

**The cross-cultural validation and adaptation of the Patient Health Questionnaire-9 (PHQ-9) and the Warwick-Edinburgh Mental Wellbeing scale (WEMWBS) amongst persons affected by leprosy in India.**



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## Abstract

**Introduction:** There is need for validated instruments that measure the mental status amongst persons affected by leprosy in India. The Patient Health Questionnaire-9 (PHQ-9) and the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) are such tools. The PHQ-9 measures symptoms of depression and the WEMWBS measures mental wellbeing in general. Both instruments are already used amongst different target groups and in different contexts.

**Objective:** This study cross-culturally validates the PHQ-9 and WEMWBS to measure the level of depression or mental wellbeing amongst Hindi speaking persons affected by leprosy in India.

**Methods:** A cross-sectional study design with a mixed methods approach was used. A qualitative pilot study was performed to assess the conceptual, item, semantic and operational equivalence of the two instruments for persons affected by leprosy. In the quantitative study, measurement equivalence was assessed by investigating the internal consistency, construct validity, floor and ceiling effects and interpretability.

**Results:** During the qualitative study, seven persons affected by leprosy were interviewed. The results showed sufficient conceptual equivalence for both instruments. The item, semantic and operational equivalence showed to be unacceptable. Adjustments were made to improve the instruments. The adjusted tools were assessed in the quantitative study. The quantitative study included 101 persons affected by leprosy and 62 controls. The results show that both instruments have sufficient measurement equivalence. The internal consistency of the PHQ-9 and WEMWBS was good ( $\alpha = 0.81$ ,  $\alpha = 0.81$ ). The construct validity was satisfactory. For the PHQ-9 and WEMWBS, floor and ceiling effects were not found and the interpretability was acceptable.

**Conclusion:** The Hindi versions of the PHQ-9 and WEMWBS have been adjusted and the instruments are cross-culturally validated to measure the level of depression or mental wellbeing amongst persons affected by leprosy in Jharkhand and similar Hindi speaking areas.

## Introduction

Currently, approximately 15% of the world's population is living with a disability (1). Most are vulnerable people, often living in developing countries (2, 3). In 2016, the proportion of people living with disabilities in India was estimated at 2.2%, which accounts for 28 million people (4). Neglected Tropical Diseases (NTDs) are a group of communicable diseases that predominantly occur in (sub-) tropical areas. NTDs contribute significantly to the rates of disabilities, as several NTDs are associated with long-term disfigurement (5, 6).

One of the NTDs associated with long-term disability is leprosy, also known as Hansen's disease (7). Leprosy is a communicable, chronic, infectious disease and is caused by *Mycobacterium leprae* (5, 7). After a varying incubation period, the *Mycobacterium leprae* affects the peripheral nerves and the appendages of the skin, such as sweat and sebaceous glands (8). If left untreated, the disease may lead to severe, yet slowly progressing deformities (7). However, when treated with multi-drug therapy (MDT), leprosy itself is curable. Nevertheless, nerve damage is irreversible (e.g. loss of sensation in hands or feet, or muscle paralysis in eyes, hands or feet) and therefore the risk of secondary impairments remains (e.g. wounds or contractures) (9).

Despite many advances in the field of medical science, leprosy continues to be a major public health challenge (10). According to the World Health Organization (WHO), globally 210,671 new cases of leprosy were detected in 2017 (3). India accounted for more than 60% of the global new cases, as 126,164 new cases were detected in India in 2017 (3, 10). Leprosy is endemic in most states of northern India, especially in Bihar, Uttar Pradesh, West Bengal, Jharkhand and Orissa (8). In Jharkhand, between April in 2016 and March 2017, 6253 new cases of leprosy were detected, which accounts for 16.8 new cases of leprosy per 100,000 population (11).

Although several interventions have been conducted, the incidence rate in Jharkhand has not declined and reducing this incidence is still priority for public health authorities (8, 11-13). As of 1983, the National Leprosy Eradication Programme is the centrally sponsored programme of the Indian Government's Ministry of Health. The programme uses a three-pronged approach: (a) active case detection and treatment of leprosy; (b) leprosy awareness campaigns in highly endemic areas; and (c) area-specific plans for case-detection in hard-to-reach areas (10). However, as the development of MDT improved the effectiveness and shortened the duration of treatment, healthcare professionals are now increasingly focussing on the disability, rehabilitation and social inclusion of persons affected by leprosy (3, 10, 13). For instance, the social-economic rehabilitation programmes that are focussed on teaching new skills to persons affected by leprosy to increase empowerment and social participation, and to help with acceptance (14, 15). The additional focus on rehabilitation is supported by research that suggests that the consequences of social exclusion, including social stigma and discrimination, have a strong negative effect on the mental health of a person affected by leprosy (14, 16-18).

The WHO defines mental health as "a state of wellbeing in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community" (19). Depression, on the other hand, is characterized by the WHO as "persistent sadness and a loss of interest in activities that you normally enjoy, accompanied by an inability to carry out daily activities for at least two weeks" (20). Previous studies in India and Bangladesh showed a higher prevalence of mental disorders in persons affected by leprosy than in the general population (16, 21). Depressive symptoms of persons affected by leprosy have been shown to correlate to the severity of the disability, as well as to the experience of being discriminated and isolated (16).

Little progress has been made in systematically addressing the consequences of stigma and discrimination amongst persons affected by leprosy in public health programmes (22). Particularly, the effectiveness of stigma reduction programmes with the aim to improve the mental status of persons

affected by leprosy is often not known (22). This is partly due to the lack of validated measurement tools that assess the mental status of persons affected by leprosy, especially in developing countries (22, 23). Therefore, in 2015, NTD experts identified the development of a toolkit including instruments that are designed to assess the morbidity and disability aspects of leprosy, such as the mental aspects, as an imperative need (24). These instruments should be culturally specific and allow for the identification of priority areas for advocacy, funding, interventions and services, provide tools for mapping, surveillance and evaluation of programmes (23). An example of a toolkit is the NTD Morbidity and Disability (NMD) Toolkit, which is based on the conceptual model of the WHO International Classification of Functioning Disability and Health and is currently being developed by the Netherlands Leprosy Relief (NLR) Foundation (23, 25).

Instruments that can be included in the NTD NMD Toolkit and assess the mental status of persons affected by leprosy, could be the Patient Health Questionnaire-9 (PHQ-9) and the Warwick-Edinburgh Mental Wellbeing scale (WEMWBS) (26, 27). The PHQ-9 measures depression, whereas the WEMWBS measures mental wellbeing in general. Both instruments have already been validated and used across different cultures and target groups (28-46). However, these tools have not yet been validated for persons affected by leprosy in India. During the validation of these instruments, differences in the conceptualization of mental health across cultures must be taken into account (47). Consequently, the aim of this study is to test the cross-cultural validity of the PHQ-9 and WEMWBS to measure the level of depression or mental wellbeing amongst Hindi speaking persons affected by leprosy in India.

## Methods

### Study design

We conducted a cross-sectional validation study with a mixed-methods approach, entailing a qualitative pilot and quantitative study between March and September 2019 amongst persons affected by leprosy in Jharkhand, India. As the instruments were already available in Hindi, only back-translations were done. Qualitative methods consisted of semi-structured interviews to pre-test the instrument by assessing the conceptual, semantic, item and operational equivalence. The quantitative methods included structured interviews to assess measurement equivalence. The study phases are depicted in figure 1.

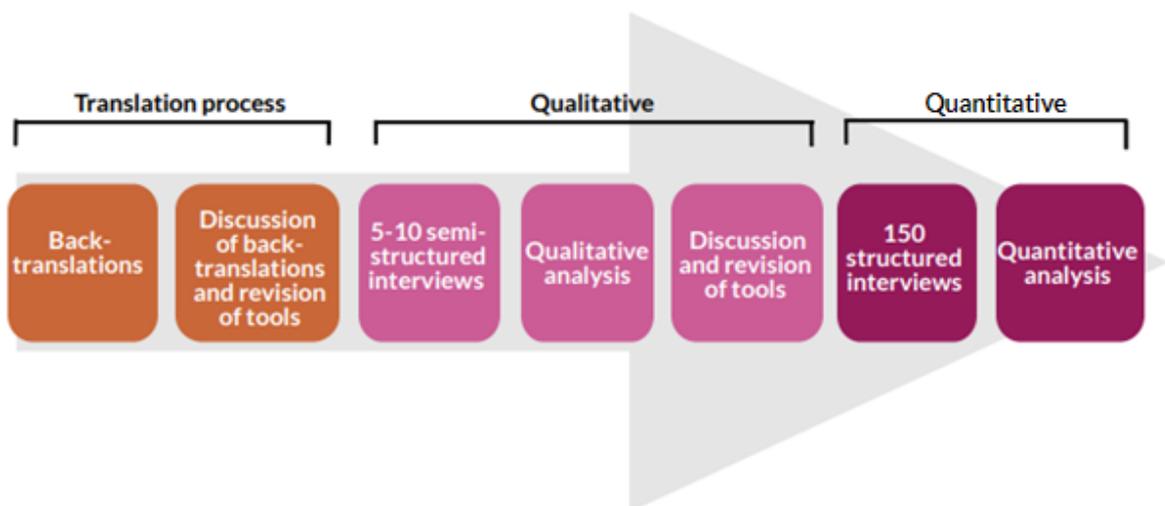


Figure 1 – Visualization of the cross-cultural validation study phases.

## Study population and setting

The study population consisted of persons affected by leprosy in Jharkhand, India. Persons not affected by leprosy were included as their controls. Jharkhand is the second poorest state of India and has a population of approximately 33 million people of which 37% lives below the poverty line (<1.25 USD) (48, 49). Most people live in rural compared to urban areas (76 vs. 24%), and in the former, the difference between male and female literacy is especially high (73 vs. 47%), indicating gender disparity (50, 51). The majority of the population practices Hinduism (68%) and Jharkhand's official language is Hindi (51, 52).

## Inclusion and exclusion criteria

Respondents were eligible for study enrolment in the case group if they were diagnosed with leprosy and were under treatment or had completed treatment. Respondents were eligible for study enrolment in the control group if they had never been diagnosed with leprosy before. For both the case and control group, respondents had to be eighteen years or above, had to be able to communicate in Hindi and had to live in Jharkhand, India. Respondents were excluded from study enrolment when they were not capable of responding independently, not willing to give clear consent or when they had a visible disability not caused by leprosy.

