

Tool to Estimate Patients' Costs

Guidelines for Adaptation of Questionnaire to local circumstances

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1. Language

The validity of results is heavily affected by the answers given in an interview. The language used is an important component to guarantee that the questions are properly understood and adequately answered. This is especially the case when interviewing vulnerable populations such as ethnic minorities, the very poor, migrants, and refugees. Unless the population to be interviewed is native English speaking, the questionnaire needs to be translated as there is evidence that the reliability of questions is greater when they are administered in the respondent's mother tongue, even if the respondent is multilingual. The translation can be written underneath the English questions or a separate questionnaire can be designed.

The translation is best done by someone who understands the objective of the questionnaire, the intent of the questions and who speaks both languages fluently. In order to check the validity of the translation, it is recommended to translate the questionnaire back into English by someone who has not seen the original version, and is not familiar with the background context of the questionnaire. The back-translated version is then compared with the original one and differences in meaning need to be adjusted. Time-permitting, it is always recommended to have a bilingual peer compare both versions and evaluate the questions according to content, meaning and clarity of expression.

Another way of ensuring cross-validity is to interview a set of respondents in English and another set in the local language. Their answers are then compared to detect differences in understanding.

It is important that the language used in the questionnaire corresponds to the daily spoken language of the patient – rather than the high-end, sophisticated language used by academics. The translated questionnaire should therefore be pretested.

2. Pre-testing

The objectives of pre-testing are to identify questions that are poorly understood, ambiguous or evoke hostile or other undesirable responses. The already-translated questionnaire should be used for pre-testing. A pretest should answer the following questions:

- Are all words understood?
- Are the questions interpreted similarly by all respondents?
- Do the closed-ended questions have answers that are applicable to each respondent?
- Do some questions evoke answers that can't be interpreted?

Steps in Pre-testing:

1. Obtain peer evaluation of draft questionnaire
2. Test the revised questionnaire on friends, colleagues etc

3. Prepare instructions and train interviewers for pilot test
4. Pre-test the questionnaire on a sample of respondents (ca. 10-50)
5. Obtain comments from interviewers and subjects; review pre-test responses to check for potential misunderstandings
6. Revise questions that cause difficulty
7. (Pretest again – recommended if time permits)
8. (Revise again)
9. Prepare revised instructions and train interviewers for implementation of full data collection
10. Monitor performance of the questionnaire during early phase of study

3. Specific questions to be adapted

Pre-Diagnostic and Diagnostic Costs Section

Where did you go first? *Check all that apply, includes current clinic*

- Adapt the places where help is sought to local circumstances, adding the names of facilities. Depending on how far the patient is into treatment, it will be more or less difficult to recall items from the past. Attitudes towards the passage of time differ tremendously by country and culture. Instead of weeks, some might think in agricultural seasons or weather seasons (rainy season, dry season) or other time references, such as the moon calendar. The interviewer should help the patients to recall items by prompting, i.e. “Was it before Bayram, or after?”
- Interviewers should have a clear understanding of how to record costs in the questionnaire, as some costs will be recurring (e.g. transport) whereas others will happen less regularly (e.g. x-ray or sputum tests).

How much did you spend for each of these visits? *Fill one line per visit or group several visits to one type into one line*

- In order to record the costs correctly and coherently throughout the survey, the interviewers need to be instructed explicitly about the definitions of the types of costs, what is meant with cost of food, cost of travel and cost of accommodation and how they can help patients recalling items by prompting.

If other than public provider was chosen: **Why did you not go to the public health facility, such as government clinic or hospital when you first realized you were sick?**

- This question investigates the reasons behind the specific health-seeking behavior of the patient. This is usually of high interest to the program, but the WHY question actually does not yield additional information regarding costs to TB patients.

Treatment Costs Section

Where do you take your TB drugs? *Go to the appropriate section (DOT at health facility, home, community, workplace). If DOT at health facility / hospital; specify type of health facility:*

- The types of DOT differ from program to program. While the most common DOT schemes are listed here already, this section needs to be adapted to the specific DOT schemes in the country/region.

Why did someone accompany you?

- This is a gender-sensitive WHY question which does not yield additional information regarding costs to TB patients.

Other Costs Section

Do you have any kind of private or government health/medical insurance scheme? If YES: What type?

- These questions need to be adapted according to the insurance/funding schemes that are available in the respective country or region.

Do you have any chronic illness for which you are receiving treatment? If yes: which?

Are there any additional costs for you because of this other illness besides the costs that you have already mentioned? If YES: How much are these additional costs on average per month?

