

Participation Scale

Users Manual

Version 6.0



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Preface

In recent years, the emphasis on prevention of disability (POD) and (community-based) rehabilitation has strongly increased both in the field of leprosy and in other areas of work with people with disability. Needs assessments to determine the size and nature of the problems and monitoring and evaluation of POD and rehabilitation are becoming more and more urgent.

The development of a standardized tool for assessing the severity of rehabilitation needs of people with disability and those with other stigmatising conditions has long been recognised as a need. It is hoped the Participation Scale presented here will fulfil this purpose.

This manual is intended to equip the programme managers and prospective users of the Participation Scale to use the scale effectively. The manual contains an explanation of the rationale for using the Participation Scale, practical instructions regarding interviewing and the use of the scale, detailed training notes for prospective users, a sample of the Participation Scale and a copy of the Question-by-Question interview guide. It also contains a protocol for translation of the scale into other languages.

The Participation Scale Development Team (PSDT) welcomes any comments and suggestions for further improvement from all users of this instrument and readers of this manual. Kindly inform the PSDT (through Dr. Wim van Brakel) of use of the scale. A form to provide feedback is included as an Annex. The PSDT also request that copies of any further translations of the Participation Scale be sent to:

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Thank you in advance for your help! We hope and pray that the Participation Scale may contribute to the effective rehabilitation of people affected by leprosy, disability or the consequences of other stigmatised conditions. May they be able to 'live life to the full'!

The Participation Scale Development Team

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Introduction

Activity is defined as 'the execution of a task or action by an individual' and **Participation as** 'involvement in a life situation'.¹ Participation in the community refers to the phenomenon of executing one's role in society or taking part in activities in a group situation. Stigma and its consequences are as old as the history of mankind. At any point in time, certain members of society have faced participation restrictions in various domains of life, due to disease, disability, deformity, caste, creed, race, gender or other stigmatising conditions. Addressing participation restrictions is a main goal of many rehabilitation interventions. It is therefore of key importance to be able to measure participation in order to assess needs, monitor progress and evaluate the impact of rehabilitation interventions.

Understanding Participation

Participation is a person's involvement in a life situation. A life situation refers to a person's interaction and participation in wider aspects and areas of normal living or community life. These include the social, economic, civic, interpersonal, domestic and educational domains of daily living, most of which concern every person, regardless of their health, age, gender or caste. Problems experienced in participating in any of these 'life situations', are referred to as 'participation restrictions'.

The domains of participation include:

- Learning and applying knowledge (sharing skills and knowledge, solving problems, etc.)
- Communication (conversation, expressing needs and ideas, participating in discussions, etc.)
- Mobility (use of public transport, visiting public places, walking, ability to move about, etc.)
- Self Care (washing, grooming, nutrition, hygiene, clothes and appearance)
- Domestic Life (household tasks, assisting others, etc.)
- Interpersonal Interactions (relationships, etc.)
- Major Life Areas (work, education, employment, economic life, etc.)
- Community, Social and Civic (community life, recreation, leisure, religion, political life)

Participation Restriction

Participation restrictions are often referred to as 'social problems'. Causes of participation restriction include impairment, activity limitation, self-stigmatisation, disease related money problems, absence of equipment, support/relationships, attitudes and systems, environment, policies or laws.

Many instruments have been developed to measure quality of life, 'handicap' or, recently, even participation restriction. However, these have been developed for use with people living in developed countries, have been disease-specific or have covered only certain aspects of 'participation'. It was therefore decided to develop an instrument

- Suitable for use in leprosy-endemic countries,
- Suitable to measure participation restrictions in person affected by leprosy, disability or other stigmatised conditions,
- Covering the nine domains of participation as defined in the ICF as well as possible, and
- That would be culture-free.

The Participation Scale is the outcome of an international research project to develop an interview-based scale that met these criteria.

¹ International Classification of Functioning, Disability and Health (ICF). WHO, 2001

The Participation Scale Development Programme

Initial work on the development of the Participation Scale was undertaken by the INF RELEASE Project in Nepal in a project sponsored by the German Leprosy and Tuberculosis Relief Association (GLRA). It involved extensive preparatory anthropological field work to collect potential items for the scale. The excellent preparatory work was then given international dimensions under the Participation Scale Development Programme, an international programme of research to develop tools screening, monitoring and evaluation in rehabilitation. This programme was coordinated by The Leprosy Mission International (TLMI) and funded by TLMI and the American Leprosy Missions (ALM).

The main outcome of the programme is the Participation Scale,² a new 18-item interview-based instrument to measure perceived problems in major domains of life. The scale will allow quantification of participation restrictions experienced by people affected by leprosy, disability or other stigmatised conditions. The Participation Scale covers eight out of nine major life domains defined in the International Classification of Functioning, Disability and Health (ICF), published by the WHO in 2001. The Participation Scale can be administered, on average, in less than 20 minutes. Most questions ask the respondent to compare him or herself with an actual or hypothetical 'peer' (see below), someone who would be similar to them in all aspects, except for the disease or disability. The respondent is asked whether (s)he perceives their level of participation to be the same or less than that of their peer(s). If the respondent indicates a potential problem, (s)he is asked how big a problem this is to them ('no problem', 'small problem', 'medium problem', 'large problem').

Culture free nature of the scale

The Participation Scale intends to measure the restrictions due to leprosy, disability or other health conditions, not the restrictions due to practices that are part of their culture. For example, women and children are restricted in certain rituals, children do not take decisions in the family, the elderly are restricted from taking up heavy jobs, non citizens of a state are restricted from participating in the elections, low caste members are restricted from performing certain activities and so on. To eliminate these cultural influences, the questions ask the respondents to compare their situation with that of his or her peers.

Concept of Peers

Peers are people known to the interviewee who are similar to him or her in all respects (socio-cultural, economic and demographic) except for the health condition or disability. In the first nine items, the respondent is asked whether (s)he is restricted in participation in comparison to his or her peers. Of course, one particular person may not be a peer in all respects. The respondent may identify different people as his peers in different situations depending on the specific area of life. If a question refers to age, sex, occupation, position in the family or community, then peers would be those of similar age, sex, occupation, etc. Examples: If a young daughter-in-law suffering from leprosy is the respondent, her peer would be another young daughter-in law in her community, not suffering from leprosy. The peer of a 50-year-old farmer with disability in a rural village would be another farmer of similar age from the same village, who does not have disability. It is necessary to keep reminding the respondent to compare his or her situation with that of their peers. This will allow an assessment of the perceived participation restrictions due to the health condition or disability, regardless of cultural and other factors. Sometimes it may be necessary to ask the respondent to think of a particular, named person they regard to be similar to them. Once such a person has been identified, the interviewer can ask the respondent each time to compare him or herself to this person. One should bear in mind that peers differ according to situation. A peer in the home situation is likely to be a different person from a peer at work.

