

Additional file 1 - Perception Study Toolkit (PST)

Annex 1 - Demographic information

Date of the interview:	Name of interviewer:	
District name:	Area of residence: Rural / Urban	
Block name:	Type of participant: <input type="checkbox"/> Community member <input type="checkbox"/> Contact <input type="checkbox"/> Index case <input type="checkbox"/> Health worker	
Village name:	<i>If the participant is affected by leprosy:</i> Type: MB / PB Disability grade: 0 / 1 / 2	
First name:	Last name:	
Address:	Age:	Sex: Male / Female
Occupation: <input type="checkbox"/> Paid work <input type="checkbox"/> Self-employed (e.g. own business/farming) <input type="checkbox"/> Non-paid work or student <input type="checkbox"/> Retired <input type="checkbox"/> Unemployed <input type="checkbox"/> Other	Highest education completed: <input type="checkbox"/> Illiterate <input type="checkbox"/> Can read and write but no formal education <input type="checkbox"/> Primary school completed <input type="checkbox"/> Secondary school completed <input type="checkbox"/> Higher education completed	
Monthly household income in (add currency): <input type="checkbox"/> <i>Please add context-specific, categorical, answer options</i>	Ethnic group: <input type="checkbox"/> <i>Please add context-specific answer options</i>	
Marital status: <input type="checkbox"/> Never married <input type="checkbox"/> Married <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Widowed <input type="checkbox"/> Living together	Religion: <input type="checkbox"/> Hinduism <input type="checkbox"/> Buddhism <input type="checkbox"/> Christianity <input type="checkbox"/> Islam <input type="checkbox"/> Other, please specify:	

Do you have a close relationship, family or non-family, with someone diagnosed with leprosy?

- Yes
 No
 Don't know

This question is for persons affected only.

How many months ago were you diagnosed with leprosy?

Annex 2 - Communication Needs Assessment (CNA) English

Please note:

- The answer options should be adjusted to the specific country and context.
- Do not suggest any answers. If multiple answers are possible, this has been indicated with a (box) in front of each answer option.

1	A	<p>What (up to) five main channels of communication do you use?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Radio (please also answer question 2) <input type="checkbox"/> TV (please also answer question 3) <input type="checkbox"/> Newspapers <input type="checkbox"/> Posters and banners <input type="checkbox"/> Leaflets <input type="checkbox"/> Mobile phone voice or text messages <input type="checkbox"/> Social media <input type="checkbox"/> WhatsApp <input type="checkbox"/> Community group meetings <input type="checkbox"/> Through health workers or health volunteers <input type="checkbox"/> Loudspeakers <input type="checkbox"/> Street play or theater <input type="checkbox"/> Other, please specify:
	B	<p>Of these five channels of communication, which medium do you prefer to use?</p> <ul style="list-style-type: none"> a. Radio b. TV c. Newspapers d. Posters and banners e. Leaflets f. Mobile phone voice or text messages g. Social media h. WhatsApp i. Community group meetings j. Through health workers or health volunteers k. Loudspeakers l. Street play or theater m. Other, please specify:
2	A	<p>If TV is mentioned: When do you usually watch TV? (Multiple answers possible)</p> <ul style="list-style-type: none"> <input type="checkbox"/> In the morning <input type="checkbox"/> In the afternoon <input type="checkbox"/> In the evening <input type="checkbox"/> Anytime <input type="checkbox"/> N/a
	B	<p>If TV is mentioned: What channels do you watch? (Multiple answers possible)</p> <ul style="list-style-type: none"> <input type="checkbox"/> (Public) television channel <input type="checkbox"/> Private cable TV

