Measuring social participation restrictions of persons affected by leprosy in Central Java through validating the Participation Scale Short Simplified (PSSS)

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1 Abstract

Introduction: Persons affected by leprosy are still likely to experience social stigma and participation restrictions. Measuring the level of participation is essential for the development, implementation and evaluation of appropriate stigma reduction, rehabilitation and other services and so diminish leprosy-related stigma in Indonesia. The Participation Scale is an 18-item questionnaire that is internationally used to measure the severity of restrictions experienced by persons with disabilities and others with conditions that are stigmatised or that may limit their social participation. However, some problems were reported with conducting the P-Scale, especially when used with low-literate respondents. An earlier attempt to simplify the P-Scale was not entirely satisfactory and thus there still was a need to further develop an improved shortened and simplified version of the P-scale to enable a quick participation assessment.

Objective: The purpose of this study was (A) to develop a simplified and shortened version of the P-scale that can be used to assess participation restrictions in Indonesia and (B) to measure the level of participation restrictions experienced by persons affected by leprosy in Central Java, Indonesia.

Methods: This study took place in Central Java, Indonesia. After developing the Participation Scale Short Simplified (PSSS), a focus group discussion and fifteen semi-structured interviews were conducted to assess the operational, item and semantic validity. The PSSS was refined after analysing the qualitative results. In the quantitative phase, interviews took place using both the PSSS and P-Scale in random order. The sample consisted of 112 persons affected by leprosy and 54 control persons. After six to nine days, 47 interviews with persons affected by leprosy were repeated. To assess to measurement validity, the following psychometric properties were calculated: criterion validity, internal consistency, reproducibility, floor and ceiling effects ad interpretability.

Results: After a few adjustments, the questionnaire was understood sufficiently well and was considered relevant and acceptable by the vast majority of respondents. The criterion validity was assessed with Spearman correlation, showing a positive correlation between the PSSS and full Participation Scale (r=0.688). The cut-off to obtain an optimal combination of sensitivity and specificity (respectively 0.82 and 0.75) was nine. A Cronbach's alpha of 0.84 showed a good internal consistency. An Intra Class Correlation coefficient of 0.74 indicated good reproducibility. No floor and ceiling effects were present. Within our study sample, 38.5% of the persons affected by leprosy experienced participations restrictions, compared to 9.3% of the control group.

Conclusion: The PSSS shows good qualitative and psychometric properties, just as the full Participation Scale and enables a rapid assessment which reduces the burden of patients. It is a suitable tool for assessment of the severity of participation restrictions among persons affected by leprosy, and for evaluation and comparison of participation restrictions between groups and programmes in Central Java, Indonesia. We recommend the use of the PSSS, instead of the full version, especially in a target group with a low education level and when a rapid assessment is needed.

2 Background

In this section, the definitions of disability, stigma and participation will be explained, as well as the current possibilities for measuring these concepts. Furthermore, the use of the Participation Scale will be discussed. Lastly, participation among persons affected by leprosy in Indonesia will be discussed.

2.1 Disability

According to the WHO, more than one billion people worldwide live with a disability.(1) This means that one in seven people lives with a form of disability, though this is not always noticed by the community. When speaking about disability, the physical impairment is often the first thing to come into our minds. The residual impairment that remains after the injury, disease or birth defect can lead to difficulties in functioning.(2) However, the physical impairment is only the first conceptual component of disability, which can restrict people on many other levels than the psychical and thus visible one. In order to achieve consistency in the definitions of disability, the WHO has made a framework named the International Classification of Functioning, Disability and Health (ICF). According to the ICF, disability is defined as: 'An umbrella term for impairments, activity limitations or participation restriction. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).' (3) However, this definition has been the product of a long debate. In the view of Leonardi, the definition should not only focus on the medical aspect, but be placed in the context of one's environment.(4) With this bio-psycho-social model, we are able to compare those who experience disability and, most important of all, identify and reduce this inequality. Altman describes disability as a process, from medical condition to restricted participation.(2) As we now know, the interaction with one's environment influences the levels of functioning of person with disability. For instance, behaviour from people in the environment, such as stigma, influences the disabled person and can lead to a restricted participation. This relationship with the disabled person and his or her environment will have our focus on in this study.

Disability is often linked to disadvantage, although this is not always the case.(5) This inequality in disability is seen in women or people with mental health conditions, who seem to be more disadvantaged than other persons with disabilities in certain settings.(5) When we look at the distribution of disabled people worldwide, we also see an unequal distribution. Some groups are disproportionally affected by disabilities, as is the case for people with a low socio-economic status in the Global South, who are at a higher risk of contracting disabling conditions such as leprosy.(6,7)

Leprosy belongs to the group of neglected tropical diseases (NTDs) and is also known as Hansen's Disease. The disease is caused Mycobacterium leprae, which mainly affects the skin and peripheral nerves. Transmission occurs through inhalation of droplets from the nose or mouth.(7) The physical impairment caused by the nerve damage often leads to disabilities, limiting the activities that involve the use of hands, feet and eyes. Since 1981, it is possible to cure this disease with Multi Drug Therapy (MDT) and prevent disability with early detection. However, persons affected by leprosy are still likely to experience social stigma and participation restriction, leading to economic loss.(8)

2.2 Stigma and participation

Stigma is defined as ‘A social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group’.(9) Jones states that this social phenomenon was already known in early Greek and Roman society when the word stigma was used for the tattoos or marks that described the social status of criminals or slaves.(10) A broader perspective has also been adopted by Corrigan who writes that stigma nowadays not refers to individuals, but rather to the sociocultural process.(11) The term ‘stigma’ is often associated with health, because sickness or disability is perceived as undesirable and may give rise to negative attitudes from society. In the past decades, health-related stigma has become a topic of growing interest among health professionals and researchers.(9) According to Weiss et al., stigma can be divided into three types: enacted, anticipated and internalized stigma. Enacted stigma includes ‘discrimination’, which refers either to negative attitudes enacted by the community or to the various forms of social exclusion experienced by the affected person. Anticipated stigma is the perceived likelihood of this happening. The third type of stigma is internalized stigma, where the negative stereotypes or attitudes are internalized by the affected person, leading to feelings of guilt, shame and even withdrawal from society.(12)

Stigmatization impacts individuals in many ways, ranging from psychological problems to participation restrictions.(13) These aspects of disability are described in the ICF, where activity is defined as ‘the execution of a task or action by an individual’ and activity limitations as difficulties experienced in performing these activities. Another concept used is participation or ‘involvement in a life situation’. When participation is restricted, this refers to the problems one may experience in involvement in life situations. The ICF includes nine domains of participation, ranging from domestic life to interpersonal interactions and relationships.(3) In addition, health-related stigma has many negative effects on public health programmes and interventions, while it also delays the help-seeking behaviour of patients. For example, in the case of leprosy we should keep in mind that ‘the absence of diagnosis of leprosy is not the same as the absence of leprosy’. (14) This means that not all cases are detected due to the absence of help-seeking behaviour, which forms a barrier to interrupting transmission and to measuring the overall disability of leprosy.

Participation restrictions are often caused or aggravated by social stigma.(8) This can be anticipated or internalised stigma, or actual negative attitudes or enacted stigma in the community. For example, in Indonesia, stigma is commonly seen in persons with external manifestations of leprosy. Research showed that persons affected by leprosy who have visible signs tend to experience more stigma resulting in more severe participation restrictions than those without visible signs of the disease.(15) Therefore, the level of restriction experienced by the person with disability can be used in the measurement of (the impact of) stigma. In order to quantify and assess the level of these restrictions, there is need for validated measurement tools.

2.3 Measuring disability

The high prevalence of disability in low and middle-income countries demands for appropriate approaches and suitable tools for measuring their disability.(16) Multiple tools have been designed to measure the severity of different types of disability. Unfortunately, these tools use different concepts of disability, making it difficult to compare the outcomes.(16)

The ICF gives a framework for the description of health and disability.(3) Through defining the different domains of life that relate to the experience of disability, universal tools have been developed to measure and monitor the effect of interventions and their impact on the level of disability people experience. Furthermore, the WHO introduced a disability grading system for leprosy – no sensory or visible impairments is grade 0; an impaired sensation without visible impairments is grade 1; visible impairments is grade 2 – which was used to calculate the 'grade 2 disability proportion among new cases'. This is used as a proxy indicator for delay in case detection. The system is also used to assess changes in disability during and after treatment.(17) With the implementation of this system, a universal system for measuring impairment severity in leprosy was born. According to the WHO report of 2011, many countries and international agencies are making efforts to improve the knowledge and data on disability. However, especially in developing countries this requires more comparable data collection.(5) To plan stigma reduction measures and to promote social inclusion of persons affected, there is an urgent need for validated instruments to map the existence of stigmatization and its effect on participation of persons with disabilities in the community. With evidence-based information, new or improved services can be planned, monitored and evaluated.

2.4 Measuring stigma and participation restrictions

Measurement of stigma and participation restrictions is important for the understanding of its determinants. This knowledge is essential for comparing stigma between groups and for implementation, monitoring and evaluation of intervention programmes. For this measurement, multiple tools have been designed, tested and validated in different settings. Van Brakel performed a systematic review to identify all available tools to measure health-related stigma. The research pointed out that the consequences of stigma were remarkably similar in the different health conditions, cultures and health programmes. However, besides the Explanatory Model Interview Catalogue (EMIC), most other stigma tools were condition-specific and could not be generically used. Therefore, the need was identified for existing instruments to be adapted, where necessary, and validated in order to provide instruments for generic use.(13)

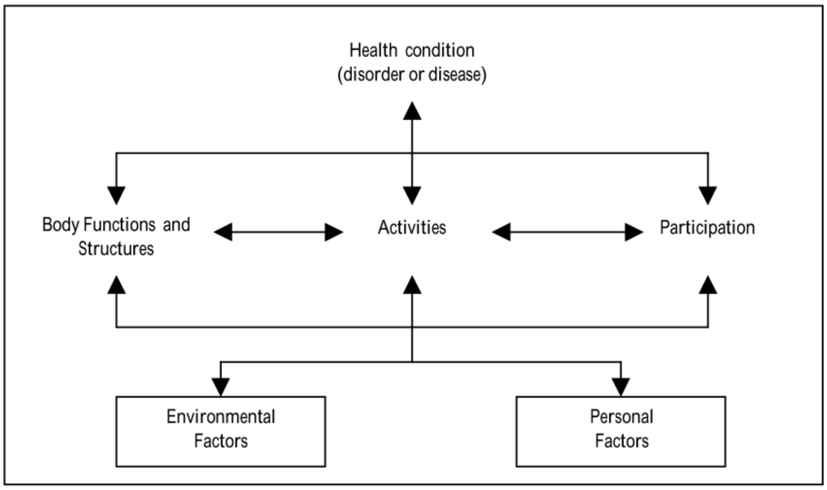
In the case of assessment of social participation, a review was done on the cross-cultural equivalence of the existing instruments.(18) Unlike the study on instruments for stigma, this review focussed on the differences in cultural setting in which participation is assessed. The meaning of the items and format of the instrument may vary between different cultures. Therefore, an instrument cannot simply be used in a different culture than initially designed for. Most instruments are developed in the English language and should be tested for cultural validity before use. Unfortunately, the cross cultural validation of these instruments is often insufficient.(18)

Participation is a relatively new construct, resulting in a limited number of available tools.(19) Most studies have used qualitative assessment to indicate the level of participation. However, quantitative methods are more suitable for conducting representative, generalizable assessments.(20) Examples of quantitative scales for measuring participation are the Perceived Handicap Scale (PHQ) and the London Handicap Scale (LHS), which are both based on the participation domains of the ICF. Furthermore, the Impact on Participatory and Autonomy Questionnaire (IPAQ), the Assessment of Life-Habits (LIFE-H) and the Participation Scale (P-scale) are commonly used. Only the latter was initially developed for use in low and middle-income countries.

2.4.1 The Participation Scale

The Participation Scale (P-scale) was developed to meet needs identified by a rehabilitation programme in Nepal in 1999. At that time, other instruments for measuring participation were only applicable in high-income countries and not suitable for evaluating the impact of interventions. The Participation Scale Development Programme, coordinated by Van Brakel and colleagues, used a rigorous scale-development programme that resulted in an 18-item questionnaire.(19) The P-scale is suitable for use in low and middle income countries and can be used for monitoring and evaluating interventions, comparing the level of social participation of individuals compared to the perceived level of participation of their peers.(21) The P-scale is based on the participation domains of the ICF (*Figure 1*). The positive aspect of activity and participation is called functioning, in contrast to the negative aspect of activity limitations and participation restrictions. The P-scale is based on the nine domains of participation that are described in this model: Learning and applying knowledge, Communication, Mobility, Self-care, Domestic life, Interpersonal interactions and relationships, Major life areas and Community, Social and Civic life, General tasks and demands.(3) Only the latter domain is not included in a question of the instrument.

Figure 1. ICF-model



Source: International Classification of Functioning, Disability and Health (2001)(3)

The instrument consists of 18 items, of which each question has a two-level structure. Each item asks the respondents to compare themselves with a peer (*'someone like you in every aspect, but without the condition under review'*). First, the respondent is asked whether they experience their participation to be the same as their peers, for instance: '*Are you as socially active as your peers are?*' If not or sometimes, they are asked whether they experience this restriction as a problem, on a scale from 'no problem' to 'large problem'.

The P-scale is now internationally used to measure the severity of restrictions experienced by persons with disabilities and others with conditions that are stigmatised or that may limit their social participation.(22,23) Data may be used for research, e.g. to examine factors that influence social participation or the influence of participation on other outcomes, such as mental wellbeing or quality of life.(19) Data are also used to plan, monitor and evaluate intervention services or specific measures to reduce stigma.(19,24) However, some problems in using the P-scale have been reported.

Understanding the scale:

- Respondents with a low level of education had difficulties in understanding the questions
- Some respondents found the two-levels structure was too difficult to understand
- Some questions appeared to have a similar meaning, which confused the respondents

The peer concept:

- Some participants had sufficient knowledge of language, but were not able to grasp the concept of a peer
- No suitable peer could be identified

Assessment time:

- The assessment time was too long (10 minutes to 1-2 hours)

Consequently, an attempt was made to simplify the format of the tool. Kelders et al. performed a study in 2010, in which they tested a shortened and simplified version of the Participation scale.(22) Items with a poorer item-to-total correlation were omitted, and a question about starting or maintaining a long-term relationship was added, resulting in a 15-item questionnaire. The questions were transformed into more direct and short questions and difficult words were replaced. In addition, the peer concept was replaced by the use of 'other people'. Lastly, the two-level structure was integrated into one question. The results of this research showed that the simplified version was still perceived to be too difficult in some areas of Indonesia. People with low education had difficulties understanding the questions, whereas a 'good' tool needs to be understood immediately. In the case of Kelders' study, this might have been due to language differences between the participant groups, because not all participants spoke Bahasa Indonesia fluently. Afterwards, Stevelink et al. conducted a study to shorten the P-scale. Their Participation Scale Short (PSS) consists of 13 items and was tested in multiple datasets, with the main goal of reducing the time needed for conducting the scale interview, meeting the needs of a quick assessment.(21) Afterwards, Jansen tested this short version (PSS) in India, showing good psychometric properties.(25) The PSS distinguished well between different groups and reduced the average interview time with 3 minutes to 6.30 minutes.(25) However, the format of the scale, the question structure, peer comparison and answer options of the PSS are identical to that of the full P-scale. Given the above difficulties in certain target groups and the equivocal results of the study of Kelders et al, there was still a need to develop an improved shortened and simplified version of the P-scale. Previous studies gave suggestions for further simplifying the scale.

2.5 Sociographic data of the research area

Indonesia is a large country with over 260 million inhabitants, spread over more than 16,000 islands. As mentioned before, the global distribution of disability this unequal. In the case of Indonesia, the number of people with disability is higher than in other countries.(26) However, this exact number remains unknown. The Census 2010 estimates the overall disability rate to be 4.3%, while 13.3% of the Indonesian households exist of one or more persons with disability, making all family members more vulnerable to a low socio-economic status.(27) In Indonesia, the majority of disability is estimated to be caused by disease.(26,27) Furthermore, the prevalence of disability in Indonesia increases with age and is significantly more seen in rural areas and among women. The main effects of disability in Indonesia are: reduced years of education and prospects on work, reduced access to public health services and a lower socio-economic status.(27) Furthermore, the Riskesdas 2007 shows significant differences between the provinces of Indonesia.(28) Our research will be executed in the province Central Java that has an estimated number of 32.2 million inhabitants according to the Census 2010. The percentage of people with disability in Central Java is only 3.77%, which is below the mean of Indonesia (4.3%).(29) However, due to the high population of this area, the number of people with disability is still the highest here (*Figure 2*). Our qualitative research will be executed in Semarang district, the capital of Central Java. This urban-rural district is mainly based on large manufacturing industries.(30) The quantitative part of the research was mainly located in and around Donorojo Hospital, which is specialised for leprosy. The hospital has a number of patients that are there for longer treatment (70 beds) and a few patients that live there permanently. There are two operation theatres, to operate the patients for their ulcers and other effects of leprosy. The hospital also provides psychological help and a physiotherapy room, where the staff makes protheses themselves.