² See Annex 1

Applications of the scale

Because the Participation Scale measures the severity of participation restrictions, it can be used to assess a person's need for (socioeconomic) rehabilitation. It can also be used for needs assessment in groups of people, for example as part of resource or programme planning, and for cross-sectional surveys, for example to compare participation restrictions among groups of people with different types of disability. The Participation Scale should be incorporated in the routine assessment of clients in rehabilitation programmes and may be used for monitoring or impact assessment of rehabilitation interventions in individual clients. The scale will provide a quantitative measure of their (perceived) participation restrictions. However, it does not provide a comprehensive overview of all areas of life where there may be problems that need to be addressed in a holistic rehabilitation intervention. The scale is therefore not meant to replace existing socio-economic assessment instruments used by rehabilitation programmes to get a detailed overview of the status of the client and their areas of difficulty. An in-depth interview will be needed to make a comprehensive assessment of all problems that may need to be addressed. For a goal-oriented rehabilitation assessment, we recommend that the Participation Scale be used in conjunction with the SALSAS scale (Screening Activity Limitation and Safety Assessment), which provides a quantitative measure of limitations in functioning and safety in the area of activities of daily living. The Participation Scale was validated for children of 15 and above and may be used, despite the fact that some of the items are irrelevant. The same applies to the elderly. The current scale is not considered suitable for people with intellectual impairment, unless their guardians could answer on their behalf. However, this application has not been validated.

Psychometric properties

The validity, reliability, stability and responsiveness to change (dynamicity) of the scale scores have been thoroughly checked in six major languages in three countries. The results of this psychometric testing have been excellent. The scale has been validated for use with people affected by leprosy, people with spinal cord injuries, polio and other disabilities. Extensive validation and field testing have confirmed that the scale works well under different operational circumstances.

Users of the scale

The scale is intended for use by field workers, CBR workers, rehabilitation workers, paramedical workers, medical staff and other staff involved in (socio-economic) rehabilitation, including community-based rehabilitation. Staff should receive special instruction in the use of the scale, but specialist training is not necessary.

Question-by-Question Guide

The Participation Scale is an interview-based instrument. The items in the scale are closed, structured questions. The questions therefore should be asked as they are. In practice, not all questions will be self-explanatory; some will need additional explanation by the interviewers. The interviewer may explain the question as well as (s)he can, using standard practical examples. To minimize interviewer bias a Question-by-Question Guide (Q/Q, pronounced 'Q by Q') has been developed to accompany the questionnaire.³ The Q/Q helps the interviewer and respondent to understand the underlying meaning of the individual questions in uniform way in different cultural contexts. The Q/Q is structured and should not be changed by the interviewer, without written permission of the Participation Scale Development Team. If a question needs to be explained it should be explained using one or more examples given in the Q/Q.

³ The Q/Q is given in Annex 2

Translation

The Participation Scale should be used in the vernacular language and, where needed, translations into the vernacular should be done using the English scale as a basis. Since the items in the scale have an intrinsic meaning that needs to be retained in any translation, the translated document has to be back-translated into English, which is the master questionnaire, to verify that the meaning of the items has not changed substantially. Translation should be done by someone experienced in the field of socioeconomic problems and rehabilitation and back-translation by an expert in both the vernacular and English language. Detailed guidelines are given in Annex 4.

Administering the scale

The programme will need to decide who will administer the scale. The questions should be asked the way they are written. Only explanations given in the Q/Q should be used if the question itself is not clear. At times the interviewers may use different terms to explain a question but they should never go out of the scope defined by Q/Q. Before the actual scale interview is started, the interviewer should build rapport with the respondent and make the respondent feel at ease as much as possible. Where possible, the interview should be done in private and by a same-sex interviewer. Once the scale interview has started, it should not be interrupted for answering other questions, giving explanations that do not relate to the scale or for discussing other topics. If the respondent wishes to elaborate, ask a question or discuss another topic, the interviewer should insist in a friendly, but firm manner that the scale interview needs to be completed first and that (s)he will then come back to the other questions or concerns of the respondent. This is very important.

Response options

Not specified, answered

“I won’t tell you”, or “I forgot to ask”

Use this response when the client does not give an answer, for example when they are too embarrassed to do so. It may also be used when the interviewer forgets, or for some other reason does not ask the question.

YES

“Yes, I am similar to my peers in this.” “There is no difficulty”; use this response when there is no participation restriction, or a negligibly mild one. Occasionally, a respondent says, “No, mine is better” or “I work harder than my peers”. For the time being, this is coded the same as ‘Yes’ (i.e. ‘0’)

Sometimes

There are problems with this sometimes or with some people

NO

“No, I am different from my peers in this.” There are problems with this

Irrelevant/I don’t have to/I don’t want to

The person may answer a question with ‘no’ but say that it is nevertheless irrelevant for them. For example, they may not travel outside their village, in which case the answer is ‘no’, but it may be irrelevant for them because they have no relatives or family living outside the village.

The person may say that they don’t travel outside their village because their children go to the bazaar and they therefore *don’t have* to leave the village. This response can also be used when a patient does not expect to be able to do this, e.g. questions about marriage for children. This response may also be used where there is an issue due to caste, gender etc, rather than disease. For example, in some cultures, women are excluded from community leadership positions, regardless of their health status. The person may also say that they don’t *want* to leave the village or have no interest in doing so. Interviewers must note that there is a difference between a patient saying they don’t want to because they have no interest in something, and not wanting to do something because of fear of rejection or paranoia.

Problem assessment

IF NO or Sometimes is answered, the importance of the participation restriction must be assessed:

It is no problem

There is a participation restriction, but it does not matter to the client either practically or emotionally. This can include situations where the client has fully adapted. Be careful to distinguish between this, and the situation where the client did not ever have expectations of participating

It is a small problem (in time or intensity) (mild restriction)

There is a participation restriction. It matters to the client either practically or emotionally. But it is only a small problem because it doesn't happen often or isn't a big difficulty.

