**INTERVIEWER ADMINISTERED QUESTIONNAIRE FOR SOURCE (INDEX) PATIENTS**

**General instructions:**

*Before the interview with the participant, be sure to carefully check the participants’ eligibility and that they have signed the informed consent. Before they begin the interview, explain to the participant that all information is confidential.*

**ELIGIBILITY CRITERIA**

**Inclusion criteria:**

1. **Newly diagnosed** patients with microbiologically confirmed active pulmonary TB - smear/culture/GeneXpert positive or PCR/NAAT (Any positive) Yes|\_\_\_\_| No|\_\_\_\_|
2. **Treatment** for active TB initiated at least 2 months ago, with contact investigation underway and at least one household contact identified Yes|\_\_\_\_| No|\_\_\_\_|
3. **Age** ≥ 18 years old Yes|\_\_\_\_| No|\_\_\_\_|
4. Signed informed **consent** Yes|\_\_\_\_| No|\_\_\_\_|

**Exclusion criteria:**

1. **Health care worker** Yes|\_\_\_\_| No|\_\_\_\_|
2. Only **extra-pulmonary** TB Yes|\_\_\_\_| No|\_\_\_\_|

**ADMINISTRATIVE DETAILS**

**Country**: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Health facility** Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Location** of interview: Home |\_\_\_\_|

 Hospital/ Clinic |\_\_\_\_|

 Other, (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date of the Interview: **day**|\_\_\_\_\_\_|/**month**|\_\_\_\_\_\_|/**year**|\_\_\_\_\_\_|

Date Active TB treatment started: **day**|\_\_\_\_\_|/**month**|\_\_\_\_\_|/**year**|\_\_\_\_\_|

Primary **language**: ­­­­­­­ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Translator** used? Yes|\_\_\_\_| No|\_\_\_\_|

**Instructions to the Interviewers***:*

*Before starting the questionnaire check that the participant understands what Latent TB infection is (see below). If they do not understand, take the time needed to explain them.*

* *Latent TB infection (LTBI): Persons with latent TB infection do not feel sick, do not have any symptoms, are not infectious and cannot spread TB infection to others. They have been infected with the bacteria that causes tuberculosis by someone with active TB, but are not sick with TB disease.*

*For the majority of questions in the questionnaire you can just read the question out loud to the participant, with no other explanation (e.g. do not read the possible answers to the participant). Some common categories or themes for answers are listed below each question. More than one answer may be possible. If the response given by the participant fits into one of the categories listed, place a tick mark in the corresponding box. If the response given does not correspond to any of the categories shown, write the response in the "Other" category. Remember that for this type of question, we are interested in what the participant thinks. There are no incorrect answers. Avoid suggesting to the participant what you think the answer might be. If the participant answers "I don't know", ask them again and encourage them to respond. Do NOT suggest any of the possible responses to them. Avoid reacting or commenting on their responses. If the participant did not understand the question, then read it again carefully*

*A few questions require the participant to choose a response from a list of answers that should be read out loud to the participant after you read them the question.*

*The specific instructions on how to ask each question are provided after each question.*

***To read to participant:***

This is a short questionnaire with 9 questions. We have invited you to participate because you are on treatment for tuberculosis (TB), and we are interested in hearing your opinion and thoughts that might help us to improve our health services. All information that you provide will remain confidential. No health care providers (nurses, doctors) nor your family will have access to your answers. If something is not clear, do not hesitate to ask me for an explanation.