		<input type="checkbox"/> Other, please specify <input type="checkbox"/> N/a
	C	If TV is mentioned: What programme(s) do you watch? (Multiple answers possible) <input type="checkbox"/> News <input type="checkbox"/> Series <input type="checkbox"/> Movies <input type="checkbox"/> Other, please specify: <input type="checkbox"/> N/a
3	A	If radio is mentioned: when you usually listen to the radio? (Multiple answers possible) <input type="checkbox"/> In the morning <input type="checkbox"/> In the afternoon <input type="checkbox"/> In the evening <input type="checkbox"/> Anytime <input type="checkbox"/> N/a
	B	If radio is mentioned: what channel(s) do you listen to? (Multiple answers possible) <input type="checkbox"/> Add context-specific answer options
	C	If radio is mentioned: what radio programme(s) do you usually listen to? (Multiple answers possible) <input type="checkbox"/> Agriculture <input type="checkbox"/> Drama <input type="checkbox"/> News <input type="checkbox"/> Other, please specify: <input type="checkbox"/> N/a
4	A	Do you have electricity connection in your home? a. Yes b. No
	B	If so, how many hours of electricity do you get daily?
5	A	Are you the owner of a mobile phone? a. Yes b. No
	B	If so, what is the name of your local service provider? a. Aircel b. Geo c. Vodafone d. Other, please specify: e. N/a
	C	Do you use the internet on your phone? a. Yes b. No c. N/a
	D	If so, what do you use the internet for? (Multiple answers possible) <input type="checkbox"/> Social media such as Facebook and Instagram <input type="checkbox"/> YouTube <input type="checkbox"/> Communication - chatting or video calls

		<input type="checkbox"/> Communication - email <input type="checkbox"/> Browsing/Google – to search for information <input type="checkbox"/> Online shopping <input type="checkbox"/> News <input type="checkbox"/> Other, please specify: <input type="checkbox"/> N/a
	E	What apps do you use on your phone, if any?
6	A	At present, how do you get health-related information from governments or related government schemes? (Multiple answers possible) <input type="checkbox"/> Radio <input type="checkbox"/> TV <input type="checkbox"/> Newspapers <input type="checkbox"/> Posters and banners <input type="checkbox"/> Leaflets <input type="checkbox"/> Mobile phone voice or text messages <input type="checkbox"/> Social media <input type="checkbox"/> WhatsApp <input type="checkbox"/> Community group meetings <input type="checkbox"/> Through health workers or health volunteers <input type="checkbox"/> Loudspeakers <input type="checkbox"/> Street play or theater <input type="checkbox"/> Other, please specify:
7	A	What would be the most acceptable means of communication to your community? (Multiple answers possible) <input type="checkbox"/> Radio <input type="checkbox"/> TV <input type="checkbox"/> Newspapers <input type="checkbox"/> Posters and banners <input type="checkbox"/> Leaflets <input type="checkbox"/> Mobile phone voice or text messages <input type="checkbox"/> Social media <input type="checkbox"/> WhatsApp <input type="checkbox"/> Community group meetings <input type="checkbox"/> Through health workers or health volunteers <input type="checkbox"/> Loudspeakers <input type="checkbox"/> Street play or theater <input type="checkbox"/> Other, please specify:

Annex 3 – Knowledge, Attitudes and Practices (KAP) measure

Please note:

- Please tick or circle the preferred answer option(s).
- Please note that question 1 and the final five questions should be asked to persons affected only. This has been indicated in the questionnaire.
- The correct answers are indicated by a *. If the correct answer is given, indicate this by circling the '1' in the 'points' column. An incorrect answer is marked by circling the '0' in the 'points' column. A total of two points can be scored for the question about early symptoms of leprosy, because there are two correct answers on this question.

