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# **Costs faced by (multidrug resistant) tuberculosis patients during diagnosis and treatment**

Report from a pilot study in Kokshetau, Akmola Oblast, Kazakhstan

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## 2 Abbreviations

DOT	Directly Observed Treatment
FLD	First Line Drug
OTBD	Oblast TB Dispensary
MDR-TB	Multi-drug resistant tuberculosis
SLD	Second Line Drug
SS-	Sputum smear negative
TB	Tuberculosis
ToR	Terms of Reference
USAID	United States Agency for International Development



### 3 Executive summary

TB patients face costs due to charges for health services, costs for transport, accommodation, nutrition and inability to work. These costs are expected to be higher for MDR TB patients than for other TB patients. In most countries, MDR-TB is more prevalent in socially more vulnerable groups, for which the economic impact of the disease may be even bigger. Policy makers such as Ministries of Health and National Tuberculosis Control Programs need to understand patient costs to identify and mitigate potential bottlenecks in access to and adherence to (MDR)TB treatment and the negative impact on the economic status of patients and their families.

We adapted the existing TBCAP Tool to Estimate Patients' Costs to also cover costs of MDR TB patients. The tool has been tested in Ethiopia, Kazakhstan and Indonesia and this report presents the results from Kazakhstan. The patient cost tool itself will be further improved using the experience obtained in the three countries.

We collected data on the direct (out of pocket) and indirect (loss of income) costs of patients and their families related to the diagnosis and treatment of (MDR) TB through interviews for patients in different stages of treatment. Direct costs included costs for hospitalization, follow-up tests, transport costs health care visits for directly observed treatment (DOT), and food supplements. Calculation of indirect costs were based on time needed for diagnosis and treatment, considering full-time hospitalization during the intensive phase and only time for health care visits during the continuation phase. Costs were extrapolated over the patient's total treatment phase. Medians, interquartile ranges (IQR), means and ranges were calculated for all cost components.

In September 2012, a total of 94 MDR-TB patients and 54 other TB patients were interviewed on costs related to TB illness in Kokshetau, Akmola, Kazakhstan.

The reported median cost for TB diagnosis was 800 KZT. Most patients required only 2 diagnostic visits before they received a diagnosis of TB, and most of the, fairly limited, costs for TB diagnosis in KZ was related to transport to health care facilities. We could not measure these for MDR-TB patients but the median duration of TB treatment until MDR-TB diagnosis was six months, implying that their costs are almost equal to total treatment costs for TB patients.

The reported treatment costs are significant, with an estimated total median cost for treatment of 102,802 KZT for TB patients, and 393,669 for MDR-TB patients.

The largest cost component during the intensive phase was loss of income due to hospitalization, while the largest cost component reported during the continuation phase constituted of out-of-pocket costs for food supplements and transport costs for DOT visits. However, loss of income due to inability to work before diagnosis and during the continuation phase was not included in these estimations - only the loss of income due to the time spent for obtaining a diagnosis and DOT. Also, they do not include costs after the end of treatment, especially further loss of income for those who have lost their jobs or who have developed disabilities not allowing them to do the work they did before.



Before TB illness, 33/94 (35%) MDR-TB patients and 7/54 (13%) other TB patients did not earn any income. During the interview, this had changed to 32/54 (59%) and 62/94 (66%), respectively. The percentage of patients with an income-earning job before TB illness who had lost their job at the time of the interview was 41% among MDR-TB patients and 31% among other TB patients. The median percentage of income reduction was 33% for MDR-TB patients and 56% for other TB patients. Selecting only those patients that did have an income before TB illness, the median reduction in income was 100%, both for MDR-TB and other TB patients.

An important finding is that the values of the vouchers only appears to cover a small part of the patient costs and only 27% of MDR-TB patients and 17% of other TB patients reported to receive assistance from the government or other organizations. Most of that assistance was not cash to compensate income loss though, but food packages and transport vouchers.

We could only identify the economic burden for patients who did access TB diagnostic and treatment facilities. Still, the data provide important insights for TB control programs. While the financial burden of MDR TB patients was (much) higher than that of TB patients, all patients experienced substantial socioeconomic impact of TB disease, most importantly due to inability to work and job loss. If the patient is the breadwinner of the family the combination of lost income and extra costs are generally catastrophic.

During a national workshop, policy options to decrease the economic burden of (MDR) TB among patients were developed. These recommendations are not mutually exclusive – it may be necessary to provide more than one at the same time. The recommendations are separated into two areas: service delivery and social protection:

1. **TB service improvements:**

- a. **Reduce hospitalization.** Kazakhstan has moved in recent years from full in-patient treatment to partial outpatient treatment, usually in the continuation phase. Akmola is a pilot site for further reduction of hospitalization, and the country plans to move towards full outpatient care. This has the potential to greatly reduce indirect costs.
- b. **Ensure that policy of free care for all (MDR)TB services is fully implemented.** Currently some TB services such as tomography are either unavailable at designated diagnostic TB health facilities while physicians prescribe them. As a result patients sometimes have to go to other health facilities and pay for these tests. Agreements between the TB program and public health facilities need to be in place so that presumed TB patients can make use of these diagnostic tools for free.
- c. **Bring services closer to patients.** TB services are to be integrated into primary health care in Kazakhstan. However, this task shifting has not been completed yet, and may require coordination by the Ministry of Health. Such integration of diagnostic and DOT services should reduce patient expenditures on transport and patient time and should reduce detection and treatment delays. For areas where there is no public transport, arrangement of transport for patients or home visits should be arranged. Other options for bringing services closer to patients are DOT at school and at the work place.
- d. **Detect and treat MDR-TB cases earlier.** Especially detection of drug-resistant TB should reduce the time to appropriate treatment, and thus reduce direct and indirect treatment costs for patients, especially the amount of income lost due to



inability to work during initial first-line drug treatment. Full implementation of new diagnostics such as Xpert MTB/RIF should reduce time to diagnosis and thus patient costs.

- e. **Involve local NGO's and civil society organizations** to improve (MDR)TB treatment adherence.

## 2. Social protection improvements.

- a. **Include direct (transport, food support) costs in social support schemes provided through TB services.** Such incentives and enablers should reduce direct costs associated with TB treatment and improve treatment adherence.
- b. **Include indirect (sick leave allowance) costs in social protection schemes.** Review, standardize and expand current social protection mechanisms and schemes by the government. Social protection schemes, including temporary disability allowances, should be made available to those (MDR)TB patients who need it, from the moment they are diagnosed. Include social protection for (MDR)TB under disability policy strategies while ensuring that the protection is provided from the time of confirmed diagnosis to those who are risk of becoming poor or not seeking or completing treatment. Professional guidance by health care workers or social workers for submitting applications for social support is needed for many patients. Possibilities for agreements on delaying or waiving payments (e.g. mortgage loans, school fees) are to be investigated.
- c. **Improve employment protection.** Advocate for regulations and policies that mandate that private employers pay employees (a portion of) their salary while they are unable to work. Also advocate for patients to be able to return to previous positions once they are fully cured and clinically fit to perform their assignments.
- d. **Assure continuation of education.** When rendered non-infectious, children and students need to be able to continue their education.
- e. **Increase re-socialization and employment possibilities.** Develop mechanisms to involve socially vulnerable patients in different re-socialization activities provided e.g. through temporary, assisted living facilities. Develop mechanisms to involve patients in income generating activities and advocate government to support this, for example through microfinance.
- f. **Reduce stigma and acceptance of outpatient treatment.** Improve education to the public on TB and MDR-TB, e.g. through primary level services, in order to reduce stigma of (MDR)TB and reduce fear of transmission during outpatient treatment.

