your peers? [If sometimes, no or irrelevant] How big a problem is it to you?		0								
14	In your home, do you do household work? [If sometimes, no or irrelevant] How big a problem is it to you?		0								
15	In family discussions, does your opinion count? [If sometimes, no or irrelevant] How big a problem is it to you?		0								
16	In your home, are the eating utensils you use kept with those used by the rest of the household? [If sometimes, no or irrelevant] How big a problem is it to you?		0								

(continued)

Annex (Continued)

No	Participation Scale Compared to your peers ...	Not specified, not answered	Yes 0	Sometimes	No	Irrelevant, I don't want to, don't have to	NO problem 1	Small 2	Medium 3	Large 5	SCORE
17	Do you take part in major festivals and rituals as your peers do? (e.g., weddings, funerals, religious festivals) [If sometimes, no or irrelevant] How big a problem is it to you?		0								
18	Do you feel confident to try to learn new things? [If sometimes, no or irrelevant] How big a problem is it to you?		0				1	2	3	5	
							1	2	3	5	

Comment:

Name: _____

Age: _____ Gender: _____

Reason for the assessment: _____

Interviewer: _____ Date of interview: ____ / ____ / ____

Grades of participation restriction

No significant restriction	Mild restriction	Moderate restriction	Severe restriction	Extreme restriction
0 – 12	13 – 22	23 – 32	33 – 52	53 – 90

Disclaimer: The Participation Scale is the intellectual property of the Participation Scale Development Team. Neither the Team or its sponsors can be held responsible for any consequences of the use of the Participation Scale.