Explain that this questionnaire is about the disease leprosy. Ask if the person knows this disease, or find out if the person knows it by any other name.		Points
1.	<p><i>This question is for persons affected only.</i></p> <p>Did the health worker tell you the name of your disease (or condition) when you started your treatment? If so, what condition did s/he say it was?</p> <ul style="list-style-type: none"> a. Leprosy b. Hansen's disease c. (Infectious) skin disease d. Allergy e. Eczema f. I don't remember g. The health worker did not tell me a name for my condition h. Different, namely: 	
2.	<p>How would you prefer us to refer to this illness in this interview?</p> <ul style="list-style-type: none"> a. Leprosy b. Hansen's disease c. (Infectious) skin disease d. Different, namely: 	
3.	<p>What are the early symptoms of leprosy (or use the name indicated by the person)? (Multiple answers possible. Do not suggest answers, just tick the answers given by the interviewee spontaneously)</p> <ul style="list-style-type: none"> <input type="checkbox"/> Itchiness <input type="checkbox"/> Skin patches* <input type="checkbox"/> Wounds on the skin <input type="checkbox"/> Loss of sensation* <input type="checkbox"/> Disabilities <input type="checkbox"/> Different, namely: <input type="checkbox"/> Don't know 	0 / 1 / 2
4.	<p>Do you know what causes leprosy? (Multiple answers possible. Do not suggest answers, just tick the answers given by the interviewee spontaneously)</p> <ul style="list-style-type: none"> <input type="checkbox"/> Leprosy is caused by an unclean environment <input type="checkbox"/> Leprosy is a divine punishment for sins <input type="checkbox"/> Leprosy is God's will <input type="checkbox"/> Leprosy is a result of karma <input type="checkbox"/> Leprosy is due to impure blood <input type="checkbox"/> Leprosy is caused by witchcraft <input type="checkbox"/> Leprosy is hereditary <input type="checkbox"/> Leprosy is caused by immoral conduct <input type="checkbox"/> Leprosy is caused by germs/bacteria* 	0 / 1

	<input type="checkbox"/> Different, namely: <input type="checkbox"/> Don't know	
5.	Do you know how is leprosy transmitted? (Multiple answers possible. Do not suggest answers, just tick the answers given by the interviewee spontaneously). Leprosy is transmitted by <ul style="list-style-type: none"> <input type="checkbox"/> Air* <input type="checkbox"/> Contaminated soil <input type="checkbox"/> Insects and mosquitoes <input type="checkbox"/> Sexual contact with a leprosy patient <input type="checkbox"/> Skin contact with a leprosy patient <input type="checkbox"/> Eating together with a leprosy patient <input type="checkbox"/> Shaking hands with a leprosy patient <input type="checkbox"/> Sharing personal items (towel, toothbrush etc.) with a leprosy patient <input type="checkbox"/> Different, namely: <input type="checkbox"/> Don't know 	0 / 1
6.	Can leprosy be treated? If yes, how? (Multiple answers possible. Do not suggest answers, just tick the answers given by the interviewee spontaneously) <ul style="list-style-type: none"> <input type="checkbox"/> No, leprosy can't be treated <input type="checkbox"/> Yes, with medicines* <input type="checkbox"/> Yes, by avoiding taboo food <input type="checkbox"/> Yes, with medicinal herbs <input type="checkbox"/> Yes, through religious rituals <input type="checkbox"/> Different, namely: <input type="checkbox"/> Don't know 	0 / 1
7.	Do you think leprosy can be cured? <ul style="list-style-type: none"> a. Yes* b. No c. Don't know 	0 / 1
8.	Is leprosy still contagious after a patient has started treatment? <ul style="list-style-type: none"> a. Yes b. No* c. Don't know 	0 / 1
9.	Can the disability that some patients have be prevented? <ul style="list-style-type: none"> a. Yes* b. No c. Don't know 	0 / 1
10.	Can leprosy be prevented? If yes, how? (Multiple answers possible. Do not suggest answers, just tick the answers given by the interviewee spontaneously) <ul style="list-style-type: none"> <input type="checkbox"/> No, leprosy can't be prevented <input type="checkbox"/> Yes, with (preventive) medicines* <input type="checkbox"/> Yes, by preventing contact with a patient <input type="checkbox"/> Yes, with medicinal herbs <input type="checkbox"/> Yes, through religious rituals <input type="checkbox"/> Yes, by isolating persons affected by leprosy <input type="checkbox"/> Different, namely: <input type="checkbox"/> Don't know 	0 / 1
The following questions (13 to 17) are for persons affected only.		
11.	Do you know how long it will take to cure your illness? <ul style="list-style-type: none"> a. 1 month 	

	<ul style="list-style-type: none"> b. 6 months c. 1 year d. It will never be cured e. Different, namely: f. Don't know 	
12.	If possible, would you prefer to keep people from knowing that you have leprosy? <ul style="list-style-type: none"> a. Yes b. Not sure c. No 	
13.	Do your neighbours, colleagues or others in your community have less respect for you because of your illness? <ul style="list-style-type: none"> a. Yes b. Not sure c. No 	
14.	Would some people refuse to visit your home even after you have been treated? <ul style="list-style-type: none"> a. Yes b. Not sure c. No 	
15.	Have you decided by yourself to stay away from work or social group? <ul style="list-style-type: none"> a. Yes b. Not sure c. No 	
	Total:	

Before finishing your interview, please check if there is any question unanswered.