Based on the above analysis, it is clear that some of the options open to the Government of Kazakhstan to address the issues identified are short term and others are long term. The most important place to start in the short term seem to be to accelerate the expansion of outpatient treatment in order to reduce income loss, including acceleration of expansion of DOT services closer to the patients, and to analyze and improve the existing social support system. We trust that the results of this study are useful to further guide the development of policies to relieve financial hardship for (MDR) TB patients and hereby potentially improve treatment outcomes.



## 4 Introduction

### 4.1 Background on the project

Since May 2011 KNCV Representative Office in Central Asia implements the USAID funded TB CARE I project. The main objective of the project is the development of efficient and effective strategies for tuberculosis (TB) control and strengthening of management capacity for both drug sensitive and multidrug-resistant TB.

Economically vulnerable populations have a higher risk of tuberculosis (TB) infection and progression to disease. TB patients face income loss because of charges for health services, costs for transport, accommodation, nutrition and inability to work. During treatment, patients with MDR TB face 5-20 times higher costs than patients with susceptible TB, mainly due to relocation costs and longer pre-diagnosis and treatment periods involving more visits and procedures. MDR TB is more prevalent in high risk populations, like the homeless, which are often also economically more vulnerable. Policy makers like Ministries of Health and National Tuberculosis Control Programs may want to use patient costing data to describe financial hardship and to identify and tackle bottlenecks in access to and continuation of (MDR)TB treatment.

A Tool to Estimate Patients' Costs was developed by TBCAP. This tool enables a thorough insight into patient costs but does not cover MDR TB patient costs. Besides, it contains a lengthy questionnaire which can be simplified if the main aim is to estimate major cost components and their approximate size. Thus, rather than giving a precise estimate of all direct and indirect costs of diagnosis and treatment of (MDR) TB, we aim to identify the main financial bottlenecks that can be addressed through policy changes.

We have developed a tool that identifies the components causing the highest financial burden for (MDR) TB patients in order to encourage countries to formulate interventions to relieve this burden.

In August 2012, a workshop and pre-test was held to prepare for piloting the patient cost tool in Kokshetau, Akmola oblast, Kazakhstan. In this report, we summarize the findings of the pilot, which will be used to finalize the tool, and to further guide the development of policies to relieve financial hardship for (MDR) TB patients and hereby potentially improve treatment outcomes.

### 4.2 Background TB control program structure in Akmola oblast, Kazakhstan

In Akmola oblast TB Services are provided at three different levels:

1. There are four TB dispensaries where patients are hospitalized: the oblast-level dispensary in the oblast capital Kokshetau (OTBD) and three regional dispensaries, in Stepnogorsk, Atbasar and Marinovskiy.
2. There are 17 TB facilities at district level
3. Each rayon has at least one primary health care facility

The four regional/oblast level dispensaries each hospitalize different groups of TB patients, as shown in Figure 1.





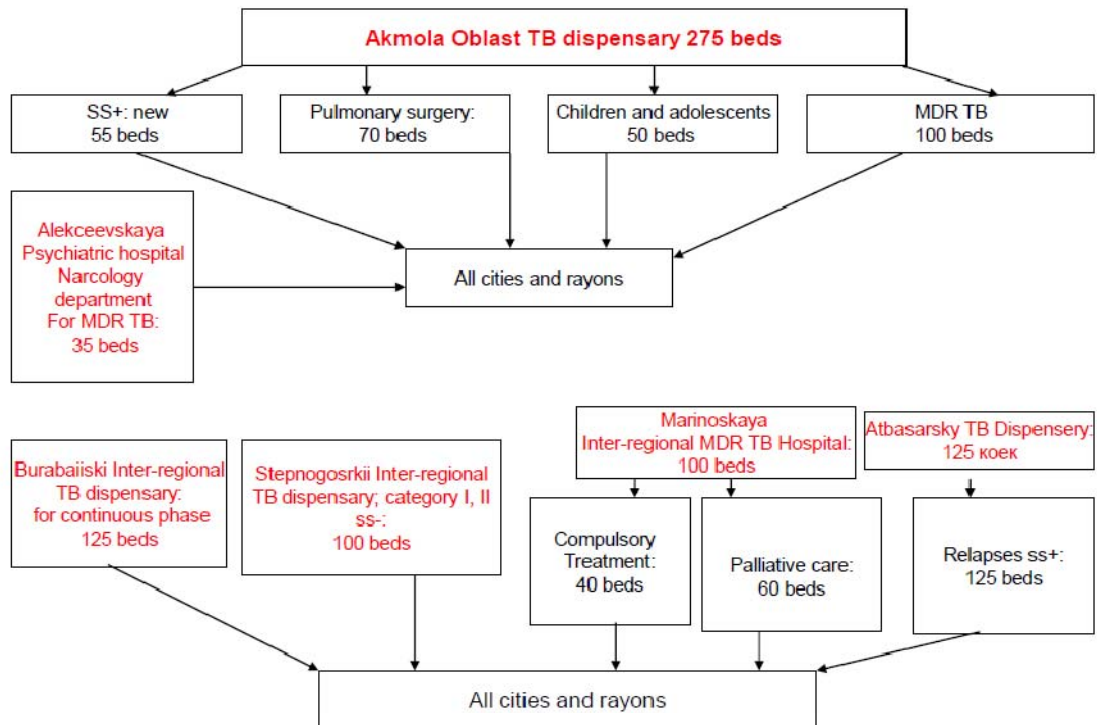


Figure 1. Tuberculosis control program in Akmola oblast, Kazakhstan

In Akmola oblast, transport vouchers and food packages are available for all outpatient TB patients. Government employees are entitled to payment of their salary for the first four months (with a maximum of 25965 tenge per month, and they are ensured that they can return to their job or to an alternative position. Private companies do not have to pay their employees during sick-leave. All TB patients can apply for a disability allowance. With a statement from the CVKK (central doctor's committee, available at every regional TB dispensary), they can receive a disability allowance. The amount of the allowance depends on your disability. TB usually is graded II (out of III), and entitles patients to a monthly allowance of 34500 tenge. After a year, CVKK can provide a new statement, if necessary. Since 2007, after conversion (and hospital discharge), patients can also apply for a document with CVKK that they are able to resume work.



## 5 Methods

### 5.1 Study design

We did a cross-sectional survey, in which patients per country in different phases of (MDR) TB treatment were interviewed once.

### 5.2 Study population

Costs related to TB diagnosis and treatment may prevent TB cases from seeking care and treatment. Without large scale population-based surveys, it is impossible to identify TB cases not seeking TB care due to financial constraints. Also, it is logistically challenging to identify those seeking diagnosis but interrupting the diagnostic process because of associated costs.

Therefore, with the new tool, we aimed to address the population that seeks TB diagnosis and care and may experience financial hardship.

To answer this question, we interviewed patients (in different phases of treatment. We included (MDR) TB patients in all different stages from diagnosis till end of treatment.

We included 5 groups in different phases of diagnosis and treatment:

1. TB patients who completed at least one month of treatment and now are (or should be, in case of default,) within last month of the intensive phase of category I, II, and III TB treatment (recall period: last three months including pre-treatment period; but including all major coping costs outside the 3-month period);
2. TB patients who started at least 3 months ago with the continuation phase of category I, II, and III TB treatment (recall period: last three months i.e. covers a part of the continuation phase; but including all major coping costs outside the 3-month period);
3. diagnosed as MDR TB patient within the month before the interview (recall period: last three months before diagnosis of MDR TB; but including all major coping costs outside the 3-month period)
4. MDR TB patients who started at least 3 months ago with the intensive phase of MDR TB treatment (recall period: last three months i.e. covers a part of the intensive phase; but including all major coping costs outside the 3-month period);
5. MDR TB patients who started at least 3 months ago with the continuation phase of MDR TB treatment (recall period: last three months i.e. covers a part of the continuation phase; but including all major coping costs outside the 3-month period).

