

Annex 4: Questionnaire tables

Anticipated stigma

Explanatory Model Interview Catalogue (EMIC) stigma scale for affected people	
From the perspective of:	Persons affected
Measures:	Perceived and experienced stigma
Health condition:	Leprosy, HIV/AIDS, disability, generic
Languages:	Available in multiple languages, including English, Bengali, Nepali, Tamil
Number of questions:	15, 17
Answer options (score):	4 options: Yes (3), possibly (2), uncertain (1), no (0)
Method of administration:	Interview-based
Outcome:	Sum of all items: the scores on the single questions should be added up to get a sum score. The higher the score, the higher the level of perceived stigma
Pay attention!	One reverse coded item (item 2). Before calculation of the sum score, question 2 should be recoded to get the correct results question (3=>0, 2=>1, 1=>2, 0=>3)
Generic application:	Yes, insert the specific health condition into the questions

Please note:

- If you want to use this in a health condition other than leprosy, please change 'leprosy' in each question to this specific health condition.

Scientific reading (please see supporting website or contact InfoNTD.org):

- Weiss, M. 1997. Explanatory Model Interview Catalogue (EMIC): Framework for comparative study of illness. *Transcultural Psychiatry*, 34, (2) 235-263

For children: Internalised stigma

Child Attitude Toward Illness Scale (CATIS)	
From the perspective of:	Persons affected
Measures:	Internalised stigma
Health condition:	Epilepsy, asthma, chronic physical conditions
Languages:	Available in English, possibly more
Number of questions:	13
Answer options (score):	Opposite adjectives (e.g. 'sad' to 'happy', 'fair' to 'unfair') in a 5-point response format as well as a frequency response scale ('never' to 'very often')
Method of administration:	Self-report
Outcome:	Mean of all items: scores on the single questions can be summed and divided by the total number of questions (13). The higher the mean score, the more positive the attitude towards having a certain health condition
Tips:	The questionnaire can be used in a self-report format among children from the age of 8, as well as with adolescents.
Pay attention!	Eight reverse coded questions: 1, 2, 4, 5, 7, 9, 11, 13. To calculate a mean attitude sum score, the reverse coded questions should be recoded (score 1=>5, 2=>4, 4=>2, 5=>1)
Generic application:	Yes, insert the specific health condition in the questions

Please note:

- Please change '[condition]' into the specific health condition you are investigating, such as 'leprosy'.

Scientific reading (please see supporting website or contact InfoNTD):

- Heimlich, T.E. Westbrook, L.E., Austin, J.K., Cramer, J.A., & Devinsky, O. 2000. Brief report: adolescents' attitudes toward epilepsy: further validation of the Child Attitude Toward Illness Scale (CATIS). *Journal of Paediatric Psychology*, 25, (5) 339-345
- Austin, J.K. & Huberty, T.J. 1993. Development of the Child Attitude toward Illness Scale. *Journal of Paediatric Psychology*, 18 (4) 467-480

Impact of stigma

Participation Scale (P-scale)	
From the perspective of:	Persons affected
Measures:	Severity of participation restrictions
Health condition:	Leprosy, HIV/AIDS, disability, generic
Languages:	Available in at least 25 languages, including Arabic, Bahasa Indonesia, Bangla, English, Hindi, Kiswahili, Nepali, Tamil, Thai, Vietnamese and Yoruba
Number of questions:	18 (a 13-item version and a short, simplified version are also available)
Answer options (score):	First level: 5 options: 'Not specified', 'Yes', 'Sometimes', 'No', 'Irrelevant' If 'Yes' or 'Sometimes' on the first level then second-level problem assessment: 4 options: no problem (1), small problem (2), medium problem (3), large problem (5)
Method of administration:	Interview-based
Outcome:	Item sum score: A high sum score indicates a high level of participation restrictions
Tips:	A cut-off point for what is 'normal' (not having significant participation restrictions) was found to be 12 in several countries. However, this may differ between areas
Pay attention!	Two-level answer options
Generic application:	Yes. No specific adaptations necessary

Please note:

- There is a User manual of this questionnaire available at the supporting website: <https://www.infontd.org/toolkits/participation-scale>.
- A shortened, 13-item version was developed by Stevelink et al. (2012) – see above website.
- A short simplified version was developed by Coltof et al (2019) – see website.
- A paediatric version was developed by Beeres et al (2018) – see website.