Annex 4 - EMIC Community stigma scale (EMIC-CSS)

The EMIC-CSS is for all target groups [except](#) for persons affected.

		Yes	Possibly	No	Don't know	Score
		2	1	0	0	
1	Would a person with leprosy try to keep others from knowing?					
2	If a member of your family had leprosy, would you think less of yourself, because of this person's problem?					
3	In your community, does leprosy cause shame or embarrassment?					
4	Would others think less of a person with leprosy?					
5	Would knowing that someone has leprosy have an adverse effect on others?					
6	Would other people in your community avoid a person affected by leprosy?					
7	Would others refuse to visit the home of a person affected by leprosy?					
8	Would people in your community think less of the family of a person with leprosy?					
9	Would leprosy cause problems for the family?					
10	Would a family have concern about disclosure if one of their members had leprosy?					
11	Would leprosy be a problem for a person to get married?					
12	Would leprosy cause problems in an ongoing marriage?					
13	Would having leprosy cause a problem for a relative of that person to get married?					
14	Would having leprosy cause difficulty for a person to find work?					
15	Would people dislike buying food from a person affected by leprosy?					
					Total	

Annex 5 - Social Distance Scale (SDS)

The SDS is for all target groups except for persons affected. Please check country-specific and gender-specific statement. The statement provided here is an example from India.

Please read out the following (gender-specific) statement:

For men	For women
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 organization, 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.	Rahmi is a 27-year-old woman. She has been in treated for leprosy during the past year. The doctor has declared her cured even though some of the fingers on her right hand are still bent and her skin is still dark because of treatment. Rahmi has a job in the local small business that belongs to her uncle. She earns Rp 1.2 million per month and is doing well in her job. She is a little bit slower than before, because of the effects of leprosy on her hand, but the employer never complained about that. At her job, Rahmi gets along well with her colleagues. Rahmi would like to get married. She is considering joining a local youth organization, so she can meet people of the same age. She also hopes to get a better job to be able to earn more than her present job.

		Definitely willing	Probably willing	Probably not willing	Definitely not willing	
		0	1	2	3	Score
1	How would you feel about renting a room in your home to someone like <name>?					
2	How about being a worker on the same job with someone like <name>??					
3	How would you feel having someone like <name> as a neighbour?					
4	How about having someone like <name> as caretaker of your children for a couple of hours?					
5	How about having one of your children marry someone like <name>?					
6	How would you feel about introducing <name> to a young woman you are friendly with?					
7	How would you feel about recommending someone like <name> for a job working for a friend of yours?					
					TOTAL:	

Annex 5 - Semi-structured interview guide topic list

Below you will find relevant topics and example questions to ask. Not all questions are relevant for all participant types. Relevant questions can be added.

Each interview should start with an introduction where the interviewer introduces him/herself and the study objectives.

