Nationwide generic TB patient cost survey

Part I. Patient information to be obtained from TB treatment card before interview

Patient registration number in facility TB register

Questionnaire number (District / Dispensary no./ Patient no.)

Date of interview

yyyy-mm-dd

Name of province

- District A
- District D
- District G
- District B
- District E
- District C
- District F

Name of district

Place of interview (facility name)

Interviewer name

Category of treating facility

- Family health center
- Public clinic
- NGO
- Private clinic
- Other
Specify other.

Name of the patient

Sex

- Male
- Female

Age of the patient

Date of bacteriological TB test result

yyyy-mm-dd

Date of diagnosis

yyyy-mm-dd

Place of diagnosis

- Family health center
- Public clinic
- NGO
- Private clinic
- Other

Specify other.

Type of TB

- Pulmonary, bacteriologically confirmed
- Pulmonary, bacteriologically unconfirmed
- Extra-pulmonary
On MDR-TB treatment?

- Yes
- No

Total duration of planned intensive treatment from start (months)

Total duration of planned continuation treatment from start (months)

Treatment registration group

- 1st line, new
- 1st line, relapse
- 1st line, re-treatment after loss to follow-up
- 1st line, re-treatment after failure

Treatment registration group

- MDR, new (initial MDR)
- MDR, relapse
- MDR, re-treatment after loss to follow-up
- MDR, re-treatment after failure of first treatment with 1st-line drugs
- MDR, re-treatment after failure of retreatment regimen with 1st-line drugs
- Other

Specify other.

Start date of current TB treatment

yyyy-mm-dd

The patient is currently in intensive or continuation treatment phase?

- Intensive phase
- Continuation phase

How many days of this phase has the patient completed?
HIV status
(as indicated on treatment card)

- HIV positive
- HIV negative
- Not done
- Unknown

Part II. Informed Consent

My name is (name). The organization I am working for, (name of organization), is interested in the costs that people face when they are treated for TB as well as the costs faced while seeking health care before the diagnosis of TB.

The information that you choose to share will be used for research purposes. It will be shared with other researchers for further analysis and published, but all your personal information will first be deleted in order to ensure full confidentiality.

It is important for you to understand that your participation in this study is completely voluntary. We would be really grateful if you would agree to participate in this study, but do feel free to decline. If you decline, there will be no consequence for you and you will receive all the care and treatment you need at the health facility as usual. If you decline to participate you will not lose any benefit that you are entitled to such as receiving care and support that is provided at the clinic.

If you decide to participate, I would like to stress that will not receive reimbursements from the study organisers for the expenses that you report on in this interview. However, your eligibility for existing reimbursement schemes will be unaffected.

If you choose to participate in this study, you may still withdraw from the study at any stage without giving any explanation for your withdrawal. Your answers will be kept confidential. At some point I will ask you about your personal income (revenue) and the income of your household. We will NOT provide this information to any tax or welfare authorities, even after the study has been completed.

In charge of this study is the Principal Investigator: (name, address, email). The outcome of this study will be disseminated in an open source journal and you may request a copy from the principal investigator.

Do you want to participate?

- Yes
- No

Why not?

- Language barrier
- Time constraint
- Not comfortable
- Other

Specify other.

Inclusion or Exclusion
Decision about inclusion or exclusion

- Included
- Excluded

If excluded, reason for exclusion
- No informed consent
- Treatment registration group is "other"

Interviewee identity
- Patient
- Guardian
- Other

Specify other.

Part III – Costs before the current TB treatment (filled for new cases in intensive phase only) • New cases in intensive phase, non-MDR TB treatment, as well as those on MDR-TB treatment.

• For retreatment case or new case interviewed in the continuation phase: skip to Part IV

Looking back, when do you think you first started having symptoms for this episode of TB?

Before your TB treatment started at this facility, from which of the following types of facilities did you seek care or advice for symptoms of the current illness (including hospitalizations; several facility types can be mentioned)?

- Family health center
- Soum health center
- Provicial central hospital
- District health department
- Regional diagnostic center
- Tertiary hospital
- NCCD
- Private clinic/hospital
Where did you go first?

- Family health center
- Provincial central hospital
- Regional diagnostic center
- NCCD
- Soum health center
- District health department
- Tertiary hospital
- Private clinic/hospital

First visit

Travel time (in hours)  

Time spent for visit (in hours)  

Day charges (for hospitalizations only)

Consultation fee

Radiography and other imaging fees

Lab test fees

Other procedures

Medicine

Other medical
Part IV. Cost during current TB/MDR-TB treatment (to be filled for all patients)

Unless specified, this section refers to the patient's current treatment phase only

How much do you estimate the net income from labour related activities of your household was per month, at the time of your diagnosis?

Are you currently hospitalized?

☐ Yes

☐ No
Have you been previously hospitalized during your current TB treatment phase and because of TB?
- Yes
- No

How many times?

Type of hospital (first stay)
- Public hospital
- Private hospital
- Other

Specify other.

Number of days hospitalized?