It is a medium problem (in time or intensity) (moderate restriction)

There is a participation restriction. It matters to the client either practically or emotionally. It has an effect on his/her life.

It is a large problem

There is a participation restriction. It matters to the client either practically or emotionally. (S)he has not found an appropriate way of coping and it is a big problem, which may have resulted in a major life change.

Marking the responses and computing the total score

The scale is pre-coded and the scores to each response are already assigned in the response boxes. During the interview, the responses are marked in the appropriate boxes, by encircling the corresponding number or by ticking the corresponding box and subsequently encircling the correct problem score (see examples in Annex 3). Boxes not applicable to a particular question are shaded. After the interview, the score for each item is transferred to the 'Score' column and added up. The sum score is then written in the box marked 'TOTAL'. Because the item scores will each be between 0-5, the sum score would be somewhere between 0 and 90. The cut-off for 'normal' (= not having significant participation restrictions) in the study sample was 12. People scoring more than 12 would be classified as having participation restrictions and would therefore need further evaluation to determine the need for and feasibility of rehabilitation assistance of any kind. The cut-off of 12 is based on the data collected during the development process. Among the control subjects interviewed, 95% scored 12 or less.

However, a different cut-off may be appropriate elsewhere. In a study in Indonesia, the cut-off for 'no participation restriction' was found to be '6'. Data on what is 'normal' in a given area may be obtained by carrying out a small normative study, in which at least 50 control subjects (people without a stigmatised condition or disability) are interviewed. In general, choosing a higher cut-off will increase the specificity and lower the sensitivity; lowering the cut-off will do the reverse. A high sensitivity will result in more people appearing to be in need of rehabilitation interventions (having participation restrictions). A high specificity will ensure that only those with significant participation restrictions are identified as having problems. The choice of cut-off will depend on the scores obtained among control subjects and on the resources available for offering rehabilitation assistance. If resources are plentiful, one can choose a lower cut-off and offer assistance to a larger number of people; if they are scarce, one may increase the cut-off and only offer assistance to those with more severe problems. It is important to enter the score along with the decision whether or not to evaluate the person for rehabilitation assistance.

Preparations before using the Participation Scale	
1.	Communicate your interest to use the new Participation Scale to the Participation Scale Development Team (see Preface)
2.	Obtain the latest version of the scale and the Training Manual
3.	Translate the Participation Scale according to the translation protocol in Annex 4
4.	Translate the Q/Q document
5.	Decide how the scale will be used (who will be interviewed, who will do conduct the interviews)
6.	Decide to whom people scoring positive on the scale will be referred and what will be the procedure for deciding on rehabilitation assistance, if this is not already in place
7.	Train the staff involved using this manual

Training module for interviewers	
Though no specialist training is not required, the staff involved in administering the scale need to be trained in the following topics. The topics marked with an asterisk are recommended but optional.	
TOPIC	OBJECTIVES
Interview technique	To discuss what is 'interview technique' and how an interview is different from a conversation. To discuss the 'do's and don'ts' of good interviewing.
Rapport establishment	To make the trainees aware of the importance of establishing good rapport before starting the interview.
Closed interview technique	To make the trainees aware of the advantages of the closed interview method, the importance of confining oneself to asking the questions as they are and to the prompts given in the Q/Q.
P-Scale interview procedure	To explain the general information, the questions in the scale, the response options, the sequence to be followed in asking the questions, the scoring method and the score cut-off and its significance.
Participation - peer group	To make to trainees understand the concept of 'peer group' and its importance in Participation Scale interviewing.
Professional bias	To make the trainees aware how the paramedical/non-professional interviewer may be biased due to his/her profession, the tendency to play role of a health worker. To emphasize the need to remain a listener rather than becoming a health educator, a counsellor or a social worker during the course of the scale interview.
Bias due to Gender	To make the trainees aware that the client or the interviewer could be biased due to their gender, viewing things from their own perspective.
Bias due to known status	To make the trainees aware how the data may be biased, when the interviewer and the respondent know each others' status.
Practical training in filling in the scale	To thoroughly familiarise the trainees with how the P-scale interview is conducted. At least 4 simulated interviews should be conducted by each interviewer.
Uses of the P-scale	To explain the different uses that could be made of the P-scale in different settings.
Basic concepts *	To familiarise the trainees with the concepts of Culture, Society (community, urban/rural/tribal), Social structure (family, cast, gender, economic and religious institutions and groups), Participation (peer group, pressure group) and Norms and patterns of behaviour.
Types of interviews *	To discuss closed and open methods of interviewing and their importance in different contexts.
Findings of the psychometric testing *	To give an overview of the psychometric properties that have been tested in the study and the main results obtained.

* Additional Training Notes are available on request from the address in the front of the Manual.

Annex 1

No	Participation Scale	Not specified, not answered					NO problem	Small	Medium	Large	SCORE
			Yes	Sometimes	No	Irrelevant, I don't want to, don't have to					
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 as much part in casual recreational/social activities as do your peers? (e.g. sports, chat, meetings)		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?					1	2	3	5		
7	Are you as socially active as your peers are? (e.g. in religious/community affairs)		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?					1	2	3	5		
8	Do you have the same respect in the community as your peers?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?					1	2	3	5		
9	Do you have opportunity to take care of yourself (appearance, nutrition, health, etc.) as well as your peers?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?					1	2	3	5		
10	Do you have the same opportunities as your peers to start or maintain a long-term relationship with a life partner?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?					1	2	3	5		
11	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		

No	Participation Scale	Not specified, not answered					NO problem	Small	Medium	Large	SCORE
			Yes	Sometimes	No	Irrelevant, I don't want to, don't have to					
12	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	
13	In your village / neighbourhood, do you visit public places as often as other people do? (including 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	
14	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	
15	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	
16	Do you help other people (e.g. neighbours, friends or relatives)?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	
17	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	
18	Do you feel confident to try to learn new things?		0			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	

Comment:

TOTAL

Name: _____

Age: _____ Gender: _____

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.