Scientific reading (please see supporting website or contact InfoNTD):

- Van Brakel, W.H., Anderson, A.M., Mutatkar, R.K., Bakirtzief, Z., Nicholls, P.G., Raju, M.S., & Das-Pattanayak, R.K. 2006. The Participation Scale: measuring a key concept in public health. *Disability and Rehabilitation*, 28, (4), 193-203.
- Rensen, C., Bandyopadhyay, S., Gopal, P.K., & Van Brakel, W. 2010. Measuring leprosy-related stigma – a pilot study to validate a toolkit of instruments. *Disability and Rehabilitation*, 33, (9), 711-719.

Perceived stigma

Explanatory Model Interview Catalogue (EMIC) stigma scale for the community	
From the perspective of:	Community
Measures:	Attitudes towards affected persons
Health condition:	Leprosy, HIV/AIDS, disability, generic
Languages:	Available in multiple languages, including English, Marathi, Bengali, Nepali, Tamil, Bahasa Indonesia
Number of questions:	15
Answer options (score):	4 options: 'Yes' (3), 'Possibly' (2), 'Don't know' (1), 'No' (0)
Method of administration:	Interview-based
Outcome:	Item sum score. To calculate the attitude towards affected persons score, the item scores should be summed up to create a total sum score. The higher the score, the more negative the attitudes from the community member towards affected persons
Generic application:	Yes, insert the specific health condition in the questions

Please note:

- If you want to use this in a health condition other than leprosy, please change 'leprosy' in each question to the specific health condition.
- The original version includes qualitative probe questions. This makes it an interesting method to use in a mixed method assessment.

Scientific reading (please see supporting website or contact InfoNTD):

- Weiss, M. 1997. Explanatory Model Interview Catalogue (EMIC): Framework for comparative study of illness. *Transcultural Psychiatry*, 34, (2) 235
- Peters, R.M.H., Dadun, van Brakel, W.H., Zweekhorst, M.B.M., Damayanti, R., Bunders, J.F.G. & Irwanto (2014) The cultural validation of two scales to assess social stigma in leprosy. *PLoS Neglected Tropical Diseases* 8(11):e3274 doi:10.1371/journal.pntd.0003274.
- Rensen, C. Bandyopadhyay, S. Gopal, P.K. & Van Brakel, W.H. 2010. Measuring leprosy-related stigma – a pilot study to validate a toolkit of instruments. *Disability and Rehabilitation*, 33, (9), 711-719.

Social distance

Social Distance Scale (SDS)	
From the perspective of:	Respondents
Measures:	Social distance to a person with a particular condition (possibly described in a vignette)
Health condition:	Mental illness
Languages:	Available in English, possibly more
Number of questions:	7
Answer options (score):	4 options: 'Definitely willing' to 'Definitely not willing'
Method of administration:	Self-report
Outcome:	Item sum score: To calculate the social distance score, the item scores should be summed. Higher mean scores indicate tendency to keep more social distance with the person affected by the health condition
Pay attention!	Questions need adaptation if the scale is used without a vignette. Also cultural adaptation is needed when using the vignette outside the USA (regarding currency)
Generic application:	Yes, insert the specific health condition in the questions and vignette

Please read the following statement (example vignette):

Rahman is a 23-year-old man. He has been treated for leprosy during the past year. The doctor has declared him cured, even though some of the fingers on his right hand are still bent and his skin is still dark because of the treatment. Rahman has a job in the local small business that belongs to his uncle. He earns Rp 1.2 million per month and is doing well in his job. He is a little bit slower than before, because of the effects of leprosy on his hand, but the employer never complained about that. At his job, Rahman gets along well with his colleagues. Rahman would like to get married. He is considering joining a local youth organisation, so he can meet people of the same age. He also hopes to get a better job to be able to earn more than in his present job.