Figure 2. Disability in Indonesia

Source: 'Disability in Indonesia: What can we learn from the data?' (27)

2.5.1 Participation among persons affected by leprosy in Indonesia

Indonesia currently has the third highest level of leprosy infection worldwide, with a prevalence of over 20,000 infections. Leprosy control programmes in Indonesia still have problems with a delay in treatment, which increases the risk of physical impairments and its effect on social participation.(31) A recent study that examined the community perception of leprosy in East-Java points out that there is a high level of stigma reflected in the community. Leprosy is seen as a shameful disease and many cause-related beliefs contribute to this negative perception. Furthermore, persons affected by leprosy were found to be treated differently in the community.(32) Additionally, multiple studies on this subject were performed in Cirebon District, West-Java.(33–37) The studies showed a positive effect of interventions to reduce stigma in people affected by leprosy. (34,36) A qualitative study showed that the experiences of persons affected by leprosy differ widely and are not limited to leprosy as a medical issue.(33) Another recent study stated that even within Cirebon District significant difference in leprosy-related stigma were found.(37) The culture between different provinces of Indonesia varies widely, therefore the perception of leprosy in Central Java may differ from other parts of Java. Therefore, not much is known about the social stigma and participation restrictions that accompany this disease in the province of Central Java.

3 Objectives and research questions

3.1 Overall objective

We aim to contribute to the development, implement and evaluation of more appropriate stigma reduction, rehabilitation and other services for persons affected by leprosy and so diminish leprosy-related stigma in Indonesia.

3.2 Specific objectives

The purpose of this study was (A) to develop a simplified and shortened version of the P-scale that can be used to assess participation restrictions in Indonesia and (B) to measure the level of participation restrictions experienced by persons affected by leprosy in Central Java, Indonesia.

3.3 Specific research questions

For this study, the first objective was to validate the Participation Scale Short Simplified (PSSS):

1. To what extent does the PSSS have adequate item, semantic, operational and measurement validity to measure social participation in persons affected by leprosy in Central Java, Indonesia?
2. Does the PSSS have adequate criterion validity (sensitivity and specificity) compared to the full version of the Participation Scale?

After validating and testing the PSSS, the data was used to answer the following questions:

1. What are the restrictions experienced by persons affected by leprosy according to the PSSS in Central Java, Indonesia?
2. What is the prevalence of participation restrictions experienced by persons affected by leprosy according to the PSSS in Central Java, Indonesia?

4 Methods

4.1 Conceptual framework

4.1.1 Quality criteria for psychometric properties

In 2007, Terwee et al. have proposed quality criteria to assess the methods, design and outcomes of studies that develop and evaluate health status questionnaires. These criteria can be used to compare the measurement properties of different questionnaires. Terwee et al. distinguish nine quality criteria and benchmarks to achieve good measurement properties, which we will briefly discuss in Table 1.(38)

The content validity, construct validity, agreement and responsiveness were not tested our study. The content of the P-scale has been extensively tested in the past and has been used in several studies in Indonesia already.(8,34,37,39,40) In addition, considering that we will not add to or remove components from the instrument, the construct of the P-scale was assumed to still be valid. Furthermore, the responsiveness cannot be calculated, because in the short time between the interviews no clinically important changes could be expected. Lastly, Stevelink et al. have already performed an exploratory and confirmatory factor analyses on a large dataset in 2013 to establish the items of the Participations Scale Short (PSS) on which the PSSS is based, therefore we will not perform a factor analysis. The rest of the properties will be assessed according to the quality criteria stated in Table 1. Of these properties, the criterion validity will be the most important. We will test the criterion validity (sensitivity and specificity) against the gold standard, which is the 18-item P-scale.

Table 1. Quality criteria for 'good measurement properties'

Property	**Definition**	**Quality criteria**
Content validity	*"The extent to which the domain of interest is comprehensively sampled by the items in the questionnaire"*	Clear description of the measurement aim, the target population, the concepts that are being measured. In the item selection, the target population and investigators or experts were involved.
Internal consistency	*"The extent to which items in a (sub)scale are intercorrelated, thus measuring the same construct"*	Factor analyses performed on adequate sample size (7 * # items and >100) and Cronbach's alpha(s) calculated per dimension and between 0.70 and 0.95.
Criterion validity	*"The extent to which scores on a particular questionnaire relate to a gold standard."*	Convincing arguments that gold standard is ''gold'' and correlation with gold standard >0.70.
Construct validity	*"The extent to which scores on a particular questionnaire relate to other measures in a manner that is consistent with theoretically derived hypotheses concerning the concepts that are being measured"*	Specific hypotheses were formulated and at least 75% of the results are in accordance with these hypotheses.
Reproducibility: Agreement	*"The extent to which the scores on repeated measures are close to each other (absolute measurement error)"*	MIC < SDC or MIC outside the LOA or convincing arguments that agreement is acceptable.
Reproducibility: Reliability	*"The extent to which patients can be distinguished from each other, despite measurement errors (relative measurement error)"*	ICC or weighted Kappa>0.70.
Responsiveness	*"The ability of a questionnaire to detect clinically important changes over time"*	SDC or SDC<MIC or MIC outside the LOA or RRO1.96 or AUC>0.70 (ROC-curve).
Floor and ceiling effects	*"The number of respondents who achieved the lowest or highest possible score"*	<15% of the respondents achieved the highest or lowest possible scores.
Interpretability	*"The degree to which one can assign qualitative meaning to quantitative scores"*	Mean and SD scores presented of at least four relevant subgroups of patients and MIC defined.

Source: Terwee et al.: Quality criteria were proposed for measurement properties of health status questionnaires (2007) (38)

4.1.2 Cross-cultural equivalence testing

Herdman et al. constructed a model to evaluate the cross-cultural validity of health questionnaires. The model can be used to test the equivalence of an instrument across different cultures.(41) The types of equivalence can be found in Table 2. Functional equivalence can also be described as cultural equivalence, and can be seen as the overall ability of an instrument to be used in another culture.(18)

Table 2. Model of equivalence by Herdman

Equivalence	Definition
Conceptual equivalence	The instrument has the same relationship to the underlying concept in both cultures
Item equivalence	Items are equally relevant and acceptable in both cultures
Semantic equivalence	Achieving a 'similar effect' on respondents who speak different languages (the meaning is the same)
Operational equivalence	The possibility to using a similar questionnaire format, instructions, mode of administration and measurement methods
Measurement equivalence	Psychometric properties of the adapted version of the instrument are equivalent to the original

Source: Herdman et al: A model of equivalence in the cultural adaptation of HRQoL Instruments: the universalist approach (1998) (41)

The conceptual equivalence was not tested, because the concept of participation has been widely examined in the context of Indonesia. The other 4 equivalences were used to assess the cultural validity of the PSSS. First, we have tested whether the phrasing and meaning of the items is clear to the respondents ('semantic validity'). Although the content has not changed substantially, we have still examined whether the items are relevant to the respondents' condition ('item validity'). Subsequently, we needed to ensure that the new format of the instrument worked well and that the response scales were easily understood ('operational validity'). The measurement validity was established using the criteria that have been stated in Chapter 3.1.1. Together these components determine the cultural validity of the PSSS.

4.1.3 Cultural validation

Furthermore, Stevelink has developed an applied cultural equivalence framework based on Herdman (41), Bowden & Fox-Rushby (42) and Terwee et al.(38), in order to further facilitate the cross-cultural validation process.(18) Stevelink made several adaptations to the framework of Herdman, mostly in the section of measurement properties. In the model of Herdman, only construct validity, reliability and responsiveness are noted as needed for measurement equivalence. Stevelink extended this with the criteria for 'good measurement properties' from Terwee et al.(38) For the scope of this research, we made a checklist based on Stevelink et al, Terwee et al and Herdman. The properties we choose to assess are shown in Table 3.

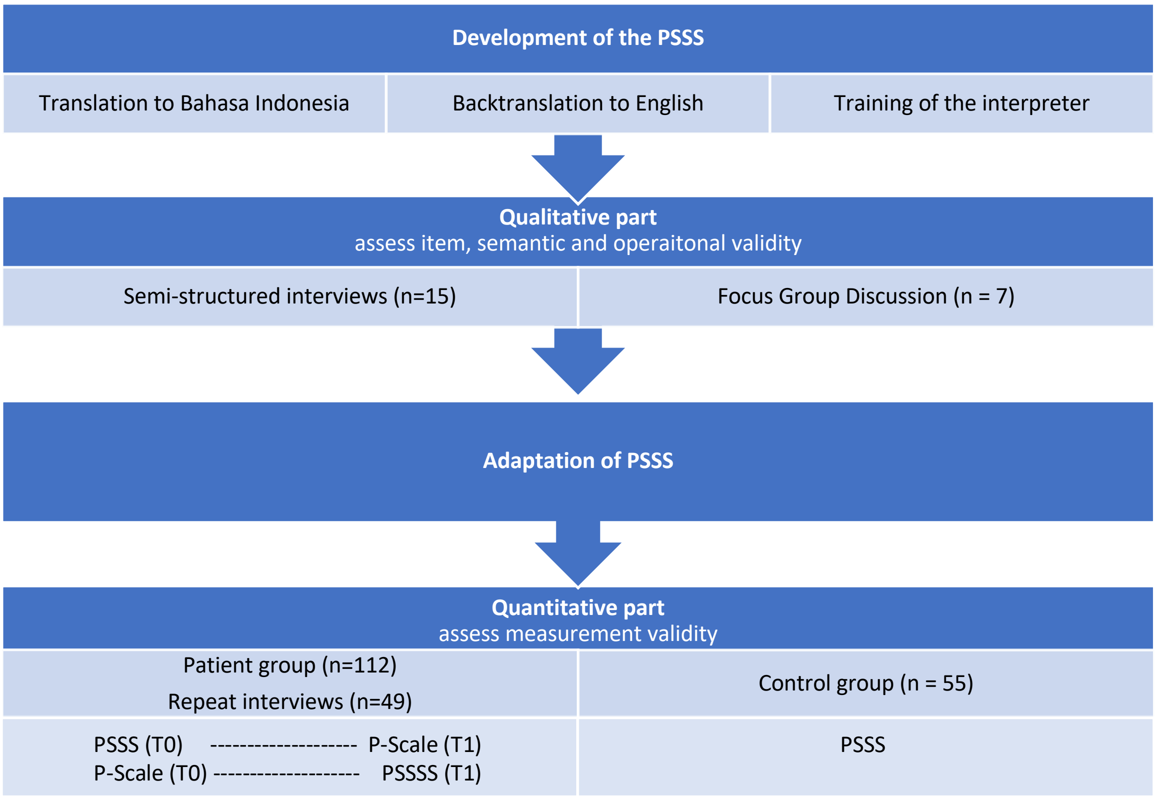
Table 3. Assessment of cultural validity

Validity	Adherence
Item	
	Description of the assessment: 1) the relevance or acceptability of individual items to the target population 2) item discussed in the light of any quantitative or quality analyses results 3) discussion of adaptations made based on findings regarding individual items
Semantic	
	Description of the key issues: 1) reference to the translation guidelines used, or user manual including translation instructions 2) details provided on the translation procedure 3) meaning of key words and phrases 4) description of any problems or difficulties encountered during the translation.
Operational	
	A description of the key issues: 1) assessment of missing data 2) discussion on administration format 3) discussion of the response scales 4) pre-testing of the instrument
Measurement	
- Criterion validity	1) Convincing arguments that gold standard is ‘‘gold’’ 2) Correlation with gold standard >0.70. 3) Acceptable sensitivity and specificity
- Internal consistency	1) Cronbach’s alpha(s) calculated per dimension and between 0.70 and 0.95.
- Reliability	1) ICC > 0.70
- Floor and ceiling effects	1) <15% of the respondents achieved the highest or lowest possible scores.
- Inter-pretability	1) Mean and SD scores presented of at least four relevant subgroups of patients

4.2 Study design

In order to answer these questions, we have performed a cross-sectional within–person comparative study using mixed methods. The research included a qualitative and a quantitative part. The Participation Scale Short Simplified was tested against the original Participation Scale. The whole process is showed in Figure 3.

Figure 3. Research process



4.3 Study site, population and sample

The data collection took place from mid-July until the end of September 2018 in the province of Central Java, Indonesia.

4.3.1 Inclusion and exclusion criteria

The study population of the qualitative and quantitative part adhered to the same inclusion and exclusion criteria. The participants consisted of people affected by leprosy living in Central Java that were able to answer questions independently. Not all Indonesians living in Central Java speak Bahasa Indonesia fluently. If this was the case, the participants were excluded from the study. The original P-scale was designed and validated for persons aged 16 years and older, so the shortened simplified version used the same age limit.

Inclusion criteria

- Persons who have been diagnosed to have leprosy
- Persons aged 16 years and older
- Persons that can speak Bahasa Indonesia with sufficient fluency
- Persons that can answer the questions independently
- Persons who live in Central-Java

Exclusion criteria

- Persons who are unwilling or unable to give informed consent
- Persons that have been interviewed with (a version of) the P-scale in the past 6 months

4.3.2 Qualitative part

The qualitative part was conducted in Semarang, which is the largest city of Central Java and home to the Diponegoro University. This university supported the study by hosting the researcher, assigning staff members to cooperate as interpreters for the qualitative part, and sharing their contacts with the Donorojo Hospital and District Health Office. The latter is in charge of the smaller community health centres, which are known as *Puskesmas*. An appointment was made to schedule the focus groups and semi-structured interviews in those *Puskesmas*. The respondents were preferably interviewed before or after visiting the *Puskesmas* around the city of Semarang for training or treatment.

4.3.3 Quantitative part

The quantitative data was collected in two locations in Central Java: Tegal District and the Donorojo Hospital in Jepara. In Tegal District, the stigma on leprosy was believed to be still high. We visited three villages for data collection, where in total 60 cases of leprosy were known. In order to broaden our study sample, we received help from *Difabel selawi mandiri*, a Disabled People's Organisation that organises workshops for disabled people, focussed on empowering this group. The second location was Donorojo Hospital, which is specialized in treatment of leprosy patients. Each day, 15-30 outpatients come from other parts of Java, to get diagnosis, treatment or further counselling. Next to the hospital, there is a leprosy rehabilitation village for people affected by leprosy that are not able to return to their old homes after diagnosis or treatment.

For validation of the PSSS, it was important to get a sample with a range of levels of social participation, but it was not necessary for all persons affected by leprosy to have disabilities. For validation of the instrument, comparison with a control group was required. This group consisted of family members and neighbours of the persons affected by leprosy and met the same criteria as described above, except that they were not affected by leprosy or other disabilities. This control group was used to confirm the normative score level of the PSSS.

4.4 Sample size and sampling method

4.4.1 Qualitative part

The study population for the qualitative part of this study consisted of two groups. We conducted one focus group with 7 persons affected by leprosy, in order to discuss the questions of the PSSS and the concept of participation. Furthermore, we conducted 15 semi-structured interviews with persons affected by leprosy. We determined this number to be 15, because at that point, the data saturation was reached. In total, 22 participants were included in the qualitative part. Because of the limited information about the number of persons affected by leprosy that were suitable for inclusion in our study, we used the convenience sampling method. All participants were selected with help of the Faculty of Public Health of the Diponegoro University and the District Health Office in Semarang.

4.4.2 Quantitative part

In order to calculate the sample size for the quantitative part, we followed Terwee et al. .(38) According to this study, the sample size had to be at least 7 * 13 [the number of items of the scale] = 91 participants.

In order to compare the participation restrictions experienced by persons affected by leprosy and controls, the age, sex, socio-economic status and education of the control group had to be similar to the leprosy group. We started with a consecutive sampling method for the control group, and ended with quota sampling, in order to obtain comparable groups. Due to the limited number of persons affected by leprosy, we had to use the consecutive sampling method for the leprosy group. Additional to the patients that were living in and around the Donorojo Hospital, all leprosy patients from Central-Java that visited the hospital during the research period were interviewed. This resulted in a sample with a wide variety of age, residency, income and other factors. However, because of the locations, the sample was biased towards more severely affected persons.

