# Perception Study Toolkit (PST)

The PST comprises separate instruments that assess different aspects of perception, it is also possible to use only one or a few of the instruments of the PST, depending on the purpose of the study.

# Annex 1 - Demographic information

|  |  |
| --- | --- |
| **Date of the interview:**  | **Name of interviewer:** |
| **District name:** | **Area of residence:** Rural / Urban |
| **Block name:** | **Type of participant:**□ Community member□ Contact□ Index case□ Health worker |
| **Village name:**  | *If the participant is affected by leprosy:***Type:** MB / PB**Disability grade:** 0 / 1 / 2 |
| **First name:** | **Last name:** |
| **Address:** | **Age:**  | **Sex:** Male / Female |
| **Occupation:** □ Paid work□ Self-employed (e.g. own business/farming)□ Non-paid work or student□ Retired □ Unemployed□ Other | **Highest education completed:**□ Illiterate□ Can read and write but no formal education□ Primary school completed□ Secondary school completed□ Higher education completed |
| **Monthly household income in (*add currency*):**□ *Please add context-specific, categorical, answer options* | **Ethic group**:□ *Please add context-specific answer options* |
| **Marital status:**□ Never married□ Married□ Separated□ Divorced□ Widowed□ Living together | **Religion:**□ Hinduism□ Buddhism□ Christianity□ Islam□ 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** | **What (up to) five main channels of communication do you use?** * Radio (please also answer question 2)
* TV (please also answer question 3)
* Newspapers
* Posters and banners
* Leaflets
* Mobile phone voice or text messages
* Social media
* WhatsApp
* Community group meetings
* Through health workers or health volunteers
* Loudspeakers
* Street play or theater
* Other, please specify:
 |
|  | **B** | **Of these five channels of communication, which medium do you prefer to use?**1. Radio
2. TV
3. Newspapers
4. Posters and banners
5. Leaflets
6. Mobile phone voice or text messages
7. Social media
8. WhatsApp
9. Community group meetings
10. Through health workers or health volunteers
11. Loudspeakers
12. Street play or theater
13. Other, please specify:
 |
| **2** | **A** | **If TV is mentioned: When do you usually watch TV?** (Multiple answers possible)* In the morning
* In the afternoon
* In the evening
* Anytime
* N/a
 |
|  | **B** | **If TV is mentioned: What channels do you watch?** (Multiple answers possible)* (Public) television channel
* Private cable TV
* Other, please specify
* N/a
 |
|  | **C** | **If TV is mentioned: What programme(s) do you watch?** (Multiple answers possible)* News
* Series
* Movies
* Other, please specify:
* N/a
 |
| **3** | **A** | **If radio is mentioned: when you usually listen to the radio?** (Multiple answers possible)* In the morning
* In the afternoon
* In the evening
* Anytime
* N/a
 |
|  | **B** | **If radio is mentioned: what channel(s) do you listen to?** (Multiple answers possible)* *Add context-specific answer options*
 |
|  | **C** | **If radio is mentioned: what radio programme(s) do you usually listed to?** (Multiple answers possible)* Agriculture
* Drama
* News
* Other, please specify:
* N/a
 |
| **4** | **A** | **Do you have electricity connection in your home?**1. Yes
2. No
 |
|  | **B** | **If so, how many hours of electricity do you get daily?** |
| **5** | **A** | **Are you the owner of a mobile phone?**1. Yes
2. No
 |
|  | **B** | **If so, what is the name of your local service provider?** 1. Aircel
2. Geo
3. Vodafone
4. Other, please specify:
5. N/a
 |
|  | **C** | **Do you use the internet on your phone?**1. Yes
2. No
3. N/a
 |
|  | **D** | **If so, what do you use the internet for?** (Multiple answers possible)* Social media such as Facebook and Instagram
* YouTube
* Communication - chatting or video calls
* Communication - email
* Browsing/Google – to search for information
* Online shopping
* News
* Other, please specify:
* 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)* Radio
* TV
* Newspapers
* Posters and banners
* Leaflets
* Mobile phone voice or text messages
* Social media
* WhatsApp
* Community group meetings
* Through health workers or health volunteers
* Loudspeakers
* Street play or theater
* Other, please specify:
 |
| **7** | **A** | **What would be the most acceptable means of communication to your community?** (Multiple answers possible)* Radio
* TV
* Newspapers
* Posters and banners
* Leaflets
* Mobile phone voice or text messages
* Social media
* WhatsApp
* Community group meetings
* Through health workers or health volunteers
* Loudspeakers
* Street play or theater
* 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 |
|  | ***This question is for******persons affected only****.***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?**1. Leprosy
2. Hansen’s disease
3. (Infectious) skin disease
4. Allergy
5. Eczema
6. I don’t remember
7. The health worker did not tell me a name for my condition
8. Different, namely: ……….
 |  |
|  | **How would you prefer us to refer to this illness in this interview?**1. Leprosy
2. Hansen’s disease
3. (Infectious) skin disease