Topic	Example questions
Knowledge about leprosy	<ul style="list-style-type: none"> • Can you tell me about the disease 'leprosy'? • What causes this (or your) disease? • What are the symptoms? • Do you think leprosy is more likely to be temporary or permanent? Why (not)?
For person affected only	<ul style="list-style-type: none"> • When did you get affected by leprosy, when did your disease start? • How did you feel when you heard you were diagnosed with leprosy? Can you explain why you felt this way? • What is your role in the household? Do you have any difficulties with tasks because of your disease?
Health education	<ul style="list-style-type: none"> • Where or from whom did you get information about leprosy? When? What did they tell you? <i>Probing: school, community, self-taught.</i>
Disclosure	<ul style="list-style-type: none"> • Have you told your family / friends / neighbours that you are affected by leprosy? Can you tell me about their reaction? How did you feel after you have told them? Did you expect this reaction? • Do you know anyone with leprosy in your community? • Would you want to know if someone is affected by leprosy? Why (not)?
Attitudes of others (perspective of person affected)	<ul style="list-style-type: none"> • Do you know someone with leprosy? What were the attitudes of the community towards this person? How do you feel about this? • Before you were diagnosed, what were your thoughts on leprosy? • Can you tell me about your friends' / family's / neighbours' beliefs about leprosy before you told them you were diagnosed with leprosy? Do you still speak openly with them about your disease? Why (not)?
Attitudes of others (perspective of person not affected)	<ul style="list-style-type: none"> • Can you tell me about the views/perceptions of people in your community regarding persons affected by leprosy? • Do people in your community treat leprosy patients differently from other people? <i>If necessary prompt regarding respect, gossip, etc.</i> How do community members behave towards persons affected by leprosy? How do you feel about this? • Does it make a difference to how people treat you whether someone has visible signs of leprosy or not?
Local beliefs	<ul style="list-style-type: none"> • Are there any stories or legends about persons affected by leprosy or leprosy in your community? What kind of stories? Can you tell me one of these stories? • Are there any local beliefs about how people can get leprosy, in your community? • Who can get leprosy? Are some people more susceptible than others or is there no difference?
PEP	<ul style="list-style-type: none"> • How would you feel if there was a medicine available to help prevent people from getting leprosy? Would you also want to take this or not? Why (not)?
For health workers only	<ul style="list-style-type: none"> • Are there leprosy patients on treatment at your health centre? If yes, do you know how many? • Are you involved in the diagnosis and treatment of leprosy yourself? If yes, in what way?

	<ul style="list-style-type: none"> • Can you tell me about the views/perceptions of health workers regarding leprosy patients? • Do health workers treat (in the sense of behaviour towards) leprosy patients differently from other patients? <i>If necessary prompt regarding touching patients; willingness to examine and treatment persons affected by leprosy.</i> How do you feel about this? Does it make a difference whether someone has visible signs of leprosy or not?
End of interview	<ul style="list-style-type: none"> • Do you have any questions for me? For example, would you like to have more information on leprosy? • Is there anything else you would like to share with us?

Additional information to record if close contacts are interviewed:

Relationship with person affected:

Additional information to record if health workers are interviewed:

Occupation / job title:	
Professional designation (post):	
Received formal leprosy training:	Yes / no
For how many years are you working as a health worker already?	
For how many years are you working with people affected by leprosy?	

Annex 6 - Focus Group Discussion (FGD) guidelines

This focus group discussion (FGD) is a group discussion about leprosy and, if relevant for your study, post-exposure prophylaxis (PEP). The FGD is composed of 5-8 participants.

The session starts with a short introduction of the facilitator to explain the research, the purpose and the content of the FGD. In addition, it is important to mention the following agreements/ground rules to establish the group norms and to invite the participants to make their own additional ground rules.

- Only one person talks at a time.
- Confidentiality is assured. No statements or opinions will be linked to a participant's name.
- There are no right or wrong answers to questions – just ideas, experiences and opinions; all are valuable.
- It is important to hear all sides of an issue – both the positive and the negative.
- It is important for women's and men's ideas to be equally represented and respected.¹

Each participant is asked to introduce themselves and to make name cards to address each other.

In the first exercise the participants will focus on leprosy in general. By drawing a body map the following questions will be addressed: Do you know someone with leprosy? What do you know about leprosy? Can you name any symptoms of leprosy? What causes leprosy? Is there treatment for leprosy?

The second exercise will focus on the perceptions and attitudes of the leprosy affected person and the community members. Questions which can be asked are: Can you tell me about how people in the community respond towards someone with leprosy? Do you know if people in the community treat the person affected by leprosy differently? In what way? And if so, what is the reaction of the person affected by leprosy? Would you disclose your disease to others in the community? Why?