4.5 Technical methods

4.5.1 Development and translation of the Participation Scale Short Simplified

The problems that users of the P-scale experience were identified through a literature study. Further adjustments to the P-scale were made in cooperation with Wim van Brakel, who is one of the developers of the initial tool. A brainstorm session about the desired format of the simplified and shortened versions of the Participation Scale with staff from the NLR, who have extensive experience in this type of work, resulted in two versions (v.1.0A and v1.0B). The questions used in the questionnaires are the same in both versions, but the response scale differs. Both versions were pre-tested in the qualitative part of this study. Afterwards, the most suitable version was chosen for assessment in the quantitative part. The shortened version by Stevelink et al. and their exploratory factor analysis was used as a starting-point for the new simplified versions: Participation Scale Short Simplified (PSSS).(21) The Simplified Participation Scale by Kelders et al. was used as an example.(22) The following adjustments were made:

- Use of ‘other people’ instead of ‘peers’
- Two level question structure became one level structure
- Simplification of the language, without losing the content
- Modification of the response scale

The initial P-scale, developed by Van Brakel and his team, adhered to the following terms of reference:(19)

- “Be based on the Participation domains of the ICF.”
- “Be cross-cultural in nature.”
- “Be client-perceived.”
- “Be generic in nature.”
- “Be suitable for non-professional interviewers.”
- “Use the ‘peer comparison’ concept.”

It was of high importance that these terms were adhered to in the PSSS, in order to maintain the content of the original instrument as much as possible, with exception of the last point, since this has been problematic for some users. After modifying the P-scale Short (English v1.0)(21), the modifications were translated into Bahasa Indonesia according to the guidelines stated in the Participation Scale User Manual.(24) This was be done by a staff member of the faculty of Public Health from the Diponegoro University, who is an expert in this field of research. Afterwards, the scale was translated back to English by an English student from the same university. Lastly, an expert in the field of disability and stigma studies reviewed the two Indonesian versions of the PSSS, after which the last modifications were made. During the qualitative part of this research, the versions in Bahasa Indonesia were tested for equivalence of the following domains, as described by Herdman et al.(41): item, semantic and operational. The psychometric properties of the scale were measured during the quantitative part.

4.5.2 Focus group and semi-structured interviews

We planned to conduct one focus group with five to ten persons affected by leprosy, in order to discuss the concept of participation and rank the importance and relevance of the items of the PSSS. Furthermore, we planned to conduct semi-structured interviews with persons affected by leprosy, in which respondents were asked to answer some questions about the relevance, ease of understanding and acceptability of the items in the instrument, the response scales and their overall experience with the tool. In this way, we gained information about how the scale was perceived, whether the questions were easily understood, relevant to their situation and acceptable.

Focus group discussion

The FGD started with introducing ourselves and the rest of the participants to the group. Next, we explained the purpose of the study and the aim of the group discussion. After explaining the ground rules and filling in the Informed Consent Form, the participants were asked to answer some exploring questions about what participation means to them and in which life situations they experience problems. The aim was to see which items of the PSSS were mentioned by the group. Afterwards, we have asked each participant to rank the items of the PSSS and the items that came up during the discussion.

1. *How important is […] to you?*
   0 marks = not important, 1 mark = little bit important, 2 marks = very important
2. *How severely do you feel restricted in […]?*
   0 marks = not restricted, 1 mark = little bit restricted, 2 marks = very restricted

With the ranking, we got a view of the relevance and importance of the items for the participants in order to establish item equivalence. Last, the items that were ranked the highest were discussed. The whole procedure of the FGD can be found in Annex 4.

Semi-structured interviews

First, we explained the purpose and time needed for the interview and informed consent (*Annex 3*) had to be given. Next, we collected sociodemographic variables: age, sex, marital status, education level, employment status, using the Personal Information Form. Consequently, we conducted the PSSS v1.0A of v1.0B. We randomly decided which version was used. The following questions were asked to assess the cultural equivalence of the PSSS (*Table 4*). The whole procedure of the semi-structured interview can be found in Annex 5.

Table 4. Assessing item, semantic and operation equivalence

Item equivalence: (questions are asked for every item)

- Can you repeat the question in your own words? (understandability)
    - It they use the exact same words, ask if they can give an example.
- Can you explain your answer?
    - *If score 1 or higher: Why is this a problem to you OR Why is this difficult for you? (We ask this question to find out if version A or B is more suitable)*
- Was this question relevant (or important) to your situation? (relevance)
    - If yes: Why? Can you give an example?
    - Of no: why not?
- Did you feel uncomfortable answering this question? (acceptability)
    - If yes, why did you feel uncomfortable?
    - Can you think of any change that would make you feel less uncomfortable?

Semantic equivalence: (questions are asked for every item)

- Were any words unclear to you?
    - If yes: which one(s) and can you think of any change that would make it more clear for you?
- Can you repeat the answer in your own words?
    - It they use the exact same words, ask if they can give an example.
- Can you explain your answer?
    - *If score 1 or higher: Why is this a problem to you OR Why is this difficult for you? (We ask this question to find out if version A or B is more suitable)*

Operational equivalence: (questions are asked after completing the questionnaire)

- What did you think of the questionnaire?
- Were the answer options clear to you?
    - If not: why not?
    - Can you think of any change that would make it more clear for you?
- How was it to compare yourself to other people? (Difficult/easy?)
    - If difficult: Why was this difficult?
- Who did you compare yourself to?
- Was the questionnaire relevant (or important) to your situation?
- Did you feel uncomfortable during this interview?
    - If yes, which question(s) or words made you feel uncomfortable?
    - Why did it make you feel uncomfortable?
    - Can you think of any change that it wouldn't make you feel uncomfortable?
- Do you have any remarks/comments on this interview?
- Do you have any questions?

4.5.3 Refining the PSSS

After the focus group and each semi-structured interview, the information that was gathered through the audio-recorded interviews was transcribed and translated by the translator. Afterwards, the data was analysed by the researcher and adjustments to the first version of the scale were made.

4.5.4 Structured interviews (questionnaire-based interviews)

To assess the criterion validity of the PSSS, the instrument was compared with the gold standard, which is the Participation Scale version 6.0.(43) During the quantitative measurement, the assessment of the psychometric properties, both tools were used with the same participants in questionnaire-based interviews. First, we explained the purpose and time needed for the interview and informed consent had to be given (Annex 3). Next, we collected sociodemographic variables: age, sex, marital status, education level, employment status, by using the Personal Information Form. After that, the PSSS and the full version of the P-scale were conducted in random order. The full procedure can be found in the interview guideline (Annex 6). To measure the reproducibility of the scale, repeat interviews were done, using the PSSS in exactly the same way as the first interview. These preferably took place between one and two weeks after the first interview, which is long enough to prevent easy recall of answers given and short enough to minimise the likelihood of changes in the participation status of the respondents. For the normative study, the control group was interviewed with the exact same procedures. With this information, we could establish the cut-off score for normal participation in the PSSS. The cut-off score of the Participation Scale is already known to be 12, but this can differ per research sample. In order to compare the PSSS with the P-Scale, we choose to assess both tools in the normative study.

4.6 Outcome measures

4.6.1 Qualitative validation

For the qualitative part, we have measured semantic, item and operational validity as described in Table 3.

4.6.2 Quantitative validation

For the psychometric validation of the scale, we have used the quality criteria proposed by Terwee et al.(38) These include measurement of the internal consistency, floor and ceiling effects, criterion validity (sensitivity and specificity), reproducibility and interpretability. The full outcome measures are described in Table 3. The sensitivity and specificity were used to determine the cut-off score of the tool. To describe the level of restriction experienced by persons affected by leprosy, the mean and median participation scores of the respondents were calculated, along with the 95%CI and inter-quartile range. The cut-off point for restriction was established during the validation, using the 95th centile of the normative controls' participation score.

4.7 Data management and analysis

4.7.1 Qualitative part

The qualitative data was analysed with the help of Atlas.ti software. The analysis was completed by the first author. To get a view of the content, the data was divided into categories based on the 13 items of the PSSS, to which multiple categories were added during the analysis. The categories consist of situations or subjects that the participants mentioned in relation to their disease. All responses were assessed for significance and coded if considered useful. To assess the semantic, item and operational equivalence, additional questions were asked to each respondent and managed in an Excel data base.

4.7.2 Quantitative part

The quantitative data was entered and managed in an Excel software database and analysed using SPSS Statistical software. If a questionnaire contained more than 10% missing values, the whole questionnaire was excluded from the study. When a questionnaire contained less than 10% missing values, the missing data was replaced by the mean score of the research sample.

The scores of each item were added up to a Participation sum score, which was divided into a dichotomous value of 'restricted' and 'not restricted', after the cut-off value was established. The following psychometric properties were measured: internal consistency, floor and ceiling effects, criterion validity, reproducibility (reliability) and interpretability. For these measurements, we used the following calculations:

- Internal consistency was measured using Cronbach's alpha. According to Terwee et al., this is optimal between 0.70 and 0.95.
- Floor and ceiling effects are present if more than 15% of the respondents achieved the highest or lowest possible scores.
- Criterion validity was measured using Spearman's rank correlation, the sensitivity and specificity and concordance (with the use of two-by-two tables)
- Reproducibility was measured with the use of an intra-class correlation coefficient (ICC). The inter-interviewer reliability was measured with the $\text{ICC}_{\text{agreement}}$, which measures the absolute score differences and has to be higher than 0.70
- Interpretability was established through measuring the mean and the standard deviations.

5 Ethical considerations

The Diponegoro University has its own ethical approval committee that approved our research proposal. Furthermore, the government of Central-Java gave approval to conduct the research in this province. All participants were asked to give signed informed consent (or verbal informed consent if signing was physically not feasible) after receiving information on the aim, procedure and time of the research. Because of the private and emotional topic, we made arrangements with the health centres for referral of interviewee in case this was needed.

Strict data confidentiality was maintained, and no personal identifying information was stored in the database. No incentives were paid. However, we gave a small symbolic incentive to thank the respondents for participating in our research. Furthermore, we reimbursed the travel costs made for participating in our research.

6 Results

6.1 Qualitative results

The qualitative part of this study consisted of one focus group discussion (n=7) and multiple semi-structured interviews (n=15). First, we will describe the sociographic characteristics of both groups and elaborate on the transcript of the focus group discussion. Next, we will assess the item, operational and semantic validity and we will give an overview of the content of the qualitative research. Last, we will state the adjustments of the scale that have been made and tested in the qualitative research.

6.1.1 Socio-demographic characteristics of qualitative study

The socio-demographic characteristics of the qualitative research participants can be found in Annex 7. In total, 15 participants interviewed with PSSS version 1.0A or 1.0B in the form of semi-structured interviews (S1-S15). The population was almost equally divided among men (n=8) and women (n=7). They were aged between 18 and 65 years old (mean 47; median 49). All participants lived in urban residence and the majority was married. 6 participants noted primary school as their highest finished education, the majority of the participants also finished secondary school, and one participant perceived higher education. Most participants were working (voluntarily) or not working because of other reasons than health. Only two participants stated to be unemployed due to health reasons. All participants were affected by leprosy, the time since diagnosis ranged from 7 months to 13 years (mean 4.62, median 3). The vast majority also had visible signs of the disease, on their arms, legs or face. The PSSS was conducted on 15 participants. Two of them also completed the P-Scale, in order to pre-test the full procedure of the questionnaire-based interviews.

The focus group discussion was held among seven persons affected by leprosy (F1-F7). The discussion included five males and two females, who all lived in urban residency. The participants of the focus group discussion were aged between 32 and 73 (mean 60) and the majority was married. All participants had visible signs of leprosy and were diagnosed between 0.5 and 5 years ago (mean 2.36). Unfortunately, the transcript of the focus group discussion was not finished until after the quantitative part of the research was completed. Thus, this information could not be used for refining the PSSS. However, the written report from the ranking was available before and was used in assessing the item validity.

6.1.2 Assessing item validity

To assess the relevance and acceptability of individual item to the target population, we asked two questions regarding each item of the PSSS during the semi-structured interviews:

1. *Is this question relevant/important to your situation?*
1. *Did you feel uncomfortable answering this question?*

As can be found in Table 5, none of the respondents reported feeling uncomfortable answering any of the questions. With the exception of the first three questions, almost all participants found the questions relevant or important to their situation. The first three questions of the PSSS are focused on working life. As expected, some respondents who were not working to earn money, mostly women and students, did not find these questions important. These questions confused the non-working sample because they did not know how to answer the questions correctly. The interpreter explained that for those who do not want to find work or work hard, the answer option 'not relevant' is suitable. Among the working part of the study population, the first three questions are rated highly relevant. Therefore, there was no need to modify the content of these questions.

Table 5. Assessment of relevance and acceptability

	Relevance		Acceptability	
	Yes	No	Yes	No
Q1	12	3	15	0
Q2	10	5	15	0
Q3	13	2	15	0
Q4	14	1	15	0
Q5	14	1	15	0
Q6	15	0	15	0
Q7	15	0	15	0
Q8	15	0	15	0
Q9	15	0	15	0
Q10	15	0	15	0
Q11	14	1	15	0
Q12	15	0	15	0
Q13	14	1	15	0

During the questionnaire-based interviews, the respondents could choose the option '*irrelevant'*. For instance, when they did not want to find a job or finding a job was difficult because of another factor than their disease. This option was chosen more often for items of the P-Scale than the PSSS, with only a minor difference between the scales. For the P-Scale, question one was reported as irrelevant by 4.5% of the respondents, followed by 3.7% for question 10. For the PSSS the highest percentage was only 2.7% for question one.

Furthermore, we will discuss the items in the light of qualitative analyses results. During the semi-structured interviews, we asked the respondents to explain their answer to each question of the PSSS. To establish the item validity, it is essential to know whether the respondents understood the questions correctly by analysing their answers thoroughly. As Herdman et al. described: '*The validity of items as measures of a particular domain may vary across cultures*.' (41) Therefore, each answer explanation was analysed and coded by the researcher. Additionally, the researcher examined whether each item was answered with the corresponding code. For instance, the corresponding code to question 1 is finding work. If the question was answered by another code, such as '*working hard'* or '*visit public places'*, we can assume that the respondent did not completely understand the content of the question. The answer of one respondent could contain multiple codes. A few respondents (n=5) did not give a clear explanation to a question; these answers are not coded.

6.1.3 Assessing semantic validity

The translation process was done according to the guidelines stated in the Participation Scale User Manual.(24) First, the English version of the PSSS was translated into Bahasa Indonesia by a staff member of the faculty of Public Health from the Diponegoro University. In this translation process, there was special attention for the use of simple language since the PSSS has to be suitable for all education levels. The back-translation was done by a student from the same university, who was not further involved in the process of research. The researcher compared the original version and back-translated English version. No significant differences were found. The original English version and back-translation are shown in Annex 9. Lastly, an expert in the field of disability and stigma studies reviewed the two Indonesian concept versions of the PSSS on semantic equivalence. Again, no issues were found regarding the use of Bahasa Indonesia.

One essential difference between the full version of the P-scale and the PSSS is the omission of the word '*peer*'. The translation of '*peer'* appeared to be a difficult word in Bahasa Indonesia. The P-scale was pre-tested on two respondents during the semi-structured interviews. Both respondents experienced difficulties in understanding this word since it is present in each question. Therefore, we choose to omit '*peer'* and instead use '*other people'* in the PSSS. We started the interviews a short explanation of the concept '*other people'* in which we emphasised that this had to be someone without their condition, and no further problems in understanding were reported. However, some respondents already forgot to compare themselves to others after answering a few questions. For this reason, we choose to start each question with '*Compared to other people…*'.

To further assess the semantic validity, it was necessary to examine whether the PSSS can be translated into Bahasa Indonesia without losing its effect on respondents. For each item of the PSSS, we asked two questions to assess to which extent the items have been understood and whether the meaning has been preserved in Bahasa Indonesia:

1. *Were any words unclear to you?*
2. *Can you repeat the question in your own words?*

In Table 6, the answers are noted for each item of the PSSS. The vast majority of respondents reported understanding all questions without experiencing any trouble. However, this can also be due to the fact that the respondent wants to give positive answers to the questions and may feel ashamed to tell us they did not understand. To get insight in the similarity between the original English version and Bahasa Indonesia version, we asked them to paraphrase the questions. However, this exercise could not be done by everyone and confused the respondent. Some respondents did not understand the concept of repeating the question and found it difficult to replace the question with their own words. Nonetheless, the respondents that were able to repeat the question did this successfully for almost all questions. Again, the only exception is question 4: '*How easy is it for you to make visits outside your village/neighbourhood? (e.g. bazaars, markets*)'. Only four respondents were able to repeat this question and preserving its content, compared to eight respondents that changed the meaning of the question. Most respondents repeated the question as follows:

S5: Can I go to market like other people?
S6: Can I go by myself to other places like store or market?
S9: If compared to others how easy go to the market or mall?

These eight respondents did not mention the aspect of going outside the village or neighbourhood, which is essential for this question. The repeated versions of question 4 are very similar to question 10: '*How easy is it for you to visit public places in your village/neighbourhood? (e.g. schools, shops, offices, market and tea/coffee shops)*'. Therefore, modification of question 4 was required.