**QUESTIONNAIRE FOR SOURCE (INDEX) PATIENTS**

1. **Gender**:

|\_\_\_| Male

|\_\_\_| Female

|\_\_\_| Other

1. What **year** were you born in?

|\_\_\_||\_\_\_||\_\_\_| |\_\_\_|

1. **Did someone** at the clinic **explain** to you that your household members should be checked or tested for TB? (***Ask*** *the participant to answer Yes or No)*

|\_\_\_| Yes

 |\_\_\_| No

1. How do you think TB is transmitted from one person to another?

***(Just read the question, with no other explanation. DO NOT read the response options to the participant. Tick any responses that fit into the following general categories (tick as many responses as given by the participant). If the response does not match any categories, then write the response in the "other" section below.)***

|\_\_\_|**Indirect** contact (through **air**) - living in same house or room / breathing the same air

 |\_\_\_|**Indirect** contact (through **objects**) - same dishes / cups / toothbrush

|\_\_\_|**Direct physical** contact- touching / hugging / kissing

|\_\_\_|**Fate** / bad luck / up to God / no control / will just happen

|\_\_\_|Not taking care of yourself- Becoming **too tired** / exhausted / poor diet

|\_\_\_|**Bad habits** / unhealthy lifestyle / smoking / drinking alcohol / drugs

|\_\_\_|**Unclean** living environment

 |\_\_\_|**Travel**/ visit to another country / return visit to home country

|\_\_\_|**Other** (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Did you encourage *all* of the members of your household to be checked or tested for TB?

***(Ask the participant to answer Yes/No and to explain why, with no other explanation, e.g. do not read the possible reasons to the participant. Tick any responses that fit into the following general categories (tick as many responses as given by the participant). If the response does not match any category, then write in the "other" section below.)***

|  |  |
| --- | --- |
| |\_\_\_| Yes, why? | |\_\_\_|No, why? |
| |\_\_\_|The contacts were **sick**, had symptoms of  possible TB (such as cough, fever, night  sweats) | |\_\_\_|**Disbelief**, not sick, not infected, no need for  tests or treatment, no proof of TB |
| |\_\_\_|Fear, **worried**, concerned about TB,  concerned about sickness, they might die. | |\_\_\_|Fear of **side effects** of treatment, dislike  antibiotics/pills, fear blood tests |
| |\_\_\_|**Advised** by and believe doctor or nurse or  other Health care worker. Trust doctor/nurse. | |\_\_\_|Shame of TB, **stigma** of TB, lose face,  embarrassment, social consequences |
| |\_\_\_|**Protect others**. Protect family / friends / co- workers. Prevent transmission | |\_\_\_|**Inconvenience** - clinic location, clinic hours |
| |\_\_\_|**Protect their health,** stay healthy, prevent  illness. | |\_\_\_|**Cost** for **travel**, time off work |
| |\_\_\_| **Other** (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | |\_\_\_|**Cost** for **tests**, medications, cost for doctor  visit. |
| |\_\_\_|The **HCW** said there was no need to have them all checked/ HCW says not needed for older individuals |
| |\_\_\_|I did not know the clinic offered testing for  household contacts/ I was **not told** by HCW to bring my contacts to clinic |
|  | |\_\_\_| Don’t **trust** health system/ health care  workers  |
|  | |\_\_\_| **Language** barriers/ Cultural barriers/ has problems understanding the health system  |
|  | |\_\_\_|**Other** (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |

1. How **worried** are you that someone else in your household might get sick with TB?

***(Read the response options to the participant. Ask them to choose ONE)***

 |\_\_\_| A great deal

|\_\_\_| Quite a bit

|\_\_\_| Somewhat

|\_\_\_| Very little

|\_\_\_| Not at all

1. Did any of your household contacts start preventative treatment for TB?

***(Ask the participant to answer Yes/No with no other explanation, e.g. do not read the possible reasons to the participant. Ask for the reasons and tick any responses that fit into the following general categories (tick as many responses as given by the participant). If the response does not match any category, then write in the "other" section below.***