## Sampling

For the qualitative pilot study, we aimed to interview 5 to 10 persons affected by leprosy. For the quantitative study, we aimed to interview 100 persons affected by leprosy and 50 controls. The quantitative sample sizes were based on the numbers of respondents recommended by Terwee et al (53). Selection techniques involved purposive and convenience sampling. The study population was targeted in collaboration with NLR Foundation and local health workers in different ways. First, the NLR Foundation had the personal particulars of the persons affected by leprosy who were under treatment or had completed treatment in Jharkhand. Depending on the local hospital where NLR Foundation already needed to work, we asked the local health workers, who work on a daily basis with the persons affected, to contact the respondents by phone. The respondents were invited to be interviewed at the hospitals. Second, occasionally we visited meetings amongst persons affected by leprosy, NLR employees and local health workers that were already scheduled. Third, NLR Foundation contacted the community leaders of several leprosy colonies (self-established settlements for persons affected by leprosy often due to social exclusion). In the colonies, the community leader gathered the respondents for interviewing. Fourth, mostly for respondents who were not able to travel, NLR Foundation contacted the respondents themselves. They were asked if they wanted to participate in the research via house visits. Also, during those house visits, other villagers were invited to participate in the control group. We aimed for a sample that would represent a range of severity of disabilities due to leprosy, different ages, gender, marital statuses and social-economic statuses, to be able to differentiate between groups and increase reliability. We aimed for a control group that was comparable with the study population in terms of sex and age distribution.

## Conceptual framework

To assess the suitability of the PHQ-9 and the WEMWBS in another culture, Stevelink and van Brakel's enhanced Cultural equivalence framework was used (47). The framework is an adapted version of the Herdman and Fox-Rushby Framework (54). The framework consists of five categories of equivalence: conceptual, item, semantic, operational and measurement equivalence. The five categories are illustrated in Figure 2 and defined in Appendix 1. The first four categories should be qualitatively assessed, while the last category; measurement equivalence should be mostly quantitatively assessed (47). To further distinguish between measurement equivalence, we used the quality criteria of Terwee et al (53). Measurement equivalence can be divided into eight components or psychometric properties; content validity, internal consistency, criterion validity, construct validity, reproducibility (agreement and reliability), responsiveness, floor and ceiling effects and interpretability

(53). The first, content validity, is the only psychometric property that should be qualitatively assessed. This psychometric property is highly related to the first four categories of equivalence. Therefore, in this study, content validity was to be assessed by investigating the conceptual, item, semantic and operational equivalence. The eight components of measurement equivalence are illustrated in Figure 3 and defined in Appendix 2.

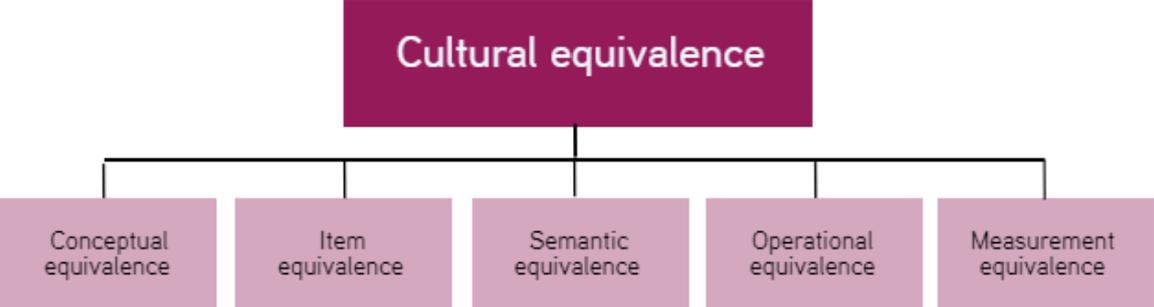


Figure 2 – Visualisation of Stevelinks and van Brakel’s Cultural equivalence framework (47).

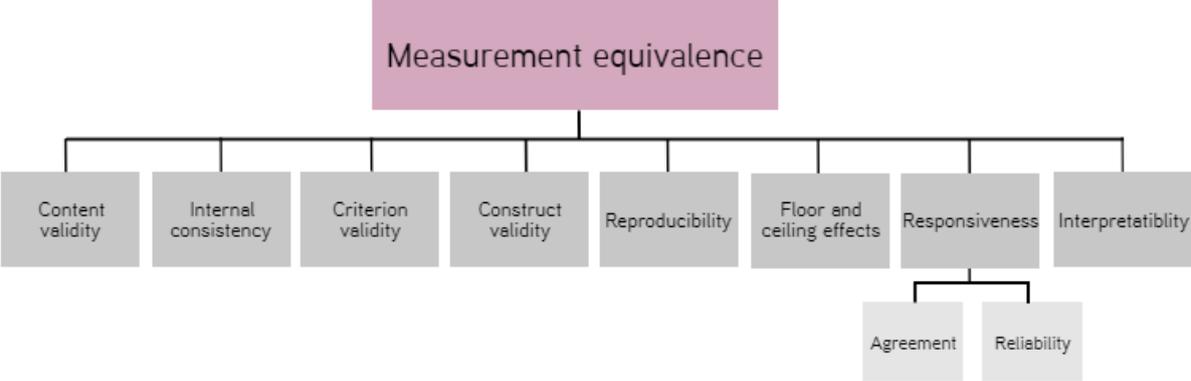


Figure 3 – Visualisation of measurement equivalence (53).

For this study, three psychometric properties were not to be assessed. First, the criterion validity was not to be investigated, since psychiatrists’ diagnoses would be considered as the golden standard and this was not available for comparison in the study setting. Second, reproducibility was not to be investigated as this requires repeated measures, which was out of scope of this study. Third, responsiveness was also considered to be out of scope, as this psychometric property requires longitudinal validation research (53).

**Measures**

All measures included in this study were interviewer-administered.

**Personal Information form (PIF)**

Demographic information of the respondents was gathered via the PIF (Appendix 3). The PIF consists of an assessment of the respondents’ living area, age, marital status, living situation, level of education, employment status, level of monthly income, religious affiliation and age of onset of the disability. Also, a question was included in which was asked whether the respondents were ever diagnosed by a psychiatrist with a mental disorder or not. Last, an assessment on the severity of disability was included in the PIF.

## **PHQ-9**

The PHQ-9 is a brief generic instrument which can be used for screening, monitoring and measuring the severity of depression. The PHQ-9 asks respondents to rate how often they were bothered by specific problems over the last two weeks (27). The questionnaire consists of ten items, of which nine are derived from the diagnostic criteria of the DSM-IV for depression: anhedonia; depressed mood; trouble sleeping; feeling tired; change in appetite guilt, self-blame, or worthlessness; trouble concentrating; feeling slowed down or restless; and thoughts of being better off dead or hurting oneself (55). Each of these nine items is rated on a 4-point Likert type scale from 0 to 3, according to the frequency of the problem during the two weeks prior to the interview (0 = not at all; 1 = several days; 2 = more than half the days; and 3 = nearly every day). The overall score of the nine items ranges from 0 to 27. Moreover, the tenth item asks patients "How difficult have these problems made it for you to do your work, take care of things at home or get along with other people?" This item has to be scored at least as "somewhat difficult", to be able to assess any level of depression (27). The Hindi version of the PHQ-9 and its English translation used in this study are presented in Appendix 4 and 5 (56).

## **WEMWBS**

The WEMWBS focusses on mental wellbeing during the two weeks prior to the interview and consists of positively phrased statements. The instrument consists of 14 items, all of which are positively worded and all of which incorporate positive aspects of mental health. Each of the 14 items is rated on a 5-point Likert type scale from 1 to 5 (1 = none of the time; 2 = rarely; 3 = some of the time; 4 = often; 5 = all of the time). The total score is calculated by summing the scores of all 14 items and ranges from 14 to 70 (26). The Hindi version of the WEMWBS and its English translation used in this study are presented in Appendix 6 and 7 (57).

## **Beck Depression Inventory (BDI)**

For the quantitative study, a third instrument was used to assess construct validity. Since the BDI is already validated for adolescents and students in India, this instrument was used to assess the construct validity of the PHQ-9 and WEMWBS (58-60). The BDI used in this study consists of 16 items which are derived from clinical symptoms and attitudes frequently displayed by depressed patients. Every item is rated on a 4-point Likert type scale from 0 to 3 in terms of intensity. The sum-score ranges from 0 to 48 (60). The Hindi version of the BDI and its English translation are presented in Appendix 8 and 9.

## **Severity of disability**

Data on the severity of disability due to leprosy was measured to assess the construct validity and describe the interpretability. Both the WHO disability grading and the Eyes Hand Feet score (EHF score) were chosen as these are simple instruments for which the data was often already available (61). If the WHO disability grade or EHF score of a respondent was not documented already, this was assessed by a local leprosy health professional. The WHO disability grading classifies impairment into three grades from 0 to 2 and distinguishes between impairment of the hands and feet and impairment of the eyes. The EHF score evaluates the level of impairment of both eyes, both hands and both feet individually from 0 to 2, yielding a sum-score between 0 to 12 (61). Both scores are included in the PIF.

## **Process of translation**

As Hindi versions of the PHQ-9 and WEMWBS were already available no forward translations were performed in this study (56, 57). Firstly, each item of the PHQ-9 and the WEMWBS was blindly back-translated into English by a native Hindi speaker, who was fluent in English and was an expert in the field of Leprosy. Also, he critically compared the meaning of the concepts and their related items in the original and Hindi versions. A second back-translation was performed by a local Hindi and English

speaking independent interpreter who was not familiar with the original instruments. The main reason to conduct a second back-translation was to double-check whether the PHQ-9 and the WEMWBS were in line with the Hindi dialect spoken in Jharkhand. Of both back-translations, notes were kept and any discrepancies, sensitive topics or inadequate expressions were discussed with a co-research student and an expert in the field of leprosy. After the back-translations, no revisions of the instruments were made.