Travel time to hospital (in hours)?

How much in total did you spend so far on the following categories in this hospital stay:

Day charges
(total for stay)

Consultation fee (total for stay)

Radiography and other imaging (total for stay)

Lab tests including cost of transporting samples (total for stay)
<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other procedures, including surgery, biopsy, etc.</td>
<td></td>
</tr>
<tr>
<td>Medicines to treat TB</td>
<td></td>
</tr>
<tr>
<td>(total for stay)</td>
<td></td>
</tr>
<tr>
<td>Other medicines (total for stay)</td>
<td></td>
</tr>
<tr>
<td>Total medical (if cannot disaggregate)</td>
<td></td>
</tr>
<tr>
<td>Travel</td>
<td></td>
</tr>
<tr>
<td>(total for stay)</td>
<td></td>
</tr>
<tr>
<td>Food</td>
<td></td>
</tr>
<tr>
<td>(total for stay)</td>
<td></td>
</tr>
<tr>
<td>Nutritional supplements (total for stay)</td>
<td></td>
</tr>
<tr>
<td>Other (payment for linen, soap, other services &amp; administrative)</td>
<td></td>
</tr>
<tr>
<td>(total for stay)</td>
<td></td>
</tr>
<tr>
<td>Non-medical out-of-pocket payments</td>
<td></td>
</tr>
<tr>
<td>Total out-of-pocket payments</td>
<td></td>
</tr>
</tbody>
</table>
Health insurance reimbursement

Click "+" to add additional stay

Costs for DOT during ambulatory care

On a daily basis, do you currently take your medicines yourself without supervision or support (self-administered) or do you have a treatment supervisor or supporter (DOT)?

- Self-administered
- DOT
- Intensive DOT
- Continuation DOT

If DOT, how many times a week?

Did you take your medicines in the intensive phase yourself without supervision or support (self-administered) or did you have a treatment supervisor or supporter (DOT)?

- Self-administered
- DOT
- Intensive DOT
- Continuation DOT

Who is the DOT provider/supporter?

- Health facility
- Volunteer
- Family member
- Other

Specify other.

How long did the last DOT visit take, including travel time and waiting time (total turnaround time)?
What was the cost of transport (return) for the last DOT visit, including parking costs, in total for you and any accompanying household member?

Was there a fee paid to the DOT provider?
- Yes
- No

How much?

How much did you spend on food and drinks for the last DOT visit (on the road, while waiting, lunch etc.), in total for you and any accompanying household member?

Costs of picking up drugs and food costs during ambulatory care

Do you or a household member pick up TB drugs (for self-administered treatment or to bring to your DOT supervisor/supporter)?
- Yes
- No

How often do you or a household member pick up TB drugs in the current treatment phase?
- Every day
- Every week
- Every two weeks
- Every month
- Other

Specify other.
Where do you or your household member pick up your TB drugs?

- Family health center
- Soum health center
- Provicial central hospital
- District health department
- Regional diagnostic center
- Tertiary hospital
- NCCD
- Private clinic/hospital
- Other

Specify other.

Was there a fee paid to pick up the drugs?

- Yes
- No

How much?

What accommodation cost did you and any accompanying household member have when you last picked up drugs?

How long did the last visit to pick up drugs take, including travel time and waiting time (total turnaround time) in hours?

What was the cost of transport (return) last time you picked up drugs, including parking costs, in total for you and any accompanying household member(s)?

How much did you spend on food and drinks last time you picked up drugs (on the road, while waiting, lunch etc.), in total for you and any accompanying household member?

Cost during outpatient visits for medical follow-up (see the doctor or nurse, have tests)
How many TB-related medical follow-up visits have you had so far during this treatment phase (to see the doctor or nurse, have follow-up tests, etc.)?

How long did the last follow-up medical outpatient visit take, including travel time and waiting time (total turnaround time) in hours?

What was the cost of transport (return) at the last follow-up medical outpatient visit, including parking, in total for you and any accompanying household member?

What accommodation cost did you have for the last visit, in total, for you and any accompanying household member?

What fees did you pay during your last follow-up medical outpatient visit for registration/consultation?

What fees did you pay during your last follow-up medical outpatient visit for radiography and other imaging?

What fees did you pay during your last follow-up medical outpatient visit for other procedures?

What fees did you pay at your last follow-up medical outpatient visit for TB medicines, including prescriptions for medicines bought outside the facility?

What fees did you pay during your last follow-up medical outpatient visit for other medicines, including nutritional supplements?

What other fees not listed in the previous questions did you pay during your last follow-up medical outpatient visit?

Costs for nutritional/food supplements
Do you buy any nutritional supplements outside your regular diet because of the TB illness, for example vitamins, meat, energy drinks, or fruits as recommended by health care staff?

- Yes
- No

How much did you spend on these nutritional supplements in the past week approximately?

- 

Do you buy any additional food outside of your regular diet because of the TB illness, for example meat, energy drinks, or fruits as recommended by health care staff?

- Yes
- No

How much did you spend on this additional food in the past week approximately?