Annex 2

Question-by-Question Guide to accompany the Participation Scale

Important issues in P-scale interviewing	
Rapport	Never start an interview without building a good rapport. Irrelevant answers and refusal to answer particular questions may result from an inadequate rapport between the interviewer and the respondent.
Listening skills	Listening with patience will bring out vital information.
Interviewer's behaviour	The interviewer has to be polite, even if the respondent is a regular client. Often the respondents exhibit emotional outbursts; in such situations, the interviewer should show warm and empathetic behaviour. The interviewer should <i>never</i> show a judgemental attitude towards the respondent.
Congenial atmosphere	Conduct the interview somewhere where the respondent is comfortable, making sure as much as possible that no one will interfere in the process of interview.
Privacy	Privacy should be respected. It is very important to the respondent, even if the interviewer feels that others around know everything about the respondent.
Observation	Be alert to observe the surroundings such as the place where the respondent lives and eats, others' reactions towards him or her and the expressions of others who try to interfere in the interview
The questions and responses	All questions in the scale must be asked. The interviewers should never presume (s)he knows the answer to a particular question and fill in the response without asking the question and carefully listening to the answer given.
Closed questions	The Participation Scale consists of so-called 'closed questions'. This means that questions should be asked as they are written and that the respondent will have to choose one of the pre-defined answer categories. The interviewer may have to repeat these categories after every question.
Interpretation	Do not interpret the questions beyond the explanation and examples given in the Question-by-Question document.
Sequence	Never change the sequence of the questions.
Concept of Peers	It is essential that the interviewer understands the concept of 'peers' and knows how to explain this to the respondent. "Who is the respondent's peer with reference to a particular question" has to be made clear to the respondent. Peers are those who are similar to the respondent in all respects (socio-cultural, economic and demographic) except for the health condition or disability. The respondent is asked whether (s)he is restricted in participation in comparison to his or her peers. If a question refers to age, sex, occupation, position in the family or community, then peers would be those of similar age, sex, occupation, etc. If a young daughter-in-law suffering from leprosy is a respondent, then her peer would be a young daughter-in-law in her community not suffering from leprosy. It is necessary to keep reminding the respondent to compare his or her situation with that of their peers (see also page 6).
Remarks	The interviewer can write his or her remarks on the questionnaire. These can be referred to later.

Instructions for the Participation Scale interview

1. The interviewer must read the Q/Q thoroughly before interviewing to get an understanding of the underlying concept of the questions.
2. The interview may take approximately 20 minutes.
3. All questions must be asked and the answers recorded in the appropriate boxes.
4. Ask the questions on scale exactly as they are written on the form.
 - If the respondent does not understand the question, repeat it in the same way it is written on the form.
 - If the respondent still does not understand it refer to the Q/Q and ask the prompt question as written.
 - If the person continues to have difficulty understanding the question, use one or more of the examples in Q/Q to further clarify the question.
5. Do not translate or paraphrase the questions during the interview.
6. Listen to the respondent and record his/her answer in the form as answered. Do not guess his/her answer.
7. If the person digresses from the question bring her/him back to the question and explain that (s)he may talk about or discuss the issue at the end of the interview.
8. If the respondent answers 'YES' to any of the questions, do not ask whether it is a problem for him/her. Circle '0' in the 'Yes' box and go directly to the next question.
9. If the respondent answers 'Sometimes', 'No', or something like "This is irrelevant for me, I don't want to, don't have to", check the appropriate box with a ✓ (See the example below).
10. Ensure privacy as much as possible while administering the questionnaire.
11. Give the freedom to the respondent not to reply to any question (s)he may feel uncomfortable with.
12. When scoring a question, circle the number that corresponds to the answer given and write the same number in the last box on the right in the same row. See sample below:

Key to responses

Not specified, answered

"I won't tell you", or "I forgot to ask"

Use this response when the client does not give an answer, for example when they are too embarrassed to do so.

YES

"There is no difficulty"

Use this response when there is no participation restriction, or a negligibly mild one.

Sometimes

There are problems with this sometimes or with some people

NO

There are problems with this

Irrelevant / I don't have to / I don't want to

The person may answer a question with 'no' but say that it is nevertheless irrelevant for them. For example, they may not travel outside their village / neighbourhood, in which case the answer is 'no',

but it may be irrelevant for them because they have no relatives or family living outside the village / neighbourhood. The person may say that they don't travel outside their village / neighbourhood because their children go to the bazaar and they therefore *don't have* to leave the village / neighbourhood. This response can also be used when a patient does not expect to be able to do this, e.g. questions about marriage for children. This response may also be used where there is an issue due to caste, gender etc, rather than disease. For example, in some cultures, women may be excluded from community leadership positions, regardless of their health status. The person may also say that they *don't want* to leave the village / neighbourhood or have no interest in doing so. Interviewers must note that there is a difference between a patient saying they don't want to because they have no interest in something, and not wanting to do something because of fear of rejection or paranoia.

Problem assessment

IF NO or Sometimes is answered, the importance of the participation restriction must be assessed:

It is no problem

There is a participation restriction, but it does not matter to the client either practically or emotionally. This can include situations where the client has fully adapted. Be careful to distinguish between this, and the situation where the client did not ever have expectations of participating.

It is a small problem (in time or intensity) (mild restriction)

There is now a participation restriction. It matters to the client either practically or emotionally. But it is only a small problem because it doesn't happen often or isn't a big difficulty.

It is a medium problem (in time or intensity) (moderate restriction)

There is now a participation restriction. It matters to the client either practically or emotionally. It has an effect on his/her life.

It is a large problem

There is now a participation restriction. It matters to the client either practically or emotionally. (S)he has not found an appropriate way of coping and it is a big problem, which may have resulted in a major life change.

Example: the respondent is a man who is employed, but cannot work the same number of hours a day as his peers because of a disability.

