

Question-by-Question guide to accompany the SARI Stigma Scale

Version: 30-March-2021 (reviewed by Pradeepta, Robin and Wim)

Important issues in SSS interviewing

- **Rapport:** building a good rapport should be ensured before starting the interview. Inadequate rapport building between the interviewer and the respondent can lead to irrelevant answers, refusal to answer and loss of time.
- **Listening skills:** one of the key factors in the interview is listening to the respondent. Careful listening will bring out vital information.
- **Behaviour of the interviewer:** During the interview, the interviewer should be polite. The respondent can exhibit emotional outburst in which the interviewer should show empathetic behaviour to make the respondent feel comfortable.
- **Pleasant atmosphere:** the interview should be conducted in a place that is comfortable and secure for the respondent. The place should be quiet with low risk of interruption.
- **Privacy:** the privacy of the respondent should be respected
- **Sequence:** the order of questions should not be changed.
- **Remarks:** the interviewer can write remarks on the questionnaire so they can be addressed later on.

Instructions for the SARI Stigma Scale interview

1. The interviewer must read the Q/Q in detail before the interview will start. If any unclarities come up, please let the coordinator know.
2. Make sure you know whether the person currently still on treatment for leprosy or whether this was already in the past and adapt the grammar of you question accordingly!
3. All questions must be asked and answers should be recorded in the boxes
4. Ask the questions exactly as they are written
 - a. Repeat the question if it is unclear to the respondent
 - b. Only if the question is still not understood, please refer to the prompt questions
 - c. If the prompt question is not understood, use the examples in the Q/Q
5. Repeat the answer options after each question or have them written down on a flashcard to remind the respondent.
6. Do not translate or paraphrase the questions of the instrument.
7. Listen to the respondent and record his/her answer. If you do not understand the answer well, ask the respondent to repeat his/her answer, instead of trying to guess his/her answer.
8. Explain before the interview that the respondent may choose not to answer a question when (s)he does not feel comfortable to do so.
9. When scoring a question, circle the number that corresponds to the answer given.

<p>A</p>	<p>Each question has an A question that reflects a dimension of one of the four stigma topics. These questions are reflected on separately below. The A questions have multiple-choice answers: No – indicating it has not happened, the person has not experienced it, or disagrees Yes – indicating it has happened, the person experienced this, or agrees Don't know – The person is not sure of the answer or not capable to answer the question Not relevant – The person indicates that the situation is not applicable to his/her situation</p>
<p>B</p>	<p>Each question has a B-question that requires answering in case the answer to question A was "Yes": (if yes) How often has this happened? <i>Prompt: How frequently/many times does this happen?</i> Always/often: It is common and has repeatedly happened Sometimes: It happens consistently from time to time Rarely/once: It happens on rare occasions, or has happened only one time</p>
<p>Experienced stigma</p>	
<p>1)</p>	<p>Do some people who know that you have (had) leprosy keep more distance from you?</p> <p><i>Prompt: Do you feel that people avoid being near you when they know that you are affected by leprosy?</i></p> <p>Purpose: Inquiry whether people are taking more distance from him/her if they know the person is affected by leprosy.</p> <p>For example, it may be experienced that:</p> <ul style="list-style-type: none"> - People will not sit next to you - People might avoid coming close to you
<p>2)</p>	<p>Do people you care about stop contacting you after learning you have(had) leprosy?</p> <p><i>Prompt: Have friends or family members stopped talking to you after finding out that you have(had) leprosy?</i></p> <p>Purpose: Inquiry whether the people that are close to the person are still talking to him/her and showing interest. It is important to find out whether this has changed after friends and family came to know that (s)he is affected by leprosy.</p> <p>For example:</p> <ul style="list-style-type: none"> - Family and friends not talking/talking less to you - Family and friends may not visit your home anymore - You may not be invited to family meetings anymore