In the third exercise the perceptions regarding PEP will be addressed by using post-its. Questions which can be asked are: What is your opinion about PEP? What are your positive experiences related to PEP? What are your negative experiences? What are the benefits of the distribution of PEP for the community? What are the disadvantages for the community? What do you think would be the consequences of revealing the identity of the person affected by leprosy during the PEP intervention? The participants can write their experiences on cards or post-its and organise them in groups. By reflecting on the post-its the participants can think of solutions to change or avoid the negative experiences and attitudes.

At the end of the focus group the facilitator will debrief the session briefly and ask the participants for feedback. The comments and tips can be beneficial for the next focus group.

¹ Toolkit for conducting focus groups, OMNI,
<http://www.rowan.edu/colleges/chss/facultystaff/focusgrouptoolkit.pdf>

What	Questions	Duration (minutes)	Equipment
Arrivals Sign Informed consent	-	10	Informed consent
Introductions. Explanation of the research and session Make some agreements Introduction of teachers and making name cards	- Purpose of this research - Why this focus group - Content of the focus group Make agreements on attitudes in the focus group Introduction: name, teaching class and with an affected child in the classroom.	10	Paper, pens
Drawing a body map	What is leprosy? What are the symptoms? What causes leprosy?	30	Poster paper and pens
Break			Drinks and snacks
Discussion on perceptions	Can you tell me about how people in the community respond towards someone with leprosy? Do you know if people in the community treat the person affected by leprosy differently? In what way? And if so, what is the reaction of the person affected by leprosy?	30	
Positive/negative experiences after PEP	What is your opinion about PEP? What are your positive and negative experiences related to PEP? Did people in the community think differently about leprosy after hearing from the PEP intervention, and in what way? Do	30	Post-its and pens
Debriefing, thanks and goodbye		5	

Additional file 2 - Perception Study Toolkit implementation protocol

Study design

The PST can be used in two different ways that allow for two different study designs:

1. If the PST is used to develop culture-specific messages only and/or as a baseline measurement and/or for monitoring, a cross-sectional design with a mixed methods approach is recommended.
2. If the PST is used to (also) evaluate the impact of an intervention, either a before-after survey design or a randomised controlled trial design with a mixed methods approach, is recommended.

When assessing the impact of an intervention, it can be difficult to determine whether any changes after the intervention can be attributed to the intervention. We propose the following strategies to deal with this:

- Conduct the baseline survey before any public orientation meetings and interventions have taken place.
- If ethically acceptable and practically feasible, include a control group in a similar area where no health education and behaviour change intervention is implemented. This will give an estimate of what would have happened without any intervention or activity. The intervention and control samples should be similar to minimize the impact of differences in sample characteristics on pre- and post-intervention scores.
- If possible, the intervention and control areas should be randomised, which is called 'cluster randomisation'. Randomisation ensures that factors other than the intervention are equally distributed across the intervention and control group. Therefore, any difference between the intervention and control group that is visible must be attributable to the intervention.
- If it is not ethically acceptable to include a control group that does not receive an intervention, the baseline measurement can serve as 'control measure' or a stepwise introduction of the intervention could be used (see below).
- If several different interventions are implemented, implement these interventions stepwise (one-by-one) and conduct a follow-up assessment after each intervention has been implemented, to be able to distinguish the effect of each intervention.
- Add a few questions in the follow-up assessment to check whether people have seen or interacted with the materials/interventions (and include this as independent variable in the statistical analysis)

In addition, it is important to assess whether benefits identified in the short-term are maintained in the longer-term. Ideally, several follow-up assessments are conducted over time (for example one month and one year after completion of the intervention). Unfortunately, we did not find any recommendations in the literature about the amount of time that should have elapsed since the intervention, before the intervention is evaluated. The timing of the follow-up assessment also depends on the type of intervention that is evaluated.

Study population

To understand and address perceptions in a given community, representatives from the following target groups should be included: (1) persons affected by leprosy, and (2) representatives of their community. Because experiences and perceptions may vary by stakeholder and subgroup [1,2], other relevant stakeholders can be added. For example, if used in a project that involves health workers, close contacts or family members of persons affected, these may be added as target groups. In the PEP++ project, close contacts and health workers were added as important target groups, because they are involved in the roll-out of the project. If the PST is used to evaluate an intervention, adding different subgroups as participants will also help to understand the influence of the intervention on

these subgroups.