## **Qualitative procedure**

### **Data collection**

Before pre-testing the instrument, we trained local leprosy health professionals by providing knowledge about mental well-being, depression, the methods of interviewing, the measurement instruments, the PIF and the informed consent form (Appendix 10). In addition, local health workers were trained to assist in conducting interviews on-site.

To pre-test the PHQ-9 and WEMWBS's conceptual, item, semantic and operational equivalence, we aimed to interview 5 to 10 persons affected by leprosy with the use of the PIF and the semi-structured interview guide (Appendix 11) which was based on the conceptual framework (47). The interviews took on average 45 minutes and the qualitative data collection period was two weeks. To assess conceptual equivalence we asked the participants to describe the concepts mental wellbeing and depression in their own words. Item equivalence was investigated by asking the participants two questions after each statement. The first question was "Does the statement contain any inappropriate or sensitive words?" The second question was "Do you think this statement is important to you?" Semantic equivalence was assessed by asking the participants two questions after each statement: "Did you understand the statement?" and "Could you repeat the statement in your own words?" In addition, at the end of the questionnaire, a third question was asked: "Do you have any suggestions to improve the questionnaire?" To assess operational equivalence we asked the participants to give their opinion about the PHQ-9 and WEMWBS via two questions. The first question was: "Do you understand that the statements are about the two weeks before today?" The second question was: "Did you understand the different answer options?" Every statement of each instrument was individually assessed. The interviews were recorded and additional comments were written down. The interviews were held in separate rooms of local hospitals, at communal spaces in colonies or villages, or at participant's homes. We aimed for the most neutral, stress-free and safe environment, enabling participants to speak freely.

### **Analyses**

The recordings were transcribed in Hindi and translated into English by a partner organization of NLR Foundation. The English transcripts and written comments were entered into an analysis matrix of MAXQDA 2018. The analyses were done during the data collection. The process of analyzation is described below:

1. Familiarization with the raw data: all transcripts were read thoroughly.
2. Coding the transcripts: sections of the transcripts were labelled, corresponding with the four qualitatively assessable equivalences (47).
3. Charting the data: the data of multiple transcripts were organized per equivalence to be able to view the data horizontally.
4. Interpreting the data: the organized data per equivalence were examined in Excel, interpreted and conclusions were drawn.
5. Revision of instruments: the results were discussed with one interpreter and an expert in the field of both disability and mental health to decide whether to adjust the questionnaires or not. Final versions of the PHQ-9 and WEWMBS were prepared.

## Quantitative procedure

### Data collection

Quantitative methods were used to investigate the psychometric properties (measurement equivalence). Both the case and control group were structurally interviewed with the use of the PIF, BDI, adjusted PHQ-9 and adjusted WEMWBS. The interviewer administered all questionnaires, the statements were read out loud and the answers were filled in by the interviewer. One structured interview took on average 25 minutes and the quantitative data collection period was 6 weeks. The interviews were held at similar locations as during the qualitative study.

### Analyses

All quantitative data were entered into Epi Info 7. For the analyses, the collected data were exported into SPSS statistical software version 24. Questionnaires with more than 10% missing values were excluded from the analyses. Missing values were interpolated using the mean score of the individual questionnaire. Prior to the analyses, normality of the data was assessed by plotting histograms of the numerical variables for the case and control group separately. Internal consistency was measured by calculating Cronbach's alpha. Cronbach's alphas of at least 0.70 were determined as a positive rating (47). Construct validity was measured by testing the a priori defined hypotheses and at least 75% of the results had to be in line with the hypotheses (see Textbox 1 and 2). If normally distributed, Independent Samples T-tests and Pearson's correlation coefficient's were used. If not normally distributed, Mann-Whitney U tests and Spearman's correlation coefficient's were used. Descriptive statistics were used to measure floor and ceiling effects and they were considered as being present when at least 15% achieved the highest or lowest possible scores. Interpretability was considered to be acceptable if the mean and standard deviation (SD) or median and interquartile ranges (IQR) of at least four subgroups within the study population (e.g. gender, age, education and with and without disabilities) were calculated (53).

#### Textbox 1. Hypotheses to assess construct validity of the PHQ-9

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1. The median PHQ-9 score of persons affected by leprosy is expected to be at least two points higher compared to the median score of the general population.
  2. The PHQ-9 scores are expected to show a moderately to highly positive correlation with the BDI scores ( $\rho = 0.50 - 0.80$ ).
  3. The PHQ-9 scores are expected to show a mildly to moderately negative correlation with the positively phrased WEMWBS scores ( $\rho = -0.30 - -0.50$ ).
  4. The PHQ-9 scores are expected to show a mildly positive correlation with the EHF scores of the persons affected by leprosy ( $\rho = 0.20 - 0.40$ ).
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#### Textbox 2. Hypotheses to assess construct validity of the WEMWBS

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1. The median WEMWBS score of persons affected by leprosy is expected to be at least four points lower compared to the median score of the general population.
  2. The WEMWBS scores are expected to show a mildly to moderately negative correlation with the BDI scores ( $\rho = -0.30 - 0.60$ ).
  3. The WEMWBS scores are expected to show a mildly to moderately negative correlation with the PHQ-9 scores ( $\rho = -0.30 - -0.50$ ).
  4. The WEMWBS scores are expected to show a mildly negative correlation with the EHF scores of the persons affected by leprosy ( $\rho = -0.20 - -0.40$ ).
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## Ethical considerations

Ethical approval was obtained from the Research Committee under the Rights of Persons with Disabilities Act. in Jharkhand, India. At the start of each interview, respondents were verbally informed by the interpreter about the purpose of the study to provide a full understanding of the implications of participation. The respondents were free to withdraw from the study at any time. Each respondent was asked to give written and verbal informed consent. Furthermore, no incentives were given to motivate

people to enrol in the study, however, we compensated for the respondents' travel costs. Last, in case any respondent was found to have severe depressive symptoms, if possible, he/she was referred to a local mental health service.

## Results

### Qualitative study

#### Characteristics of the study population

A total of seven persons affected by leprosy participated in the qualitative pilot study, of whom six were male. All were living in Jharkhand district. Four participants lived in urban areas. All participants were 28 years or above and were married. Two persons were illiterate, four persons had completed primary education and one person had completed secondary education. The majority of the participants ( $n = 5$ ) practiced Hinduism and the median EHF score was 3.6 (range 0 to 8).

#### Conceptual equivalence

The main underlying concepts of depression and mental wellbeing mentioned by the participants were: energy, happiness, optimism, respect, social interaction, tension-free and usefulness. The importance of social interaction was mentioned by all participants. For instance, one man said the following: *"...See, when we do some work alone, then we feel lonely. When we are working with others, then we feel good. We feel that there is someone with me, to support me. It motivates me..."* (male, age 51-55). Another man explained: *"...Me and my wife help others. Some people got the pension but a few didn't. We helped them and they got the pension. We became delighted..."* (male, age over 55).

Some participants related mental wellbeing and depression to God or supernatural powers such as ghosts and witches. One participant did not know how to give an explanation of these concepts. One man expressed his view on depression: *"...Yes I do understand. I have seen a mentally ill person. I understand what it [depression] is. There is a supernatural power. Ghosts. It [depression] is due to supernatural power. Persons become mentally ill from it. There are many types of it..."* (male, age 29-40).

None of the participants related (un)usual patterns in appetite to mental wellbeing or depression. The concept appetite was often related to the availability of food. For instance: *"...I don't feel much hunger because I am habitual of being hungry since childhood. I eat less since my childhood..."* (female, age 41-50). Therefore, we found that PHQ-9's item 5 "feeling less hungry or eating too much/overeating" showed some non-equivalence. However, after discussion with experts, we decided not to remove this item, as removing a full item from the questionnaire would influence the questionnaire's sum-score considerably. The WEMWBS was considered to be conceptual equivalent, as we found that the concepts used in the questionnaire were similar to the conceptualization of mental wellbeing in the Indian culture.

#### Item equivalence

None of the participants answered that a statement in the PHQ-9 or the WEMWBS was inappropriate or sensitive. To the question "Do you think this statement is important to you?", all participants answered 'yes'. In general, the participants were very positive about the questionnaires. However, we found that the PHQ-9's item 7; "Problem in concentrating in reading newspaper, watching TV, etc." showed some non-equivalence. Not all participants are literate or have access to television. Therefore, as discussed with a co-student researcher and recommended by experts, we decided to add "listening to music" to this statement. Adjustments of the PHQ-9's items are shown in Appendix 12. For the WEMWBS, none of the items were changed or excluded, as we found this questionnaire to be item equivalent.

## Semantic equivalence

We found that several items of both the PHQ-9 and WEMWBS showed semantic non-equivalence and had to be rephrased. When an item was difficult to understand for a participant, our interpreter often naturally added some examples or he explained the item with day-to-day used Hindi words. All findings were discussed with our interpreter and experts before adjusting an item. First, PHQ-9 item 1, "little interest or pleasure in doing things" was found to be challenging for the participants. Our interpreter stated that there is a contradiction within the sentence. He explained that 'little' only refers to 'interest' and not to 'pleasure'. Moreover, the word 'things' ('kaam') was found to be unclear and our interpreter often added 'work' ('karya') to this item, which most of the other participants understood immediately. We decided to adapt this item into: "Little interest or little pleasure in doing things or work" (Appendix 12). Second, in PHQ-9 item 2, "Feeling sad, depressed or hopeless", the Hindi word for depression ('udas rahna') was often not known by the participants. A day-to-day Hindi word for 'depression' ('dawab mey rahna') was found to be understood easily and we decided to adapt this item. Last, in PHQ-9 item 4, "feeling tired or having very little energy", the Hindi word for 'energy', 'urja' was found to be wrongly interpreted. We decided to change 'urja' into 'takat', which means energy of the body/mind'.