|  |  |
| --- | --- |
| |\_\_\_| Yes, why? | |\_\_\_|No, why? |
| |\_\_\_|Protect themselves from TB, stay healthy, avoid getting TB/reduce the risk of TB | |\_\_\_|Too **busy**, could not take time off, would take too much time for follow-ups. |
| |\_\_\_| To protect others: prevent TB transmission | |\_\_\_|**Not convenient** - location, time, hours of  operation, long wait times |
| |\_\_\_| Advised and believe doctor/nurse/other  worker | |\_\_\_|**Cost** - for **travel**, time off work |
| |\_\_\_|Treatment is effective and safe | |\_\_\_|**Cost** - for **testing**, physician visit, medication. |
| |\_\_\_|Treatment is available/cheap | |\_\_\_|Do **not need**, do not believe, not a  priority/are not sick, no symptoms of TB |
| |\_\_\_| Fear, worried, concerned about TB,  concerned about sickness | |\_\_\_| Fear of **side effects** of treatment, dislike  antibiotics/pills, fear blood tests |
| |\_\_\_| The doctor or nurse advised that the children under five should take the medication | |\_\_\_|Do **not like** the clinic, staff are not friendly, staff not knowledgeable, staff not helpful |
| |\_\_\_| Other (specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | |\_\_\_|Was **not told** to take medication, not informed, did not understand, did not know where to go  |
|  | |\_\_\_| **Advice** of family or friends or co-workers not to take medication. |
|  | |\_\_\_| Don’t **trust** health system/ health care workers  |
|  | |\_\_\_| **Language** barriers/ Cultural barriers/ problems understanding the health  system |
|  | |\_\_\_| Afraid of **stigma**, discrimination |
|  | |\_\_\_| They were **too weak**, too old to take medications |
|  | |\_\_\_| **No** children **under 5** eligible for treatment |
|  | |\_\_\_| Contact **investigation** is still **ongoing**  |
|  | |\_\_\_| **Other** (specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |

1. Has having TB led to any financial problems or hardships in your family?

 *(****Read the response options*** *to participant. Tick all responses to which the participant answered "Yes").*

|\_\_\_| **No** financial problems

|\_\_\_| **Sold** some of your belongings

|\_\_\_| Removed a child from **school**

|\_\_\_| **Salary** decreased/Using up savings/Took out a loan/ borrowed money (from bank or

 family/friends)

|\_\_\_| Could not **pay rent**, or had to change housing as could not afford current housing

|\_\_\_| Could not **work** as much/ prolonged time away from work/Lost your job/ worries about

 losing job

|\_\_\_| Could not afford to buy **food** for yourself/your family

|\_\_\_| Caused other major **change** in financial situation

|\_\_\_| **Other** (specify): ­­­­­­­­­\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. A) Can you mention anything that was good/worked well in this clinic?
2. Can you mention anything that did not work well/ could be done to improve the care that you received at this clinic? ***(Just read the question, with no other explanation. DO NOT read the response options to the participant. Tick any responses that fit into the following general categories (tick as many responses as given by the participant). If the response does not match any categories, then write the response in the "other" section below)***

|  |  |
| --- | --- |
| Things that worked well in clinic (9A) | Things to improve on in clinic (9B) |
| |\_\_\_|**Free**/ affordable/ low prices | |\_\_\_|**Free**/ affordable/ lower prices |
| |\_\_\_|**Convenience** - location, time hours  of operation, short wait time | |\_\_\_|**Shorter** **time** to wait |
| |\_\_\_|Good **quality** of care, well equipped | |\_\_\_|More convenient **hours** |
| |\_\_\_|**Trust** staff | |\_\_\_|Better **facilities** / better equipment /  better services / more services |
| |\_\_\_|It is a place I **know** (from visits in the past) | |\_\_\_|**More doctors** / nurses / social workers |
| |\_\_\_|My **family**, friends, co-workers like this clinic | |\_\_\_|**Better doctors** / nurses / social workers |
| |\_\_\_|it is a place where I can be anonymous (**stigma**) | |\_\_\_|Have more **respect** for the person / culture /  language |
|  |\_\_\_|I have **insurance** which covers my care at this place | |\_\_\_|**Other** (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
|  |\_\_\_|No suggestions. **Nothing** to be improved |  |
| |\_\_\_|**Other**(specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |  |

***(Read to participant):*** **The questionnaire is finished. Thank you**