No	Participation Scale	Not specified, not answered	Yes	Sometimes	No	Irrelevant, I don't want to, don't have to	NO problem	Small	Medium	Large	SCORE
			0			0	1	2	3	5	
1	Do you have equal opportunity as your peers to find work?		①			0					
	<i>[If sometimes or no] how big a problem is it to you?</i>						1	2	3	5	0
2	Do you work as hard as your peers do? (same hours, type of work etc)		0		✓	0					
	<i>[If sometimes or no] how big a problem is it to you?</i>						1	2	③	5	3

Question-by-Question guide (Q/Q)	
1.	<p>Do you have equal opportunity as your peers to find work?</p> <p><i>Prompt: Do you have the same chances /opportunity of finding employment or a job as your peers?</i></p> <p>Note: the question is asking whether the person has the same chances of finding paid work, as his/her peers, or whether it is harder because of his/her disability/disease (not due to any other reasons).</p> <p>For example, it may be harder to find work because:</p> <ul style="list-style-type: none"> • (S)he can't work as fast as his/her peers. • Because (s)he has deformity in his/her hands. • Because (s)he need longer rests during the day.
2.	<p>Do you work as hard as your peers do? (same hours, type of work etc)</p> <p><i>Prompt: Do you work as many hours per day as your peers? Do you do similar work to your peers?</i></p> <p>This is comparing the amount of work people are able to do. Excludes: attitude to work.</p> <p>For example:</p> <ul style="list-style-type: none"> • Does (s)he work the same hours? • Does (s)he has to do lighter work? • Does (s)he do a different type of work? • Does (s)he have more time off during the year because of illness?
3.	<p>Do you contribute to the household economically in a similar way to your peers?</p> <p><i>Prompt: Do other people (your peers), earn money / produce goods for the family? Do you do the same?</i></p> <p>Note: the question is asking whether the person is able to, i.e. has the means to contribute. To contribute means to give towards the household's finances / resources. Excludes: Contributions other than financial.</p> <p>For example:</p> <ul style="list-style-type: none"> • A person may contribute a proportion or all of his/her pay for food and other necessities of the household for their consumption. • A person may not be working or be economically productive and therefore can't afford to contribute.
4.	<p>Do you make visits (travel) outside your village / neighbourhood as much as your peers do? (except for treatment) e.g. Bazaars, nearby villages / neighbourhoods</p> <p><i>Prompt: Do you go to sell or buy food or to visit friends / relatives in other villages / neighbourhoods?</i></p> <p>Implies travelling. Excludes: travelling outside the village / neighbourhood for medical treatment. <i>For example:</i></p> <ul style="list-style-type: none"> • His/her poor mobility may prevent them from taking long journeys. • (S)he may not visit family or relatives and therefore has no need to travel as much as his/her peers. • (S)he may choose to send his/her spouse or children to the bazaar for fear of being called names.

5.	<p>Do you take part in major festivals and rituals as your peers do? (e.g. weddings, funerals, religious festivals)</p> <p><i>Prompt: Are you as involved as others in major festivals and rituals?</i></p> <p>To take part in something is to be involved. A festival in this case is a community celebration. A ritual is a ceremony or religious observance. When there are major festivals like Christmas, Diwali, Id or other festivals or rituals such as weddings and funerals, does the person attend and take part?</p> <p>For example:</p> <ul style="list-style-type: none"> • (S)he may not be invited or allowed to come. • (S)he may prefer to stay at home for fear of others making him/her feel 'shy'.
6.	<p>Do you take as much part in casual recreational/social activities as do your peers? (e.g. sports, chat, meetings)</p> <p><i>Prompt: Do you do as many recreational activities as other people?</i></p> <p>Note: the question is asking whether the person is as socially involved and active in his/her village/community as his/her peers are. A recreational activity is a social / socio-religious / casual / leisure activity, for relaxation and enjoyment. This could be: playing cards, drinking tea with friends, going to community meetings/ participating in a festival, Diwali, Christmas, Id or Pongal celebrations or visiting relatives, watching video shows, singing, dancing, playing volleyball etc. in his/her peer groups.</p> <p>For example:</p> <ul style="list-style-type: none"> • The person may not go out because (s)he has limited mobility. • (S)he may not be able to play pool / cards due to his/her hand deformity. • (S)he may have fewer friends because of his/her disease/disability.
7.	<p>Are you as socially active as your peers are? (e.g. in religious/community affairs)</p> <p><i>Prompt: Are you active socially? What about in religious / community affairs?</i></p> <p>Note: the question is asking how socially active the person is within his/her community. To be socially active is to be involved in or busy working in community affairs. Implies regular attendance, often involving membership.</p> <p>For example:</p> <ul style="list-style-type: none"> • This may involve going to community meetings. • Being involved in the religious affairs within the village or community e.g. participating in a social group or religious procession or being an active member of the local church • Participating in a political march; being a member of a political party.
8.	<p>Do you have the same respect in the community as your peers?</p> <p><i>Prompt: Do you think you are losing respect in your community?</i></p> <p>Note: the question is asking whether the person receives the same respect from community members as do his/her peers. Respect refers to position or importance and authority of someone in the community or society.</p> <p>For example:</p> <ul style="list-style-type: none"> • Some people or families have a loss of respect or importance in a community because of someone in the household being disabled or having a disease.

9.	<p>Do you have opportunity to take care of yourself (appearance, nutrition, health, etc.) as well as your peers?</p> <p><i>Prompt: Do you get a chance to wash as often as you would like? Do you get a chance to eat fruit or drink milk?</i></p> <p>Note: the question is asking the person to compare how well (s)he is able to take care of him(her)self in comparison to his/her peers, or contemporaries. ‘Opportunity’ means that a person could for example wash his/her hair as often as (s)he likes, if (s)he chooses to. It implies that there is no environmental, socio-economic or physical barrier preventing someone from doing something that (s)he wishes to do.</p> <p>Includes: styling/grooming hair, henna, body piercing, manicure/pedicure, eating properly, taking care over the way you look, being proactive about your health.</p> <p>For example, a person’s hygiene may not be as good as his/her peers if:</p> <ul style="list-style-type: none"> • (S)he is not allowed or does not have the chance to use the community water tap unless it’s dark or no one else is there. • A person also may not have the money to pay for medical treatment, soap or toiletries.
10.	<p>‘10. Do you have the same opportunities as your peers to enter into or maintain a long-term relationship with a life partner?’</p> <p><i>Prompt: Do you have the same opportunity to start or maintain an intimate long-term relationship as your peers?</i></p> <p>Note: this question is asking whether the respondent has difficulties starting or continuing a long-term intimate relationship with a life-partner.</p> <p>Excludes: those who too young for this question to be relevant (answer: ‘Irrelevant’)</p> <p>For example:</p> <ul style="list-style-type: none"> • The person may feel others are not interested in him/her as a marriage partner, because of his/her (health) condition • Some conditions may cause the non-affected partner to consider or ask for divorce (e.g. HIV/AIDS, mental illness, leprosy, spinal cord injury).’
11.	<p>Do you visit other people in the community as often as other people do?</p> <p><i>Prompt: Do you visit people in your community? Do you make visits as often as other people do?</i></p> <p>Note: the question is only asking if (s)he visits, and not if (s)he eats and drinks with them. Does the person go to or visit other households and families in the community as much as his/her peers do? Circle the ‘0’ in the YES box if (s)he visits others but doesn’t eat/drink with them but also indicate YES if (s)he visits and does eat and drink with them.</p> <p>For example:</p> <ul style="list-style-type: none"> • The person may have lost friends because of his/her condition, and have fewer people to visit. • The person’s mobility may restrict them from making visits often.
12.	<p>Do you move around inside and outside the house and around the village / neighbourhood just as other people do?</p> <p><i>Prompt: Do you move around inside and outside the house and around the community just as other people do?</i></p> <p>Note: mobility also includes the ability to move for example, from wheelchair/bed to chair, with or without the use of aids such as a wheelchair, crutches etc.</p>

