

Question-by-Question guide to accompany the Participation Scale Short Simplified

Version: 08-April-2021

Important issues in 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 empathic 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 Participation Scale interview:

1. The interviewer must read the Q/Q thoroughly before interviewing to get an understanding of the underlying concept of the questions.
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 the answers recorded in the appropriate boxes.
4. Ask the questions on scale exactly as they are written on the form.
5. If the respondent does not understand the question, repeat it in the same way it is written on the form.
6. If the respondent still does not understand it, refer to the Q/Q and ask the prompt question as written.
7. If the person continues to have difficulty understanding the question, use one or more of the examples in Q/Q to further clarify the question.
8. Repeat the answer options after each question or have them written down on a flashcard to remind the respondent.
9. Do not translate or paraphrase the questions during the interview.
10. Listen to the respondent and record his/her answer in the form as answered. If you do not understand the answer well, ask the respondent to repeat his/her answer, instead of trying to guess his/her answer.
11. If the person digresses from the question bring him/her back to the question and explain that (s)he may talk about or discuss the issue at the end of the interview.
12. If the respondent answers 'Sometimes', 'No', or something like "This is irrelevant for me, I don't want to, don't have to", check the appropriate box with a ✓ (See the example below).
13. Explain before the interview that the respondent may choose not to answer a question when (s)he does not feel comfortable to do so.
14. When scoring a question, circle the number that corresponds to the answer given and write the same number in the last box on the right in the same row. See sample below:

Concept of other people

Most questions request the interviewee to compare his/herself with “other people”, meaning his/her peers. However, when using the PSSS, we do *not* try to explain the concept of ‘peers’ to the respondents, since many find this difficult to understand.

- The ‘other people’ are people known to the interviewee who are similar to him/her in all respects (socio-cultural, economic and demographic) except for the health condition or disability.
- Examples: If a young daughter-in-law suffering from leprosy is the respondent, her ‘other people’ would be other young married women in her community, not suffering from leprosy. The ‘other people’ for a 50-year-old farmer with disability in a rural village would be other farmers of similar age from the same village, who does not have disability. It is necessary to keep reminding the respondent to compare his/her situation with that of other people in his/her community.

<p>Each question reflects a dimension of participation. These questions are reflected on separately below. The questions have multiple-choice answers:</p> <p>Not specified, answered “I won’t tell you”, or “I forgot to ask” Use this response when the participant does not give an answer, for example when (s)he is too embarrassed to do so. It may also be used when the interviewer forgets to ask the question, or for some other reason does not ask the question.</p> <p>Easy “I am similar to other people in this.” “There is no difficulty”; use this response when there is no participation restriction, or a negligibly mild one. Occasionally, a respondent says, “No, mine is better” or “I work harder than others”. For the time being, this is coded the same as ‘Yes’ (i.e. ‘0’)</p> <p>A bit difficult The respondent has some difficulty in doing this but can still do it without great effort.</p> <p>Difficult “I am different from other people in this.” There are problems with this, but the respondent is still able to do it.</p> <p>Very difficult “There is a lot of difficulty”; use this response when there is a lot of restriction. Select this option when (s)he can only do it with help and are unable to do this.</p> <p>Irrelevant/I don’t have to/I don’t want to Use this option if this question is not relevant for the respondent. For example, (s)he may not travel outside his/her village, in which case it may be irrelevant because (s)he does not need to travel outside the village. When this option is used, you do <i>not</i> fill in one of the difficulty options. The person may say that (s)he doesn’t travel outside the village because his/her children go to the bazaar and (s)he therefore doesn’t have to leave the village. This response can also be used when a patient does not expect to be able to do this, e.g., questions about work for children. The person may also say that (s)he doesn’t want to leave the village or have no interest in doing so. Interviewers must note that there is a difference between a person saying (s)he doesn’t want to because (s)he has no interest in something, and not wanting to do something because of fear of rejection or paranoia.</p>
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<p>1</p>	<p>Compared to other people, how easy is it for you to find work?</p> <p><i>Prompt: Do you have the same chances /opportunities of finding employment or a job as other people?</i></p> <p>Note: the question is asking whether the person has the same chances of finding paid work, as other people, or whether it is harder because of his/her disability/disease (not due to any other reasons).</p> <p>For example, it may be harder to find work because:</p> <ul style="list-style-type: none"> • (S)He can't work as fast as other people. • Because (s)he has a deformity in his/her hands. • Because (s)he need longer rests during the day.
<p>2</p>	<p>Compared to other people, how easy is it for you to work hard? (same hours, type of work etc)</p> <p><i>Prompt: Do you work as many hours per day as other people? Do you do similar work to other people?</i></p> <p>This is comparing the amount of work people are able to do. Excludes: attitude to work.</p> <p>For example:</p> <ul style="list-style-type: none"> • Does (s)he work the same hours? • Does (s)he have to do lighter work? • Does (s)he do a different type of work? • Does (s)he have more time off during the year because of illness?
<p>3</p>	<p>Compared to other people, how easy is it for you to contribute to the household economically?</p> <p><i>Prompt: Do other people earn money / produce goods for the family? Do you do the same?</i></p> <p>Note: the question is asking whether the person is able to, i.e., has the means to contribute. To contribute means to give towards the household's finances / resources. Excludes: Contributions other than financial.</p> <p>For example:</p> <ul style="list-style-type: none"> • A person may contribute a proportion or all of his/her pay for food and other necessities of the household for their consumption. • A person may not be working or be economically productive and therefore can't afford to contribute.
<p>4</p>	<p>Compared to other people, how easy is it for you to make visits outside your village/neighbourhood? (e.g., bazaars, nearby villages)</p> <p><i>Prompt: Do you go to sell or buy food or visit friends / relatives in other villages / neighbourhoods?</i></p>