4. Different, namely: ……….
 |  |
| 1.
 | **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)* Itchiness
* Skin patches\*
* Wounds on the skin
* Loss of sensation\*
* Disabilities
* Different, namely: ……….
* Don’t know
 | 0 / 1 / 2 |
|  | **Do you know what causes leprosy?** (Multiple answers possible. Do not suggest answers, just tick the answers given by the interviewee spontaneously)* + Leprosy is caused by an unclean environment
	+ Leprosy is a divine punishment for sins
	+ Leprosy is God’s will
	+ Leprosy is a result of karma
	+ Leprosy is due to impure blood
	+ Leprosy is caused by witchcraft
	+ Leprosy is hereditary
	+ Leprosy is caused by immoral conduct
	+ Leprosy is caused by germs/bacteria\*
	+ Different, namely: ……….
	+ Don’t know
 | 0 / 1 |
|  | **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* Air\*
* Contaminated soil
* Insects and mosquitoes
* Sexual contact with a leprosy patient
* Skin contact with a leprosy patient
* Eating together with a leprosy patient
* Shaking hands with a leprosy patient
* Sharing personal items (towel, toothbrush etc.) with a leprosy patient
* Different, namely: ……….
* Don’t know
 | 0 / 1 |
|  | **Can leprosy be treated? If yes, how?** (Multiple answers possible. Do not suggest answers, just tick the answers given by the interviewee spontaneously)* No, leprosy can’t be treated
* Yes, with medicines\*
* Yes, by avoiding taboo food
* Yes, with medicinal herbs
* Yes, through religious rituals
* Different, namely: ……….
* Don’t know
 | 0 / 1 |
|  | **Do you think leprosy can be cured?*** 1. Yes\*
	2. No
	3. Don’t know
 | 0 / 1 |
|  | **Is leprosy still contagious after a patient has started treatment?** * 1. Yes
	2. No\*
	3. Don’t know
 | 0 / 1 |
|  | **Can the disability that some patients have be prevented?** * 1. Yes\*
	2. No
	3. Don’t know
 | 0 / 1 |
|  | **Can leprosy be prevented? If yes, how?**(Multiple answers possible. Do not suggest answers, just tick the answers given by the interviewee spontaneously)* No, leprosy can’t be prevented
* Yes, with (preventive) medicines\*
* Yes, by preventing contact with a patient
* Yes, with medicinal herbs
* Yes, through religious rituals
* Yes, by isolating persons affected by leprosy
* Different, namely: ……….
* Don’t know
 | 0 / 1 |
| **The following questions (13 to 17) are for persons affected only.** |  |
|  | **Do you know how long it will take to cure your illness?** 1. 1 month
2. 6 months
3. 1 year
4. It will never be cured
5. Different, namely: ……….
6. Don’t know
 |  |
|  | **If possible, would you prefer to keep people from knowing that you have leprosy?** 1. Yes
2. Not sure
3. No
 |  |
|  | **Do your neighbours, colleagues or others in your community have less respect for you because of your illness?** 1. Yes
2. Not sure
3. No
 |  |
|  | **Would some people refuse to visit your home even after you have been treated?** 1. Yes
2. Not sure
3. No
 |  |
|  | **Have you decided by yourself to stay away from work or social group?** 1. Yes
2. Not sure
3. 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 | * 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 | * 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 | * Where or from whom did you get information about leprosy? When? What did they tell you? *Probing: school, community, self-taught.*
 |
| Disclosure | * 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) | * 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) | * 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? *If necessary prompt regarding respect, gossip, etc.* 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 | * 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 their any local beliefs about how people can get leprosy, in your community?
* Who can get leprosy? Are some people more susceptible than other or is there no difference?
 |
| PEP | * 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 | * 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?
* 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? *If necessary prompt regarding touching patients; willingness to examine and treatment persons affected by leprosy.* How do you feel about this? Does it make a difference whether someone has visible signs of leprosy or not?
 |
| End of interview | * 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]](#footnote-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.

|  |  |  |  |
| --- | --- | --- | --- |
| What | Questions | Duration (minutes) | Equipment |
| ArrivalsSign Informed consent | -  | 10 | Informed consent  |
| Introductions. Explanation of the research and session | - Purpose of this research- Why this focus group - Content of the focus group  | 10 | Paper, pens |
| Make some agreements  | Make agreements on attitudes in the focus group |
| Introduction of teachers and making name cards  | Introduction: name, teaching class and with an affected child in the classroom.  |
| 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 |  |

1. Toolkit for conducting focus groups, OMNI, http://www.rowan.edu/colleges/chss/facultystaff/focusgrouptoolkit.pdf [↑](#footnote-ref-1)