Please note:

- If you want to use this for an NTD other than leprosy, please change the vignette according to that health condition. Note that a new version should be validated first.
- You need to use a vignette with a female subject for use with women.
- There is also a possibility to use this scale without a vignette; to do this, the questions should be adjusted for this (e.g., question 1: How would you feel about renting a room in your home to a person with leprosy?).

Scientific reading (please see supporting website or contact InfoNTD):

- Link, B.G. Cullen, F.T. Frank, J. Wozniak, J.F. 1987. The Social Rejection of Former Mental Patients: Understanding Why Labels Matter. *The American Journal of Sociology*, 92 (6): 1461-1500
- Peters, R.M.H., Dadun, van Brakel, W.H., Zwekhorst, M.B.M., Damayanti, R., Bunders, J.F.G. and Irwanto (2014). The cultural validation of two scales to assess social stigma in leprosy. *PLoS Neglected Tropical Diseases* 8(11):e3274 doi:10.1371/journal.pntd.0003274.

Experienced, internalised and anticipated stigma and disclosure concerns

Stigma Assessment and Reduction of Impact (SARI) Stigma scale	
From the perspective of:	Persons affected
Measures:	Experienced, internalised, anticipated stigma and fear of disclosure
Health condition:	Leprosy or other infectious NTDs
Languages:	Available in English, Bahasa Indonesia, Persian, Hindi, possibly more
Number of questions:	21 items, with items grouped in 4 domains with a sub-score for each. The domains are experienced stigma (8 items), internalised stigma (6 items), perceived stigma (4 items) and disclosure concerns (4 items)
Answer options (score):	4 (+3) options: 'No', 'Yes', 'Don't know', 'Not relevant' If yes: 'Always/often', 'Sometimes', 'Rarely/once' The minimum total score is 0 and maximum total score is 66
Method of administration:	Self-report
Outcome:	Total score indicates level of disease-related stigma. Domain sub-scores indicate level of specific type of stigma. To calculate the disease-related stigma score, the item scores should be summed up to create a total sum score. Higher score means higher levels of stigma
Pay attention!	Further research is needed to confirm whether this instrument has the same validity for use with other NTDs
Generic application:	Yes

Scientific reading (please see supporting website or contact InfoNTD):

- Dadun, Peters, R.M.H., van Brakel, W.H., Lusli, M., Damayanti, R., Bunders, J.F.G., et al (2017). Cultural validation of a new instrument to measure leprosy-related stigma: the SARI Stigma Scale. *Lepr Rev.* 88(1):23–42.

Experienced stigma

5-Question Stigma Indicators (5-QSI-AP)	
From the perspective of:	Persons affected
Measures:	Assess and monitor presence of stigma
Health condition:	Leprosy, NTDs, generic
Languages:	Available in English, possibly more
Number of questions:	5 items
Answer options (score):	4 options: 'Never', 'Sometimes', 'Often/usually', 'Don't know' The minimum total score is 0 and maximum total score is 10
Method of administration:	Self-report
Outcome:	Total score indicates presence of stigma in person affected. To calculate the indication of the presence of stigma, the item scores should be summed up to create a total sum score. Higher score means stronger indication of stigma
Pay attention!	Further research is needed to confirm whether this instrument has the same validity in different settings and cultures and for use with other NTDs
Generic application:	Yes