	<p>In Q4, 9 and 10, you need to adapt the question to the setting. In a rural area, you should use 'other villages'; in an urban area, you should use 'neighbourhoods'.</p> <p>Implies travelling. Excludes: travelling outside the village / neighbourhood for medical treatment.</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • The person's poor mobility may prevent him/her from taking long journeys. • (s)he may not visit family or relatives and therefore has no need to travel as much as other people. • (s)he may choose to send his/her spouse or children to the bazaar for fear of being called names.
<p>5</p>	<p>Compared to other people, how easy is it for you to take part in major festivals and rituals? (e.g., weddings, funerals, religious festivals)</p> <p><i>Prompt: Are you as involved as others in major festivals and rituals?</i></p> <p>To take part in something is to be involved. A festival in this case is a community celebration.</p> <p>A ritual is a ceremony or religious observance. When there are major festivals like Christmas, Diwali, Id or other festivals or rituals such as weddings and funerals, does the person attend and take part?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • (s)he may not be invited or allowed to come. • (s)he may prefer to stay at home for fear of others making him/her feel 'shy'.
<p>6</p>	<p>Compared to other people, how easy is it for you to take part in social activities? (e.g., in sports, chat, meetings, religious or community activities)</p> <p><i>Prompt: Are you as involved as other people in recreational activities?</i></p> <p>Note: the question is asking how easy it is for the person to be as socially involved and active in his/her village/community as other people are.</p> <p>A recreational activity is a social / socio-religious / casual / leisure activity, for relaxation and enjoyment. This could be: chatting, playing cards, drinking tea with friends, going to community meetings/ participating in a festival such as, Diwali, Christmas, Id or Pongal celebrations or visiting relatives, watching video shows, singing, dancing, playing volleyball etc. in his/her peer groups.</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • The person may not go out because (s)he has limited mobility. • (s)he may not be able to play pool / cards due to his/her hand deformity. • (s)he may have fewer friends because of his/her disease/disability.
<p>7</p>	<p>Compared to other people, how easy is it for you to gain respect in your community?</p> <p><i>Prompt: Do you think you are losing respect in your community?</i></p>