This argument is supported by the explanation of the answers. Table 6 shows the percentage of questions that were answered with the corresponding code, which was 100% for the majority of items. A few respondents did not give clear answers to question 2, 3 and 8. In the case of question 3, one respondent did not mention the corresponding code, which is '*giving financial support*', but instead explained about '*visiting public places*'. Similarly, one respondent did not explain about '*visiting other people*' in question 8, but only elaborated on '*moving around*'. Most remarkable was question 4, to which the answer of 4 respondents did not involve '*visits outside the village*'. Instead, they explained about '*visiting public places*' (n = 3) and '*social activities*' (n = 1). This leads us to the notion that question 4 is not correctly understood by 4 out of 15 respondents (26.7%). For the other questions, this percentage was 7.7% at most. Based on the findings, only minor modifications to the scale were required. To prevent confusion between question 4 and question 10, a new example was added to question 4: '*Compared to other people, how easy is it for you to make visits outside your village/neighbourhood? (e.g., bazaars,* ***nearby villages***)'. The full coding can be found in Annex 8. During the quantitative phase of the study, the researchers noted whether a question had to be repeated because the respondent did not immediately understand it. In general, the items of the P-Scale had to be repeated more often than the PSSS.

Table 6. Assessing semantic validity

	All words clear		**Repeat the question**			Coding		
	Yes	*No*	*Same*	*Different*	*Unable to repeat*	*Corresponding code*	*Other code*	*Missing answers*
Q1: finding work	13	2	13	1	1	100%	0%	0
Q2: working hard	13	2	11	2	2	100%	0%	2
Q3: financial support	15	0	13	0	2	92.9%	7.1%	1
Q4: visits outside village	15	0	4	8	3	73.3%	26.7%	0
Q5: major festivals	14	1	12	0	3	100%	0%	0
Q6: social activities	14	1	12	0	3	100%	0%	0
Q7: gain respect	13	2	12	0	3	100%	0%	0
Q8: visit other people	14	1	11	0	4	92.3%	7.7%	2
Q9: move around	14	1	12	1	2	100%	0%	0
Q10: visit public places	15	0	12	0	3	100%	0%	0
Q11: do household work	15	0	13	0	2	100%	0%	0
Q12: family discussions	13	2	13	1	1	100%	0%	0
Q13: meet new people	15	0	12	1	2	100%	0%	0

6.1.4 Assessing operational validity

In order to assess the operational validity, a number of questions about the questionnaires have been asked. The vast majority of the respondents reported a good experience with the questionnaire. All participants found the answer options clear and experienced no problems in understanding these. As mentioned before, we tested both version A and version B, which have different answer options. Both response scales were suitable for use in this questionnaire and did not give rise to further questions or confusion.

One respondent did not feel comfortable during the interview. The reason for this feeling was not clear. The respondents did not find it difficult to compare themselves with other people. Most people choose a friend, family member or neighbour without leprosy.

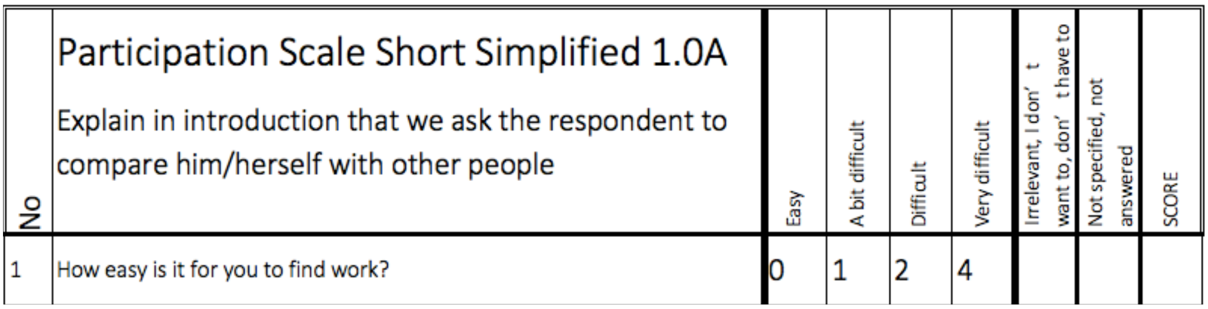
We asked each respondent what they thought of the questionnaire. Four people did not answer the question or did not give a coherent answer. Respondent 13 was a little bit confused because the questions were not ‘to the point’. However, this was probably because we asked additional questions after every item, which confused some of the respondents. Most of the respondents understood the question immediately, or after repeating the question once or twice. Lastly, no additional information on participation was missed by any respondent, and no significant remarks were made.

Table 8. Assessment of operational validity

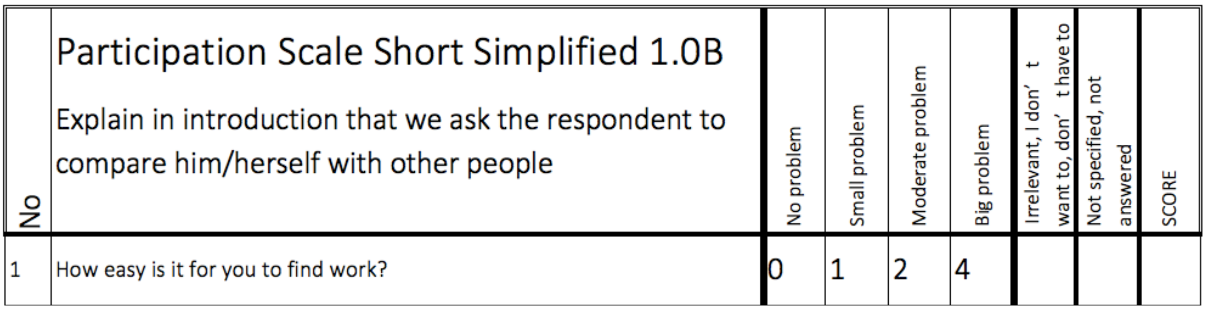
Question	**Answer**		
	Yes	*No*	*?**
The answer options are clear	15	0	0
I felt comfortable during the interview	14	1	0
I am able to compare myself to other people	15	0	0
The questionnaire is relevant to my situation	12	3	0
	Okay/Good	*Confusing*	*?**
Opinion on questionnaire	10	1	4

**? = No clear answer was given*

During the qualitative part, we used two versions of the PSSS. Respondents with uneven numbers have been interviewed with version A, and the even numbers with version B. Version A has the response scale options easy – very difficult, version B has the options no problem – large problem. No problems were reported with either these two versions. However, we noticed that most respondents that were interviewed with version B, gave answers like ‘easy’ or ‘not so difficult’. All questions begin with ‘How easy is it…’, so it is expected that the respondent will answer with these same words. With simplifying the P-scale, we wish to establish a questionnaire that can be used and understood immediately. Therefore, we choose to use version A for quantitative testing.



No	Participation Scale Short Simplified 1.0A Explain in introduction that we ask the respondent to compare him/herself with other people	Easy	A bit difficult	Difficult	Very difficult	Irrelevant, I don’ t want to, don’ t have to	Not specified, not answered	SCORE
1	How easy is it for you to find work?	0	1	2	4			



No	Participation Scale Short Simplified 1.0B Explain in introduction that we ask the respondent to compare him/herself with other people	No problem	Small problem	Moderate problem	Big problem	Irrelevant, I don’ t want to, don’ t have to	Not specified, not answered	SCORE
1	How easy is it for you to find work?	0	1	2	4			

The administration format of the PSSS is based on the P-scale, but simplified as much as possible. Similar to the P-scale, we choose to conduct the PSSS in the form of an interview. A significant proportion of the target population was illiterate, which excluded the option of a self-administered questionnaire. However, even for some interpreters, the questionnaires were quite difficult to understand. Especially the instructions for using the P-Scale took much time. The two-question structure was confusing, and some words had to be explained. During the questionnaire-based interviews, some of the interpreters felt uncomfortable asking about someone’s religion and income. This may have influenced the answer of some participants, though no one said to feel uncomfortable during the interview.

To establish operational validity, it is necessary that the questionnaire is pretested. The last adjustment was made after analysing all semi-structured interviews, which was the modification of the examples in question 4. Afterwards, the question was explicitly tested for comprehensibility in the first four questionnaire-based interviews. During the quantitative part, we asked each participant which questionnaire had their preference. In total, 42.8% of the respondents preferred the PSSS, 30.4% preferred the P-Scale and 25.5% had no preference. The respondents had various reasons for their preferences, of which only the first reason was considered. When they found the last questionnaire easier because the questions were similar to the first questionnaire, their preference was excluded. The main reasons for choosing the P-Scale were the easier questions (n=15), easier answer options (n=13) and longer questions (n=13). On the other hand, the PSSS was chosen because of the easier answer options (n=21), the easier questions (n=17), the shorter questions (n=13) and the fact that there were fewer questions (n=11).

6.1.5 Adaptation of the PSSS

After conducting each semi-structured interview and the focus group discussion, the data was analysed by the researcher and used to modify the first version of the scale. These adaptations were further tested during the semi-structured interviews to refine the PSSS. In Table 9, all adjustments that were made can be found.

Table 9. Adaptation of the PSSS

	PSSS version 1.0	**Final PSSS**
Each question	How easy is it for you to …?	**Compared to other people**, how easy is it for you to …?
Answer option	Easy – Very difficult (V1.0A) No problem – Large problem (V1.0B)	Easy – Very difficult
Question 4	How easy is it for you to make visits outside your village/neighbourhood? (e.g. bazaars, markets)	Compared to other people, how easy is it for you to make visits outside your village/neighbourhood? (e.g. bazaars, **nearby villages**)

6.1.6 Conceptual validity

The conceptual validity of the PSSS is already established because the content of the questions does not differ from the original version of the P-scale. However, during the semi-structured interviews and focus group discussion, the researcher obtained noteworthy quotes from the respondents. More quotes from the semi-structured interviews and focus group discussion can be found in Annex 10.

6.1.6.1 Focus group discussion

The focus group was held with a group of 7 persons affected by leprosy. The discussion took 60 minutes. First, we identified the existing knowledge about participation and what participation means to the participants, but this concept was not known by all participants. After a brief explanation, we held a brainstorm to find out what aspects of participation are important to the participants. The majority of participants mentioned the importance of being physically healthy, even though the researcher explained that participation means involvement in a life situation. Additionally, multiple participants agreed that contact with children is an important item to discuss because this is often troubled by their disease.

The last part of the focus group discussion was devoted to comparing yourself with persons without leprosy. The group agreed that they were able to compare themselves with other people, but there was no consensus on the difference between persons with and without leprosy. The explanations ranged from 'people more healthy than us' to 'people that can do a lot of physical activities'. However, every participant agreed that the difference was purely in their physical condition, such as not being as strong as others and getting tired more easily. The last respondent stated the following to close the discussion:

> *'Yes, we are not as healthy as other people without leprosy. But it is not a limitation I think, because everyone has their own aspect which they are lacking. Even though I have leprosy, I still can do a lot of things. So I don't feel inferior or something like that.'*

6.2 Quantitative results

6.2.1 Socio-demographic characteristics of quantitative study

In September and October 2018, a total number of 166 respondents were interviewed in the districts Jepara and Tegal. We conducted 54 interviews for the control group and 112 questionnaire-based interviews with people affected by leprosy, of which we repeated 47 interviews after 6 to 9 days. Two persons affected by leprosy lived in East-Java, but after examination of their results, we decided to include both in the study. One participant was excluded from the study because of disturbing factors during the interview. Another 7 questionnaires, either PSSS or P-Scale, were excluded because of disturbing factors, poor understanding of the questionnaire or more than 10% missing values.

The population affected by leprosy (n=112) was almost equally divided among men (n=58, 51.8%) and women (n=54, 48.2%). They were aged between 20 and 79 years old (mean 48.2). The normative population was equally divided among men and women (n=27, 50%). Their age ranged from 19 to 70 years old (mean: 41.8, median 40). The data of the normative group was only used to determine the cut-off score for the P-Scale and PSSS. All participants lived in Central-Java, with exception of two participants from East-Java. However, their results did not show significant differences compared to the sample from Central-Java. Therefore, we decided to include them in the study. The vast majority of participants lived in rural areas. No significant other diseases were found. The socio-demographic characteristics of the leprosy group and control group are shown in Table 10.

Table 10. Socio-demographic characteristics of quantitative study

Characteristic		**Leprosy group** *N (%)*	**Control group** *N (%)*
Total		112 (100%)	54 (100%)
*P-Scale**	Mean scores (0-90)	8.11±9.55 (0-58)	4.92±3.73 (0-19)
*PSSS**	Mean scores (0-52)	9.28±8.11 (0-38)	3.98±4.28 (0-20)
*Age***	Years	48.2 (20-79)	41.8 (19-70)
Sex	Male	58 (51.8%)	27 (50%)
	Female	54 (48.2%)	25 (50%)

Table 10. Socio-demographic characteristics of quantitative study

Characteristic		**Leprosy group** *N (%)*	**Control group** *N (%)*
Education	Illiterate	9 (8%)	2 (3.7%)
	Read and write only	6 (5.4%)	1 (1.9%)
	Primary	83 (74.1%)	34 (63%)
	Secondary or higher	14 (12.5%)	17 (31.5%)
*Employment****	Employed	60 (53.6%)	43 (79.6%)
	Unemployed (health)	41 (36.6%)	0 (0%)
	Unemployed (other)	11 (9.8%)	11 (20.4%)
*Income*****	No income	52 (46.4%)	13 (24.1%)
	<2.3 million Rp.	60 (53.6%)	36 (66.7%)
	>2.3 million Rp.	0 (0%)	5 (9.3%)
Marital status	Unmarried	14 (12.5%)	5 (9.3%)
	Married	76 (67.9%)	47 (87%)
	Divorced/Widowed	22 (19.7%)	2 (3.7%)
Religion	Muslim	102 (91.1%)	44 (81.5%)
	Christian	9 (8%)	10 (18.5%)
	Other	1 (0.9%)	0 (0%)
Type of residence	Rehabilitation village	60 (54.1%)	14 (25.9%)
	Leprosy Hospital	4 (3.6%)	0 (0%)
	Other	47 (42.3%)	40 (74.1%)

* Mean score±SD (range) ** Mean score (range) *** health reason / other reason **** Rp. = Rupiah

First, we compare the scores of the PSSS and the P-Scale per question. The answer options of PSSS and P-Scale differ, but the three options that indicate participation restrictions are similar. These corresponding options are: *a little bit difficult* (PSSS) - *small problem* (P-Scale), *difficult* (PSSS) - *medium problem* (P-Scale), and *very difficult* (PSSS) - *large problem* (P-Scale). The other answer options do not indicate participation restrictions. When looking at the percentage of participants that choose one of these three options (*Figure 4 and 5*), it is evident that the PSSS is generally answered indicating more difficulty than the P-Scale. Especially questions one to four of the PSSS score high, more than 50 participants stated to experience restrictions in these life situations. This is in contrast to the P-Scale, where the highest score to any question is 37 persons that felt restricted. The five questions of the P-Scale that are omitted in the PSSS have low scores, with only three to eight persons that reported to experience problems in social participation. The option '*irrelevant'* was chosen by two participants for question 1 and 2, and by one participant for question 3 and 7.