We aimed to include a total of 50 patients in each of these 5 groups. However, the number of participants is determined by the caseload. In case more than 50 patients could be identified from the TB register per group, a random selection was made. All participants were asked to recall costs made and income losses over the last three-month period (for MDR TB patients who are just diagnosed with MDR TB: over the last three months before diagnosis of MDR TB) and major coping costs since start of TB symptoms. Only adults (aged 21 years and above) were included. We chose this age limit because we consider that most of those below the age of 21 are not economically independent and still mainly live on their parent's earnings.

#### 4.3. Exclusion

In accordance with the protocol, we excluded patients younger than 21 years and patients not consenting to the study or those not able to answer the questions in the interview. Also, we excluded patients who died or transferred out while on treatment because of logistic difficulties.

In Kokshetau we decided to apply extra exclusion criteria.

First, GeneXpert has recently (13 August 2012) been introduced in Kokshetau OTBD for MDR-TB and HIV/TB risk groups. Patients diagnosed with Xpert MTB/RIF were excluded from the study.



Second, for patients for whom it is difficult to go to the TB dispensary, a home-based program is available: nurses bring the medication to their homes daily. This is based on the "Sputnik" program, firstly introduced in Tomsk, Russia. We decided to exclude these patients, as they are a small group with very distinct costs compared to other patients.

Last, we also excluded the few patients known to have MDR-TB but currently (still) on FLD treatment. The main reason for this was that these patients refused the long and toxic MDR-TB treatment.

### 5.3 Justification for piloting the patient cost tool in Kokshetau

There is a commitment in the oblast for expanding outpatient care to the intensive phase of treatment. Kokshetau city was selected as a pilot site for the TB patient cost tool, as current major cost components for TB patients at different stage of TB diagnosis and treatment is planned to be compared to the situation after expansion of outpatient care at a later stage.

As it was logistically and financially not feasible to perform the pilot in different sites of this oblast, we only included patients hospitalized in the OTBD and those on outpatient treatment in Kokshetau city.

### 5.4 Modifications to the generic questionnaire

Before a workshop preparing for the pilot, the questionnaire had been translated into Russian and translated back by another translator into English. By comparing the original and back-translated questionnaire, some necessary adjustments could be made to the Russian version to ensure that the questions were asked in the correct way.

During the workshop, more adjustments were made to adapt the questionnaire to the local situation. The major changes were:

1. As staff was afraid that patients would think that they would be reimbursed for costs (and therefore might not respond truthfully), an explanation was added to the introduction: "If you choose to participate, I would like to stress that you will not receive any reimbursements for the costs that you have made and tell us about during the interview".
2. DOT supporters beyond health care staff are non-existent in Kokshetau, so this answer option was deleted.
3. Patient group A-E was renamed group 1-5, in concordance with the protocol
4. The questions on previous treatment were regarded as highly sensitive by the staff. Default can be due to lack of medication and/or the patient may feel 'offended' when asked this question at the beginning of the interview. If the interviewer would take treatment history from the patient card, the staff was afraid that the patients would feel their privacy was not respected. It was decided to leave the two questions on previous treatment and reason for default out.
5. Instead, this block of questions was designed only for MDR-TB patients, and the question "If on Cat IV treatment, how long had you been on TB treatment before you were diagnosed with MDR-TB?" was rephrased and expanded into:
  - a. How long had you been on TB treatment before you were diagnosed with MDR-TB?
  - b. If on MDR-TB treatment with second-line drugs, what was the duration between diagnosis of MDR-TB and start of MDR-TB treatment?
  - c. If not on MDR-TB treatment with second-line drugs, what was the duration of TB treatment until now?
6. It was clarified that the questions on diagnostic costs were for all patients in group 1-3, as in the original version of the questionnaire it was phrased as being for patients on cat I-III treatment and this way we would miss out on diagnostic costs for MDR-TB for patients just diagnosed with MDR-TB (group 3).
7. The questions related to costs for picking up drugs were excluded, as in Kokshetau patients never pick up drugs themselves.



8. The question on loss of income by an accompanying person when coming with the patient to the hospital was asked twice and therefore one of these questions (Q33 in the original version) was deleted.
9. The question on relocation costs was removed because almost all patients are hospitalized in Kazakhstan at the moment, so relocation costs are already included in the question on costs related to hospitalization.
10. With regard to coping costs, question 43a in the original questionnaire was deemed unnecessary and deleted; question 43b was rephrased in concordance with question 42. So instead of asking first whether property was sold, and then which property, the question was rephrased into: "if you sold property, which items were sold?", as question 41 already shows whether property was sold.

After the pre-test including five TB patients, only minor modifications were made to the questionnaire, mainly to correct cross-references ("go to question x after this answer"). Other modifications were: asking about months of hospitalization instead of days (as all patients stay at least a few months), and asking about the value of food packages instead of food vouchers (as packages are distributed in Akmola oblast, for which patients do know the value).

The questionnaire used in the pilot is included as an annex to this report.

## 5.5 Study approval and ethical issues

Official study approval was sought from the National Center for Problems of Tuberculosis, and the Akmola OTBD. The three interviewers and the supervisor signed a confidentiality agreement (see annex). All interviews were kept in the supervisor's room, which she locked when she left it. The interviewers were university students not involved in TB care. They wore N95 respirators when interviewing hospitalized patients, as patients are only released after they become culture-negative. Interviews were done in separate rooms to ensure confidentiality.

## 5.6 Definitions

- **TB patient**: a person diagnosed with tuberculosis.
- **MDR TB patient**: a person diagnosed with tuberculosis resistant against rifampicin and isoniazid by phenotypic or genotypic drug susceptibility testing or with rifampicin resistance according to Xpert MTB/RIF testing and no drug susceptibility test result ruling out MDR TB (according to prevailing (inter)national guidelines).
- **Direct costs**: out-of-pocket costs linked to seeking diagnosis and treatment including medical expenses, fees, transport, accommodation and food expenditures.
- **Indirect (opportunity) costs**: these include the cost of foregone income due to the inability to work because of the illness and loss of time due to visits to health facilities, time spent on the road to and at health facilities, lost productivity and loss of job.
- **Coping costs**: household costs to meet daily requirements despite extra expenditures or loss of income. These include the sale of assets, taking up debt, saving on food or other items, taking a child out of school to care for the patient or taking up a job, or taking up another job.
- **Pre-treatment period (TB)**: period from onset of symptoms until start of treatment
- **Pre-treatment period (MDR TB)**: period from being earmarked as a MDR TB suspect until start of MDR TB treatment
- **Intensive phase of treatment**: First phase of treatment, in accordance with WHO definitions and local guidelines. Usually, 2-3 months for TB and 6-8 months for MDR TB



- Continuation phase of treatment: Second phase of treatment, in accordance with WHO definitions and local guidelines. Usually, 4-6 months for TB and 12-18 months for MDR TB

## 5.7 Data entry and analysis

Data were entered in a pre-designed EpiData data entry file ([www.epidata.dk](http://www.epidata.dk)). After ten percent of the data were double entered, they were double checked. No cases of greater than 1% discrepancies in key variables were encountered, which was a criterium for double entry of all data. After data validation, descriptive analyses were performed in SPSS.

Most questions asked were about the previous three-month period, some on the previous month, and some on the whole TB illness period. Where possible, costs were extrapolated per treatment phase. The main outcomes therefore were total costs incurred by (MDR) TB patients per stage of treatment. Secondary outcomes are the most important cost components.

We calculated costs of getting a (MDR) TB diagnosis, costs of treatment (in the intensive and continuation phase of TB and MDR TB treatment) and money involved in coping as outlined in Figure 2.

For the duration of treatment phases, we applied WHO guidelines, to make results comparable to those from the other countries where this tool was piloted, and because no data were available on the distribution of treatment phase duration. However, according to national guidelines, the intensive phase of category I and III treatment can be expanded up to 4 months, and the intensive phase of category II treatment up to 5 months.