<p>3)</p>	<p>Did you lose friends by telling them you have(had) leprosy?</p> <p><i>Prompt: Do you have any friends that do not want to be friends with you anymore after you told them that you are affected by leprosy?</i></p> <p>Purpose: Inquiry whether the person has lost any friends from the moment that (s)he told his/her friends that (s)he is affected by leprosy.</p> <p>For example:</p> <ul style="list-style-type: none"> - You feel like your friends stopped doing things together with you - Friends are not inviting you to their home anymore
<p>4)</p>	<p>Do people avoid touching you after knowing that you have(had) leprosy?</p> <p><i>Prompt: Do you experience that people touch you less or have stopped touching you, now that they know you have(had) leprosy?</i></p> <p>Purpose: Inquiry whether people are afraid and avoid touching a person with leprosy. This question specifically concerns the physical touching of people affected by leprosy.</p> <p>For example:</p> <ul style="list-style-type: none"> - People have stopped shaking hands with you when greeting them, if culturally appropriate - People avoid touching you when handing something over (food, cash, etc) - People avoid sitting close to you to avoid accidental touching
<p>5)</p>	<p>Have people physically backed away from you when they learn that you have(had) leprosy?</p> <p><i>Prompt: Do people keep physical distance after they found out you have(had) leprosy?</i></p> <p>Purpose: Inquiry whether people keep distance after finding out the person has(had) leprosy. Important to note is that this question concerns people in the public area.</p> <p>For example:</p> <ul style="list-style-type: none"> - People move away when finding out you have (had) leprosy? - People walk around you in the street - People will not stand next to you in a shop or when waiting in line
<p>6)</p>	<p>Do people seem afraid of you once they learn you have(had) leprosy?</p> <p><i>Prompt: Do you experience that people are scared of you or worried when they find out that the person has(had) leprosy?</i></p> <p>Purpose: Inquiry whether people get scared of the person or worried after they find out that the person has (had) leprosy. People can be afraid of getting leprosy themselves.</p> <p>For example:</p> <ul style="list-style-type: none"> - People may act scared - People may show avoidance behaviour/walk around you

	<ul style="list-style-type: none"> - People may ask questions whether they are at risk to get leprosy themselves
7)	<p>Do you feel set apart and isolated from the community since learning you have(had) leprosy?</p> <p><i>Prompt: Do you feel like an outsider compared to your peers/relatives/friends because you are affected by leprosy?</i></p> <p>Purpose: Inquiry whether the person feels like s/he is no longer part of the community or peer group.</p> <p>For example:</p> <ul style="list-style-type: none"> - You feel different on social level - You may not have the same work opportunities - You may not participate in certain activities
Disclosure concerns	
8)	<p>Are you careful who you tell that you have(had) leprosy?</p> <p><i>Prompt: Do you think about who you are telling you have(had) leprosy because you may worry about the consequences of telling them?</i></p> <p>Purpose: Inquiry about whether the person is concerned about who s/he would disclose to that s/he is affected by leprosy, considering the possible negative consequences of disclosing to others.</p> <p>For example:</p> <ul style="list-style-type: none"> - You are not likely to tell many people you have (had) leprosy - You are not telling anyone at all - You find it difficult to tell you have (had) leprosy - You are afraid of the consequences of telling a person
9)	<p>Do you feel the need to hide your leprosy?</p> <p><i>Prompt: Are you feeling a need to hide the fact that you are affected by leprosy?</i></p> <p>Purpose: Inquiry whether the person feels a need to conceal the fact that (s)he has (had) leprosy</p> <p>For example:</p> <ul style="list-style-type: none"> - You may feel ashamed that you have (had) leprosy - You may think that people change their opinion about you when they find out that you have (had) leprosy - You may feel embarrassed to tell people you have (had) leprosy
10)	<p>Do you believe telling someone you have(had) leprosy is risky?</p> <p><i>Prompt: Do you think there may be negative consequences of telling others that you have(had) leprosy?</i></p>

	<p>Purpose: Inquiry whether the person thinks there is a risk in telling people that s/he is affected by leprosy. The person may think that telling people that s/he is affected by leprosy may have negative effects.</p> <p>For example:</p> <ul style="list-style-type: none"> - You may think that people will behave differently towards you after telling you have (had) leprosy. - You may fear rejection after you tell other people - You may be afraid to lose friends/family/work - You may fear that you will be left out or neglected
<p>11)</p>	<p>Do you worry that people may judge you when they hear you have(had) leprosy?</p> <p><i>Prompt: Do you worry that people will start forming negative opinions about you after finding out that you have(had) leprosy?</i></p> <p>Purpose: Inquiry whether the person is worried that people will start forming negative opinions and may judge him/her after they find out that (s)he is affected by leprosy.</p> <p>For example:</p> <ul style="list-style-type: none"> - You may fear rejection - You may fear that you may be blamed for having (had) leprosy - You may worry that people think less of you because you have (had) leprosy
<p>Internalised stigma</p>	
<p>12)</p>	<p>Do you feel guilty because you have(had) leprosy?</p> <p><i>Prompt: Do you feel that it may be your fault that you have(had) leprosy?</i></p> <p>Purpose: The question is about internal guilt the person may experience. The person may feel responsible for wrongdoing (s)he believe may have caused leprosy.</p> <p>For example:</p> <ul style="list-style-type: none"> - You may feel that something bad you have done is the reason that you have (had) leprosy - You may feel responsible for bringing shame on yourself or your family members - You may feel like a burden to your family, friends or community - Guilt can reflect on the perception that extra care or money is needed.
<p>13)</p>	<p>Do you feel you are not as good a person as others because you have(had) leprosy?</p> <p><i>Prompt: Do you feel like a less respectable person because you have(had) leprosy?</i></p> <p>Purpose: Inquiry whether the person feels that s/he might be a bad person and different in a negative way in comparison to his/her peers. This includes not being able to offer to help others or be of value in other ways.</p> <p>For example:</p> <ul style="list-style-type: none"> - You feel like you are worth less than others - You feel others are not interested in you