Study sample

Quantitative and qualitative data are collected. We recommend the following sample size:

- Semi structured interviews: until data saturation is reached. This is likely when at least 5-10 persons from each target group are included.
- Focus group discussions: at least one focus group discussion (5-8 participant per focus group) per target group.
- Questionnaire interviews: at least 100 persons of each target group.

One-hundred persons per target group is based on an assumed prevalence of, for example, 'negative attitudes' of 50% at baseline and wanting to be able to detect a reduction of 20% or more (i.e. prevalence of negative attitudes in the 2nd survey is 30% or less). Using these parameters, a significance level of 0.05 and a power of 80%, at least 186 subjects are needed in total, 93 before and 93 after the intervention is implemented (calculated using Epi Info StatCalc for cross-sectional studies). To compensate for records that may not be usable for any reason or loss to follow up (in case one particular sample is followed over time), including at least 100 participants per target group is recommended. This can be either the same 100 participants or a comparable random sample of 100 participants before and after the intervention.

Eligibility criteria

The inclusion and exclusion criteria depend on the objectives of the study.

Sampling methods

Randomly selecting participants means that all individuals have an equal chance to be included in the study. We recommend a simple random sample or stratified systematic sampling with a random start.

Participants for the quantitative questionnaire interviews are best selected as follows:

1. One or more districts are selected by random sampling from a list of endemic districts in the target area.
2. A certain number of health centres are randomly selected from a list of health centres with registered patients in the selected district(s). The number of health centres would depend on how many patients are registered or expected eligible per health centre. If the total sample needed is 100 and you expect to be able to enrol 10 per health centre, you need to sample 10 health centres.
3. The persons affected are selected by random sampling from a list of leprosy patients registered at the primary health care centre. If a person selected is not available or not eligible, the next eligible person on the list is selected.
4. Other participants (e.g. community members) are best selected by random sampling from among those living in the same village or neighbourhood as persons affected. Care should be given that the gender and age distributions (and other factors, if relevant) are representative of the demographic profile of the community.

The participants for the qualitative interviews are selected using purposive sampling to ensure adequate representation of age, sex and villages. These participants can be a subset of those in the quantitative sample. A sampling grid can be used to ensure an equal number of men and women are included.

Data collection

The PST uses a mixed methods approach. Cross-sectional data on attitudes and perceptions of the

participants towards (persons affected by) leprosy are obtained using the instruments described above. All tools can be found in the Annex.

All participants should be interviewed by a trained local interviewer in or near their home or the health centre, or in case of focus group discussions, at a convenient location, such as a community centre or health centre, to create a comfortable and open environment. The interview guide should be pilot tested before use and adjusted if necessary. Participants of the pilot interviews can be included in the final sample if the interview guide has not changed, otherwise they should be excluded in the final sample. The in-depth interviews and focus group discussions should be audio recorded. Quantitative data can be recorded on paper or electronically (for example using free apps like Epi Info, ODK, Kobo or REDCap).

Data analysis

Recordings of interviews should be transcribed, and if necessary, translated. Qualitative data can be analysed in software such as NVivo, Atlas.ti, MAXQDA, OpenCode or by hand. Quantitative data can be analysed using free software such as Epi Info or R (e.g. Jamovi), or licensed software such as SPSS, Stata or SAS. All data should be anonymised before analysis. Methods of analysis depend on the objectives of the study.

Ethical considerations

Informed consent is an inevitable requirement prior to every research involving human beings as subjects for study. Participation of individuals should be entirely voluntary. One should always obtain written informed consent (handwritten signature), unless individuals are illiterate. For illiterate individuals a thumbprint should be obtained. Nowadays, audio-recorded consent, in which the person states his or her name and their consent, may also be valid. It is important to translate consent forms into the local language and, in case the participant is not literate, for the interviewer to read out the consent forms to ensure they are understood. Ethical approval from an institutional ethical review board should be obtained before the study commences.

References:

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