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Guide 4 Annex 2: Assessing stigma in the field: a practical description of the methods used

Translation and back translation

Questionnaires, scales and interview guides should always be used in the local language of the interviewees. It is bad practice for interviewers to translate the questions during the actual interview. If the selected method is not yet available in the language(s) of your target population, you need to have the questionnaire or interview guide translated. To avoid mistakes, it is recommended that you first have it translated into the target language and then have it translated it back to the original language, often English, independently (i.e. so the translator is not aware of the original English version). In this way you can see whether the meaning of the questions has remained the same.

The translation into the local language of the target population should be done by someone whose mother tongue is the same as that of the target population, who is also fully conversant with the original language of the questionnaire and who has an adequate technical understanding of the subject of the questionnaire.

The back translation should be done by someone who is fluent in both languages and who is *not* a technical expert in the subject. This is to avoid the translator guessing what a particular translation might mean, even if the meaning is not very clear. Small differences are likely to occur, but you only need to reconsider the translation of a specific question when the meaning has changed from the original intention of the question during the translation process.

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Tools you need for recording and analysis

For recording your quantitative findings, you may need to print the forms and you need pencils or pens to fill in the forms. You may also need to use a computer to make a database or spreadsheet in which you can enter the stigma score(s) and other relevant information on your participants; it can help you calculate the sum scores. The 'Tips' and 'Pay attention!' sections (see *Guide 4 - Annex 4 Questionnaire tables*) often describe if and how you could calculate a sum score. Databases for the various stigma measures may already be available. Please contact InfoNTD to find out (www.infontd.org).

If you use qualitative methods, it is important to record the interview with an audio-recorder. The audio file should then be transcribed prior to analysis. Software is available to make transcribing and data analysis easier.

Selection of people to interview (sample)

The number of respondents you need depends on the purpose of your assessment.

If you are applying a quantitative method and, for example, want to estimate the level of stigma by getting the percentage of people with negative attitudes (i.e., perceived stigma), you should aim for a random sample of at least 100 respondents from your target population for an accurate estimate. To get a sample that is representative of your target population, you need to make an appropriate selection. This selection needs to resemble your target population as a whole. So, if your target population is half male and half female, and three quarters live in a rural area, you need to try to get the same balance in your selection.

One way to achieve this balance, for example in a household survey, is to select the households in such a way that every household has an equal chance to be included in your selection. If you want to include 100 households in a certain village that consists of 500 households, you randomly choose the first household, for example by throwing dice, and then select every fifth household based on lists of the municipality or another developmental organisation (NGO). If no lists are available, you can also select every fifth house in subsequent streets until you have interviewed a sufficient number of people.

If you are applying a qualitative method, for example to get a thorough understanding of the impact of stigma on the lives of women with a certain stigmatised condition, you should aim to interview people who represent the group you are interested in. You may do this 'purposively' i.e., rather than randomly, you are deliberately choosing people you are interested in. The numbers do not need to be large (as when you are seeking qualitative data with sufficient numbers for strong conclusions to be made, but are seeking for data saturation, meaning that you continue to interview people until no new themes or topics emerge in the interview. Often about 20 to 30 interviews are needed for each population you are interested in.

Training

Photo credit: Silatham Sermrittirong

Photo credit: Alex Jaucot, Damien Foundation

You and your assistants should be familiar with a method as a whole before using it. One way to get familiar with a method is to interview or observe each other using role play. Ask yourself whether you understand the meaning behind the themes and questions. If you are using a questionnaire, check whether the translation and answer options are easy to understand. If they make sense to you, you are more likely to be able to explain the questions to your respondents. Next, get the interviewers to test the questionnaire with a small number of people (see 'Field testing', below). Make sure that they have information about the purpose and the planning of the data collection. It is essential to train your assistants to approach the respondents in an open and non-judgemental way.

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Building a relationship with the respondent

Photo credit: Layla Aerts for Damien Foundation

To get good quality answers or observations, you and your assistants need to build a relationship of trust with the respondents. You should introduce yourself properly and tell the respondent how the interview will take place, how long it will take and why their help is important. If you are conducting a survey or interview, consider the following:

- Does the respondent have enough time to answer all the questions? If not, ask for an appointment on another day.
- Find a place where the respondent feels comfortable and at ease. Preferably, this is a relatively quiet and anonymous location.
- Explain beforehand what will happen with the data after the interview, specifically how confidentiality is ensured.
- Explain beforehand whether an incentive will be given, so that respondents know what to expect.
- Tell the respondent that there are no right or wrong answers. It is important to know what the respondent thinks.
- In some countries or areas, respondents prefer the interviewer to be of the same gender. Make sure that there are both male and female interviewers.
- Give respondents time to answer the questions and do not rush them.
- Tell the respondent that they can end the interview at any time, that they are not obliged to answer questions if they do not feel comfortable answering them and that any treatment or other services they receive won't be affected by their decision.

Field testing (validation)

Photo credit: TLM Nepal

Before you start the data collection, you should first test the methods you want to apply. If an instrument has already been validated and used in your country – say, among a different target group – but in the same language, the piloting guidelines below will help to ensure that the instrument works well with your target group. If the instrument has not been validated before or if you plan to use it in a different language, a proper cultural validation should be done to ensure that the instrument actually measures what you expect it to measure. Describing the protocol for this is outside of the scope of this Guide. However, the authors would be happy to advise on this and/or point you to examples of studies that have done this. Kindly contact InfoNTD.org to get in touch with someone appropriate.

Piloting an instrument:

Photo credit: NLR India

Select a small number of respondents to administer the method to for the first time. It is important to get to know the experience of both the interviewer and the respondent. During this testing phase, you need to keep the following in mind:

- Questions may be interpreted differently in other areas of the country or in a different dialect of the language.
- You need to know whether the respondents of your target population are able to understand the questions correctly. Some words may need to be changed.

- The interviewer needs to know which questions may be sensitive to ask, and how to react when a respondent hesitates or refuses to answer.
- When you are testing the interviews, it is useful to time them so you can plan the number of questionnaires, interviews or observations to be conducted in a day.

Piloting is a procedure to make sure that the questions in the questionnaire work well in your local context. If certain questions are problematic during the testing phase, you need to adapt the wording, but without changing the meaning behind the question. Also, using examples that are more locally appropriate can be helpful. The same examples should be used with all respondents (except if gender specific). If a question is completely inappropriate in your cultural context, you can omit the question.

Ethical considerations

If data is collected in the context of a research project, it is essential to obtain the informed consent of the participants. 'Informed consent' means that the interviewer explains the purpose of the research and the interview, the risks and benefits of participation, and how the data will be used and confidentiality, before asking the respondent to participate. The participant should then sign the 'Informed consent' form.