Since the distributions of almost all costs were highly skewed towards higher values, we chose to present median values with 25<sup>th</sup> and 75<sup>th</sup> percentiles.



Figure 2. Methods used to estimate different types of costs for TB diagnosis and treatment.

Type of cost	Elements included in cost type	Methods used to calculate costs
<b>Diagnostic</b>	Food, travel, accommodation, medical costs, and loss of income during visits	Summed direct and indirect costs of visits  Indirect costs (income loss) as calculated from total time spent x income/time
<b>Treatment</b>	Hospitalization, DOT visits, follow-up tests, food, travel and loss of income	Summed direct and indirect costs, multiplied by number visits/week, weeks/ month, and internationally defined duration of treatment phase  Indirect costs (income loss) for hospitalization as calculated based on internationally defined duration of intensive phase x income/time  Indirect costs (income loss) for DOT as calculated from total time spent x income/time
<b>Other Costs</b>	Food supplements, adverse events,	Summed costs over last month, extrapolated over treatment phase to internationally defined duration of treatment phase
<b>Coping costs</b>	Remaining sources of patient and household income after TB diagnosis, amount borrowed, assets sold	Summed costs

Though we aimed to include patients who were at least three months in their current phase of treatment (except for patients in the intensive phase of cat I/II treatment since this generally lasts only 2 months, and patients just diagnosed with MDR TB), also a few patients who had been in their current treatment phase for less than 3 months were included. Since changing from intensive to continuation phase of cat I/II treatment usually results in changes in frequency of visiting health care facilities, these patients might have reported mixed costs of intensive and continuation phase of treatment. Therefore, we conducted a sensitivity analysis excluding these patients and compared the results of this analysis to the analysis of all patients. As results were hardly affected, we do not show the results of this sensitivity analysis in this report.



## 6 Results

### 6.1 Response

Identified as eligible for inclusion were 228, while 150 (66%) questionnaires have been received. Unfortunately we have no information on demographics of non-responders and reasons for non-response. According to the interviewers the main reason for non-participation was that patients did not want to disclose financial information.

More than 50 patients in the intensive phase of MDR-TB treatment were included, while this target number was not reached in the other four categories of patient groups (Table 1). In total 96 MDR-TB patients were interviewed and 54 other TB patients.

### 6.2 Characteristics of participants

Table 1 shows the characteristics of the participants. Overall, 67% of patients were male, 88% were under 50 years of age, and 62% of patients had been diagnosed with MDR-TB. All new TB patients were on category I or III treatment, all retreatment patients on category II treatment, and all MDR-TB patients on category IV treatment. None of the patients were HIV-positive. Nearly three-quarters (72%) of the patients were hospitalized at the time of interview. The other patients were interviewed at the primary health care facilities where they received DOT.

Characteristics of MDR-TB and other patients were similar, except that on average MDR-TB patient were younger, reflecting more recent transmission of TB.

Table 2 shows that most of the patients in the intensive phase of treatment were hospitalized at the time of the interview, while most of those in the continuation phase of treatment were not. At the time of the interview, two patients in the intensive phase of treatment were not hospitalized, both were MDR-TB patients in seventh month of the intensive phase treatment. One of them had not been hospitalized at all, as he started treatment in home-based care. Five out the 32 MDR-TB patients in the continuation phase of treatment were still hospitalized. Both patients just diagnosed with MDR-TB were hospitalized at the time of interview.



Table 1. Characteristics of all participants

		Category I-III treatment		Category IV treatment	
		Count	Column %	Count	Column %
TB patient group	intensive phase Cat I-III	41	76%	0	0%
	continuation phase Cat I-III	13	24%	0	0%
	just diagnosed with MDR	0	0%	2	2%
TB group	intensive phase Cat IV	0	0%	62	65%
	continuation phase Cat IV	0	0%	32	33%
	new SS+	42	78%	0	0%
	new SS-	9	17%	0	0%
	retreatment	3	6%	0	0%
TB treatment phase	MDR SS+	0	0%	78	81%
	MDR SS-	0	0%	18	19%
	intensive cat1	40	74%	0	0%
	continuation cat1	14	26%	0	0%
gender	intensive cat4	0	0%	64	67%
	continuation cat4	0	0%	32	33%
age group	male	37	69%	63	66%
	female	17	31%	33	34%
	21-29	13	24%	34	35%
nationality	30-39	19	35%	24	25%
	40-49	12	22%	30	31%
	50+	10	19%	8	8%
education level	Kazakh	28	52%	45	47%
	Russian	19	35%	35	36%
	Ukrainian	0	0%	4	4%
	other	7	13%	12	13%
TB type	no education	0	0%	0	0%
	elementary	5	21%	11	33%
	secondary	19	79%	22	67%
	higher	0	0%	0	0%
hospitalized at time of interview	other	0	0%	0	0%
	pulmonary TB, SS+	43	80%	78	81%
	pulmonary TB, SS-	10	19%	17	18%
HIV status	extrapulmonary TB	1	2%	1	1%
	no	13	24%	29	30%
	yes	41	76%	67	70%
	negative	54	100%	96	100%





Table 2. Hospitalization status at the time of interview by patient group

		hospitalized at time of interview			
		no		yes	
		Count	Row N %	Count	Row N %
TB patient group	intensive phase Cat I-III	0	0%	41	100%
	continuation phase Cat I-III	13	100%	0	0%
	just diagnosed with MDR	0	0%	2	100%
	intensive phase Cat IV	2	3%	60	97%
	continuation phase Cat IV	27	84%	5	16%
Total		42	28%	108	72%

### 6.3 Travel time to diagnostic and treatment facilities

Table 3 shows the time needed for transport to the closest diagnostic and treatment TB facilities. If both time needed by walking and by other transport means were filled out, the option taking up less time is shown in the table. To reach the closest diagnostic facility, 18% of patients need to travel at least one hour, and 3% at least two hours. To reach the closest treatment facility, 42% need to travel at least one hour and 29% at least two hours.

Table 3. Travel time to the closest diagnostic facility and to the closest treatment facility.

		Count	Column N %
travel time to nearest TB diagnostic facility (minutes)	0 min	0	0%
	1-29	75	50%
	30-59	47	32%
	60-89	21	14%
	90-119	2	1%
	120+	4	3%
travel time to nearest TB treatment facility (minutes)	0 min	0	0%
	1-29	10	21%
	30-59	18	38%
	60-89	4	8%
	90-119	2	4%
	120+	14	29%



## 6.4 Time to diagnosis of MDR-TB and start of MDR-TB treatment

For MDR-TB patients Table 4 shows the duration of FLD treatment before a diagnosis of MDR was made, and the duration between MDR diagnosis and start of SLD treatment. This information was known for 43 MDR-TB patients, of whom 29 (67%) had received at least 6 months of therapy before diagnosis of MDR. This is remarkable as in principle all patients get culture and DST at diagnosis, and conventional DST results should be available within weeks (in case of liquid culture) and maximal three months (in case of solid culture). After MDR diagnosis, 25 (58%) were started on SLD treatment within three months, while 8 (19%) had to wait over half a year. Reasons for delays unfortunately were not evident from this questionnaire.

Table 4. Duration of treatment before MDR diagnosis, and duration between MDR diagnosis and start of MDR treatment.