	<p>For example:</p> <ul style="list-style-type: none"> • (S)he may find it difficult to walk up/down steps, hills, gates or other physical barriers because of his/her mobility. • People's attitude might prevent them from moving about the same as his/her peers, for example, (s)he may feel self-conscious.
13.	<p>In your village / neighbourhood, do you visit public places as often as other people do? (including schools, shops, offices, market and tea/coffee shops)</p> <p><i>Prompt: Do you go to common meeting places as often as other people do? Do you go into tea shops and drink tea? Do you go inside public buildings like schools or offices?</i></p> <p>For example:</p> <ul style="list-style-type: none"> • (S)he may be unable to visit tea shops because (s)he can't get his/her wheelchair through the door. • (S)he may be restricted by people's attitudes. • (S)he may choose not to go to certain public places because (s)he feels shy or self-conscious.
14.	<p>In your home, do you do household work?</p> <p><i>Prompt: Do you participate in daily household chores like cleaning floors, utensils, clothes, looking after cattle in the house, help in cooking or kitchen, purchasing of household/kitchen materials or vegetables etc.?</i></p> <p>Note: the emphasis is on whether the person participates in the routine household activities along with the people he/she lives with. Several items under this question may be gender specific. The expected response is whether he/she is allowed to participate in the activities that are acceptable to a gender in the given culture.</p> <p>For example:</p> <ul style="list-style-type: none"> • Others may not want the person to participate because they think that they will become contaminated or impure.
15.	<p>In family discussions, does your opinion count?</p> <p><i>Prompt: Are you asked for your opinion or do you offer your opinion when family matters are discussed, to the same extent as your peers would?</i></p> <p>Note: the question is asking whether the person speaks, voices his/her opinion, shares ideas and generally joins in when his/her family are discussing things. It would include whether (s)he feels his/her opinion is taken into account, even if this is be in the form of silent (dis)approval, as may be appropriate in some cultural settings.</p> <p>Family discussions could be about anything, but may include:</p> <ul style="list-style-type: none"> • Arranging a daughter's marriage. • Buying animals. <ul style="list-style-type: none"> • Money.
16.	<p>Do you help other people (e.g. neighbours, friends or relatives)?</p> <p><i>Prompt: Do you help other people in their economic and social activities such as farming, pastoral, house repair etc. ?</i></p> <p>Note: the question is asking about unpaid help and friendly assistance. Excludes: Paid work or employment To help is to offer assistance, often in a practical way. The question is asking whether the person helps those people/families he/she is associated with.</p>

	<p>For example:</p> <ul style="list-style-type: none"> • Collecting water for them if they are unable to get it themselves. • Attending to their animals in their absence • Accompanying the person or taking their children to the hospital when they are sick • Match making • Looking after their children
17.	<p>Are you comfortable meeting new people?</p> <p><i>Prompt: Do you try to stay out of someone's way if you don't know them?</i></p> <p>Note: the question is asking whether the person tries to avoid talking to people who (s)he doesn't know or hasn't met before. To avoid someone is when you try not to see or meet someone, for example by going a different way home. New people are those whom you don't know, haven't seen before or haven't spoken to before.</p> <p>For example:</p> <ul style="list-style-type: none"> • The person may be embarrassed by the way (s)he looks, or fear rejection, or because (s)he is wary of strangers.
18.	<p>Do you feel confident to try to learn new things?</p> <p><i>Prompt: If someone suggested that you should try new occupations or skills or new vocations like embroidery, stitching, scooter repair, cycle repair, making incense sticks, envelopes, keeping rabbits or chickens, would you feel that you could learn or take up the new work?</i></p> <p>Note: the question is asking whether (s)he would TRY and learn new things, it is not asking whether (s)he actually does. The question is aiming to find out how hopeful the person is, and how (s)he feels about change. It also assesses how the person feels about him(her)self and his/her abilities, because of his/her disability / disease. A person may learn a new skill so that (s)he can earn an income for his/her family. This question is asking how the person feels about learning something new.</p> <p>For example:</p> <ul style="list-style-type: none"> • Some people may feel very hesitant and unsure about learning anything new because of their disease / disability.

- Add any comments the respondent may wish to make after the interview.
- Complete the respondent's information carefully.
- Write the name of the interviewer and date of the interview in the appropriate space.
- Add up the score and write the total in the box on the right, marked 'Total'.

Annex 3

Examples

Case 1

A 30-year-old male leprosy patient has mobile finger contractures of his right hand since one year. He also has a foot drop of his right foot, but this, he says, he has had since 3 years. His right hand and foot are both anaesthetic, but he says he has not had any ulcers so far. His left hand and foot and his eyes are OK. The patient has just taken dose 12 of his MB MDT. He is a farmer by profession, but has had difficulty doing his farming work because of the weakness in his right hand. Because of his leprosy, the villagers will not let him take part in joint farming activities anymore. He lives in a small village on a hillside, half a day's walk from the nearest road.