With regards to the WEMWBS, item 2 "I am feeling useful" was found to be difficult to interpret for the participants. The item was found to be understandable when "for instance in my work, for my community or family" was added. Similar difficulties were observed for WEMWBS item 4 "I am feeling interested in other persons". We decided to add "like my neighbours, friends and family" to this statement. In WEMWBS item 5, "I have a lot of energy", some participants indicated that the word 'energy' ('urja') was unclear. An example of a man's explanation of the word 'energy' was: "...*Energy means Light. The Netherlands Leprosy Relief is supporting us. Gradually it is bringing light in our life...*" (male, age over 55). Another participant related having less 'energy' to hot weather. 'Urja' refers to energy in general and had to be changed into 'power in my body/mind' ('takat'). In item 7 "I am thinking clearly", the word 'clearly' ('spast'), was found to be difficult to understand. We chose to replace this word with 'properly' ('sahi parkar se'). For item 9: "I am feeling myself close to others", we found that 'close' ('kareeb') was difficult to understand and had to be changed into 'near' ('nikat'). Our interviewer often used the word 'near' instead of 'close' and the results showed that 'near' was correctly understood. Lastly, the findings suggested that the participants' interpretation of item 13 "I am showing interest in new things" varied. One man answered the following: "...*Interest towards new work? I am interested towards new products...*" (male, age 29-40) and another man responded "...*For me new things is for example a house. I am trying for a house. It will be good if we get it...*" (male, age 41-50). We decided to add the word 'changes' ('paritwarta') and therefore this item was rephrased into: "I am showing interest in new things or changes".

## Operational equivalence

The operational format of the Hindi version of the PHQ-9 and WEMWBS and the original scales were similar. All interviews were interviewer-administered, meaning that the participants did not really see the format of the questionnaires. No missing values were found for both the PHQ-9 and WEMWBS during this pilot study. Sometimes, the interviewer naturally rephrased the statements into questions. It was noted that participants found it easier to understand when statements were rephrased into questions. Furthermore, all participants understood that the statements are about the two weeks before the day of the interview. With regards to the answer options, there was only one participant who did not fully understand the answer options of the PHQ-9 and needed extra explanation. In contrast, all participants understood the answer options of the WEMWBS. Last, PHQ-9's item 8 "Walking or speaking so slowly that these draw others attention. Or just opposite, you are very unstable, restless and waffle excessively or move excessively", was found to be a too-long sentence and difficult to understand. Nevertheless, we agreed that this was the best way to phrase the sentence. After assessment of operational equivalence, it was decided to rephrase the statements of both the PHQ-9 and WEMWBS into questions to avoid misunderstandings (Appendix 12 and 13).

## Quantitative study

### Characteristics of the study population

The characteristics of the quantitative study population are described in Table 1. In total 101 persons affected by leprosy were interviewed during the quantitative study, of whom 53.5% were males. 62 respondents were interviewed as controls, of whom 37.1% were males. Amongst the case group, most respondents were illiterate (63.4%) or primary educated (17.8%). The education level of the control group was relatively higher, as most controls were primary (30.6%) or secondary educated (25.8%). Most cases received income via begging (35.6%) and almost half of the cases earned less than 3000 Rupees a month (47.5%). 22 respondents of the control group were housewife or homemaker (35.5%). Moreover, most controls earned less than 3000 Rupees a month (35.5%). Last, the majority of both the case and control group were married (87.1% vs. 91.9%) and practiced Hinduism (83.2% vs. 91.1%).

**Table 1.** Characteristics of the quantitative study population

	Persons affected by leprosy (n = 101)		Controls (n = 62)	
	n	(%)	n	(%)
<b>Gender</b>				
Male	54	(53.5)	23	(37.1)
Female	47	(46.5)	39	(62.9)
<b>Age</b>				
18-28	8	(7.9)	10	(16.1)
29-40	16	(15.8)	25	(40.3)
41-50	25	(24.8)	14	(22.6)
51-55	14	(13.9)	6	(9.7)
55+	38	(37.6)	7	(11.3)
<b>Living area</b>				
Rural	49	(48.5)	40	(64.5)
Urban	52	(51.5)	22	(35.5)
<b>Education level</b>				
Illiterate	64	(63.4)	14	(22.6)
Can read and write	10	(9.9)	4	(6.5)
Primary education	18	(17.8)	19	(30.6)
Secondary education	7	(6.9)	16	(25.8)
University	2	(2.0)	9	(14.5)
<b>Marital status</b>				
Married	88	(87.1)	57	(91.9)
Separated	1	(1.0)	0	(0.0)
Widowed	7	(6.9)	0	(0.0)
Never married	5	(5.0)	5	(8.1)
<b>Employment status</b>				
Beggar	36	(35.6)	1	(1.6)
Farmer	18	(17.8)	5	(8.1)
Student	4	(4.0)	0	(0.0)
Employed in business	4	(4.0)	12	(19.4)
Housewife/homemaker	18	(17.8)	22	(35.5)
Working for someone paid	10	(9.9)	12	(19.4)
Unemployed	9	(8.9)	2	(3.2)
Other	2	(2.0)	8	(12.9)
<b>Monthly level of income</b>				
No income	28	(27.7)	5	(8.1)
< 3000 Rupee	48	(47.5)	22	(35.5)
3000-5000	17	(16.8)	13	(21.0)
5000-8000	6	(5.9)	10	(16.1)
> 8000 Rupee	2	(2.0)	12	(19.4)
<b>Religious affiliation</b>				

	Persons affected by leprosy (n = 101)		Controls (n = 62)	
	n	(%)	n	(%)
Christian	6	(5.9)	2	(3.2)
Hindi	84	(83.2)	57	(91.1)
Muslim	11	(10.9)	3	(4.8)
<b>Mental disorder diagnosis</b>				
Yes	4	(4.0)	4	(6.5)
No	97	(96.0)	58	(93.5)
<b>WHO disability grading</b>				
0	13	(12.9)	-	-
1	20	(19.8)	-	-
2	68	(67.3)	-	-
	<b>Median (IQR)</b>			
<b>EHF-Score</b>	4.0	(2.0-8.0)	-	-
<b>Age of onset of the disability</b>	24.0	(15.0-40.0)	-	-

### PHQ-9 and WEMWBS score characteristics

The PHQ-9's median sum-score of the persons affected by leprosy was 12.0 and for the control group this score was 3.0 (Table 2). For the PHQ-9, we found four missing values, distributed over two items. With regards to the WEMWBS, the median sum-score of the persons affected by leprosy was 52.0 and for the control group this score was 64.0 (Table 2). For the WEMWBS, we found ten missing values distributed over six different items. No questionnaires were excluded from the analyses of both the PHQ-9 and WEMWBS, because all records had less than 10% missing values.

**Table 2.** Characteristics of the sum-score of the PHQ-9 (score 0-27) and WEMWBS (14-70)

	PHQ-9			WEMWBS		
	Median (IQR)	Min	Max	Median (IQR)	Min	Max
Persons affected by leprosy (n = 101)	12.0 (4.0-15.0)	0	27	52.0 (46.0-57.0)	26	70
Controls (n = 62)	3.0 (0.0-7.3)	0	17	64.0 (58.0-68.0)	37	70

### Measurement equivalence

#### Internal consistency

Cronbach's  $\alpha$  coefficient for the PHQ-9 was high ( $\alpha = 0.81$ ), which suggests that the internal consistency of the instrument is satisfactory. When looking at the item-total statistics, we found that question 7 ("Have you been facing problems in concentrating in reading newspaper, watching TV or listening to music?") had the lowest item-total correlation of 0.27. However, removal of this item or any of the other items did not improve the coefficient value. For the whole WEMWBS a Cronbach's  $\alpha$  coefficient of 0.81 was found, which indicates an adequate internal consistency. When looking at the Cronbach's  $\alpha$  per item, we found that question 3 ("Have you been feeling tension free?") had a low item-total correlation of 0.065; if left out the Cronbach's  $\alpha$  slightly increased to 0.83.

#### Construct validity

100% of the a priori defined hypotheses of the PHQ-9 was supported, indicating sufficient construct validity. First, as hypothesised, the median PHQ-9 sum-score of the persons affected by leprosy was more than two points higher than the median sum-score of the control group (12.0 vs. 3.0) (Table 2). Second, to assess the correlation between instruments, Spearman's correlation test was used. We found a moderately positive correlation between the sum-score of the PHQ-9 and BDI ( $\rho = 0.64$ ), which supports our hypothesis. Third, the results showed a mildly negative correlation between the sum-score of the PHQ-9 and WEMWBS ( $\rho = -0.39$ ). This is in line with our hypothesis. Fourth, with regards to the correlation test between the sum-score of the PHQ-9 and EHF score, we found a mildly positive correlation ( $\rho = 0.25$ ) and this supports our hypothesis.

75% of the hypotheses of the WEMWBS was confirmed, which suggests that the construct validity of the WEMWBS is satisfactory. First, we found a median difference of the WEMWBS sum-score between the persons affected by leprosy and control group of 12.0 (Table 2). This is in line with our hypothesis. Second, as hypothesized, Spearman's correlation test showed a moderately negative correlation between the sum-scores of the WEMWBS and BDI ( $\rho = -0.48$ ). Third, we found the negative correlation between the sum-score of the WEMWBS and PHQ-9 ( $\rho=-0.39$ ), which is in line with our hypothesis. Fourth, the results showed a positive correlation close to 0 between the WEMWBS and EHF score ( $\rho=0.027$ ). This does not support our hypothesis as we expected a mildly negative correlation ( $\rho=-0.20 - -0.40$ ).

### Floor and ceiling effects

For the PHQ-9, 11 persons affected by leprosy (10.9%) scored the lowest possible score (0) and one person (1.0%) scored the highest possible score (27). For the WEMWBS, none of the persons affected by leprosy scored the lowest possible score (14). Six persons affected by leprosy (5.9%) scored the WEMWBS's highest possible score (70). Therefore, no floor and ceiling effects were found for either the PHQ-9 or the WEMWBS.

### Interpretability

The medians and IQRs of the different subgroups of the persons affected by leprosy ( $n = 101$ ) are shown in Table 3. The PHQ-9 median sum-score was higher for females compared to males (12.0 vs. 10.0). Amongst the age groups, the median PHQ-9 sum-score was similar for the age group of 28 to 40 and 41 to 55 (11.0), but slightly higher amongst persons over 55 (13.0). The median sum-score was much higher for non-educated compared to educated persons (12.0 vs. 6.0), suggesting more depressive symptoms amongst non-educated persons. Furthermore, the median PHQ-9 sum-score steadily increased with the WHO disability grading (8.0 vs. 9.5 and 12.0). With regards to the WEMWBS, the median sum-score was higher for males compared to females (55.5 vs. 49.0), indicating better a mental wellbeing amongst males. The age group of 28 to 40 had the highest median sum-score (56.0), suggesting a lower mental wellbeing amongst persons affected by leprosy who are over 40 years old. The WEMWBS median sum-score was higher amongst educated compared to non-educated persons (57.0 vs. 51.0). Lastly, the WEMWBS median sum-score was highest amongst persons with WHO disability grading 0, followed by grading 1 and 2 (55.5 vs. 51.5 and 52.0).