		Count	Column N %
months on FLD treatment before diagnosis of MDR-TB <i>median (IQR): 6 (3-7)</i>	0	2	5%
	1	5	12%
	2	2	5%
	3	1	2%
	4	3	7%
	5	1	2%
	6	10	23%
	7	10	23%
	8	5	12%
	9	4	9%
months between diagnosis of MDR-TB and SLD treatment <i>median (IQR): 2 (0-6)</i>	0	14	33%
	1	6	14%
	2	5	12%
	3	1	2%
	4	1	2%
	5	3	7%
	6	5	12%
	7	1	2%
	8	4	9%
	9	2	5%
	11	1	2%



## 6.5 Time and costs for diagnosis of TB

Table 5 shows the number of diagnostic visits until TB diagnosis for patients in the intensive phase of category I-III treatment. 29/40 (73%) received a diagnosis of TB within two visits, and two (5%) needed more than 3 visits. It also shows the sum of time needed for all diagnostic visits combined. The median time needed for diagnostic visits was 2 hours (120 minutes).

Table 5. Number of diagnostic visits until TB diagnosis for patients in the intensive phase of category I-III treatment.

		Count	Column N %
Number of visits till diagnosis of TB	1	4	10%
	2	25	61%
	3	9	22%
	4	2	5%
	5	0	0%
	7	1	2%
Sum of time needed for diagnostic visits (hours) <i>median (IQR): 120 (78-273) minutes</i>	<2h	18	44%
	2-4h	11	27%
	4-8h	6	15%
	>=8h	6	15%

Table 6 shows costs involved for diagnosis of TB, for the 41 patients in the intensive phase of category I-III.

The median costs related to these diagnostic visits were 800 tenge, mostly due to direct costs. Most of direct costs in turn were caused by travel costs (see annex). No patients had received reimbursements for costs related to diagnostic visits. Six (15%) patients reported travel costs and/or income lost for persons accompanying them to clinic visits for diagnosis of TB (median (IQR): 1900 (623-3950) tenge).



Table 6. Costs involved for diagnosis of TB, for the 41 patients in the intensive phase of category I-III. Costs are shown in Kazakh tenge (10 USD ≈ 1500 Kazakh tenge).

		sum of direct costs related to diagnostic visits (tenge)	sum of indirect costs related to diagnostic visits (tenge)	sum of total (direct and indirect) costs related to diagnostic visits (tenge)	sum of reimbursements for costs related to diagnostic visits (tenge)
N	Valid	41	41	41	41
	Missing	0	0	0	0
Mean		1932	688	2228	0
Std. Deviation		3151	837	3802	0
Minimum		0	0	0	0
Maximum		13000	3477	18000	0
Percentiles	25	105	169	190	0
	50	720	379	800	0
	75	2000	724	2210	0

Table 7. Detailed direct costs involved for diagnosis of TB, for the 41 patients in the intensive phase of category I-III. Costs are shown in Kazakh tenge (10 USD ≈ 1500 Kazakh tenge).

		sum of administrative costs paid during diagnostic visits (tenge)	sum of costs for tests during diagnostic visits (tenge)	sum of costs for X-ray during diagnostic visits (tenge)	sum of costs for drugs paid during diagnostic visits (tenge)	sum of costs for travel during diagnostic visits (tenge)	sum of costs for food during diagnostic visits (tenge)
N	Valid	41	41	41	41	41	41
	Missing	0	0	0	0	0	0
Mean		141	0	129	329	792	297
Std. Deviation		648	0	399	1292	1026	599
Minimum		0	0	0	0	0	0
Maximum		4000	0	2000	6500	5000	2500
Percentiles	25	0	0	0	0	25	0
	50	0	0	0	0	450	0
	75	0	0	0	0	1000	0



Table 8. Costs for persons accompanying the 41 patients in the intensive phase of category I-III during diagnostic visits.

		sum of costs for travel of accompanying person during diagnostic visits (tenge)	sum of costs for accommodation for accompanying person during diagnostic visits (tenge)	sum of income lost by accompanying person during diagnostic visits (tenge)	Total
N	Valid	41	41	41	41
	Missing	0	0	0	0
Mean		207	0	117	324
Std. Deviation		833	0	540	1048
Minimum		0	0	0	0
Maximum		5000	0	3000	5000
Percentiles	25	0	0	0	0
	50	0	0	0	0
	75	0	0	0	0



## 6.6 Duration of and costs associated with hospitalization

As expected in Kazakhstan, all but one of the 150 patients had been hospitalized during TB treatment. This one MDR-TB patient had started treatment in home-based care and continued on an outpatient basis.

To assess total duration of hospitalization, we selected patients in the continuation phase on outpatient care at the time of the interview. Duration of hospitalization was 2-5 months for patients on category I-III treatment, which is more or less in agreement with the length of the intensive phase (2-4 months).

For patients on category IV treatment, 22/27 (82%) had been hospitalized for at least 6 months. The remaining five seem to have been discharged during the intensive phase already, as they had been hospitalized for 2-4 months. On the other hand, five out of 32 patients in the continuation phase of category IV treatment were still hospitalized.

Table 9. Duration of hospitalization per patient group. Selected are those patients on in the continuation phase of treatment, who were on outpatient care at the time of the interview.

		TB patient group			
		continuation phase Cat I-III		continuation phase Cat IV	
		Count	Column N %	Count	Column N %
time in hospital during TB treatment (months)	2	4	31%	3	11%
	3	3	23%	0	0%
	4	4	31%	2	7%
	5	2	15%	0	0%
	6	0	0%	8	30%
	7	0	0%	7	26%
	8	0	0%	5	19%
	9	0	0%	2	7%

Out of the 149 patients who had been hospitalized during treatment, 142 (95%) reported to not have had any direct costs related to hospitalization. Reported costs by the other seven patients varied from 90 to 40,000 tenge, mostly spent on food. We calculated total hospital costs for those who had been hospitalized earlier during treatment, separately for patients on category I-III and on category IV treatment (Table 10 and 11).

Only two out of 149 patients indicated that a family member or friend had stayed with them during hospitalization. One of the two indicated that costs had been involved (45,000 tenge for food and transport). In addition, 113 (76%) patients had been visited by other family members or friends during hospitalization. Costs for these visitors were reported for 107 (72%) of them. Median costs were 42000 (IQR 0-10,045) tenge (see annex for details).



Table 10. Reported direct patient costs related to hospitalization for patients on category I-III treatment already discharged from the hospital.

		Hospital administration fee	Hospital bedding fee	Hospital food fee	Hospital transport fee	Hospital drugs fee	Hospital tests fee	Other hospital fees	total payment for hospital stay (tenge)
N	Valid	11	11	11	11	11	11	11	11
	Missing	2	2	2	2	2	2	2	2
	Mean	0	0	909	0	0	0	0	909
	Std. Deviation	0	0	3,015	0	0	0	0	3,015
	Minimum	0	0	0	0	0	0	0	0
	Maximum	0	0	10,000	0	0	0	0	10,000
	25	0	0	0	0	0	0	0	0
Percentiles	50	0	0	0	0	0	0	0	0
	75	0	0	0	0	0	0	0	0

Table 11. Reported direct patient costs related to hospitalization for patients on category IV treatment already discharged from the hospital.

		Hospital administration fee	Hospital bedding fee	Hospital food fee	Hospital transport fee	Hospital drugs fee	Hospital tests fee	Other hospital fees	total payment for hospital stay (tenge)
N	Valid	26	26	26	26	26	26	26	26
	Missing	1	1	1	1	1	1	1	1
	Mean	0	0	1,538	0	0	0	0	1,538
	Std. Deviation	0	0	7,845	0	0	0	0	7,846
	Minimum	0	0	0	0	0	0	0	0
	Maximum	0	0	40,000	0	0	0	0	40,000
	25	0	0	0	0	0	0	0	0
Percentiles	50	0	0	0	0	0	0	0	0
	75	0	0	0	0	0	0	0	0



## 6.7 Time and costs related to DOT

All patients receive DOT 6 (91%) or 7 (9%) times per week. Table 12 shows time and costs related to DOT for the 42 patients not hospitalized at the time of the interview. Total time needed for a DOT visit was between 30 and 60 minutes for 30 (71%) of the 42 patients treated on an outpatient basis at the time of interview, while it took at least 60 minutes for another four (10%) patients.