Figure 4. Scores PSSS leprosy group in Central Java, Indonesia

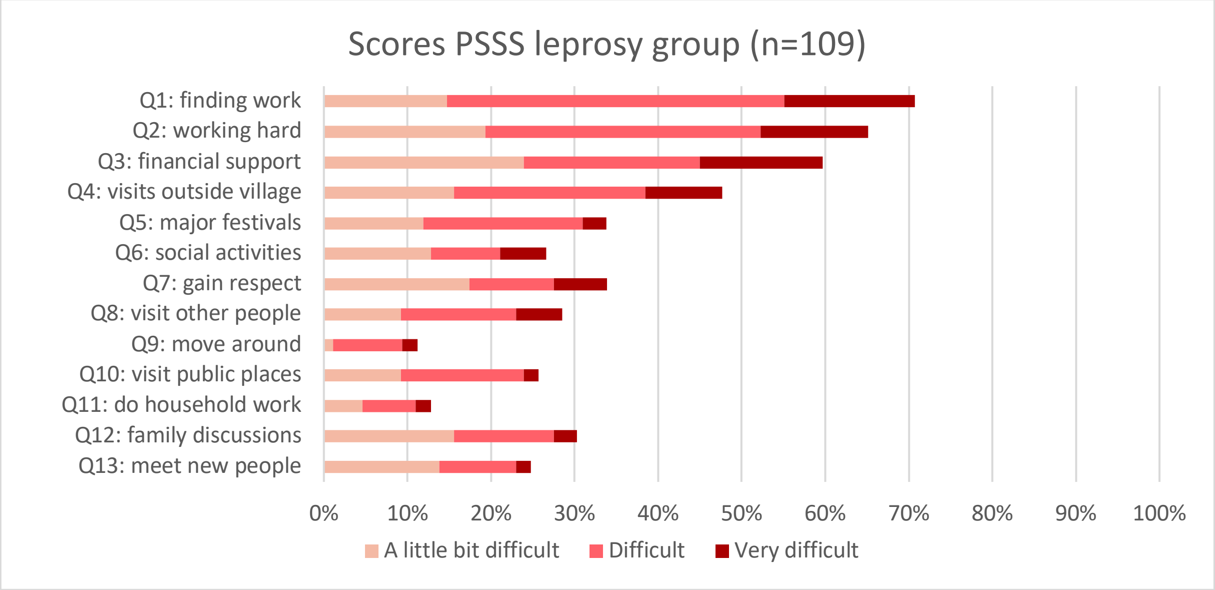
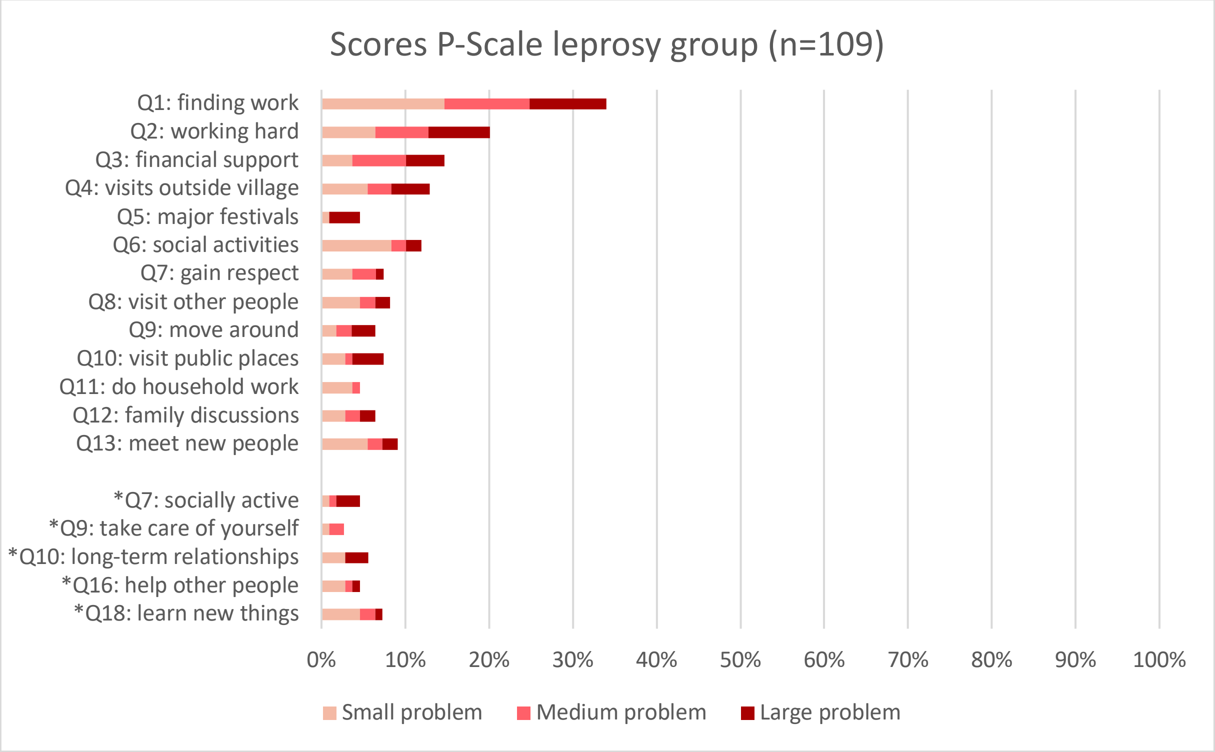


Figure 5. Scores P-Scale leprosy group in Central Java, Indonesia



The average time needed to conduct the P-Scale on persons affected by leprosy was 5 minutes and 45 seconds. For the PSSS, this was only 3 minutes and 59 seconds. With shortening and simplifying the P-Scale, the average time needed for the interview is reduced by 1 minute and 46 seconds.

To examine which response scale weighting of the PSSS was most suitable, a Pearson correlation has been used. In Table 11, the correlation between the scores of the PSSS and the P-Scale are shown. Given this outcome, we decided to recode the PSSS, using the 0-1-2-4 coding.

Table 11. Response scale weighting

	Coding 0-1-2-3		**Coding 0-1-2-4**	
	Pearson correlation	*Sig.**	*Pearson correlation*	*Sig.**
Leprosy group	0.690	p<0.0001	0.703	p<0.0001
Control group	0.673	p<0.0001	0.683	p<0.0001
Total	0.695	p<0.0001	0.709	p<0.0001

** Significance*

6.2.2 Criterion validity

The scores of the PSSS were converted into a dichotomous value, using the 95th percentile of the normative group and a ROC-curve. Based on the 95th percentile of the normative group, the cut-off score for the P-Scale is determined to be 11 and results in 20.2% participants that experience participation restrictions. This cut-off score is almost similar to the cut-off score of the P-Scale that is internationally used, which is 12 and results in 18.3% of restrictions.

The cut-off score of the PSSS is 13 when using the 95th percentile of the control group. However, the scores of the P-Scale and PSSS of the normative group are not normally distributed (*Figure 6*). Therefore, the optimal cut-off score of the PSSS is calculated to be 9 with a ROC-curve. Lowering the cut-off score to 9 increases the sensitivity of the questionnaire, whereas the specificity remains above 0.70. Table 12 shows the sensitivity and specificity for both cut-off scores of the PSSS.

Figure 6. PSSS scores of control group

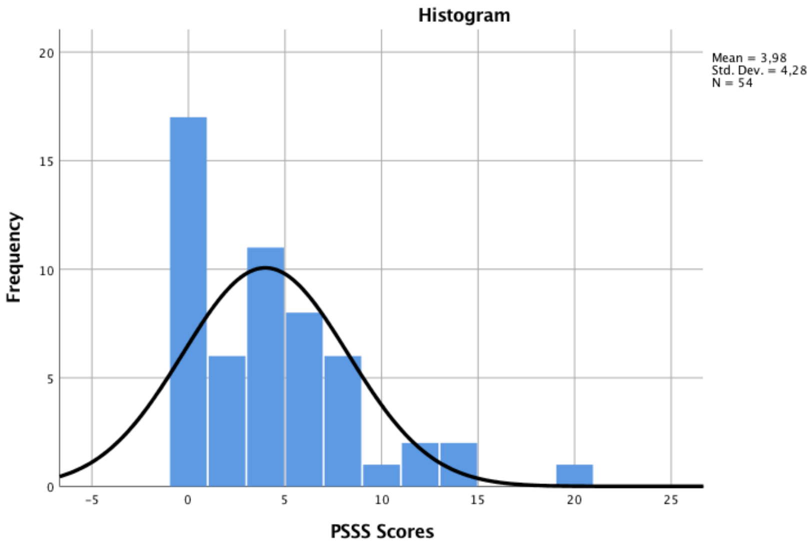


Table 12. Sensitivity and specificity of PSSS

	Participation restrictions	**Sensitivity**	**Specificity**
Cut-off score 9	38.5%	0.82	0.75
Cut-off score 13	25.7%	0.68	0.88

A Spearman's rank correlation, using the Participation Scale as golden standard, showed a significant correlation ($p<0.01$) of 0.688 between the total score of the P-Scale and PSSS in the group of persons affected by leprosy. A Pearson correlation had a correlation coefficient of 0.703 ($p<0000.1$) in this group. The sensitivity and specificity of the PSSS are determined to be respectively 0.82 and 0.75.

6.2.3 Internal consistency

Previous factor analyses that were performed on the Participation Scale showed that the scale could be both unidimensional and two-dimensional. When using a unidimensional structure, Cronbach's alpha for all 13 items of the PSSS was 0.842 for the group of persons affected by leprosy. The corrected item to total correlation ranged between 0.388 and 0.674 for the leprosy group. Cronbach's alpha for the normative group was 0.728 and for both groups combined 0.844 (*Table 13*). None of the items raised the alpha when deleted in any group, except for Q2 in the control group. If a two-dimensional structure is used for the people affected by leprosy group, Cronbach alpha for the work-related restrictions (Q1-Q3) is 0.589. For general participation restrictions (Q4-Q13) this is 0.833.

Table 13. Cronbach's alpha

	People affected by leprosy		**Control group**		**Both groups together**	
Unidimensional (Q1-13)	0.842		0.728		0.844	
Two-dimensional (Q1-3)	0.589		0.544		0.642	
Two-dimensional (Q4-13)	0.833		0.592		0.824	
	Cronbach's Alpha if item deleted	*Corrected item - total correlation*	*Cronbach's Alpha if item deleted*	*Corrected item - total correlation*	*Cronbach's Alpha if item deleted*	*Corrected item - total correlation*
Q1	0.840	0.408	0.676	0.575	0.837	0.477
Q2	0.833	0.482	0.733	0.208	0.834	0.502
Q3	0.835	0.464	0.665	0.627	0.833	0.524
Q4	0.821	0.617	0.715	0.355	0.827	0.587
Q5	0.827	0.565	0.717	0.340	0.831	0.559
Q6	0.826	0.566	0.692	0.537	0.829	0.568
Q7	0.834	0.458	0.715	0.343	0.834	0.484
Q8	0.818	0.674	0.711	0.411	0.822	0.665
Q9	0.835	0.432	0.715	0.358	0.837	0.445
Q10	0.832	0.493	0.740	0.089	0.836	0.455
Q11	0.829	0.565	0.721	0.348	0.833	0.550
Q12	0.838	0.388	0.721	0.274	0.840	0.388
Q13	0.834	0.451	0.716	0.319	0.838	0.419

6.2.4 Reproducibility

Forty-seven interviews with persons affected by leprosy were repeated under the same circumstances after six to nine days. The inter-interviewer reliability of the PSSS was evaluated using the $ICC_{agreement}$ (two-way random effects model), which compared the scores of the first and second interview with the PSSS. The $ICC_{agreement}$ is 0.74 (95%CI 0.48-0.86).

6.2.5 Floor and ceiling effects

No floor and ceiling effects for the PSSS were present in the leprosy group. No participants scored the maximum score of 52 points, and only 7.3% (n=8) of the leprosy group scored 0 points. In the control group, this percentage was 31.5 (n=17).

6.2.6 Interpretability

The scores of the PSSS were divided into multiple subgroups in order to examine the interpretability of the scale. The median scores and interquartile ranges (IQR) per subgroup of the control group and leprosy group are shown in Table 14, a summary of the findings of the whole scale can be found in Table 15.

Table 14. Median scores and interquartile ranges per subgroup

Characteristics		**Leprosy group**		**Control group**	
		N	*Median (IQR1-IQR3)*	*N*	*Median (IQR1-IQR3)*
Total	Scores (0-52)	112	7 (IQR 3-14)	54	4 (IQR 0-6)
Sex	Male	57	6 (IQR 3-14)	27	1 (IQR 0-6)
	Female	52	7 (IQR 4-13)	27	4 (IQR 1-6.5)
Age in years	< 50	52	5 (IQR 3-10)	39	4 (IQR 0-6)
	≥ 50	57	8.5 (IQR 4-17)	15	3 (IQR 0-5)
Marital status	Unmarried	35	10.5 (IQR 4.5-20)	7	1 (IQR 0.5-4)
	Married	74	5 (IQR 2.5-11.5)	47	4 (IQR 0-6.5)
Type of residence	Leprosy hospital	4	19 (IQR 15-21.5)	0	-
	Rehabilitation village	59	7 (IQR 4-11)	14	4 (IQR 1-7)
	Other	45	4 (IQR 2-20)	40	4 (IQR 0-6)
*Employment status **	Unemployed (health)	39	16 (IQR 5-21)	0	-
	Unemployed (other)	11	5 (IQR 2-9)	11	5 (IQR 1-6.5)
	Employed	59	5 (IQR 3-9)	43	4 (IQR 0-6)
*Income level***	No income	52	11 (IQR 4-19)	13	4 (IQR 1-6)
	< 2.3 million Rp.	60	4 (IQR 2-8)	36	4 (IQR 0-6)
	> 2.3 million Rp.	0	-	5	0 (IQR 0-3)
*Physical problems****	No	20	4 (IQR 1.5-6.0)		
	Yes	89	8 (IQR 4-16)		
Visible signs of leprosy	No	17	3.5 (IQR 0.5-7.5)		
	Yes	92	7.5 (IQR 4-16)		
Time since diagnosis	< 19	59	4 (IQR 2-10)		
	≥ 20	49	10 (4.5-16)		

* health reason / other reason ** Rp. = Rupiah *** Leprosy-related

Table 15. Summary of psychometric properties of the PSSS

Characteristic	**Result**	**Norm**
Number of respondents	112	
PSSS median score (range)	7 (0-38)	
Criterion validity		
Spearman correlation	r = 0.688 ($p<0.01$)	(>0.7)
Sensitivity	0.82	
Specificity	0.75	
Internal consistency		
Cronbach's alpha whole scale	$\alpha = 0.842$	(0.70 – 0.95)
Cronbach's alpha work-related participation	$\alpha = 0.589$	(0.70 – 0.95)
Cronbach's alpha general participation	$\alpha = 0.833$	(0.70 – 0.95)
Reproducibility		
$\text{ICC}_{\text{agreement}}$ (two-way random effects model)	ICC = 0.737 (CI=0.481-0.861) (n=47, μ = 7 days)	(>0.7)
Floor and ceiling effects		
Lowest score (0)	n = 8 (7.3%)	(<15%)
Highest score (52)	n = 0 (0%)	(<15%)

7 Discussion

We succeeded in achieving the first objective of this study, which was to develop a simplified and shortened version of the P-scale to assess participation restrictions in Indonesia. We examined the item, semantic, operational and measurement validity of this simplified P-scale and used this tool to measure the prevalence of participation restrictions experienced by persons affected by leprosy in Central Java, Indonesia, and to find out which restrictions were most common.

7.1 Item validity

The results of the semi-structured interviews showed a good item validity of the PSSS, with a high relevance and acceptability of each item. Only the first three questions about work and contributing to the household financially were considered irrelevant by more than one participant. However, this was mainly due to the fact that the participants were not interested in working at all. During the quantitative research, the answer option *'irrelevant'* was chosen by not more than 2.7% of participants per question. Several studies share the conclusion that the items of the P-scale are relevant to assess participation restrictions.(19,44,45) All participants answered no to the question we asked for each item of the scale: '*Did you feel uncomfortable answering this question?'* There was no noticeable difference in acceptability of the items during the questionnaire-based interviews. Overall, the item validity of the PSSS was found to be good during both the qualitative and quantitative phase of this study.

7.2 Semantic validity

During this research, the results of the qualitative research and advice of experts in the field of leprosy led to adjustments of the Bahasa Indonesia version of the PSSS. No major difficulties were experienced during the primary translation process of the tool. However, the difficulty of translating an instrument into a foreign language is described by many previous researchers. Misajon described the difficulty of ensuring the congruent meanings into different languages.(46) In the present research, the semi-structured interviews were of good quality, but the English transcripts had limited vocabulary. Therefore, it is possible that some valuable and distinguishing information was lost in translation. For instance, the Indonesian word '*malu*' means being embarrassed or ashamed, which can be a result of having leprosy. The interpreter translated this word with '*shy'*, which is a characteristic of one's personality. This subtle change in translation can have a high impact on the interpretation of the overall meaning and emotion of the interviews. The semi-structured interviews have been transcribed by one interpreter, which improves the consistency of the study.

The qualitative data extracted from the semi-structured interviews showed that all questions were understood properly (>90%), with the exception of question 4: '*Compared to other people, how easy is it for you to make visits outside your village/neighbourhood? (e.g., bazaars, nearby villages*)'. After adjusting this question with an additional example, the understanding of the content of the items were excellent. In general, the questionnaire-based interviews showed that the simplified language of the PSSS was understood more easily than that of the full version of the P-Scale. An example of this improvement is the deletion of the word '*peer'*, which caused confusion among many participants. The first item of the P-Scale, '*Do you have equal opportunity as your peers to find work?*', was changed into: '*Compared to other people, how easy is it for you to find work?*' By changing '*peer'* to '*other people'*, the meaning of the questions was clearer to the respondents, and the concept of comparison was better understood. This transformation may be suitable in other cultures as well, since previous studies have reported problems with the translation of '*peer'* as well.(22,45) In 2012, Jansen et al already recommended this change in the study of a shortened version of the P-Scale in India.(25) Rolink et al have previously implemented this change in a validation study in Mozambique with positive results.(45)

During the quantitative study, one participant was unable to understand the questions of both questionnaires sufficiently to participate in the study. Additionally, one participant did not understand the PSSS sufficiently, but experienced no problems when answering the P-Scale. Conversely, this happened for the P-Scale with one respondent as well. This insufficient understanding could also be due to the interpreter's limited understanding of the questionnaires in the first set of interviews and the insufficient knowledge of Bahasa Indonesia of some respondents. A previous validation study of a simple version of the Participation Scale in Indonesia reported similar problem, where the respondents found the words and concepts of both versions of the Participation Scale difficult to understand.(22)

7.3 Operational validity

During the analysis of the quantitative part of the study, five interviews were excluded from the study because there were more than 10% of the questions unanswered. This missing data is most likely caused by confusion about the questions. Additionally, two interviews with the PSSS and two interviews with the P-Scale were not included in the analysis because the respondents were not able to understand the questions sufficiently. Overall, only four out of 166 interviews could not be used due to limited understanding, whereas the rest of the interviews showed positive results for operational validity.