**Table 3.** Median and IQR of the sum-score of the PHQ-9 and WEMWBS of sub groups within the persons affected by leprosy ( $n = 101$ )

	n (%)	PHQ-9 Median (IQR)	WEMWBS Median (IQR)
Gender			
Male	54 (53.5)	10.0 (1.8-14.3)	55.5 (49.0-55.5)
Female	47 (46.5)	12.0 (8.0-15.0)	49.0 (43.0-55.0)
Age			
28-40	24 (23.8)	11.0 (2.0-13.8)	56.0 (48.3-59.0)
41-55	39 (38.6)	11.0 (4.0-14.0)	51.0 (46.0-51.0)
55+	38 (37.6)	13.0 (5.0-17.0)	51.5 (44.0-56.0)
Education			
Not educated	74 (73.3)	12.0 (5.8-15.0)	51.0 (44.0-56.0)
Educated*	27 (26.7)	6.0 (0.0-14.0)	57.0 (49.0-57.0)
WHO disability grading			
0	13 (12.9)	8.0 (0.0-12.5)	55.0 (43.5-59.5)
1	20 (19.8)	9.5 (3.0-16.5)	51.5 (48.3-58.3)
2	68 (67.3)	12.0 (5.0-15.0)	52.0 (44.3-57.0)

\* Primary, secondary or higher education.

## Discussion

To our knowledge, this was the first study to test the cross-cultural validity of the Hindi PHQ-9 and WEMWBS to measure the level of depression or mental wellbeing amongst persons affected by leprosy in India. Investigating the cultural equivalence is needed to ensure that the instruments provide valid data and measure what they intend to measure. The Hindi version of the PHQ-9 and WEMWBS have been adapted to improve the item, semantic and operational equivalence. Both questionnaires were found to have adequate conceptual equivalence and measurement equivalence. However, there is still room for improvement, as will be discussed below.

### Conceptual equivalence

The present study showed that almost all items of both the PHQ-9 and WEMWBS are related to depression or mental wellbeing as conceptualised in India. This indicates that the conceptual equivalence of both instruments was satisfactory. Only PHQ-9 item 5 “Feeling less hungry or eating too much/overeating” seemed to be less appropriate to measure the level of depression in this setting. This was also found in validation studies amongst persons affected by leprosy in Nepal and Indonesia (35, 43). In the present study and the study in Nepal, instead of relating changes in appetite to depression, persons affected by leprosy related feeling hungry to the absence of food (35). Overeating may not be possible at all due to the lack of financial resources. In contrast, when looking at the PHQ-9’s internal consistency, Cronbach’s alfa would not improve while removing item 5. The PHQ-9’s good internal consistency suggests that the questionnaire items are measuring the same concept. Moreover, removing item 5 would influence the questionnaire’s sum-score considerably. It requires more in-depth research to find out whether this item should be replaced or not. With regards to PHQ-9 item 9, “thoughts that it would have been better to die or hurting yourself in some way”, the results of the studies in Nepal and Indonesia showed that this item was somewhat inappropriate, but both studies did not remove this item from the questionnaire (35, 43). In contrast, the results of the present study did not show any indication this item was considered sensitive or inappropriate. In the present study, most respondents were Hindu. The majority of the respondents of the Indonesian validation study were Muslim. Compared to the Islamic religion, the Hindu religion has a very tolerant view on suicide, which might be an explanation for the different findings (62).

### Item equivalence

For the PHQ-9 some item non-equivalence was found, whereas the WEMWBS was found to be item-equivalent. We decided that PHQ-9 item 7 “Problem in concentrating in reading newspaper, watching TV, etc.” had to be adjusted. Not all persons affected by leprosy can read or have access to a television, therefore we added: “or listening to music”. The same revision of item 7 was done during the validation of the Nepali PHQ-9 (35). For similar reasons, the validation study in Indonesia added; “or cooking” to this statement (43). Our viewpoint is that the addition of “or cooking” would have been suitable in the present study’s context as well. With regards to the WEMWBS’s item-equivalence, no revisions were made. Also, for the Nepali WEMWBS validation amongst persons affected by leprosy no revisions were needed on account of item equivalence (35).

### Semantic equivalence

Substantial issues were found with regards to semantic equivalence of the PHQ-9 and the WEMWBS. To solve these problems, two items of the PHQ-9 and six items of the WEMWBS had to be rephrased. Revisions were made to maintain the original meaning or to make a statement easier to understand by using a day-to-day Hindi word. For instance, in both questionnaires the Hindi word ‘urja’, which refers to energy in general, was used. ‘Urja’ had to be changed into ‘takat’, which means ‘energy of the body/mind’, to maintain the original meaning of the item. Also, we chose to add some standard examples to prevent the interviewers from using different examples when administering the questionnaires. For instance, for WEMWBS item 4 “I am feeling interested in other persons”, we

added "like my neighbours, friends and family". For similar reasons, comparable revisions were made in the Nepali and Indonesian validation studies amongst persons affected by leprosy (35, 43). For example, in the Nepali WEMWBS validation study, "such as family, relatives, neighbours and friends" was added to item 4 (35).

## **Operational equivalence**

Both the PHQ-9 and WEMWBS were found to be operational non-equivalent. We decided to rephrase statements into questions to achieve operational validity, as we found that questions were easier to understand than statements. For the same reason, statements were revised into questions in other validation studies amongst persons affected by leprosy in Asia (35, 63). Besides, the present study suggested that the answer possibilities of both scales were appropriate as only one participant did not fully understand the options. This is in line with the findings of PHQ-9 and WEMWBS validation study in Nepal (35). In contrast, the PHQ-9 validation studies in Indonesia and Kenya showed that there was confusion regarding the answer possibilities and therefore they were modified (31, 43). The Kenyan validation added extra explanation for respondents who have difficulties with the answer options. For instance, the answer possibility "not at all" was further explained with "0 or 1 days in the past two weeks" (31). To our opinion, if we have found non-equivalence regarding the answer possibilities in the present study, the extra explanation of the answer possibilities used in the Kenyan validation study could have been used as well.

## **Measurement equivalence**

The newly adjusted instruments were used to assess measurement equivalence. The internal consistency of the PHQ-9 in this study was excellent ( $\alpha = 0.81$ ). The Cronbach's alpha found in this study is equivalent to values found in other validation studies in Asia ( $\alpha = 0.71 - 0.90$ ) (28, 29, 34, 35, 43-45, 64). The construct validity of the instrument was found to be sufficient, as 100% of our hypotheses was supported. Floor and ceiling effects were not present in this study. Other PHQ-9 validation studies did not detect any floor or ceiling effects either (31, 35, 43). This finding suggests that people with very low or very high levels of depression can still be distinguished from each other and that it makes it more likely to be able to measure changes over time (responsiveness) (53). The interpretability was found to be acceptable, as an overview of the PHQ-9 sum-scores was provided. An overview aids to interpreting the scores of the questionnaire. For instance, PHQ-9 sum-scores amongst non-educated were much higher compared to educated persons affected by leprosy. This is consistent with findings from the Indonesian validation study and suggests that more depressive symptoms are present amongst non-educated compared to educated persons affected by leprosy (43). Overall, the PHQ-9 is found to have good measurement equivalence amongst Hindi Speaking persons affected by leprosy in India.

The internal consistency of the Hindi version of the WEMWBS was good, as Cronbach's alpha was 0.81. Other studies in Asia, Europe and South America showed good internal consistency of the WEMWBS as well ( $\alpha = 0.85 - 0.95$ ) (35, 36, 39, 41, 42). The construct validity was satisfactory, as 75% of the a priori defined hypotheses was confirmed. An interesting finding was that we did not find a negative correlation between the WEMWBS and EHF score, meaning the higher the grade of disability, the lower the level of mental well-being of a person. In contrast, our results showed a positive correlation close to 0. A reason for this might be the distribution of the EHF scores in and outside leprosy colonies. In the colonies, the persons affected by leprosy had generally higher EHF scores than persons affected living outside these colonies. However, we noticed that the persons affected by leprosy who were living in the colonies feel accepted and get a lot of support from each other. For persons affected by leprosy living outside these colonies may be less support and acceptability. This affects their mental health and this may be an explanation for that we did not find a correlation between the disability grade and WEMWBS scores. The results of an ethnographic study in India showed that persons affected by leprosy living in or outside a colony are both stigmatized. However,

the persons affected by leprosy living outside the colonies have to hide their deformities more often to maintain community ties, while persons affected by leprosy living in a colony feel accepted in their community (65). With regards to measurement equivalence, the WEMWBS is found to be sufficient.

## **Strengths and limitations**

This study has both strengths and limitations. A major strength of this study is the strong methodological framework we adhered to. The framework provides clear guidance to assess the validity of instruments in a particular context. A limitation of this study is that we were not able to assess all aspects of measurement equivalence due to the limited timeframe of the research. Another limitation of this study is that all our interviewers were male. The gender difference might have influenced the answers of female respondents. In the Indian culture, males have been known to be dominant over females for ages (66). Female respondents might have felt more hesitant to express their opinion to our interviewers compared to male respondents. However, the interviewers built very good rapport with all respondents. Therefore, to our opinion, the influence of male interviewers on our results is minor. A third limitation, we tried to arrange the safest environment for the interviews. However, often the extended family and community members were present. This might have encouraged the respondents to give socially desirable answers. The extent of this effect is difficult to determine. On the one hand, previous research suggests that the presence of family eases the mind of Indian respondents (67). On the other hand, mental health is a sensitive topic and is often not disclosed outside of Indian families (67). Last, the presence of a Dutch researcher could also have caused an interviewer effect. Some participants might not have felt completely free to express their opinion. We tried to mitigate this effect by emphasizing our interest in their personal view and by explaining none of the posed statements are either true or false. From our point of view, the effect on conceptual, semantic, operational and measurement equivalence is likely to be small, but could have influenced the item equivalence in our study. For instance, during the qualitative study, all participants stated the relevance and acceptability of all statements. We are not completely sure whether this were socially desirable answers, as the interviewer did not ask them to explain why.