Assuming that all patients are hospitalized during the entire intensive phase and all are treated ambulatory during the continuation phase of treatment, we calculated DOT costs over the continuation phase. For non-MDR-TB patients, assuming a 4 month continuation phase, median costs were estimated to be 13,850 (IQR 10,987-175,357) tenge. For MDR-TB patients, assuming a 12 month continuation phase, median costs were estimated to be 12,721 (8,847-38,256) tenge. Unexpectedly, total DOT costs for MDR-TB patients were lower than for non MDR-TB patients despite the longer treatment duration. This can be explained by the fact that 13/27 indicated to spend no money on transport for DOT visits compared to 1/13 of non-MDR-TB patients.

If we assume that the lower DOT costs for MDR-TB patients are due to chance, and apply median monthly costs for all TB patients, including MDR-TB patients, to internationally recommended duration of the treatment phase, the median costs for the whole treatment phase would be 15636 (IQR 9288-27531) tenge for non-MDR-TB patients and 46909 (IQR 27864-82592) for MDR-TB patients.

Table 12. Time and costs related to DOT, for 42 patients in the continuation phase, not hospitalized at the time of interview.

		continuation phase Cat I-III		continuation phase Cat IV		total	
		time needed to reach DOT facility (minutes)	total time needed per DOT visit (minutes)	time needed to reach DOT facility (minutes)	total time needed per DOT visit (minutes)	time needed to reach DOT facility (minutes)	total time needed per DOT visit (minutes)
N	Valid	13	13	29	29	42	42
	Missing	0	0	0	0	0	0
	Mean	25	25	46	22	38	40
	Std. Deviation	11	11	25	9	14	18
	Minimum	5	5	15	5	15	15
	Maximum	40	40	120	40	90	120
	Percentiles						
	25	18	33	15	30	15	30
	50	20	45	20	35	20	40
	75	35	50	30	40	30	45





Table 13. Direct and indirect costs per month, related to DOT visits, stratified by treatment category

		continuation phase Cat I-III			continuation phase Cat IV		
		direct costs DOT per month (tenge)	indirect costs DOT per month (tenge)	total costs DOT per month	direct costs DOT per month (tenge)	indirect costs DOT per month (tenge)	total costs DOT per month
N	Valid	13	13	13	27	27	27
	Missing	0	0	11,610	0	0	0
Mean		2,759	3,763	6,521	1,768	2,387	4,155
Std. Deviation		2,265	2,093	3,375	2,850	1,662	3,490
Minimum		0	0	2,322	0	0	0
Maximum		7,482	7,623	13,590	12,900	5,131	15,099
Percentiles	25	2,382	3,635	0	0	1,527	18,324
	50	3,848	6,170	774	2,932	3,420	41,045
	75	5,222	8,882	2,322	3,665	5,376	64,512

Table 14. Direct and indirect costs related to DOT visits, extrapolated over the treatment phase, stratified by treatment category

		continuation phase Cat I-III			continuation phase Cat IV		
		direct costs DOT over treatment phase (tenge)	indirect costs DOT over treatment phase (tenge)	total costs DOT over treatment phase	direct costs DOT over treatment phase (tenge)	indirect costs DOT over treatment phase (tenge)	total costs DOT over treatment phase
N	Valid	13	13	13	27	27	27
	Missing	0	0	11,610	0	0	0
Mean		12146	16,084	28,230	21,213	28,644	49,857
Std. Deviation		10406	9,401	16,045	34,199	19,941	41,882
Minimum		0	0	11,610	0	0	0
Maximum		37410	37,410	30,540	154,800	61,568	181,186
Percentiles	25	9,288	10,445	14,539	0	0	18,324
	50	9,288	15,392	24,680	9,288	35,182	41,045
	75	11,610	23,638	39,437	27,864	43,977	64,512



### 6.8 Costs related to follow-up tests and drugs during treatment

Almost all patients reported having had tests (e.g. X-rays) during follow-up appointments but none of the patients indicated to have paid for tests of drugs prescribed during these appointments.

### 6.9 Costs for persons accompanying patients during treatment.

Five out of 42 (12%) patients currently not hospitalized had been accompanied at least once during follow-up appointments; no loss of income was reported for the accompanying person.

### 6.10 Costs for supplements

In total 89 (59%) of 150 patients indicated to have bought supplements for their diet, additional to costs for food not provided by the hospital. The proportion was higher for patients in the continuation phase, reflecting longer duration of treatment. Accordingly, reported costs were higher for patients in the continuation phase. Fruits were purchased most often, followed by drinks (see annex). Costs extrapolated to the treatment phase are shown in Table 16.



Table 15. Costs for supplements per month, stratified by TB patient group.

		intensive phase Cat I-III	intensive phase Cat I-III	just diagnosed with MDR	intensive phase Cat IV	intensive phase Cat IV
N	Valid	41	13	2	62	32
	Missing	0	0	0	0	0
Mean		5560.98	5961.54	2500.00	9685.48	12368.75
Std. Deviation		9656.730	7752.584	3535.534	18529.603	15391.754
Minimum		0	0	0	0	0
Maximum		30000	25000	5000	99000	75000
Percentiles	25	0.00	1000.00	0.00	0.00	200.00
	50	0.00	3000.00	2500.00	2250.00	6000.00
	75	5500.00	6500.00		10000.00	20000.00

Table 16. Costs for supplements by TB patient group, extrapolated to the treatment phase

		intensive phase Cat I-III	intensive phase Cat I-III	just diagnosed with MDR	intensive phase Cat IV	intensive phase Cat IV
N	Valid	41	13	N.A.	62	32
	Missing	0	0		0	0
Mean		11121.95	26538.46		77483.87	148425.00
Std. Deviation		19313.460	36220.656		148236.822	184701.047
Minimum		0	0		0	0
Maximum		60000	125000		792000	900000
Percentiles	25	0.00	4000.00		0.00	2400.00
	50	0.00	15000.00		18000.00	72000.00
	75	11000.00	26500.00		80000.00	240000.00



## 6.11 Costs for treatment of adverse events

Adverse events during their treatment phase were reported by 42 (28%) of the 150 patients. Treatment was required for 24 (57%; 16% of all 150) patients. Costs for treatment of adverse events were reported by 10 (42%; 7% of all 150) patients. Adverse events were reported more often by MDR-TB patients, and the proportion of patients who had experienced adverse events were similar for MDR-TB patients in the intensive phase and the continuation phase. However, treatment for adverse events was required more often for those in the intensive phase. This may reflect the most common occurrence of serious adverse events during the early stages of treatment. Ten out of 24 patients requiring treatment for adverse events reported costs for treatment of adverse events, ranging from 1,000 to 40,000 tenge.

Table 17. Number of patients reporting adverse events during TB treatment, by patient group

		Adverse events experienced during TB treatment			
		No		Yes	
		Count	Row N %	Count	Row N %
TB patient group	intensive phase Cat I-III	34	83%	7	17%
	continuation phase Cat I-III	10	77%	3	23%
	just diagnosed with MDR	2	100%	0	0%
	intensive phase Cat IV	40	65%	22	35%
	continuation phase Cat IV	22	69%	10	31%
	Total	108	72%	42	28%

Table 18. Number of patients reporting treatment for adverse events experienced during TB treatment, by patient group

		Treatment required for adverse events					
		No		Yes		No adverse events	
		Count	Row N %	Count	Row N %	Count	Row N %
TB patient group	intensive phase Cat I-III	2	5%	5	12%	34	83%
	continuation phase Cat I-III	2	15%	1	8%	10	77%
	just diagnosed with MDR	0	0%	0	0%	2	100%
	intensive phase Cat IV	7	11%	15	24%	40	65%
	continuation phase Cat IV	6	19%	3	9%	23	72%
	Total	17	11%	24	16%	109	73%



Table 19. Costs related to adverse events during treatment.

		intensive phase Cat I- III	continuation phase Cat I-III	just diagnosed with MDR	intensive phase Cat IV	continuation phase Cat IV
N	Valid	41	13	2	62	32
	Missi ng	0	0	0	0	0
Mean		0	0	0	1,024	188
Std. Deviation		0	0	0	5,168	738
Minimum		0	0	0	0	0
Maximum		0	0	0	4,000	300
Percen tiles	25	0	0	0	0	0
	50	0	0	0	0	0
	75	0	0	0	0	0

## 6.12 Insurance and reimbursements

Two (1%) of the 150 patients reported to have insurance, of whom one patient just diagnosed with MDR-TB received reimbursement; for costs related to diagnosis of TB (1000 tenge).