Community stigma

5-Question Stigma Indicators (5-QSI-CS)	
From the perspective of:	Community
Measures:	Assess and monitor presence of stigma
Health condition:	Leprosy, NTDs, generic
Languages:	Available in English, Hindi, possibly more
Number of questions:	5 items
Answer options (score):	4 options: 'Never', 'Sometimes', 'Often/usually', 'Don't know' The minimum total score is 0 and maximum total score is 10
Method of administration:	Self-report
Outcome:	Total score indicates presence of stigma in the community. To calculate the indication of the presence of stigma, the item scores should be summed up to create a total sum score. Higher score means stronger indication of stigma
Pay attention!	Further research is needed to confirm whether this instrument has the same validity in different settings and cultures and for use with other NTDs
Generic application:	Yes

Mental distress

The Self-Reporting Questionnaire (SRQ)	
From the perspective of:	Persons affected
Measures:	Screening for mental disorders, including depression, anxiety-related disorders and somatoform disorders
Health condition:	Generic
Languages:	Available in English, Portuguese, Nepali, Bengali, Amharic, Spanish, possibly more
Number of questions:	20 items
Answer options (score):	2 options: 'No', 'Yes' The minimum total score is 0 and maximum total score is 20
Method of administration:	Interview-based
Outcome:	Total score indicates the presence of mental health problems. To calculate the SRQ score, the item scores should be summed up to create a total sum score. Higher score means a stronger indication for the presence of mental health problems
Pay attention!	SRQ was developed as a screening and training tool
Generic application:	Yes

The Self-Reporting Questionnaire (SRQ) was developed by the WHO as an instrument to screen for mental conditions, including depression, anxiety-related, and somatoform disorders (where psychological distress is expressed as physical suffering or illness). Of the many screening tools available, the SRQ is one of the few specifically designed for the Low and Middle Income Country (LMIC) primary care settings. The tool is quick to administer (usually less than 15 minutes). The short format and simple yes/no answers make it simple to use for most people, including by self-completion. A number of studies, for example in Brazil, China, Vietnam and India, show this tool is suitable for use in LMIC contexts. Although designed to be sensitive to multiple expressions of distress, it may still be valuable to explore the local applicability of the questions. It is able to indicate that a person may be distressed, but it cannot provide a diagnosis and is not ideal for measuring change.

Mental wellbeing

Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)	
From the perspective of:	Persons affected
Measures:	Monitors mental wellbeing at a population level
Health condition:	Generic
Languages:	Available in English, Nepali, Hindi, Bahasa Indonesia, possibly more
Number of questions:	14 items
Answer options (score):	5 options: 'None of the time', 'Rarely', 'Some of the time', 'Often', 'All of the time' The minimum total score is 14 and maximum total score is 70
Method of administration:	Self-report
Outcome:	Total score represents mental wellbeing. A higher score means a high level of mental wellbeing
Tips:	All WEMWBS items are worded positively and cover both feeling and functioning aspects of mental wellbeing
Pay attention!	The instrument is not designed as a screening instrument to detect mental illness; it does not provide a cut point to indicate mental wellbeing
Generic application:	Yes

The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) was developed in the UK by Waqas et al. to assess and monitor mental wellbeing in the general population or within particular target groups. The original WEMWBS comprises simple, positively phrased statements. A cross cultural evaluation showed that the WEMWBS has a good internal consistency and a high test-retest reliability at one week (Tennant et al., 2007). This was supported by various studies, which demonstrated the validity and reliability of this questionnaire in different contexts (Clarke et al., 2011; Stewart-Brown et al., 2011). The WEMWBS scales can be used free of charge. Officially, use needs to be registered and a licence obtained through the scale's website (<https://warwick.ac.uk/fac/sci/med/research/platform/wemwbs/>).