## **Recommendations**

We recommend more in-depth research to assess the conceptualization of depression in relation to appetite in India. Furthermore, the present study did not assess the responsiveness and reproducibility. In the future, to be able to use the instruments for monitoring and evaluation, the responsiveness and reproducibility should be tested to broaden the evidence base of the PHQ-9's and WEMWBS's measurement equivalence. Another recommendation is to test the instruments in other Indian areas. Ideally, each area and language would have access to a validated and translated version of the PHQ-9 and WEMWBS. For other Hindi speaking areas a small pilot study is proposed, whereas for non-Hindi speaking areas a full validation study may be required. Finally, we recommend testing the validity across different NTDs in India.

## **Conclusion**

In conclusion, the Hindi versions of the PHQ-9 and WEMWBS have been adjusted and the instruments are cross-culturally validated to measure the level of depression or mental wellbeing amongst persons affected by leprosy in Jharkhand and similar Hindi speaking areas. To our knowledge, the instruments are the first tools validated in this way to assess the mental health amongst Hindi speaking persons affected by leprosy. The instruments are short, easy to administrate for local health workers and seem to be very promising for monitoring and identification of priority areas. Future research is needed to assess the validity of the Hindi PHQ-9 and WEMWBS in different settings and for other NTDs.

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# Appendixes

## Appendix 1 – Definitions of the categories of cultural equivalence

Definitions of the categories of cultural equivalence (47)

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Equivalence	Definition
Conceptual	A questionnaire has the same relationship to the underlying concept in both cultures, primarily in terms of domains included and the emphasis placed on different domains.
Item	A questionnaire has equally relevant and acceptable items in both cultures and the items estimate the same parameters on the latent trait being measured.
Semantic	A questionnaire has a similar effect on respondents who speak different languages, the transfer of meaning across languages is adequate.
Operational	A questionnaire can be used with a similar format, instructions, mode of administration and measurement methods.
Measurement	The psychometric properties are equivalent in the translated version.

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## Appendix 2 – Definitions of the psychometric properties

### Definitions of the psychometric properties (53)

Property	Definition
Content validity	<i>'The extent to which the domain of interest is comprehensively sampled by the items in the questionnaire'.</i>
Internal consistency	<i>'The extent to which items in a (sub)scale are intercorrelated, thus measuring the same construct'.</i>
Criterion validity	<i>'The extent to which scores on a particular questionnaire relate to a gold standard'.</i>
Construct validity	<i>'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'.</i>
Reproducibility	
· Agreement	<i>'The extent to which scores on repeated measures are close to each other (absolute measurement error)'.</i>
· Reliability	<i>'The extent to which patients can be distinguished from each other, despite measurement errors (relative measurement error)'.</i>
Responsiveness	<i>'The ability of a questionnaire to detect clinically important changes over time'.</i>
Floor and ceiling effects	<i>'The number of respondents who achieved the lowest or highest possible score'.</i>
Interpretability	<i>'The degree to which one can assign qualitative meaning to quantitative scores'.</i>

## Appendix 3 – Personal Information Form

### Personal information form

Please tick one of the boxes after each question.	
Respondent number	.....
Date of interview	...../...../..... (day/month/year)
Gender	<input type="checkbox"/> Female <input type="checkbox"/> Male
To which of the following age groups do you belong? Please choose one of the following options:	<input type="checkbox"/> From 18 up to 28 <input type="checkbox"/> From 29 up to 40 <input type="checkbox"/> From 41 up to 50 <input type="checkbox"/> From 51 up to 55 <input type="checkbox"/> Over 56
What state do you live?	<input type="checkbox"/> The state of Jharkhand <input type="checkbox"/> Other:.....
Could you specify the area where you live?	<input type="checkbox"/> Urban area <input type="checkbox"/> Rural area
Are you married?	<input type="checkbox"/> Married <input type="checkbox"/> Remarried <input type="checkbox"/> Widowed <input type="checkbox"/> Separated <input type="checkbox"/> Never married
What is your living situation?	<input type="checkbox"/> Living with parents <input type="checkbox"/> Living with partner <input type="checkbox"/> Living alone <input type="checkbox"/> Living with others (not parents or partner)
What is your level of education?	<input type="checkbox"/> Illiterate <input type="checkbox"/> Read and write only <input type="checkbox"/> Primary education <input type="checkbox"/> Secondary education <input type="checkbox"/> Higher education (e.g. university)
What is your employment status?	<input type="checkbox"/> Student <input type="checkbox"/> Farmer <input type="checkbox"/> Employed in business <input type="checkbox"/> Official (in government) <input type="checkbox"/> Housewife/homemaker <input type="checkbox"/> Working for someone paid <input type="checkbox"/> Unemployed due to health reasons <input type="checkbox"/> Unemployed due to other reasons <input type="checkbox"/> Other: .....
What is your level of income?	<input type="checkbox"/> No income <input type="checkbox"/> Less than 3000 Rupees per month <input type="checkbox"/> 3000-5000 Rupees per month <input type="checkbox"/> 5000-8000 Rupees per month <input type="checkbox"/> More than 8000 Rupees per month
What is your religion?	<input type="checkbox"/> Buddhism <input type="checkbox"/> Hinduism

	<input type="checkbox"/> Muslim <input type="checkbox"/> Christian <input type="checkbox"/> Other:.....
Are you diagnosed with a mental disorder?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Eyes Hand Feet score (Draw a circle around the right answer: 0, 1, or 2)	1. Right eye 0 – 1 – 2 2. Left eye 0 – 1 – 2 3. Right hand 0 – 1 – 2 4. Left hand 0 – 1 – 2 5. Right foot 0 – 1 – 2 6. Left foot 0 – 1 – 2 Sum score: .....
WHO grading score	0 – 1 – 2
Age of onset of condition/disability	..... years

## Appendix 4 – PHQ-9 English version

### PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

Over the **last 2 weeks**, how often have you been bothered by any of the following problems? (Use “✓” to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
FOR OFFICE CODING <u>  0  </u> + _____ + _____ + _____ =Total Score: _____				

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all ⑤	Somewhat difficult ⑤	Very difficult ⑤	Extremely difficult ⑤
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## Appendix 5 – PHQ-9 Hindi version

### रोगी स्वास्थ्य प्रश्नावली – 9 (PHQ-9)

पिछले 2 सप्ताहों में, आप इन समस्याओं में से किसी से भी कितनी बार परेशान रहे/रही हैं?  
(अपना उत्तर बताने के लिए “✓” का प्रयोग करें)

	बिल्कुल नहीं	कई दिन	आधे से अधिक दिन	लगभग हर दिन
1. कुछ करने में बहुत कम दिलचस्पी या मज़ा आना	0	1	2	3
2. उदास, अवसादग्रस्त या निराश महसूस करना	0	1	2	3
3. नींद आने या सोये रहने में परेशानी, या फिर बहुत अधिक सोना	0	1	2	3
4. थकान महसूस करना या बहुत कम ऊर्जा होना	0	1	2	3
5. भूख कम लगना या ज़्यादा खाना	0	1	2	3
6. अपने बारे में बुरा महसूस करना - या ऐसा महसूस करना कि आप नाकाम इंसान हैं और आपने खुद को और अपने परिवार को नीचा दिखाया है	0	1	2	3
7. अखबार पढ़ने या टेलीविज़न देखने जैसी चीज़ों पर ध्यान देने में परेशानी	0	1	2	3
8. इतना धीमे चलना-फिरना या बोलना कि लोगों का ध्यान जाये? या इसका उल्टा - इतना अस्थिर या बेचैन होना कि आप सामान्य से काफी ज़्यादा हिलते-डुलते और चलते-फिरते रहे हैं	0	1	2	3
9. ऐसे विचार कि आप मर जाते तो अच्छा होता या किसी ढंग से खुद को नुकसान पहुंचाना	0	1	2	3

FOR OFFICE CODING 0 + \_\_\_\_\_ + \_\_\_\_\_ + \_\_\_\_\_  
=Total Score: \_\_\_\_\_

अगर आपने किन्हीं समस्याओं पर निशान लगाया है, तो बतायें कि इन समस्याओं ने आपके लिए काम करना, घर पर चीज़ों की देखभाल करना, या दूसरे लोगों के साथ मेल-जोल रखना कितना मुश्किल किया है?

बिल्कुल मुश्किल नहीं

थोड़ा-बहुत मुश्किल

बहुत मुश्किल

बेहद मुश्किल

## Appendix 6 - WEMWBS English version

Below are some statements about feelings and thoughts. Please tick (✓) the box that best describes your experience of each over the last 2 weeks

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

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## Appendix 7 - WEMWBS Hindi Version

### Warwick Edinburgh Mental Health Scale (Hindi Version)

नीचे भावनाओं और विचारों के बारे में कुछ वाक्य दिए गये हैं। हर एक वाक्य को ध्यान से पढ़ें और उन जवाबों पर निशान लगाइए जो पिछले दो हफ्तों में इन भावनाओं और विचारों के मामले में आपके अनुभव को व्यक्त करते हैं।

STATEMENTS	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं भविष्य के बारे में आशावादी महसूस कर रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं अपने आपको उपयोगी महसूस कर रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं अपने आपको तनाव मुक्त महसूस कर रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मुझे दूसरे लोगों में रुचि महसूस हो रही है।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मुझमें बहुत ऊर्जा है।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं समस्याओं का सामना अच्छी तरह कर रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं स्पष्ट रूप से सोच रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं अपने बारे में अच्छा महसूस कर रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं खुद को दूसरों के करीब महसूस कर रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मुझे खुद में आत्मविश्वास महसूस हो रहा है।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं चीजों के बारे में अपना मन बना पा रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मुझे लगता है कि लोग मुझे प्यार करते हैं।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं नयी चीजों में रुचि दिखा रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं अपने आपको खुश/आनंदित महसूस कर पा रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा

(Developed by Dr Sandeep Grover, Dr Pradyumna and Dr Subho Chakrabarti from Department of Psychiatry, Post Graduate Institute of Medical Education and Research (PGIMER), Chandigarh, India)

## Appendix 8 – BDI English version

### English-Beck Depression Inventory (E-BDI)

**Instructions:** Following are group of statements conveying the same thought in varying degree of intensity, which are being experienced by students during higher. Read group of statement carefully and encircle the digit provided before the statement which defines your occurring thoughts completely.