Previous research has shown that shortening and simplifying the P-Scale has a positive effect on participants by reducing the time needed for assessment and making the questions more understandable.(22,25) The present research supports this statement. In the qualitative part, the questions we asked each respondent about the total questionnaire showed excellent results. Only three out of fifteen participants did not find the questionnaire fully relevant to their situation. In total, 43% of the respondents of the quantitative study preferred the PSSS, 30% preferred the P-Scale and the rest had no preference. However, the researcher noticed that not all respondents understood this question properly, which may be the reason why a high percentage reported no preference. The main reasons for choosing the P-Scale were easier questions, easier answer options, and longer questions. The PSSS was also chosen because of the easier answer options and easier questions, besides the shorter questions, and the fact that there were fewer questions. Remarkably, both the P-Scale and PSSS were chosen because of easier questions and answer options. Furthermore, 13 respondents preferred the P-Scale because of the longer questions, but also 13 respondents preferred the PSSS for its shorter questions. According to these outcomes, the respondents differ widely in their understanding and preferences in use of language and question formatting. Similar findings were previously reported from a validation study of a simplified version of the P-Scale in Indonesia, where some of the respondents were confused by the shorter question structure of the simplified scale, opposed to respondents that found the new structure better suited.(25) In the current study, the questions and answer options of the PSSS were generally found to be easier than the P-Scale, for both the respondents and interpreters. The difficulties in explaining how to administer the P-Scale to the interpreters was reported by several other studies.(22,45)

Another important objective of this study was to reduce the time needed for the assessment. The PSSS has only 13 questions, in contrast to the 18-item P-scale. Also, the structure and language of the scale have been simplified. The time needed to conduct an interview with persons affected by leprosy using the PSSS was reduced on average by 1 minute and 46 seconds, compared to using the P-Scale (3:59 vs 5:45). On average, the PSSS can be conducted in less than four minutes, which makes a quick assessment of the social participation possible. Both the P-Scale and the PSSS were conducted 1.5 times faster than in the validation study of a short version of the P-Scale that was performed in India.(25)

7.4 Measurement validity

7.4.1 Criterion validity

In the development of the shortened and simplified version, no new items were added to the Participation Scale. For developing the P-Scale Short (PSS) in 2012, an exploratory factor analysis and item analysis were performed to identify the five items that were most suitable for deletion.(21) The remaining 13-items of the PSS were used as basis for the PSSS. Therefore, we may assume that the content of the three versions of the Participation Scale is equivalent. A positive correlation between the PSSS and P-Scale was found (r=0.688, Spearman correlation), which indicates a good criterion validity. However, given the equivalence between the items of the PSSS and P-Scale, this correlation was hypothesised to be higher.

Furthermore, the cut-off scores of the Participation Scale and the PSSS were both calculated, using the normative group. As described in the Participation Scale Users' Manual, the international cut-off score of the Participation was determined to be 12 but may differ between location and cultures. The correct cut-off score may be obtained by conducting a normative study with at least 50 participants.(24) In order to establish a cut-off score suitable for our particular study population, we included a small normative research sample (n=47). With the 95th percentile of the normative group, we determined the cut-off score for normal participation of the Participation Scale to be eleven. We used two ways to determine the cut-off score of the PSSS. First, the 95th percentile of the normative group led to a cut-off score of thirteen. This is an appropriate way of estimating the normal cut-off, given the skewed distribution. Next, a ROC-curve was used to determine the cut-off score of the PSSS for normal participation. The P-Scale was again used as gold standard, with a cut-off score of eleven. The advantage of using a ROC-curve is the comparison with a gold standard.(47) The ROC-curve showed optimal specificity and sensitivity of 0.82 and 0.75, respectively, for a cut-off value of nine. This outcome is slightly lower compared to the Participation Scale Short by Jansen (0.85; 0.88) and the Simplified P-Scale by Kelders (0.88; 0.80).(22,25) In general, lowering the cut-off score will increase the sensitivity, i.e., the number of persons found with participation restrictions. Conversely, raising the cut-off score will lead to only persons with more severe restrictions being classified as restricted.(48) A cut-off score of thirteen reduces false positive results, whereas a cut-off score of nine reduces the proportion of false negatives. The latter will ensure that persons with less severe participation restrictions are not missed. In case of the PSSS, selecting persons that may not be in need of interventions will do no harm. Therefore, a cut-off score of nine is deemed to be the most suitable for using the PSSS in Central Java.

7.4.2 Internal consistency

Previous factor analyses that were performed on the Participation Scale showed that the scale was essentially unidimensional.(19) However, Stevelink identified two different factor structures: a unidimensional structure, measuring general participation, and a two-dimensional structure, measuring work-related participation and general participation. (21,49) When assuming a unidimensional structure, the Cronbach's alpha for the group of persons affected by leprosy is 0.842, in contrast to a Cronbach's alpha of 0.589 and 0.833 for the two-dimensional structure. Only the work-related participation (Q1-3) has a Cronbach's alpha lower than 0.7 for each group. However, the alpha is likely to be lower than 0.7, because the sub-scale comprises on three items. With a unidimensional structure, the alpha of this study was lower than the internal consistency of the P-Scale Short (α=0.91).(21) Multi-country studies using the full version of the P-Scale reported higher alpha's as well (α>0.90) (15,19,21), in contrast to a lower alpha in Mozambique and China (r<0.8).(45,50) Still, the internal consistency can be rated positively, with an alpha of 0.84 and a good item to total correlation (α>0.3) for all items.

7.4.3 Reproducibility

The reproducibility of the PSSS is good, with an inter-interviewer reliability above 0.70 (ICC = 0.74) tested in 47 repeat interviews.(51) Previous studies showed a good to excellent test-retest coefficient (>0.8) for the full version of the P-Scale.(15,19,49) This outcome was expected, because a longer scale (P-Scale) is more likely to have a higher correlation than a shorter scale (PSSS). However, in Mozambique, a very low inter-interviewer reliability of the P-Scale was found (ICC=0.13).(45) Comparison with the P-Scale Short is not possible, for some validation studies have not included reproducibility as a psychometric property.(18) It is unknown whether the PSSS would have a lower inter-interviewer reliability than the P-Scale in our study sample, because the latter was not included in the repeat interviews.

7.4.4 Floor and ceiling effects

There were no floor and ceiling effects present for the PSSS, meaning that differentiation between mildly and more severely restricted persons is possible. According to the categories of participation restriction of the P-Scale, only one participant experienced extreme restrictions, followed by three participants with severe restrictions.(24)

7.4.5 Interpretability

Using a non-parametric test, there was a significant difference found between the median scores of the group of persons affected by leprosy and the control group (p=0,005), respectively 7 (IQR 3-14) and 4 (IQR 0-6). Other significant differences have been found between the subgroups of persons affected by leprosy.

The minor difference in median scores between men and women was not statistically significant. This is in contrast to previous studies using shortened or simplified versions of the P-Scale, where men scored higher.(22,25) In the control group, the score for women was significantly higher than for men, which may point towards a gender-based difference in the Javanese culture. The median score of the participants who were unmarried was more than five points higher than those that were married. This outcome is in accordance to previous research that has pointed out the major role stigma plays in (the prospects of) marriage.(52) A study in Indonesia concluded that problems to find a partner and problems in marriage are strongly related to stigmatising attitudes.(8) Similar to the current study, their study sample contained a high percentage of persons affected by leprosy that were unmarried (38%) compared to the normative community. Remarkably, only five percent of the respondents reported to have a problem in question 10 of the P-Scale; *'Do you have the same opportunities as your peers to start or maintain a long-term relationship with a life partner?'* This question was newly added to the P-Scale and therefore not included in the factor analyses performed by Stevelink, that formed the basis of the PSSS.(21) However, despite the higher scores of unmarried participants, the item was not missed in the PSSS by any respondent during the qualitative testing.

The median score of persons without income or employment because of health reasons was six to eleven points higher than the other groups. This outcome was expected, because income and employment play a major role in the severity of participation restrictions, and vice versa. The three questions focussing on this topic scored significantly higher than the other questions. The economic burden of leprosy has previously been described by many studies.(8,27,33,53) Rensen discussed that experiencing stigma often leads to difficulties in finding work or losing employment.(15)

Lastly, people living in the Donorojo Leprosy Hospital scored higher than people living in the Rehabilitation village or elsewhere in Central Java. This could be explained by their high disability and living circumstances. Some of them were forced to live in the hospital, because of excluding behaviour from their families and friends. Even though the Rehabilitation village is an inclusive environment for persons affected by leprosy, where medical and psychological care is nearby, the persons there have scored three points higher than people living in the rest of Central Java. This is probably due to the higher severity of their disabilities.

7.4.6 Differences between the P-Scale and the PSSS

The PSSS is a short and simplified version of the Participation Scale, and is based on the Participation Scale Short (PSS).(21) In the PSS, five questions were omitted from the P-Scale (Q7, Q9, Q10, Q16, Q17) after performing a factor analyses, in order to reduce the time needed for assessment. In the PSSS, the language of the questions was simplified by shortening the sentences and replacing difficult words, such as the word '*peer*'. Additionally, the two-level structure of the P-Scale was simplified into a one-level structured questionnaire. The response scale was modified and one (neutral) answer option was omitted. Similar adjustments have been previously made by Kelders et al., resulting in the Simplified Participation Scale.(22) The results of this research showed that the simplified version was still perceived to be too difficult in some areas of Indonesia and people with low education had difficulties understanding the questions. In developing the PSSS, a new question structure and use of language have been applied. Within our study sample, the scale was perceived well and understood sufficiently. The difficulties in understanding the concepts of the scale as described by Kelders et al., seem to have been overcome when using the PSSS.

When looking at the distribution of the answer options for the P-Scale and PSSS (Graph 2 and 3), there is a significant difference. The five questions of the P-Scale that were omitted in the PSSS score similar or lower compared to the other questions of the P-Scale. However, the number of participants who reported feeling restricted was higher for every question of the PSSS compared to the P-Scale. This interesting outcome is different from the results of the PSS.(25) The mean scores of the PSS and the P-

Scale were similar to each other, with higher scoring of the PSS for six questions and higher scoring for the P-Scale for the other six questions.

It is essential to discuss the relative advantages and disadvantages of the PSSS compared to the P-Scale. The percentage of persons classified as experiencing participation restrictions is much higher when using the PSSS. In total 38.5% of the participants scored positively in having participation restrictions when using the PSSS, compared to only 20.2% when using the original P-Scale. More than half of the persons that scored positive on the PSSS, have scored negative on the P-Scale. This means that more persons will be classified as restricted when the PSSS is used instead of the P-Scale. Despite the fact that the maximum that can be scored on the P-Scale is 38 points higher than the PSSS (90 vs 52), the latter generally scored higher. The difference between the scores of the P-Scale and the PSSS may have been caused by the different answer options. The P-Scale has a neutral option, which respondents can choose if they feel similar to their peers. In the PSSS, this answer option is '*easy*', which may have a positive emotion attached. For this reason, respondents may have been more likely to choose the option '*a bit difficult'*. However, also the options '*difficult*' and '*very difficult'* were more often chosen in the PSSS. Another plausible explanation for the higher scores of the PSSS is the improved understanding of the scale. As described in the qualitative part of this study, the questions and answer options were more easily understood, which may have encouraged people to choose a more complicated answer. Therefore, we recommend using the PSSS especially in a target group with a low education level. Furthermore, the PSSS is well-suited when a rapid assessment is needed, such as in a survey setting.

7.5 Participation restrictions for persons affected by leprosy in Central Java

Within our study sample, the PSSS showed that more than one third of the persons affected by leprosy experience participations restrictions (38.5%; sum score > 9), compared to 9.3% of the control group. Compared to previous research in Indonesia that found a prevalence of 60%, the outcome is low.(8) The mean score of the P-Scale was 8.1 in the present study, which is close to the mean score of 9.4 found in West Java.(37) The persons affected by leprosy score highest on the first four questions of the PSSS, which indicates that '*finding work', 'working hard', 'contributing to the family financially'* and *'making visits outside the village or neighbourhood'* are most commonly restricted. The rest of the items had similar sum-scores. However, our study sample was not random and may thus be biased, so we cannot give a true prevalence estimate of participation restrictions that is generalizable to the rest of Central Java.

7.6 Limitations

In this study, several limitations were identified. The first main limitation was the language and cultural difference between the researcher, interpreter and study participants. Because of the language barrier, it is possible that valuable information and deeper understanding of the answers of the participants was lost. Besides the language barriers, we experienced problems with social desirability. The outcomes of this study may be influenced by the desire to give the right answer, which many participants seemed to have. Even though we repeatedly explained the purpose of the interview and study, some participants seemed concerned to draw too much negative attention to themselves and their disease. This made it difficult to distinguish the real information from the socially acceptable answers that may have been given. This may have led to the lower participation scores in general. The culturally coloured behaviour of the interpreters may have had an impact on the interviews. For instance, some interpreters felt uncomfortable to ask about someone's religion or income. Furthermore, due to logistic problems we needed to work with multiple interpreters. This may have caused variation between the interviews, for instance in time needed for assessment.

Another main limitation was the difference in the study population of different parts of the study. In order to validate the PSSS, persons affected by leprosy with a wide range of participation restrictions were included. However, some major differences between the qualitative and quantitative study sample were found. All qualitative study participants lived in an urban residence, compared to the majority of quantitative participants living in a rural area. Also, the severity of leprosy differed between these two groups, showing far less participation restriction in the qualitative part of the research. It would have been preferable to pre-test the PSSS on a more similar group, for instance with more severe disabilities, in order to know whether the scale was acceptable and correctly understood by all respondents. Additionally, the control group of the quantitative study was not representative for the whole of Central Java. We mostly included the family of persons affected by leprosy and people living in the rehabilitation village for the normative sample. It is likely that this group experiences more restrictions than others living in Central Java. Therefore, the cut-off for normal participation found in this group may have been too high.

Lastly, it is relevant to specify that more than half of the persons affected by leprosy lived in the rehabilitation village, which is a special leprosy inclusive environment. This may have affected the outcomes of the prevalence of participation restrictions. Additionally, we performed this validation study in the province of Central Java, but the sample for the quantitative survey was not randomly selected. We used a consecutive sampling method, which may have led to a sample biased towards severe participation. This may give an incomplete view of the restrictions experienced in this province. Therefore, the outcomes on the prevalence of participation restrictions are not to be generalised for the whole province.

7.7 Recommendations

The PSSS showed good psychometric properties, but further research is needed to determine a cut-off for normal participation based in a non-biased sample of the general population. This research has shown positive results for the version in Bahasa Indonesia, but further validation in other languages and cultures within Indonesia is required for expanding the use of the PSSS. The favourable results with regard to the validity of the PSSS will only apply if the number of items and the translation are used as they are. If changes are made, the instrument will need to be re-validated. In particular, by using '*other* people' instead of 'peers', the ease of understanding of the tool has increased. However, future research comparing the P-scale and PSSS would be useful to investigate the differences in participation restriction reported with the two instruments. Currently, the PSSS is valid for assessment of participation restrictions in persons affected by leprosy, but additional validation is necessary to extend the validity to other populations, such as persons affected by other NTDs.

8 Conclusion

According to current international standards, our study indicates that the PSSS has adequate item, semantic, operational and measurement validity to measure social participation in persons affected by leprosy in Central Java. The PSSS had a mean administration time of less than four minutes, enabling a rapid assessment of participation restrictions in Indonesia and reducing the burden to respondents. The PSSS can be used as one scale, or two subscales for assessing '*general participation*' and '*work-related participation*' separately. The PSSS has sufficient psychometric properties compared to the full Participation Scale and was preferred by the majority of respondents. We recommend the use of the PSSS, instead of the full version, especially in a target group with a low education level and when a rapid assessment is needed. Overall, the PSSS is a suitable tool for assessment of the severity of participation restrictions among persons affected by leprosy, evaluation and comparison between groups and programmes in Central Java, Indonesia.