Depression

The 9-item Patient Health Questionnaire (PHQ-9)	
From the perspective of:	Persons affected
Measures:	Screening, diagnosing, monitoring and measuring the severity of depression
Health condition:	Generic
Languages:	Available in English, Bahasa Indonesia, Nepali, possibly more
Number of questions:	9 items
Answer options (score):	4 options: 'Not at all', 'Several days', 'More than half the days', 'Nearly every day' The minimum total score is 0 and maximum total score is 27
Method of administration:	Self-report
Outcome:	The sum score represents depression severity. To calculate the PHQ-9 score, the item scores should be summed up to create a total sum score, categorised into mild, moderate, moderately severe and severe depression
Pay attention!	The final question on the PHQ-9 screens for the presence and duration of suicidal thoughts
Generic application:	Yes

This is an instrument for screening, monitoring change and measuring the severity of depression. The tool is brief, usually takes less than 15 minutes to administer and is widely used in clinical practice and research settings. It has 9 questions with one additional question on functioning/disability. The interview starts with asking the person, 'Over the past 2 weeks, how often have you been bothered by any of the following problems?' The main advantage of this tool is that it can be administered repeatedly to assess any change in depression severity following an intervention/treatment. The PHQ-9 has been used and validated in a wide variety of different settings, and many language versions are available. It should not be used for definitive diagnosis, which must be confirmed by a proper clinical assessment prior to treatment. It is also limited to a focus on depression, which, although the most common mental condition arising from extreme stressors or stigma, is not the only potential consequence, so distress may be missed, if manifesting for example as anxiety or another condition.

Anxiety

General Anxiety Disorder-7 (GAD-7)	
From the perspective of:	Persons affected
Measures:	Key symptoms of anxiety without addressing physical symptoms
Health condition:	Mental health
Languages:	Available in Afrikaans (South Africa), Arabic (Tunisia), Bulgarian, Cebuano (Philippines), Chinese, Croatian, Czech, Danish, Dutch, English, Filipino, Finnish, French, German (Austria, Switzerland), Greek, Gujarati, Hebrew, Hindi, Hungarian, Indonesian, Italian, Kannada, Korean, Latvian, Lithuanian, Malay, Malayalam, Marathi, Norwegian, Polish, Portuguese (Portugal, Brazil), Punjabi, Romanian, Russian, Slovakian, Spanish, Swedish, Tamil, Telugu, Thai, Turkish, Ukrainian, Urdu
Number of questions:	7 items
Answer options (score):	4 options: 'Not at all' (0 rating), 'Several days' (1), 'More than half the days' (2), or 'Nearly every day' (3)
Method of administration:	Self-report
Outcome:	To calculate the GAD-7 score, the item scores should be summed up to create a total sum score, which represents the severity of symptoms (minimum 0 and maximum 21). Higher scores indicate more severe anxiety. The scores are categorised into: 0-4: no anxiety; 5-9: mild anxiety; 10-14: moderate anxiety; 15 and above: severe anxiety. When used as a screening tool, further evaluation is recommended when the score is 10 or greater
Pay attention!	There is an additional question on '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 question does not count towards the sum score, but can be used as an indicator of the person's global impairment and to track treatment response
Generic application:	Yes

The General Anxiety Disorder-7 (GAD-7) scale measures severity of anxiety. It is self-administered, takes around 1 to 2 minutes to complete, and can be used for screening and monitoring symptom severity of Generalised Anxiety Disorder (it is also moderately good for screening of Panic Disorder, Social Anxiety Disorder and Post-Traumatic Stress Disorder (PTSD)). The GAD-7 contains 7 questions, which ask the person how often they have been bothered by various feelings, for example being worried, anxious or afraid, over the past 2 weeks. Each of the 7 questions is rated as either 'Not at all' (0), 'Several days' (1), 'More than half the days' (2), or 'Nearly every day' (3).

- A pdf version of the GAD-7, in various different languages, can be accessed here:
<https://www.phqscreeners.com/select-screener>
- An electronic version of the GAD-7 (in English language) can be accessed here:
<https://www.mdcalc.com/gad-7-general-anxiety-disorder-7>, or here:
<https://patient.info/doctor/generalised-anxiety-disorder-assessment-gad-7>.
- The original reference for the GAD-7 is Spitzer RL, Kroenke K, Williams J et al. A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med. 2006. 22; 166(10): 1092-7.