S. No.	One thoughts given varying degree of intensity
1	0- I do not feel sad. 1- I feel sad. 2- I am sad all the time and I can't snap out of it. 3- I am so sad and unhappy that I can't stand it.
2	0- I am not particularly discouraged about the future. 1- I feel discouraged about the future. 2- I feel I have nothing to look forward to. 3- I feel the future is hopeless and that things cannot improve.
3	0- I do not feel like a failure 1- I feel I have failed more than the average person 2- As I look back on my life, all I can see is a lot of failures 3- I feel I am a complete failure as a person
4	0- I get as much satisfaction out of things as I used to 1- I don't enjoy things the way I used to 2- I don't get real satisfaction out of anything anymore 3- I am dissatisfied or bored with everything
5	0- I don't feel disappointed in myself 1- I am disappointed in myself 2- I am disgusted with myself 3- I hate myself
6	0- I don't feel I am any worse than anybody else 1- I am critical of myself for my weaknesses or mistakes 2- I blame myself all the time for my faults 3- I blame myself for everything bad that happens
7	0- I don't cry any more than usual. 1- I cry more now than I used to. 2- I cry all the time now 3- I used to be able to cry, but now I can't cry even though I want to.
8	0- I am no more irritated by things than I ever was 1- I am slightly more irritated now than usual 2- I am quite annoyed or irritated a good deal of the time 3- I feel irritated all the time
9	0- I have not lost interest in other people 1- I am less interested in other people that I used to be 2- I have lost most of my interest in other people 3- I have lost all of my interest in other people
10	0- I make decision about as well as I ever could 1- I put off making decisions more than I used to 2- I have greater difficulty in making decisions more than I used to 3- I can't make decision at all anymore
11	0- I don't feel that I look any worse than I used to 1- I am worried that I am looking old or unattractive 2- I feel there are permanent changes in my appearance that make me look unattractive 3- I believe that I look ugly
12	0- I can work about as well as before 1- It takes an extra effort to get started at doing something 2- I have to put myself very hard to do anything 3- I can't do any work at all.

13	0- I can sleep as well as usual 1- I don't sleep as well as I used to be 2- I wake up 1-2 hours earlier than usual and find it hard to get back to sleep 3- I wake up several hours earlier than I used to and cannot get back to sleep
14	0- I don't get more tired than usual 1- I get tired more easily than I used to. 2- I get tired from doing almost anything 3- I am too tired to do anything
15	0- I haven't lost much weight, if any, lately 1- I have lost more than two Kg. 2- I have lost more than four Kg. 3- I have lost more than seven Kg.
16	0- I have not noticed any recent change in my interest in sex. 1- I am less interested in sex than I used to be. 2- I have almost no interest in sex. 3- I have lost interest in sex completely

## Appendix 9 – BDI Hindi version

*Beck Depression Inventory: Hindi Translation and Psychometric Properties for the Students of Higher....*

### APPENDIX-B

#### Hindi-Beck Depression Inventory (H-BDI)

**निर्देश :** नीचे कुछ कथनों के समूह दिए गये हैं। एक समूह एक ही विचार को विभिन्न तीव्रता के अनुसार प्रकट करता है जो कि छात्रों द्वारा उच्च शिक्षा के दौरान अनुभव किया जा सकता है। कृपया कथनों के समूह को ध्यानपूर्वक पढ़िए तथा उक्त कथन के सामने लिखे अंक पर घेरा बनाइए जो आपके आने वाले विचार को पूर्ण रूप से व्यक्त करता है।

क. सं.	आने वाले विचार
1	0. मैं दुखित महसूस नहीं करता हूँ। 1. मैं दुखित महसूस करता हूँ। 2. मैं हर समय दुखित होता हूँ और मैं इससे उबर नहीं पाता हूँ। 3. मैं इतना ज्यादा दुखित और अप्रसन्न हूँ कि इसको सहन नहीं कर सकता।
2	0. मैं विशेषकर भविष्य के बारे में हतोत्साहित नहीं हूँ। 1. मैं भविष्य के लिए हतोत्साहित महसूस करता हूँ। 2. मैं महसूस करता हूँ कि मेरे पास आगे करने को कुछ नहीं है। 3. मैं महसूस करता हूँ कि भविष्य निराशाजनक है और चीजें सुधर नहीं सकती हैं।
3	0. मैं असफल महसूस नहीं करता हूँ। 1. मैं महसूस करता हूँ कि मैं एक औसत आदमी से ज्यादा असफल रहा। 2. जब मैं अपनी पिछली जिन्दगी देखता हूँ तो उसमें बहुत सारी असफलताएँ देखता हूँ। 3. मैं महसूस करता हूँ कि मैं पूर्ण रूप से असफल आदमी हूँ।
4	0. मैं वस्तुओं से उतनी ही संतुष्टि प्राप्त करता हूँ जितना कि पहले करता था। 1. मुझे वस्तुओं से वैसा आनन्द नहीं मिलता जैसा कि पहले मिलता था। 2. मैं किसी चीज से किसी प्रकार की वास्तविक संतुष्टि प्राप्त नहीं करता हूँ। 3. मैं सभी चीजों से असंतुष्ट तथा ऊब चुका हूँ।
5	0. मैं अपने आप में निराशा महसूस नहीं करता हूँ। 1. मैं अपने आप में निराशा महसूस करता हूँ। 2. मैं अपने आपसे निराश हूँ। 3. मैं अपने आपसे घृणा करता हूँ।
6	0. मैं ऐसा महसूस नहीं करता कि मैं किसी और से ज्यादा खराब हूँ। 1. मैं अपनी कमियों और खामियों के बारे में आलोचनात्मक हूँ। 2. मैं हर समय अपने आप को अपनी गलतियों के लिए दोषी ठहराता हूँ। 3. मैं अपने आपको दोषी ठहराता हूँ उन सबके लिए, जो कुछ भी मेरे साथ बुरा होता है।
7	0. मैं जल्दी रोता नहीं हूँ। 1. मैं आजकल जल्दी रोने लगता हूँ, पहले की अपेक्षा। 2. मैं आजकल हर समय रोता रहता हूँ। 3. मैं रोने के लिए तत्पर हूँ पर मैं रो नहीं सकता, यहाँ तक कि ऐसा चाहने पर भी।
8	0. मैं उतना ज्यादा चिडचिडा नहीं हूँ, जैसा कि पहले था। 1. मैं आजकल पहले से ज्यादा चिडचिडा हूँ। 2. मैं अधिकतर समय गुस्से में या चिडचिडेपन में रहता हूँ। 3. मैं हर समय चिडचिडा महसूस करता हूँ।
9	0. मैं दूसरे लोगों से मिलने-जुलने का आनन्द नहीं खोया हूँ।

	<ol style="list-style-type: none"> <li>1. मैं पहले की अपेक्षा, दूसरे लोगों से कम मिलता-जुलता हूँ।</li> <li>2. मैं दूसरे लोगों से मिलने-जुलने का आनन्द नहीं खो चुका हूँ।</li> <li>3. मैं दूसरे लोगों से मिलने-जुलने का आनन्द, पूर्णरूप से खो चुका हूँ।</li> </ol>
10	<ol style="list-style-type: none"> <li>0. मैं वैसा ही निर्णय करता हूँ जैसा पहले करता था।</li> <li>1. मैं वैसे निर्णय लेना बन्द कर दिया हूँ जैसा कि पहले करता था।</li> <li>2. मुझे निर्णय लेने में, पहले से ज्यादा कठिनाई का सामना करना पड़ता है।</li> <li>3. अब से मैं किसी प्रकार का निर्णय नहीं ले सकता हूँ।</li> </ol>
11	<ol style="list-style-type: none"> <li>0. मैं ऐसा महसूस नहीं करता हूँ कि मेरा रूप पहले से ज्यादा खराब है।</li> <li>1. मैं चिन्तित हूँ कि मैं बुढ़ा या बदसूरत दिखायी देता हूँ।</li> <li>2. मैं महसूस करता हूँ कि मेरे चेहरे पर स्थायी परिवर्तन हुए हैं जो कि मेरे रूप को बदसूरत बनाते हैं।</li> <li>3. मेरा विश्वास है कि मैं बड़ा बदसूरत दिखता हूँ।</li> </ol>
12	<ol style="list-style-type: none"> <li>0. मैं पहले की तरह काम कर सकता हूँ।</li> <li>1. मुझे कोई काम शुरू करने और करते रहने के लिए अब ज्यादा प्रयास करना पड़ता है।</li> <li>2. मुझे कोई भी करने के लिए अपने आप से ज्यादा प्रयास करना पड़ता है।</li> <li>3. मैं कोई काम नहीं कर सकता हूँ।</li> </ol>
13	<ol style="list-style-type: none"> <li>0. मैं पहले की तरह अच्छे से सो सकता हूँ।</li> <li>1. मैं पहले की तरह अच्छे से सो नहीं पाता हूँ।</li> <li>2. मैं हमेशा समय की अपेक्षा से 1-2 घण्टे पहले जग जाता हूँ और बहुत कठिनाई से दुबारा नींद आती है।</li> <li>3. मैं हमेशा समय की अपेक्षा से कई घण्टे जग जाता हूँ और फिर दुबारा से नींद नहीं आती है।</li> </ol>
14	<ol style="list-style-type: none"> <li>0. मैं थकान महसूस नहीं करता हूँ।</li> <li>1. मैं पहले की अपेक्षा जल्दी थक जाता हूँ।</li> <li>2. मैं कुछ भी करने में थकान महसूस करता हूँ।</li> <li>3. मैं इतना ज्यादा थका हुआ हूँ कि कुछ भी नहीं कर सकता।</li> </ol>
15	<ol style="list-style-type: none"> <li>0. यदि ऐसा कुछ है तो हाल ही में मेरा वजन कम नहीं हुआ है।</li> <li>1. मेरा 2 किलो वजन घट गया है।</li> <li>2. मेरा 4 किलो वजन घट गया है।</li> <li>3. मेरा 7 किलो वजन घट गया है।</li> </ol>
16	<ol style="list-style-type: none"> <li>0. हाल ही में मेरी यौन-क्रिया की इच्छा में कोई परिवर्तन नहीं आया है।</li> <li>1. मैं पहले की अपेक्षा यौन-क्रिया के लिए कम इच्छुक हूँ।</li> <li>2. मैं यौन-क्रिया करने की इच्छा लगभग खो चुका हूँ।</li> <li>3. मैं यौन-क्रिया करने की इच्छा पूरी तरह से खो चुका हूँ।</li> </ol>

## Appendix 10 - Informed consent form

### INTRODUCTION

We kindly ask you to participate in a practical research and thank you in advance for your participation. We will be very grateful if you want to participate. Participation is completely voluntary. To participate, your permission is required. Before you decide whether you want to participate (in this study) or not, you will receive an explanation of what the research entails.