- This question should elicit costs for any other wide-spread illnesses such as malaria, HIV/AIDS, and diarrhea allowing us to later compare TB costs to other illnesses costs. It may be useful to assess these additional costs by category of disease, rather than as aggregate additional illness.
- Depending on the program practice in the country, it may or may not be possible ask directly for the patient's HIV status. Local privacy policies should be respected. If people are likely to say No when asked whether they are co-infected, although they are, it does not make sense to ask for additional costs.

Socioeconomic Information Section

Are you currently formally employed?

When was the last time you were working?

Is the reason for Not Working related to the TB illness?

How regularly did you work before you became ill with TB?

What is your main occupation?

How are you usually paid?

- These are questions to derive more information regarding socioeconomic status, and may be problematic in areas with extensive subsistence agriculture, high unemployment or a large informal sector. Their value to the questionnaire should be tested to decide whether to include them or not.

Are you currently formally employed?

What is your main occupation?

Current place of residence?

- The suggested answers to these questions have to be adapted to current practices in the country/region. If not known, consult a recent Demographic and Health Survey (available at national statistics office) or a Living Standards Measurement Survey/Questionnaire (available under <http://www.worldbank.org/LSMS/guide/select.html>)
- It may be useful to subdivide occupational categories into formal, informal and subsistence groupings for analysis.

What is the highest level of education for ...?

Primary income earner?

Head of household?

Spouse of head of household?

- Adapt the pre-defined answers to the question according to local schooling system.

Household Income and Spending Section

How much do you estimate was the average income of your household per month BEFORE TB?

How much do you estimate is the average income of your household per month NOW ?

- For these questions it is suggested to provide different ranges for the respondent to pick from, to avoid social desirability bias and to make the question less threatening to the respondent. These ranges have to be adapted to local levels. If not known, results from Living Standards Measurement Surveys can be used (available under <http://www.worldbank.org/LSMS/guide/select.html>) or alternatively the ranges given by UNDP Human Development Reports can be used (available at <http://hdr.undp.org/en/reports/> choose Theme 'Income and economic growth'). It is important that all questions asking for any kind of expenditure should be recorded in the same currency and with regard to the timeframe listed in the question throughout the questionnaire!
- Ensure that the question is posed to uncover the total income of the household, not limited to the income available to the patient. For those survey areas where cash income is less likely, develop a list of prompt questions that interviewers can use to quantify less cash-based incomes.

Socioeconomic Indicators Section

What is your electricity supply?

What is your source of drinking water?

What type of toilet facility is available?

How many rooms are there in your house?

- These aspects of housing amenities are popular, but they are only a suggestion. These questions might not give information about socioeconomic situation of the respondent. For example, if almost everybody has an electricity supply, it doesn't make sense to ask for it. Additional questions could ask about housing tenure (rented, owned), housing conditions (type of building, materials, crowding), assets (electric appliances, furniture, bicycle etc), cooking fuel source, land ownership, productive assets.
- Which housing indicators are used depends on the type of housing present in the region, materials used, and customs. The applicability of these questions can be tested by regression analysis.

What is your tribe/ethnic group/religion?

- This question has been left open (and therefore in italics), because it is aimed to distinguish minorities and vulnerable populations from majority populations. This depends on the prevalence of minorities and ethnic groups in the country. For example, in Sri Lanka it is useful to know whether the respondent is Sinhala or Tamil, in the Philippines it would be useful to ask whether the respondent is Christian, Muslim or Buddhist.
- This question has been deliberately put at the end of the questionnaire, for ethnicity and religion are always sensitive subjects and asking it in the beginning might influence the way how subsequent questions are answered.

How much food did your household consume every month on average BEFORE the TB illness?

If home production: **If the food that you consumed per month before the TB illness was sold on the market: How much would it be worth?** (plus how much you spent on average on food not produced at home?)

How much food does your household consume NOW every month on average?

If home production: If the food that you consume per month now was sold on the market: How much would it be worth? (plus how much you spent on average on food not produced at home?)

If answer to xy differs from xy: Has the amount of food consumed per month changed due to the TB illness?

- Since income is difficult to measure, it is often preferred to measure consumption as a proxy for income. The best way is to distinguish between food and non-food items. This also lets us calculate the % of food costs of total costs, which also gives an idea about the social welfare of the household.
- In this questionnaire, the question on non-food item consumption is not included, because it takes at least ½ hour to estimate all costs that occur in a month on an item by item basis and it is heavily dependent on the type of expenditures that residents in a certain country have. If enough time is available, it should be considered to include a question on non-food expenditures with a list of items derived from the last Demographic and Health Survey.
- As an alternative approach, basic foodstuffs used but not produced by most households could be investigated (such as sugar, cooking oil and flour) for household expenditure proxy. Attention should be paid to inflation in food staple prices and accounted for in data interpretation.

References

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