The quantitative results of the study show that more than one-third of the persons affected by leprosy that were included in this study experienced participation restrictions. However, due to the non-representative study sample, these results cannot be generalised for the whole study population in Central Java.

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11 Annexes

11.1 Annex 1: Participation Scale v6.0 in English

	Participation Scale 6.0	Not specified, not answered	Yes	Sometimes	No	Irrelevant, I don’t want to, don’t have to	NO problem	Small	Medium	Large	SCORE
1	Do you have equal opportunity as your peers to find work?		0			0					
	[if sometimes or no] 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					
	[if sometimes or no] 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					
	[if sometimes or no] 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					
	[if sometimes or no] 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					
	[if sometimes or no] 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					
	[if sometimes or no] 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					
	[if sometimes or no] 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					
	[if sometimes or no] 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					
	[if sometimes or no] 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					
	[if sometimes or no] 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					

	Participation Scale 6.0	Not specified, not answered	Yes	Sometimes	No	Irrelevant, I don’ t want to, don’ t have to	NO problem	Small	Medium	Large	SCORE
	[if sometimes or no] How big a problem is it for you?						1	2	3	5	
12	Do you move around inside and outside the house and around the village / neighbourhood just as other people do?		0			0					
	[if sometimes or no] 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? (e.g. schools, shops, offices, market and tea/coffee shops)		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
14	In your home, do you do household work?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
15	In family discussions, does your opinion count?		0			0					
	[if sometimes or no] 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					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
17	Are you comfortable meeting new people?		0			0					
	[if sometimes or no] 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					
	[if sometimes or no] 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.

11.2 Annex 2: PSSS in English

No	Participation Scale Short Simplified Explain in introduction that we ask the respondent to compare him/herself with other people	Easy	A bit difficult	Difficult	Very difficult	Irrelevant, I don’ t want to, don’ t have to	Not specified, not answered	SCORE
1	Compared to other people, how easy is it for you to find work?	0	1	2	4			
2	Compared to other people, how easy is it for you to work hard? (same hours, type of work etc)	0	1	2	4			
3	Compared to other people, how easy is it for you to contribute to the household economically?	0	1	2	4			
4	Compared to other people, how easy is it for you to make visits outside your village/neighbourhood? (e.g., bazaars, nearby villages)	0	1	2	4			
5	Compared to other people, how easy is it for you to take part in major festivals and rituals? (e.g. weddings, funerals, religious festivals)	0	1	2	4			
6	Compared to other people, how easy is it for you to take part in social activities? (e.g. in sports, chat, meetings, religious or community activities)	0	1	2	4			
7	Compared to other people, how easy is it for you to gain respect in your community?	0	1	2	4			
8	Compared to other people, how easy is it for you to visit other people in the community?	0	1	2	4			
9	Compared to other people, how easy is it for you to move around inside and outside the house and around the village/neighbourhood?	0	1	2	4			
10	Compared to other people, how easy is it for you to visit public places in your village/neighbourhood? (e.g. schools, shops, offices, market and tea/coffee shops)	0	1	2	4			
11	In your home, how easy is it for you to do household work?	0	1	2	4			
12	How easy is it for you to get people to listen to you in family discussions?	0	1	2	4			
13	How easy is it for you to meet new people?	0	1	2	4			

Sum score:

Time:

Comment: ____

____

Respondent number: ____________________________________

Interviewer: ____

Date of interview: ___ / ___ / ___

Disclaimer: The Participation Scale Short Simplified is the intellectual property of the Participation scale development team. Neither the team nor its sponsors can be held responsible for any consequences of the use of the Participation Scale Short Simplified.

11.3 Annex 3: Informed Consent Form

Informed Consent Form

Mode of administration: Verbal
Principle investigator: Dr. Bagoes Widjanarko
Organizations: Diponegoro University and VU University

Title of study A: Measuring social participation restrictions of persons affected by leprosy in Central Java through validating the Participation Scale Short Simplified.
Title of study B: Cross-cultural validation of the Patient Health Questionnaire-9 (PHQ-9) in Bahasa Indonesia to measure depression among people affected by leprosy in Central Java, Indonesia.

Introduction

The aim of study A is to adapt a questionnaire that can be used in Indonesia. The questionnaire is about the participation of persons affected by leprosy in the community, work etc. and how leprosy influences their way of life. The results will help health services in Indonesia to support people with leprosy better. The aim of study B is to perform a cultural validation of the PHQ-9 in Bahasa Indonesia and to measure the depression status of people affected by leprosy with the validated PHQ-9.

We want to translate the words and the sentences in the questionnaire so that everyone can understand. If you feel that the questions are too personal, we can skip this question. Thank you very much for participating in this study.

Voluntary participation

Your participation in this research is voluntary, which means that you decide to stop at any time.

Procedures

To protect your privacy, we will not share your information with anyone outside the research team. The information will be stored in a safe place and all the collected data will be saved without personal identifying information. Do you have any questions?

Consent of participants

I have understood the information, and the researcher has answered my questions. I have the opportunity to refuse to participate in this study. I am a voluntarily participant in this study.

Name participant:
Signature:
Date: __ / __ / __ (dd/mm/yyyy)

Name researcher:
Signature:
Date: __ / __ / __ (dd/mm/yyyy)

11.4 Annex 4: Guideline focus group

Steps of the focus group discussion:

1. **Introduce ourselves (5 minutes)**
    a. Thank the participants for wanting to participate in this study.
    b. The translator and researcher introduce their selves and explain the procedure of translation during the focus group.
    The researcher does not speak Bahasa Indonesia so sometimes small words or sentences will have to be translated during the discussion.
    c. Ask the participants to introduce themselves to the rest of the group.
    d. Ask the participants to make a nameplate.
2. **Introduce study and aim of discussion (5 minutes)**
    a. The translator introduces the study and explains the aim of today to the participant.
    The aim of this study is to adapt a questionnaire for use in Indonesia. The questionnaire is about your participation in the community, work etc. and how leprosy influences your way of life. The results will help health services in Indonesia to support people with leprosy better. Today we will discuss some topics from the questionnaire, because we want to know how you feel about your life with leprosy and about answering these questions. Do you have any questions about that?
    b. The procedure of the focus group will be explained.
    The focus group discussion will take around 60-90 minutes. We will start with explaining the rules of the discussion. After we want to ask you some open questions about your disease and how that effects your life. Lastly, we will give you some examples and ask you about your feelings/opinion about those examples.
3. **Ground rules (5 minutes)**
    a. There are no right or wrong answers
    b. The focus groups will be recorded
    c. Confidential: what is shared in this room, will stay in this room. The data will be processed anonymously.
    d. Participation is important, we want to hear everyone just as much
    e. Do you want to add anything? Do you agree with the rules we discussed?
4. **Ask for informed consent (5 minutes)**
    The form needs to be discussed, understood and signed/verbally agreed before starting with the discussion. (See informed consent form)
5. **Continue with Part A (20 minutes), B (30 minutes) and C (10 minutes)**
6. **Ask if there are any further questions (5 minutes)**
    Are there any things we did not discuss, that are important to you?
7. **Thank the participant for cooperation and give small incentive (5 minutes)**
8. **We need to fill in the Personal Information Form of each participant after the focus group**

Part A: Exploring the field

We will ask you some open questions about how having leprosy affects your life at home and in your community. With these questions, we want to get an overview of the participation restrictions that the participants experience. Make sure everyone gives an answer to each question. Explain participation: *Participation means the involvement in different life situations. Think about your daily activities, work, education, your social life in your village and at home.*

Question 1: *What does participation mean to you?*

Participants writing down their definition of participation. After this, the interviewer will read out loud all the answers and discuss the answers with the group.

Question 2: *In which life situations do you experience problems?*

Participants writing down life situations in which they experience problems. After this, the interviewer will read out loud all the answers and discuss the answers with the group. Besides that, the factors will be ranked.

Part B: Ranking participation subjects

Next, we will use the answers we have discussed to make rankings. If not already mentioned, we will add the following items to the list of participation subjects, because we want to know how important the items of the PSSS are for the participants and how severely they feel restricted in these life situations. For this, we will use the Ranking Form.

Question 3: *How important is […] to you?*

0 marks = not important, 1 mark = little bit important, 2 marks = very important

Question 4: *How severely do you feel restricted in […]?*

0 marks = not restricted, 1 mark = little bit restricted, 2 marks = very restricted

Part C: Ending questions (if time)

We would like to discuss the problems you experience with the group. The subjects that are ranked the highest will be discussed.

Question 5: *Why do you feel restricted in […]?*

Question 6: *Can you compare yourself with other people without disability?*

If yes: which person would you compare yourself with?

11.5 Annex 5: Guideline semi-structured interviews

Steps of the interview:

1. Introduce ourselves

The translator and researcher introduce their selves and explain the procedure of translation. Thank the participant for wanting to participate in this study.

Tessa: Thank you very much for wanting to participate in this study! My name is Tessa Coltof, I am a medical student from the Netherlands and together with Diar I am conducting the interview. Diar will ask you the questions, because she speaks Bahasa much better than I do. Diar: …

2. Introduce study and interview

The translator introduces the study and explains the aim to the participant. Furthermore, the procedure of the interview will be explained.

The aim of the study is to develop a questionnaire that can be used in Indonesia. The questionnaire is about the participation of persons affected by leprosy in the community and how leprosy influences their way of life. The results will help health services in Indonesia to support people with leprosy better. This interview will help us find out if the questionnaire can be used in Indonesia. The total interview will take around 30 to 60 minutes. Do you have any questions?

3. Ask for informed consent

The form needs to be discussed, understood and signed/verbally agreed before starting with the interview questions. (See Informed Consent Form)

Before we start, we need to sign the informed consent form. The interview will be recorded. You have to know that all the data will be anonymously. If you feel uncomfortable or for any reason don't want to answer a question, you can stop anytime. There are no right or wrong answer. [Sign Informed Consent Form]

4. Fill in respondent's information

Ask the questions about personal information. (See Personal Information Form)

First, we need some personal information from you. [Fill in Personal Information Form]

5. Start with Part A

Randomly decide if you will use v1.0A or v1.0B

6. After completing the questionnaire, start with part B

7. Ask if there are any further questions or comments the participant wants to make

8. Check if all information is completed

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'.

9. Thank the participant for cooperation (and give small incentive)
Tessa: The interview is now finished. Thank you very much for your time and participation.

Part A: Item and semantic equivalence

1. Explain the concept of 'other people' and determine a suitable peer/'other people'
During this part, we ask you to compare yourself to someone else in your community. This has to be someone who is similar to you, for instance a man/woman of your age, but does not have leprosy. We will practice this one time: 'Compared to other people, how easy is it for you to start a long-term relationship with a life partner?' Find out what type of person the participant is comparing him/herself with. Explain that the 'other people' does not have to be the same person for every question.

2. Explain answer options
The answer options go from (v1.0A) easy to very difficult OR (v1.0B) no problem to big problem. You can also choose the option: I don't want to or I don't have to. For instance, when you don't want to have a long-term relationship.

3. Explain procedure
After every item of the questionnaire, we will ask you some extra questions. Remember, there are no right or wrong answers.

4. Ask all questions and record answer in appropriate boxes

a. If the respondent does not understand the question, repeat it in the same way.
b. If the respondent still does not understand it refer to the Q/Q and ask the prompt question as written. (See Annex 9)
c. 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.

- Do not translate or paraphrase the questions during the interview.
- Listen to the respondent and record his/her answer in the form as answered.
- 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.
- Give the freedom to the respondent not to reply to any question (s)he may feel uncomfortable with.

5. After every question, the following questions will be asked:

3. *Can you repeat the question in your own words?*
    a. *It they use the exact same words, ask if they can give an example.*
4. *Were any words unclear to you?*
    a. *If yes: which one(s) and can you think of any change that would make it more clear for you?*
5. *Can you explain your answer?*
    a. *If score 1 or higher: Why is this a problem to you OR Why is this difficult for you? (We ask this question to find out if version A or B is more suitable)*
6. *Was this question relevant (or important) to your situation?*

        a. *If yes: Why? Can you give an example?*
        b. *Of no: Why not?*

7. *Did you feel uncomfortable answering this question?*
    a. *If yes, why did you feel uncomfortable?*
    b. *Can you think of any change that would make you feel less uncomfortable?*

Part B: Operational equivalence

After completing the questionnaire there the following questions will be asked:

1. *In what way does leprosy affect your (way of) life?*
2. *In what area do you feel restricted the most?*
3. *Do people around you know you have leprosy?*
    a. *If not: why not? Are you afraid they will find out? Why?*
    b. *If yes: How did/do they react?*
4. *What did you think of the questionnaire?*
5. *Were the answer options clear to you?*
    a. *If not: why not?*
    b. *Can you think of any change that would make it more clear for you?*
6. *How was it to compare yourself to other people? (Difficult/easy?)*
    a. *If difficult: Why was this difficult?*
7. *Who did you compare yourself to?*
8. *Was the questionnaire relevant (or important) to your situation?*
9. *Did you feel uncomfortable during this interview?*
    a. *If yes, which question(s) or words made you feel uncomfortable?*
    b. *Why did it make you feel uncomfortable?*
    c. *Can you think of any change that it wouldn't make you feel uncomfortable?*
10. *Do you have any remarks/comments on this interview?*
11. *Are there any things we forgot to ask?*
12. *Do you have any questions?*

11.6 Annex 6: Interview guideline

1. Introduction

   Thank you for wanting to participate in this study. My name is … and this is … from the Netherlands. Together we are doing a research about social participation and depression among people affected by leprosy. We will conduct four questionnaires and it will take around thirty to forty minutes.
2. Informed consent: reading out loud + signing

   Do you have any questions?
3. Fill in personal information form
4. Questionnaire 1
5. Questionnaire 2
6. Questionnaire 3
7. Questionnaire 4
8. Check if all information is completed
9. Thanking for participating + incentive

Participation Scale

In this questionnaire, we ask you to compare yourself to a peer. This has to be someone who is similar to you in every way, for instance a man/woman of your age, but does not have leprosy. The peer does not have to be the same person for every question. Do you understand this?

The answer options are: *(read question 1 as example)*

☐ **Not specified, answered**: when you don't want to answer the question.

☐ **YES:** when there is no difficulty

☐ **Sometimes:** when there are problems with this sometimes or with some people

☐ **NO:** when there are problems with this

☐ **Irrelevant/I don't have to/I don't want to:** For example, when you don't want to or don't have to find a job. You can also choose this option when the problem is not because of leprosy, but because of something else (like age or gender).

If NO or Sometimes, the importance of the participation restriction must be assessed

☐ **No problem**

☐ **Small problem**

☐ **Medium problem**

☐ **Large problem**

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.*

After completing both Participation Scales, ask: Which Participation Scale do you prefer and why? Write the answer on the comment line.

Participation Scale Short Simplified

In this questionnaire, we ask you to compare yourself to someone else in your community. This has to be someone who is similar to you in every way, for instance a man/woman of your age, but does not have leprosy. The 'other people' does not have to be the same person for every question. Do you understand this?

The answer options are: *(read question 1 as example)*

☐ **Easy**
☐ **A bit difficult**
☐ **Difficult**
☐ **Very difficult**
☐ **Irrelevant/I don't have to/I don't want to:** For example, when you don't want to or don't have to find a job. You can also choose this option when the problem in finding a job is not because of leprosy, but because of something else (like age or gender).
☐ **Not specified, answered**: when you don't want to answer the question.

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.*

After completing both Participation Scales, ask: Which Participation Scale do you prefer and why? Write the answer on the comment line.

Patient Health Questionnaire-9

During this part of the research statements will be read out loud to you one by one. After each statement you answer how often that was for the last two weeks. The answer possibilities are not at all, several days, more than seven days and nearly every day. For example:

'How many days did you watch television for the last two weeks?'

☐ Not at all
☐ Several days
☐ More than seven days
☐ Nearly every day

Beck Depression Inventory-II

Ask the participant if he/she can read and write. If the participant can read and write, the questionnaire can be used as a self-report questionnaire. If not, read the statements out loud and let the respondent choose one.