### TITLE OF STUDY

Cross-cultural validation of the Patient Health Questionnaire (PHQ-9) and the Mental Wellbeing Scale (WEMWBS) amongst persons affected by leprosy, in Jharkhand, India.

### PRINCIPAL INVESTIGATOR

**Name interpreter:**.....

**Organization:** Netherlands Leprosy Relief

**Name researcher:** Janine van der Staaij

**Email:** j2.vander.staij@student.vu.nl

### PURPOSE OF STUDY AND STUDY PROCEDURES

The purpose of this study is to culturally validate the PHQ-9, WEMWBS and the BDI. Therefore, we will kindly ask you some questions about your experience with leprosy, your life and how you feel about yourself. The questions will be asked verbally. Examples of questions are: 'do you have little interest or pleasure in doing things?' or 'do you feel tired or having less energy?'. If you find a question too personal you can indicate this and then we can skip the question. Lastly, the interview will be recorded, but we will not share your information to anyone outside the research team.

### CONFIDENTIALITY

Your responses to this interview will be anonymous. The following measures are taken to ensure confidentiality:

- Assigning code names/numbers for participants that will be used on all research notes and documents.
- Notes, interview transcriptions and any other identifying respondent information will not be disclosed to others, outside the research team.

### VOLUNTARY PARTICIPATION

Your participation in this study is voluntary. It is up to you to decide whether or not to take part in this study. If you decide to participate, you will be asked to sign this form. After signing the form, you are always capable of withdrawing from the study without having to give a reason. Withdrawing from this study will not affect the relationship you have, if any, with the researcher. If you withdraw from the study before data collection is completed, your data will be destroyed. Do you have any questions about the form or study?

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### CONSENT

I have read and I understand the provided information and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time. I understand that I will be given a copy of this consent form. I voluntarily agree to take part in this study.

Participant's signature \_\_\_\_\_ Date \_\_\_\_\_

Investigator's signature \_\_\_\_\_ Date \_\_\_\_\_

# Appendix 11 – Semi-structured interview guide

## Interview guide

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### Semi-structured Interviews

#### Introduction

Hello Mr./Ms. [name], thank you very much for your time and doing an interview with us. This is Nikky/Janine from the Netherlands. She will observe the interview, and may take some notes. She does not speak Hindi but speaks English. My name is [name interpreter], and I will take this interview with you. We work together for the Netherlands Leprosy Relief.

In this interview we will ask you some questions related to your life, your experiences with being affected by leprosy, and your mental wellbeing. The duration of the interview will be approximately 45 minutes. There are no wrong answers, and your experiences and opinions are most important; only these matter to us. If there is something you do not understand, please ask me to stop and I will take time to explain. If you have questions later, you can ask them at any time. Do you have any questions so far?

#### Informed consent

We would now kindly like to ask you to sign the following form [*discuss informed consent, appendix V*]. We would like to record the interview, are you okay with this?

#### Explanation of the interview

The interview consists of 4 parts. The first part involves general questions, the second part focuses on your experiences of living with leprosy. The third part is mainly about terms of mental wellbeing. In the last part, statements will be read out loud, and we will ask you questions about these statements. The reason why I will ask you these questions, is to make both questionnaires understandable for everyone in Hindi. The results of this interview will be used to improve health services for leprosy.

#### Personal information

Now we would like to ask you some general questions; for example, about your age, living area etc. [filling in personal information, appendix I].

#### Questions concerning leprosy

1. I understand you have been affected by leprosy, could you tell me what you know about leprosy?
  - When did it start, how did you find out about the condition?
2. Could you tell me in if the condition (or disability) affects your daily activities? If so, in what way?

3. Can you tell me about the perceptions of people in your community regarding leprosy patients? (Probing: are people affected by leprosy treated differently than other people in the community?)
4. Could you tell me something about how the condition is making you feel?

**Questions concerning PHQ-9 and WEMWBS**

5. Could you please tell me what you think depression is?
  - Are there any words which come into your mind when you hear the word ‘depression’?
  - Are there any other words in your local language for the word ‘depression’?
6. Could you please tell me what you think mental wellbeing is?
  - Are there any words which come into your mind when you hear the word ‘mental wellbeing’?
  - Are there any other words in your local language for the word ‘mental wellbeing’?

From now on, I will read out a statement and will kindly ask you some questions about this. [PHQ-9 and WEMWBS statements will be read out loud and after each statement the following questions 7-11 will be asked]:

7. Did you understand the Statement?
  - If not: could you tell me what was difficult to understand about the statement?
  - Are there any words that you do not understand? What are they? How would you change it to make it clear?
  - Is there anything about this statement/question that is confusing? What? How would you change it to make it clear?
8. Why did you choose this answer?
9. Could you repeat the statement by using your own words?
10. Could you tell me if the statement was about something important in your life?
11. Was it easy or difficult to answer this statement? If respondent did not feel good about the statement ask:
  - Could you tell me what part of the statement made you feel like this?
  - Why?
  - Do you have any suggestions how this statement could be changed?
12. Did you understand the different answer possibilities?

We now have some questions about the whole instrument (PHQ-9/WEMWBS).

13. Was this instrument relevant to you personally? Why (not)?
14. Does this instrument say anything that might offend or embarrass someone in your community?
15. Is there anything about this instrument that you really like? What and why?

We are almost at the end of the interview now. “[Interviewer gives a short summarization of the most important findings of the interview]”

16. Did I understand you correctly?

Then I would like to ask some final questions:

17. Is there something that you think is important that hasn’t been discussed yet?
18. Do you have any questions for us?

The interview is now finished. Thank you very much for your time. We really appreciate that you wanted to participate in this study.

## Appendix 12 - Overview of adjustments of the Hindi version of the PHQ-9

### Overview of adjustments of the Hindi version of the PHQ-9

Original Hindi version	Statement revisions	Final Hindi version
1. Little interest or pleasure in doing things.	1. Little interest or little pleasure in doing things or work.	1. Have you been having little interest or little pleasure in doing things or work?
2. Feeling sad, depressed or hopeless.	2. Feeling sad, depressed* or hopeless.	2. Have you been feeling sad, depressed or hopeless?
3. Problem with sleep, staying asleep or otherwise, sleeping too much.	x	3. Have you been having problems with sleep, staying asleep or otherwise, sleeping too much?
4. Feeling tired or having very little energy.	4. Feeling tired or having less power in your body/mind.	4. Have you been feeling tired or have you been having less power in your body/mind?
5. Feeling less hungry or eating too much/overeating.	x	5. Have you been feeling less hungry or eating too much/overeating?
6. Feeling bad about yourself- or feeling that you are a failed person and you have let down yourself and your family.	x	6. Have you been feeling bad about yourself- or feeling that you are a failed person and you have let down yourself and your family?
7. Problem in concentrating in reading newspaper, watching TV etc.	7. Problem in concentrating reading newspaper, watching TV or listening to music?	7. Have you been facing problems in concentrating in reading newspaper, watching TV or listening to music?
8. Walking or speaking so slowly that these draw others attention. Or just the opposite, you are very unstable, restless and waffle excessively or move excessively.	x	8. Have you been walking or speaking so slowly that these draw others attention? Or just the opposite, have you been very unstable, restless and waffle excessively or moving excessively?
9. Thoughts that it would have been better to die or hurt yourself in any way.	x	<b>9.</b> Have you been having thoughts that it would have been better to die or hurt yourself in any way?
10. If you checked of any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people.	x	10. If you checked of any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people.

\* The Hindi word of depression was changed into a simple local Hindi word for depression.

## Appendix 13 - Overview of adjustments of the Hindi version of the WEMWBS

### Overview of adjustments of the Hindi version of the WEMWBS

Original Hindi version	Statement revisions	Final Hindi version
1. I am feeling optimistic about the future.	x	Have you been feeling optimistic about the future?
2. I am feeling useful.	I am feeling useful/needed, for instance in my work, community or family.	Have you been feeling useful/needed, for instance in your work, for your community or family?
3. I am feeling myself tension free.	x	Have you been feeling yourself tension free?
4. I am feeling interested in other persons.	I am feeling interested in other persons, like my neighbours, friend or family.	Have you been feeling interested in other persons, like your neighbours, friends or family?
5. I have a lot of energy.	I have a lot of power in my body/mind.	Have you been having a lot of power in your body/mind?
6. I am facing problems properly.	x	Have you been facing problems properly?
7. I am thinking clearly.	I am thinking properly.	Have you been thinking properly?
8. I am feeling good about myself.	x	Have you been feeling good about yourself?
9. I am feeling myself close to others.	I am feeling myself near to others.	Have you been feeling yourself near to others?
10. I am feeling self-confident.	x	Have you been feeling self-confident?
11. I am able to make an opinion about things.	x	Have you been able to make an opinion about things?
12. I think that people love me.	x	Have you been thinking that people love you?
13. I am showing interest in new things.	I am showing interest in new things or changes.	Have you been showing interest in new things or changes?
14. I am feeling happy/delighted.	x	Have you been feeling happy/delighted?