	<ul style="list-style-type: none"> - You feels like you have nothing good to offer to others anymore
14)	<p>Are you embarrassed that you have (had) leprosy?</p> <p><i>Prompt: Are you ashamed that you have(had) leprosy?</i></p> <p>Purpose: Inquiry whether the person feels ashamed to <i>have(had)</i> leprosy.</p> <p>For example:</p> <ul style="list-style-type: none"> - You feel self-conscious about having (had) leprosy - You feel uneasy or awkward about having(had) leprosy
15)	<p>Does having (had) leprosy make you feel unclean?</p> <p><i>Prompt: You have(had) leprosy, does it make you feel blemished?</i></p> <p>Purpose: Inquiry whether the person feels morally unclean, blemished or ritually unclean because of having (had) leprosy.</p> <p>For example:</p> <ul style="list-style-type: none"> - You may feel another person should not touch you - You may feel that your soul is no longer clean because of having (had) leprosy - You may feel polluted because of having (had) leprosy
16)	<p>Do you regret having told some people that you have (had) leprosy?</p> <p><i>Do you wish that you had not informed certain people that you have(had) leprosy?</i></p> <p>Purpose: Inquiry whether the person would rather have not told certain people (s)he has (had) leprosy, because of the negative consequences this may have had.</p> <p>For example:</p> <ul style="list-style-type: none"> - You may have regrets telling a certain person about your disease - You may have experienced negative effects after you have told certain people (loss of job, exclusion, loss of status)
17)	<p>Does having(had) leprosy make you feel that you are a bad person?</p> <p><i>Prompt: Do you have any feelings that living with leprosy makes you an inferior person?</i></p> <p>Purpose: Inquiry whether the person feels that s/he is a bad person because s/he is/was affected by leprosy.</p> <p>For example:</p> <ul style="list-style-type: none"> - You may feel morally bad or sinful because you have (had) leprosy - You may feel that you has a weak character for having (had) leprosy) - You may feel that you are causing evil because of having (had) leprosy
	Anticipated stigma
18)	Do people affected by leprosy lose their jobs when their employers find out?

	<p><i>Prompt: When the employer finds out, is a person affected by leprosy likely to get fired?</i></p> <p>Purpose: Inquiry how likely it is for the person to lose his/her job if the employer finds out (s)he is affected by leprosy.</p> <p>For example:</p> <ul style="list-style-type: none"> - It may be more likely for a person with leprosy to be fired - Employers think that persons affected by leprosy are bad for business - Employees affected by leprosy may scare away business partners/customers - Employers are afraid that more people in the company will get leprosy
<p>19)</p>	<p>Are people affected by leprosy treated like a public nuisance?</p> <p><i>Prompt: Is a person affected by leprosy treated like a problem for the community?</i></p> <p>Purpose: Inquiry if a person with leprosy is more likely to be treated as a public problem.</p> <p>For example:</p> <ul style="list-style-type: none"> - People may treat a person affected by leprosy as an outcast - People affected by leprosy are not welcome at public events - People may exclude persons affected by leprosy from public places or occasions for which others are invited but (s)he is not
<p>20)</p>	<p>Do most people think that a person affected by leprosy is disgusting?</p> <p><i>Prompt: Do most people think that persons affected by leprosy are repulsive or that leprosy is horrible?</i></p> <p>Purpose: Inquiry to what extent people in the community think that people affected by leprosy are repulsive or horrifying.</p> <p>For example:</p> <ul style="list-style-type: none"> - People look disgusted when looking at a person affected by leprosy - Some people may say mean things about people affected or about leprosy in general indicating they find it disgusting - People clean everything a person affected by leprosy has touched after (s)he leaves
<p>21)</p>	<p>Do most people feel uncomfortable around someone affected by leprosy?</p> <p><i>Prompt: Do most people get embarrassed or distressed when they are around a person affected by leprosy?</i></p> <p>Purpose: Inquiry if people are not feeling comfortable to be around people affected by leprosy. Some people may feel very hesitant and awkward around people with leprosy. They may be embarrassed to be seen with them.</p> <p>For example:</p> <ul style="list-style-type: none"> - People are acting hesitant around a person affected by leprosy - People are avoiding eye contact with people affected by leprosy

- | | |
|--|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | <ul style="list-style-type: none">- People may try to keep the contact or the time they are near someone affected as short as possible- People do not want to talk much with the affected person |
|--|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

- Add any comments the respondent wishes to make at the bottom or the back of the paper.
- Complete the questionnaire carefully.
- Write the name of the interviewer and date of the interview in the appropriate space.
- Add up the score and write the total in the box on the right, marked 'Total'.