- 

Time loss for guardians

- Not to be filled if the patient is under 15 years – for children, all questions concerning costs, time spent, income, and income loss in sections IV and V concern cost for the guardian.

- Note: out-of-pocket costs of transport, food, accommodation for guardian should be included in questions on Part V (tables).

Did somebody in your household accompany you for your last DOT visit?

- Yes
- No

Did somebody in your household accompany you for your last visit to pick up drugs?

- Yes
- No

Did somebody in your household accompany you for your last medical follow-up visit?

- Yes
- No

Did somebody in your household accompany you for your last hospitalization?

- Yes
- No

Did that person lose an income during that time?

- 

Health insurance scheme

Do you have any of the following health insurance types?
- Reimbursement scheme
- Medical allowance
- Donor
- Family/community fund
- Private health insurance
- Other

Social Position

What is your (the patient's) education level?
- No education
- Primary education (up to grade 3)
- Incomplete secondary (up to grade 9)
- Complete secondary (up to grade 12)
- Professional
- Special professional secondary
- Higher (university)

What is your main occupation?
- School student
- Technician
- Service
- Factory worker
- Farmer
- Government employee
- Teacher
- Retiree
- Homemaker
- Unemployed
- Other
What was your primary employment, or normal work, or normal other main activity before you contracted TB?

- Formal paid worker
- Employer
- Private business
- Member of partnership
- Nonpaid work within family industry, service
- Secondary school student
- University, college student
- Retired
- Person with disability
- Other

Specify other.

What is your primary employment, or normal work, or normal other main activity now?

- Formal paid worker
- Employer
- Private business
- Member of partnership
- Nonpaid work within family industry, service
- Secondary school student
- University, college student
- Retired
- Person with disability
- Other

Specify other.

Socio-economic status of the household

Do you have a flush toilet?

- Yes
- No
Does your household have:

**Computer**
- Yes
- No

**Television**
- Yes
- No

**Refrigerator**
- Yes
- No

**Internet connection**
- Yes
- No

**Washing machine**
- Yes
- No

**Vacuum cleaner**
- Yes
- No

**Microwave**
- Yes
- No

**Watch**
- Yes
- No

**Car/truck**
- Yes
- No
Radio
  ○ Yes
  ○ No

Mobile Phone
  ○ Yes
  ○ No

Motorcycle
  ○ Yes
  ○ No

Income (reported) before contracting TB

Were you the person who earned the highest income in your household before you contracted TB?
  ○ Yes
  ○ No
  ○ Equal contributor

How many hours a week were you working before you contracted TB?

If you were in paid work, how much do you estimate your net income from labour related activities, per month was before you contracted TB?

How much do you estimate the net income from labour related activities of your household was per month, before you contracted TB?

(All family member's income must be counted)

Income changes and social consequences

If you are in paid work, how much do you estimate net income from labour related activities, per month is now?

How much do you estimate the net income from labour related activities of your household is per month now?
How many hours per week are you working now?

Approximately how many working days of income have you lost due to your TB illness overall?

Did you or your household receive any social welfare payment after you were diagnosed with TB?

☐ Yes
☐ No

What type and amount (after tax) during the last month?

Paid sick leave

Disability grant

Cash transfer for poor families

Other cash transfer

Do you currently receive vouchers or goods in kind to cope with TB illness?

☐ Yes
☐ No

What estimated amount per month?

Travel voucher

Food support

Other support
From whom do you receive the voucher/goods?

- Government
- GF supported project
- NGO
- Employer
- Private donation
- Other

Specify other.

---

How many adult and children regularly sleep in your house? (including patient, if variable, at time of diagnosis)?

---

How many rooms are there in the house excluding the bathroom?

---

Has the TB illness (including other household members treated in the last year) affected your social or private life in any way?

- No
- Food insecurity
- Divorce or separated from spouse/partner
- Loss of Job
- Interrupted schooling
- Social exclusion

Coping Costs

Coping

Did you borrow or receive any money to cover costs incurred since you started TB treatment?

- Yes
- No

How much did you borrow/receive in total?

---
From whom did you borrow/receive? (multiple answers)
- Family/ close relative
- Distant relative
- Neighbors/friends
- Financing organization other than bank
- Lombard (pawnshop)
- Employer
- Bank
- "Unofficial lender" (Black market)
- Other

Specify other.

Are you expected to pay the amount back?
- Yes
- No

Have you sold any of your property to finance the cost incurred during TB treatment?
- Yes
- No

What did you sell?
- Land
- Apartment
- Transport/vehicle
- Household item
- Farm product
- Gold/jewelry
- Other

Specify other.
How much money did you receive from the sale of all items of your property (in total)?

The impact on your household financially since you experienced TB symptoms has been that your household became:

1 = Richer  
2 = Unchanged  
3 = Poorer  
4 = Much poorer

Thank you for your cooperation! Is there anything you would like to ask or say?

_________________________________________________/

Comments by interviewer

_________________________________________________/

https://enketo.ona.io/#!Y5T9