Thirty-four (23%) patients reported receipt of other reimbursements (see Table 20). For those that received a reimbursement, the median amount was 85000 (IQR 1500-20250) tenge.



Table 20. Reimbursements, vouchers and allowances for TB patients during treatment

		Cat I-III treatment		Cat IV treatment		total	
		Count	Column N %	Count	Column N %	Count	Column N %
health insurance	no	54	100%	93	99%	148	99%
	yes	0	--	1	1%	2	1%
transport vouchers received	no	52	96%	88	94%	142	95%
	yes	2	4%	6	6%	8	5%
food packages received	no	50	93%	77	82%	129	86%
	yes	4	7%	17	18%	21	14%
monthly allowances received	no	51	94%	90	96%	143	95%
	yes	3	6%	4	4%	7	5%
other reimbursements received	no	51	94%	89	95%	142	95%
	yes	3	6%	5	5%	8	5%
total of reimbursements received (tenge)	0	45	83%	69	73%	116	77%
	1-499	0	0%	0	0%	0	0%
	500-999	0	0%	0	0%	0	0%
	1000-1999	1	2%	9	10%	10	7%
	2000-9999	1	2%	5	5%	6	4%
	10000-49999	6	11%	9	10%	15	10%
	50000+	1	2%	2	2%	3	2%



### 6.13 Financial impact of TB illness

The financial impact of TB illness on the family was scored very differently by patients; for some TB hardly had any impact, for others it had a serious impact. On average, the impact was higher for MDR-TB patients than for other TB patients: 30% of MDR-TB patients responded that TB illness had a serious impact on the family compared to 17% of other TB patients. Conversely, 21% of MDR-TB patients responded that TB had little impact compared to 38% of other TB patients (Figure 3). There was no very clear association between household income and financial impact of TB illness on the family, neither for TB and MDR TB patients (Table 21 and 22).

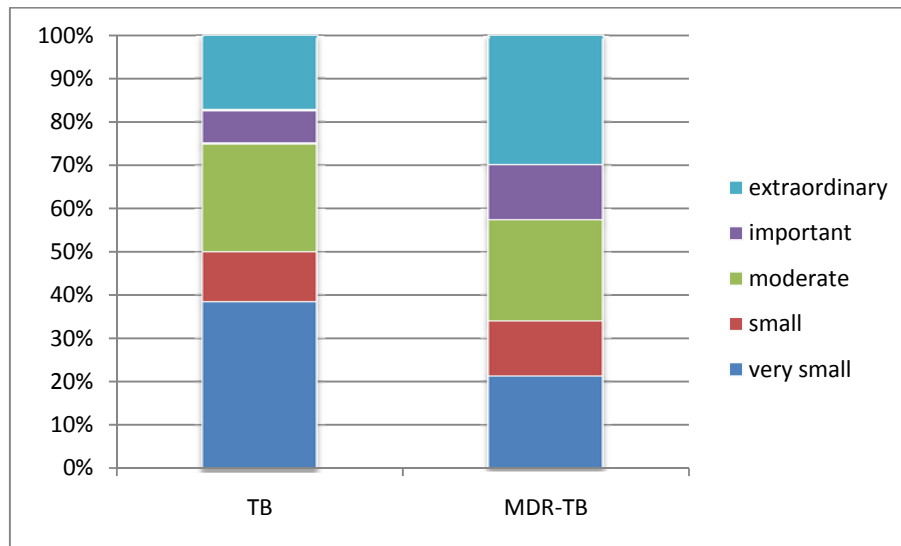


Figure 3. Reported financial impact of TB illness

Table 21. Reported financial impact of TB illness on the family, for patients on category I-III treatment

	monthly household income before TB illness divided in three equal groups (tertiles)								
	lowest income tertile (below 52.334 tenge)		middle income tertile (52.334-90.000 tenge)		highest income tertile (over 90.000 tenge)		Total		
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %	
financial impact of TB illness on the family	1 - little impact	10	53%	3	19%	7	41%	20	38%
	2	3	16%	1	6%	2	12%	6	12%
	3	1	5%	9	56%	3	18%	13	25%
	4	1	5%	0	0%	3	18%	4	8%
	5 - serious impact	4	21%	3	19%	2	12%	9	17%
	Total	19	100%	16	100%	17	100%	52	100%

Table 22. Reported financial impact of TB illness on the family, for patients on category IV treatment

	monthly household income before TB illness divided in three equal groups (tertiles)								
	lowest income tertile (below 52.334 tenge)		middle income tertile (52.334-90.000 tenge)		highest income tertile (over 90.000 tenge)		Total		
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %	
financial impact of TB illness on the family	1 - little impact	7	24%	6	18%	7	23%	20	21%
	2	4	14%	5	15%	3	10%	12	13%
	3	6	21%	10	29%	6	19%	22	23%
	4	3	10%	7	21%	2	6%	12	13%
	5 - serious impact	9	31%	6	18%	13	42%	28	30%
	Total	29	100%	34	100%	31	100%	94	100%





## 6.14 Coping with costs associated with TB illness

Donations (63%) were reported as the most common major source of money used to cope with costs associated with TB illness, followed by savings (22%) and the employer (11%).

Table 23. Sources of money to cope with costs associated with TB illness

		Cat I-III treatment		Cat IV treatment		total	
						Count	Column N %
source of money for TB illness related expenses	Health insurance	0	0%	0	0%	0	0%
	Employer	6	12%	8	9%	16	11%
	Cutting down expenses	0	0%	3	3%	3	2%
	Savings	10	20%	12	13%	22	15%
	Borrow money*	0	0%	4	4%	4	3%
	Selling assets	0	0%	0	0%	0	0%
	Donations	31	61%	62	66%	93	63%
	Other**	4	8%	5	5%	9	6%
	Total	51	100%	94	100%	147	100%

\* amount borrowed: 11000 tenge from a bank with 2% interest (n=1), 20000 tenge from a friend (n=1), 2000 tenge from bringing jewellery to a lombard (n=1), and 40000 tenge from a friend (n=1)

\*\* did not spend money (n=5), pension (n=2), renting land (n=1), social assistance (n=1)



## 6.15 Changes in employment due to TB illness

In 84 (56%) instances, the TB patient indicated to be the primary income earner in the household: 61% of patients in category I-III treatment and 54% of patients on category IV treatment. Fifty-one (34%) of the patients indicated to be currently working, including doing nonformal work. When stratified by whether the patient was hospitalized at the time of the interview, 26/42 (62%) not hospitalized reported to be currently working in comparison with 25/108 (23%) of patients who were hospitalized (data not shown). Thus, it seems the question was interpreted (at least sometimes) as whether the patient was officially employed, not whether they were actually working.

Fifty-four (37%) of the patients indicated that they had to change jobs when they became ill with TB; more MDR-TB patients (41%) than other patients (31%). Out of primary income earning patients, 23/49 (47%) and 19/32 (28%) indicated that they had to change jobs (data not shown).