No.	Participation Scale	Not specified, not answered					NO problem	Small	Medium	Large	SCORE
			Yes	Sometimes	No	Irrelevant, I don't want to, don't have to					
			0			0	1	2	3	5	
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	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	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	5
4	Do you make visits outside your village / neighbourhood as much as your peers do? (except for treatment) e.g. bazaars, markets		①			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	0
5	Do you take part in major festivals and rituals as your peers do? (e.g. weddings, funerals, religious festivals)		①			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	0
6	Do you take as much part in casual recreational/social activities as do your peers? (e.g. sports, chat, meetings)		0	✓		0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	③	5	3
7	Are you as socially active as your peers are? (e.g. in religious/community affairs)		0		✓	0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	③	5	3
8	Do you have the same respect in the community as your peers?		0		✓	0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	②	3	5	2
9	Do you have opportunity to take care of yourself (appearance, nutrition, health, etc.) as well as your peers?		①			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	0
10	Do you have the same opportunities as your peers to start or maintain a long-term relationship with a life partner?		①			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	0

No.	Participation Scale	Not specified, not answered	Yes	Sometimes	No	Irrelevant, I don't want to, don't have to	NO problem	Small	Medium	Large	SCORE
			0				0	1	2	3	
11	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	5
12	Do you move around inside and outside the house and around the village / neighbourhood just as other people do?		①			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	0
13	In your village / neighbourhood, do you visit public places as often as other people do? (including 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	2
14	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	3
15	In family discussions, does your opinion count?		①			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	0
16	Do you help other people (e.g. neighbours, friends or relatives)?		①			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	0
17	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	3
18	Do you feel confident to try to learn new things?		①			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	0

Comment:

Name: Mr. B.B. Singh _____

Age: 30__ Gender: M____

Reason for the assessment: Referral because of social problems

Interviewer Mr. N. Thapa _____ Date of interview: 14 / 06 / 2004

TOTAL	36
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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.

The total score, 36, is well above the threshold for participation restriction (12). In fact, the score falls in the category 'severe restriction' and therefore rehabilitation interventions are indicated. The nature of these will need to be determined after an in-depth interview with the client. Decisions should only be made with his/her full input, as well as that of family members, if possible.

Case 2

A man of 60 has diabetes with a deep, chronic ulcer on his right heel. The ulcer has been there off and on for the last 10 years. It heals during admission in hospital, but usually recurs within 1-2 months after discharge. He has been injecting insulin for the last 5 years. With his closed shoes, he has been able to hide his problem from anyone but his own family. As headmaster of a private boarding school, he has understood all instructions about ulcer care very well and follows the instructions meticulously. Still the ulcer will not heal. He worries what would happen to his school, if parents found out about his disease and his foot ulcer. The last two years he has been very depressed about his condition.

No.	Participation Scale	Not specified, not answered	Yes	Sometimes	No	Irrelevant, I don't want to, don't have to	NO problem	Small	Medium	Large	SCORE
			0				0	1	2	3	
1	Do you have equal opportunity as your peers to find work?		①			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	0
2	Do you work as hard as your peers do? (same hours, type of work etc)		①			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	0
3	Do you contribute to the household economically in a similar way to your peers?		①			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	0
4	Do you make visits (travel) outside your village / neighbourhood as much as your peers do? (except for treatment) e.g. Bazaars, nearby villages / neighbourhoods		0		✓	0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	⑤	5
5	Do you take part in major festivals and rituals as your peers do? (e.g. weddings, funerals, religious festivals)		①			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	0
6	Do you take as much part in casual recreational/social activities as do your peers? (e.g. sports, chat, meetings)		0	✓		0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	②	3	5	2
7	Are you as socially active as your peers are? (e.g. in religious/community affairs)		0		✓	0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	③	5	3
8	Do you have the same respect in the community as your peers?		①			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	0
9	Do you have opportunity to take care of yourself (appearance, nutrition, health, etc.) as well as your peers?		0	✓		0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						①	2	3	5	1
10	Do you have the same opportunities as your peers to start or maintain a long-term relationship with a life partner?		①			0					
	<i>[if sometimes or no]</i> How big a problem is it to you?						1	2	3	5	0
11	Do you visit other people in the community as often as other people do?				✓	0					
	<i>[if sometimes or no]</i> How big a problem is it for you?						1	②	3	5	2

No.	Participation Scale	Not specified, not answered	Yes	Sometimes	No	Irrelevant, I don't want to, don't have to	NO problem	Small	Medium	Large	SCORE
			0				0	1	2	3	
12	Do you move around inside and outside the house and around the village / neighbourhood just as other people do?		①			0					
	<i>[if sometimes or no] How big a problem is it to you?</i>						1	2	3	5	0
13	In your village / neighbourhood, do you visit public places as often as other people do? (including schools, shops, offices, market and tea/coffee shops)		①			0					
	<i>[if sometimes or no] How big a problem is it to you?</i>						1	2	3	5	0
14	In your home, do you do household work?		0		✓	0					
	<i>[if sometimes or no] How big a problem is it to you?</i>						1	②	3	5	2
15	In family discussions, does your opinion count?		①			0					
	<i>[if sometimes or no] How big a problem is it to you?</i>						1	2	3	5	0
16	Do you help other people (e.g. neighbours, friends or relatives)?		0	✓		0					
	<i>[if sometimes or no] How big a problem is it to you?</i>						①	2	3	5	1
17	Are you comfortable meeting new people?		①			0					
	<i>[if sometimes or no] How big a problem is it to you?</i>						1	2	3	5	0
18	Do you feel confident to try to learn new things?		①			0					
	<i>[if sometimes or no] How big a problem is it to you?</i>						1	2	3	5	0

Comment:

Name: Mr. M.B. Thomas _____

Age: 60__ Gender: M_____

Interviewer: Ms. S. Gracia _____

Date of interview: 15 / 06 / 2004

TOTAL	16
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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.

The total score, 16, is just above the threshold for participation restriction (12). The score falls in the category 'mild restriction' and therefore rehabilitation interventions may not be required. Whether for example counselling would be helpful in this situation will need to be determined in an in-depth interview with the client. Decisions should only be made with his/her full input, as well as that of family members, if possible.

Annex 4

Guidelines for translating the Participation Scale

Please find below some guidelines for the translation of the Participation Scale. The English version of the Scale will be referred to as the 'generic P-scale'. The translation guidelines have been modified from the translation guidelines of the WHO Disability Assessment Schedule II (WHODAS II). The 'Question-by-Question' document with explanations of each question should be thoroughly read by all interviewers and should also be translated, unless the interviewers are sufficiently fluent in English.

The Programme Manager will be responsible to get the translation work done, although (s)he may delegate the actual work to others (see page 8).