11.7 Annex 7: Socio-demographic characteristics of the semi-structured interview participants

Table 16. Socio-demographic characteristics of the semi-structured interview participants

Respon-dent	Version	Sex	Age	Marital status	Education	Income*	Employment status	Visible signs	Years since diagnosis
S1	A	Male	65	Married	Primary	<2.3 million Rp.	Unemployed (health)	Yes	0.58
S2	B	Female	41	Married	Secondary	No income	Voluntary worker	No	6
S3	A	Male	42	Married	Secondary	<2.3 million Rp.	Employed	Yes	2
S4	B	Male	39	Unmarried	Higher	>2.3 million Rp.	Employed	Yes	5
S5	A	Male	18	Unmarried	Secondary	No income	Student	Yes	5
S6	B	Female	49	Unmarried	Secondary	No income	Unemployed (other)	Yes	1
S7	A	Male	41	Married	Secondary	>2.3 million Rp.	Employed	No	3
S8	B	Male	61	Married	Secondary	>2.3 million Rp.	Retired	Yes	0.25
S9	A	Male	34	Married	Secondary	>2.3 million Rp.	Employed	Yes	5
S10	B	Male	53	Married	Primary	No income	Unemployed (health)	Yes	3
S11	A	Female	48	Married	Primary	<2.3 million Rp.	Employed	No	13
S12	B	Female	49	Married	Secondary	<2.3 million Rp.	Employed	Yes	3
S13	A	Female	49	Married	Secondary	No income	Unemployed (other)	Yes	7
S14	B	Female	53	Married	Primary	No income	Unemployed (other)	Yes	1
S15	A	Female	59	Widowed	Primary	<2.3 million Rp.	Employed	Yes	6
F1		Male	68	Married	Secondary	<2.3 million Rp.	Employed	Yes	1
F2		Female	65	Married	Illiterate	No income	Unemployed (health)	Yes	2
F3		Male	32	Unmarried	Secondary	No income	Unemployed (health)	Yes	2
F4		Female	63	Widowed	Primary	No income	Unemployed (other)	Yes	4
F5		Male	73	Married	Secondary	>2.3 million Rp.	Retired	Yes	2
F6		Male	68	Married	Primary	>2.3 million Rp.	Employed	Yes	5
F7		Male	51	Married	Primary	>2.3 million Rp.	Employed	Yes	0.5

* Rp. = Rupiah.

11.8 Annex 8: Item validity assessment

Table 17 and 18 show the full coding for the item validity assessment.

Table 17. Item validity assessment: items are codes

	Finding work	Working hard	Financial support	Visits outside village	Major festivals	Social activities	Gain respect	Visit other people	Move around	Visit public places	Do household work	Family discussions	Meet new people	*Missing answers*
Q1: finding work	**15**	2												
Q2: working hard	1	**13**												*2*
Q3: financial support			**13**							1				*1*
Q4: visits outside village				**11**		1			3	5				
Q5: major festivals					**15**	1								
Q6: social activities						**15**			1				1	
Q7: gain respect							**15**							
Q8: visit other people								**12**	1					*2*
Q9: move around						1			**15**		1			
Q10: visit public places									3	**15**				
Q11: do household work											**15**			
Q12: family discussions												**15**		
Q13: meet new people													**15**	

Table 18. Item validity assessment: variable codes

	Physical problems	Disclosing leprosy	Community reaction	Community knowledge	Feelings about having leprosy	Healthcare
Q1: finding work	1	2	1	1	1	
Q2: working hard	4					
Q3: financial support	1					
Q4: visits outside village	1	3	4		5	1
Q5: major festivals	1	6	2		2	1
Q6: social activities	1	5	2	1	1	1
Q7: gain respect		2	8	2	1	
Q8: visit other people	1	4	1		1	
Q9: move around	5					1
Q10: visit public places	1	3	1	1		1
Q11: do household work	2					
Q12: family discussions			1			
Q13: meet new people		5	3	1	3	1

11.9 Annex 9: English version versus Backtranslation

Question	English version	Backtranslation
1	How easy is it for you to find work?	How easy for you to look for a job?
2	How easy is it for you to work hard? (same hours, type of work etc)	How easy for you to work hard? (the same working hours, the same job, etc)
3	How easy is it for you to contribute to the household economically?	How easy for you to help the family economy?
4	How easy is it for you to make visits outside your village / neighbourhood? (e.g. bazaars, markets)	How easy for you to visit the area outside the village or district? (market, exhibition, etc)
5	How easy is it for you to take part in major festivals and rituals? (e.g. weddings, funerals, religious festivals)	How easy for you to join a big social activity? (for example wedding, funeral, religious event)
6	How easy is it for you to take part in social activities? (e.g. in sports, chat, meetings, religious or community activities)	How easy for you to join social activity? (for example sports, meeting, citizens meeting, recitation, and so on)
7	How easy is it for you to gain respect in your community?	How easy for you to be respected in the society?
8	How easy is it for you to visit other people in the community?	How easy for you to visit other people in the community?
9	How easy is it for you to move around inside and outside the house and around the village / neighbourhood?	How easy for you to be active and to move inside the house, outside the house, and the neighbourhood?
10	How easy is it for you to visit public places in your village / neighbourhood? (e.g. schools, shops, offices, market and tea/coffee shops)	How easy for you to visit the public places around the neighbourhood? (for example school, tore, office, market, stall, etc)
11	In your home, how easy is it for you to do household work?	How easy for you to do the house chores?
12	How easy is it for you to get people to listen to you in family discussions?	How easy for you to make other people listen to your opinion in the family discussion?
13	How easy is it for you to meet new people?	How easy for you to meet a new person?

11.10 Annex 10: Quotes from semi-structured interviews and FGD

Participation

F1 *Like involvement in the family*

F2 *Helping neighbours if they have some problems.*

F3 *Having support or supporting others? Involvement in social activities. Sometimes I also help in my neighbourhood if we conduct a social event.*

F4 *So like, helping my family in the household work? Or other people around the neighbourhood? Or if in my neighbourhood conduct an event like Independence Day, I am cooking with other women in the neighbourhood to prepare the food for the events.*

F7 *Involved in the housework like washing the dishes, washing clothes.*

Finding work

S1 *I used to work as a construction worker outside Java. but now, my children not allowed me to find work, that's why a little bit difficult for me in this condition to find work nowadays. My children did not allow me to work anymore to focus on cure the leprosy.*

S3 *I have skill, I can drive, it is easy for me to find a job. I found a great boss, I told him that I have leprosy and I might not be able to work full time and he was fine with it.*

S4 *I work in a private company even though I have leprosy. But I didn't tell my co-workers.*

Working hard

S1 *A little bit difficult for me, because my hands is not as powerful as it used to be.. Related to my hand, I cannot bring too much heavy things. Also my leg, usually I can climb the stairs well, but now it's a little bit difficult for me. I was able to do a construction work in high building that requires me to climb the stairs, but now I don't think I can climb the stairs anymore.*

S3 *I can work like my co-worker from 8 to 4pm, but it will be a little bit hard because of the reaction if I feel too tired. When I work too much, my body will make a reaction because of leprosy. I will feel sick, dizzy and want to throw up. Sometimes I feel sick for 2 days, I couldn't eat anything and because I will throw up everything I eat. So I often take a leave from my job.*

S10 *actually I want to work hard, but physically limited. So it's a small problem*

Contributing financially

S1 *I can't work to make money now. My children are supporting us financially, but I don't know when they will send money for us or how much they send money. Because they also have to support their family.*

S2 *I'm not working, but I do want to make money. I have a plan to bake cookies and sell it to my neighbour. I often make traditional snacks or cookies for my children, then I'm planning to make it more and sell it to help my household financial.*

S3 *It's not difficult [to support the household financially], because I also work. But when I was too sick to go to work, my wife also can do some work and I will take care of my kids in my house.*

Visits outside village

S2 *I still can ride motorcycle by myself even when I was diagnosed with leprosy. Maybe sometimes I feel tired if I drive too long like when I was driving from Semarang to Solo, but not because of the leprosy. Most people did not know that I have leprosy. And my leprosy was only around my stomach and my back. So I don't think it is difficult for me to go somewhere outside the village*

S3 *I think it is normal for me to go somewhere outside my village. I don’t think it is difficult, I don’t feel any restriction. Everyone also react normally when they meet me in the street. I also don’t really care what other people think of me, I took the medication regularly, and I know that this disease can be cured.*

S10 *It's a bit embarrassing to have this disease, so it's a problem. I feel limited to visit outside village.*

S14 *Some people look at me, but I don't care a lot about it. People just stare at me and not doing anything. I don't feel ashamed or anything.*

Major festivals

S1 *I frequently go to major festival, but if it’s needed to sit on the floor, it’s a little bit hard for me. Because my feet hurts if I sit in the floor too long.*

S2 *People don’t know that I have leprosy that’s why I don’t find any difficulties in going to major festival.*

S5 *I feel inferior sometimes. But actually my family rarely ask me to join them to go to a wedding or other events*

S7 *no limitation to socialization with others in wedding ceremony or funeral. It is so easy, I am like normal human with no special disorder*

Social activities

S3 *I join social activities regularly. People know that I have leprosy, and I have a neighbour that works in Puskesmas and have knowledge about leprosy. He helps me explain to other people that my disease is not infectious. But, when the first time I diagnosed with leprosy, people was avoided me, I also sent by my family and my relatives to the leprosy hospital in Jepara and they’re not allowed me to go home until I got better. But now everyone react normally when they meet me.*

S5 *I still meet with my friend around my house. They just act like usual. But, I’m only fine if I meet my friends, I don’t want to join social activities with other person that I don’t know or people that not my age. I feel inferior if I meet people I don’t know*

S13 *I don't have any problem to join the activities in the community. People sometime asked what happened with my face, but I just answer skin disease or allergy, and they stop asking. Only my family know that I have leprosy*

S15 *I still attend several religious meeting. People don’t know that I have leprosy, and I don't want to tell them*

Gain respect

S1 *People don’t really judge me because of leprosy. They just think that this is just a normal skin disease.*

S3 *People still respect me, I don’t feel any difference. But I don’t know if behind my back they talk bad about me. When I meet people in my neighbourhood, everyone just act normally.*

S5 *Actually it’s different for each person. Some people avoid me, but my close friends still respect me. My neighbour also respect me like before.*

S6 *People take care of me, pray for me so I can be cured, healthy, and active again in the social community. I don’t think people disrespect me*

S10 *When compared to others it's a small problem. I am embarrassed. Some people respect me there are those who don't*

S12 *I think it is not really related to diseases, it depends on our attitude*

S13 *Nobody react differently when I have leprosy. Maybe also because they did not know that I have leprosy. I didn't tell them about it because I was worried people will talking bad about me. Because not everyone understand that leprosy can be cured and not infectious.*

Visit other people

S2 *My leprosy was not really affects my movement and it is not visible. That's why I don't think it's difficult for me to go visit other people*

S3 *I don't really care if people avoiding me. But most people act normally around me. They know I have leprosy, and they also know that I already do the examination and rehabilitation. So they're not worried.*

S12 *I think it is not a problem because people can't really see my leprosy. I don't feel ashamed or worried to visit other people*

Move around

S1 *I cannot go to places by myself*

S2 *My leprosy did not restrict my movement. So there was no problem to move around my house or my neighbourhood*

S3 *I can move around freely. But when I have some reaction and my face or my hands become red, people asked me, "what happen with your face?. I just said that I'm sick. People will start worried a little bit and ask me to go to Puskesmas. When I got really sick during my reaction, I can't go anywhere because I feel really sick and can't get up from bed. Usually my reaction last for 3 days, and I can't do anything in the first day.*

S6 *I feel uncomfortable to go outside because of my foot. So, usually I wear socks to go anywhere.*

S13 *I'm not really going outside my house if I don't have nothing to do outside the house. I spent my time mostly at home. My leprosy did not affect my activities. Only sometime I feel tired easily, but I still do a lot of activities inside and outside my house*

Visit public places

S3 *[…] I don't have any problem with other people. There were a few people avoided, but it's gradually decreased because people already know about leprosy and they know that it's not infectious.*

S4 *I don't have any problems. Especially if I go to new place that I don't know anyone there. I can go anywhere*

S5 *It's easy, as long as I know them. Most people around my neighbourhood already know that I have leprosy.*

S15 *I don't feel ashamed or afraid to go to places around my house. I don't really care what people think of me. Most people don't know that I have leprosy*

Doing household work

S2 *I do household work every day and I don't this it is difficult. Only when I was cooking, sometimes I feel tired easily so I cannot do it as fast as before*

S6 *I do household work everyday. Like cooking, washing the dishes, do the laundry. My family said that I need to get some rest if I got tired. But I'm fine with working at home*

Family discussions

S2 *I don't find any difference between during I was diagnosed by leprosy and before that. My family act the same*

S6 *People still listen to me in my family. They just worried if I get too tired, but they not avoid me or ignore me.*

S8 *Even though my salary was lower than my wife, but it didn't matter, my family still wanted to listen to my opinion. I still communicate with my family, like usually*

Meet new people

S2 *My leprosy is not visible for other people. So I don’t find it difficult to meet new people. Because they don’t know if I have leprosy and also I did not tell them. I only tell my family and several health carer in my area that I have leprosy.*

S5 *I’m only fine if I meet my friends, I don’t want to join social activities with other person that I don’t know or people that not my age. I feel inferior if I meet people I don’t know*

S6 *I’m afraid people will worried that I will infect them.. I’m worried people will feel uncomfortable if they see my foot, as long as I wear socks, it’s fine for me to meet people.*

S12 *For me it is just normal, I don't think it's difficult to meet new people*

Community knowledge

S1 *Besides, most people don’t understand well about leprosy, they just think I got some normal skin diseases.*

S2 *Not everyone understand that leprosy can be cured with a proper medication.*

S7 *In my opinion everyone doesn't know about this disease, and no special sign in my body, no physical disability, so that’s easy when I went looking for a job and no problem with my company.*

S11 *Sometimes hearing people say bad things about Leprosy patient. They didn't say in front of me. They say that they don’t eat together with the Leprosy patient, it can be contagious*

S12 *People don't really understand about leprosy and people might be afraid or avoid me if I said I have leprosy. People and my family think that leprosy always caused disabilities, but I explain properly to my family. But I don't want to explain it to everyone in my neighbourhood.*

Healthcare

S1 *Also Puskesmas worker help me very well so I don’t feel uncomfortable meeting new people in Puskesmas or in event like this.*

S3 *I have a neighbour that works in Puskesmas and have knowledge about leprosy. He helps me explain to other people that my disease is not infectious.*

S3 *Once, there were health education in my village, my wife join it and asked the facilitator, “my husband got leprosy, is it infectious? Because our neighbour worried about it and they said it infectious.” The facilitator explains that if I’m already in proper rehabilitation for curing the diseases, took the medicine, then it is not infectious. So people who attend that health education already know about my disease and also know that it is not infectious.*

Disclosing leprosy

S2 *Actually I never told people around me that I have leprosy, except my family and a few friends which also a health carer like me. Because people still think that people with leprosy need to be avoided. Because not everyone understand that leprosy can be cured with a proper medication.*

S4 *No one knows that I have leprosy here. Only my family in my house knows that I have leprosy. Even my co-worker doesn’t know. I also didn’t want to tell them about leprosy because some people especially people that don’t know about leprosy might have negative impression on me or afraid to be infected. Only my close family knows about it. Because I afraid I might lose the job or people will start avoiding me.*

S12 *People don't know I have leprosy. Only my family knows about the leprosy. Other people around me think I just have an allergy. If people asked me about the disease, I will only answer it just a skin disease caused by allergy. Because people don't really understand about leprosy and people might be afraid or avoid me if I said I have leprosy. People and my family think that leprosy always caused disabilities, but I explain properly to my family. But I don't want to explain it to everyone in my neighbourhood.*

S13 *I didn't tell them about it because I was worried people will talking bad about me. Because not everyone understand that leprosy can be cured and not infectious.*

Feelings about having leprosy

S2 *I was afraid and a little bit depressed when I was diagnosed with leprosy. I was diagnosed with leprosy after I learn about leprosy because of my job as health carer, so I know that it can be cured. That's why I try my best to finish the treatment.*

S5 *I feel inferior sometimes.*

S8 *I know this disease about 3 months ago, I'm in shock, but I know this is my way of life, so that's no affect to my life*

S9 *Before I was given the medicine, I was down, 'how come I get this disease?'. It's quite affected in my life, especially if I accidentally meet a severe patient*

S13 *Sometimes I feel uncomfortable when people look at me*

Community reaction

S1 *Even they know that I have leprosy, some people not really judged me. They didn't say anything about my leprosy.*

S3 *Well for me it's normal if one of two people avoid me or think bad of me. But it is fine. There are more people that still friendly with me and I also have no problem doing my daily activities.*

S3 *Usually there are some ladies around my house have some bad opinion about me, but the man act like usual.*

S3 *There were a few people avoided, but it's gradually decreased because people already know about leprosy and they know that it's not infectious*

S6 *People take care of me, pray for me so I can be cured, healthy, and active again in the social community. I don't think people disrespect me*

S6 *I'm afraid people will worried that I will infect them.. I'm worried people will feel uncomfortable if they see my foot.*

S15 *Not much people know I have leprosy. Some of my relatives at first avoid me, but I don't really think about it. So it's fine. But my friends at work and neighbour don't avoid me. They react like usual even though they know I have leprosy*