	<p>Note: the question is asking whether the person receives the same respect from community members as do other people. Respect refers to position or importance and authority of someone in the community or society.</p> <p>For example:</p> <ul style="list-style-type: none"> • Some people or families have lost respect or importance in the community because they or someone in the household is disabled or has a stigmatised disease.
<p>8</p>	<p>Compared to other people, how easy is it for you to visit other people in the community?</p> <p><i>Prompt: Do you visit people in your community? Is it as easy for you to do this than for other people?</i></p> <p>Note: the question is only asking if (s)he visits, and not if (s)he eats and drinks with other people. Does the person go to or visit other households and families in the community as much as other people do? Circle the '0' in the EASY box if (s)he visits others but doesn't eat/drink with other people but also indicate EASY if (s)he visits and does eat and drink with other people.</p> <p>For example:</p> <ul style="list-style-type: none"> • The person may have lost friends because of his/her condition and have fewer people to visit. • The person's mobility may restrict him/her from making visits often.
<p>9</p>	<p>Compared to other people, how easy is it for you to move around inside and outside the house and around the village/neighbourhood?</p> <p><i>Prompt: Do you move around inside and outside the house and around the community just as other people do?</i></p> <p>Note: mobility also includes the ability to move for example, from wheelchair/bed to chair, with or without the use of aids such as a wheelchair, crutches etc.</p> <p>For example:</p> <ul style="list-style-type: none"> • (s)he may find it difficult to walk up/down steps, hills, through gates or other physical barriers because of his/her limited mobility. • The attitude of people may prevent the person from moving about in the same way as other people, for example, (s)he may feel self-conscious or is forbidden access to certain places.
<p>10</p>	<p>Compared to other people, how easy is it for you to visit public places in your village/neighbourhood? (e.g., schools, shops, offices, market and tea/coffee shops)</p> <p><i>Prompt: Do you go to common meeting places as easily as other people do? Do you go into tea shops and drink tea? Do you go inside public buildings like schools or offices?</i></p>

	<p>For example:</p> <ul style="list-style-type: none"> • (s)he may be unable to visit tea shops because (s)he can't get his/her wheelchair through the door. • (s)he may be restricted by people's attitudes. • (s)he may choose not to go to certain public places because (s)he feels embarrassed or self-conscious
11	<p>In your home, how easy is it for you to do household work?</p> <p><i>Prompt: Do you participate in daily household chores like cleaning floors, utensils, clothes, looking after cattle in the house, help in cooking or kitchen, purchasing of household/kitchen materials or vegetables etc.?</i></p> <p>Note: the emphasis is on whether the person participates in the routine household activities along with the people (s)he lives with. Several items under this question may be gender specific. The expected response is whether (s)he is allowed to participate in the activities that are appropriate for his/her gender in the given culture.</p> <p>For example:</p> <ul style="list-style-type: none"> • Others may not want the person to participate because (s)he thinks that (s)he will become contaminated or impure
12	<p>How easy is it for you to get people to listen to you in family discussions?</p> <p><i>Prompt: Are you asked for your opinion or do you offer your opinion when family matters are discussed?</i></p> <p>Note: the question is asking whether the person speaks, voices his/her opinion, shares ideas and generally joins in when his/her family is discussing things. It would include whether (s)he feels his/her opinion is taken into account, even if this is in the form of silent (dis)approval, as may be appropriate in some cultural settings.</p> <p>Family discussions could be about anything, but may include:</p> <ul style="list-style-type: none"> • Arranging or preparing for a marriage or wedding. • Buying animals. • Money matters
13	<p>How easy is it for you to meet new people?</p> <p><i>Prompt: Do you find it easy to meet new people or do you prefer to stay out of someone's way if you don't know him/her?</i></p> <p>Note: the question is asking whether the person tries to avoid talking to people who (s)he doesn't know or hasn't met before.</p> <p>To avoid someone is when you try not to see or meet someone, for example by going a different way home. New people are those who you don't know, haven't seen before or haven't spoken to before.</p>

	For example:
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- The person may be embarrassed by the way (s)he looks, or fear rejection, or because (s)he is wary that strangers may ask questions about his/her appearance or condition.

- 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'.