General translation guidelines

- Always aim at the CONCEPTUAL EQUIVALENT, not a word-by-word translation nor etymological equivalent. Think about the meaning of the original question and try to translate the question in the most relevant (to your setting) manner. Try to be simple, clear and concise.
- The minimum that needs translating is the scale itself, possibly excluding the instructions to the interviewers (such as "[If sometimes, no or irrelevant]").
- The translation in the TARGET language should aim at the most common audience. Avoid addressing only the medical, legal or any other group.
- AVOID JARGON - Do not use:
 - technical terms - that cannot be understood clearly
 - colloquialism - those idioms and vernacular terms that cannot be understood by most common people in everyday life.
- Think about gender applicability and age applicability - is the term applicable or offensive?

Translation procedure

The translation procedure should consist of a translation from the generic English version into the target language. This is followed by a back-translation into English, to check that the original meaning has been preserved.

- The initial TRANSLATION should be done by (an) EXPERT(S) in DISABILITY, i.e., those who are familiar with the concepts and, therefore, know what concept is to be translated.
- The BACK-TRANSLATION should be conducted by (a) LINGUISTIC EXPERT(S) (blind to initial - original terms and independent of the TRANSLATORS).
- A DISCUSSION between TRANSLATOR(S) and BACK TRANSLATOR(S) should be held to ensure that the translation is satisfactory and to resolve differences to arrive at a final translation.

Response scale translation

- As noted, the goal in translation is conceptual equivalence. This is particularly true when translating the 5-point response scales of the P-scale. The response scale is critical to the P-scale and therefore, translation should be carefully conducted to reflect the original response categories

and also be meaningful in the culture. Attention should be paid to the context in which the scale will be used while selecting the terms for the scales.

Problems with the translation

Linguistic differences such as problems caused by changes in the meaning of words between dialects, translation difficulties, and difficulties that arise while applying a concept across cultures constitute some of the primary cross-cultural barriers to the applicability of an assessment instrument.

During the translation process, several possible problems will be encountered. These are:

- a. The term cannot be translated into the local language, or translation is very difficult, because there is no exact equivalent idiom or concept in the local language. This may apply to local variations in the English language as well and ought to be addressed.
- b. The meaning of the original term is modified during translation because a) only part of the original meaning is present in the local language term. Part of the original connotations are lost. This makes the item too narrow in meaning. Alternatively, b) the original meaning is expanded in the local language term. The local term has more (and different) connotations than the original. This makes the translated item too broad in meaning.
- c. Two or more terms from the P-scale translate into the same term in the local language. The distinctions between the original items are lost.
- d. The term can be translated, but there are cultural applicability issues with the definition or the examples given in the definition. These issues can include cultural applicability of the item, definition, or examples; a lack of correspondence between the local resources or environment and the definition or examples; or a condition that makes the item or definition irrelevant in the local culture.

In case a translation problem cannot be locally resolved, the Principal Investigator should seek advise from the Participation Scale Development Team.

Glossary

The following terms and definitions have been taken from the ICF:⁴

Functioning is an umbrella term encompassing all body functions, activities and participation;

Disability is an umbrella term for impairments, activity limitations or participation restrictions.

In the context of health:

Body functions are the physiological functions of body systems (including psychological functions).

Body structures are anatomical parts of the body such as organs, limbs and their components.

Impairments are problems in body function or structure such as a significant deviation or loss.

Activity is the execution of a task or action by an individual.

Participation is involvement in a life situation.

Activity limitations are difficulties an individual may have in executing activities.

Participation restrictions are problems an individual may experience in involvement in life situations.

Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

Other terms:

Peers are those who are similar to the respondent in all respects (socio-cultural, economic and demographic) except for the disease or disability.

Problem refers to a participation restriction

⁴ International Classification of Functioning, Disability and Health, WHO, 2001

Participation Scale Feedback Form

Details of the institution or programme:

Name of the institution or programme:

Mailing address:

Telephone number:

Fax number:

Email address:

Superintendent or Director's name:

Training in the use of the Participation Scale

Number of staff trained in the use of the Participation Scale:

Designation:

Number:

Designation:

Number:

Designation:

Number:

Designation:

Number:

Comments on the Training instructions:

Suggestions for improvement:

Comments on the rest of the Manual:

Suggestions for improvement:

Use of the Participation Scale

Type of programme in which the scale was used (please circle as many as applicable):

- Field- or community-based rehabilitation programme
- Hospital-based rehabilitation programme
- Hospital in-patient assessment
- In an Occupational Therapy department in a hospital or rehabilitation centre
- In a Physiotherapy department in a hospital or rehabilitation centre
- In a Social Work department in a hospital or rehabilitation centre
- Other (please describe)

Number of staff involved in the interviews with the Participation Scale:

Designation:	Number:
Designation:	Number:
Designation:	Number:
Designation:	Number:

Total number of interviews conducted:

Category and number of (potential) clients interviewed:

Leprosy:
 Locomotor disability (polio, injury, etc.):
 Neuro-disability (spinal cord injury, stroke, etc.):
 Hearing impairment:
 Visual impairment:
 HIV/AIDS:
 Mental disability:
 Other:

Average interview duration:

Assessment of the ease of asking the questions in the scale (please tick):

Very easy	Easy	Not too difficult	Difficult	Very difficult

Comments on the Question by Question guide:

Suggestions for improvement:

Assessment of the ease of use of the response scales (please tick):

Very easy	Easy	Not too difficult	Difficult	Very difficult

Assessment of the ease of calculating the Participation sum score (please tick):

Very easy	Easy	Not too difficult	Difficult	Very difficult

Overall assessment of the ease of use of the Participation Scale (please tick):

Very easy	Easy	Not too difficult	Difficult	Very difficult

Who used the results of Participation Scale?

Category of staff:

Purpose:

Category of staff:

Purpose:

Overall assessment

Overall assessment of the utility of the Participation Scale in your (rehabilitation) work (please tick):

Not useful	Sometimes useful	Useful	Very Useful	Essential

Will you continue to use the Participation Scale in your institution or programme (please tick)?

No	Only after revision	For some clients only	For most clients	Yes, always

If yes, in which programme(s):

- 1.
- 2.
- 3.

Are there any additional comments you would like to make?

Name of the person who filled in the form:

Designation:

Date:

Please email the form to <w.v.brakel@kit.nl>
Thank you very much for your kind cooperation!