Before TB illness, 27% of MDR-TB patients and 13% of other TB patients did not work at all, while this was true for 74% and 78%, respectively, at the time of interview. Remarkably, 8 (5%) patients worked more now than before their TB illness. From the questionnaire it is not clear whether this is to earn money for TB related costs.

In total 104 (69%) patients indicated that the numbers of hours they worked had changed, and 100 of them indicated that this was related to their TB illness. Their work was done now by another member of their household (12%), another person (59%) or not taken over (28%).

Before TB illness, 33/94 (35%) MDR-TB patients and 7/54 (13%) other TB patients did not earn an income before TB illness. During the interview, this had changed to 32/54 (59%) and 62/94 (66%), respectively (see annex).

From the table in the annex it can be observed that 104 (69%) patients indicated that they had to stop doing non-formal work. This work was usually taken over by another household member (60%) or not done any more (38%), while in two cases someone else from outside the household took over (in one case a payment of 40000 tenge was reported).

Thirty-one (21%) patients indicated that someone stayed home to specifically take care of them, in 11 instances this person quit their income-earning job to stay with them, and once a payment (6000 tenge) was reported.

Fifteen (10%) patients indicated that someone else in the household started to work more to finance costs due to TB illness.



Table 24. Changes in employment status

		Cat I-III treatment		Cat IV treatment		total	
		Count	Column N %	Count	Column N %	Count	Column N %
primary income earner in household	patient	33	61%	50	53%	84	56%
	other member of household	21	39%	44	47%	66	44%
currently working	no	36	67%	61	65%	99	66%
	yes	18	33%	33	35%	51	34%
change of job due to TB illness	no	35	65%	47	50%	84	56%
	yes	19	35%	47	50%	66	44%
Loss of job due to TB illness	no	35	69%	54	58%	91	62%
	yes	16	31%	38	41%	54	37%
	Other, cannot work for 2 years	0	0%	1	1%	1	1%
daily hours of work before TB illness	0h/day	7	13%	25	27%	32	21%
	1-7h	3	6%	5	5%	8	5%
	8h	35	65%	33	35%	68	45%
	9-12h	6	11%	26	28%	34	23%
	>12h	3	6%	5	5%	8	5%
daily hours of work at time of interview	0h/day	40	74%	73	78%	115	77%
	1-7h	2	4%	8	9%	10	7%
	8h	9	17%	5	5%	14	9%
	9-12h	3	6%	8	9%	11	7%
	>12h	0	0%	0	0%	0	0%
change in daily number of hours of work	more hours/day	3	6%	5	5%	8	5%
	no change	15	28%	31	33%	46	31%
	1-7h less	3	6%	15	16%	18	12%
	8h less	25	46%	17	18%	42	28%
	9-12h less	5	9%	21	22%	28	19%
	>12h less	3	6%	5	5%	8	5%



## 6.16 Changes in patient income and household income due to TB illness

The most apparent shift in household income was in the income of the patient (Figure 4). Overall, before TB illness, 7/54 (13%) patients on category I-III treatment and 33/94 of TB patients on category IV treatment did not earn an income compared to 32/54 (59%) and 62/94 (66%), respectively, at the time of the interview, while there also was a shift visible from higher (at least 50,000 tenge) to lower (10,000-49,999 tenge) incomes. The income of other household members increased: the number of other household members earning an income increased from 2/54 to 5/54, and from 4/94 to 13/94, respectively. The number of households receiving welfare decreased from 43/54 to 39/54, and from 85/94 to 74/94. The number of households receiving government or NGO assistance increased from 0 to 1, and from 1 to 4, respectively. The number of households not having any income increased from 5 to 8, and from 5 to 9, respectively. As with patient income, a shift to lower total income was visible.

The overall median patient income decreased from 30,000-35,000 tenge to 0 tenge, the overall median total income of the household decreased from 72,500 to 50,000 tenge. Extrapolated over the treatment phase the patient was in at the time of interview, the estimated median loss of patient income due to TB illness was 51,000 tenge, the estimated median loss of household income due to TB illness was 80,000 tenge (Table 18).

Patient and household income before TB illness and change in income differed between patient categories; the proportion of MDR-TB patients not earning an income before TB illness was higher than for non MDR-TB patients. Still, the median loss of income over the treatment phase will be higher for MDR-TB patients than non MDR-TB patients, due to the longer treatment duration.

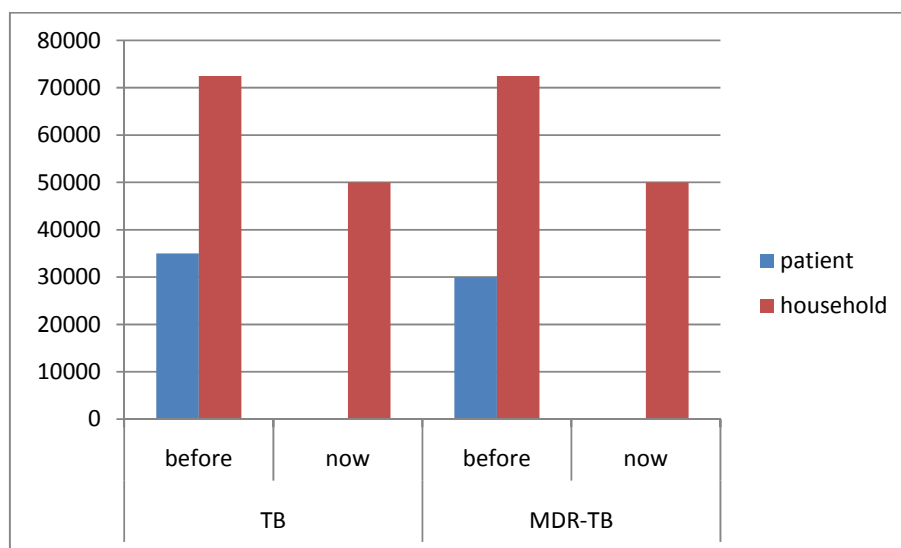


Figure 4. Changes in median monthly patient income and household income (in KZT), comparing income before TB illness to income at the time of interview.



Table 25. Monthly patient and household income before TB illness, stratified by source of income, for patients on category I-III treatment.

		monthly patient income before TB illness (tenge)	monthly income by other household members before TB illness (tenge)	monthly welfare payments before TB illness (tenge)	monthly income from government assistance before TB illness (tenge)	monthly other income before TB illness (tenge)	monthly total household income before TB illness (tenge)
N	Valid	54	54	54	54	54	54
	Missing	0	0	0	0	0	0
Mean		36741	1296	45759	0	0	73778
Std. Deviation		22531	6949	38774	0	0	47504
Minimum		0	0	0	0	0	0
Maximum		90000	45000	160000	0	0	205000
Percentiles	25	25000	0	15000	0	0	42500
	50	35000	0	40000	0	0	72500
	75	50000	0	70000	0	0	105000

Table 26. Monthly patient and household income before TB illness, stratified by source of income, or patients on category IV treatment

		monthly patient income before TB illness (tenge)	monthly income by other household members before TB illness (tenge)	monthly welfare payments before TB illness (tenge)	monthly income from government assistance before TB illness (tenge)	monthly other income before TB illness (tenge)	monthly total household income before TB illness (tenge)
N	Valid	94	94	94	94	94	94
	Missing	0	0	0	0	0	0
Mean		34798	979	48213	170	585	75915
Std. Deviation		42711	4765	33402	1650	4138	44843
Minimum		0	0	0	0	0	0
Maximum		300000	26000	150000	16000	35000	245000
Percentiles	25	0	0	30000	0	0	47500
	50	30000	0	40000	0	0	72500
	75	50000	0	70000	0	0	100000



Table 27. Monthly patient and household income at the time of the interview, stratified by source of income, for patients on category I-III treatment

		monthly patient income at time of interview (tenge)	monthly income by other household members at time of interview (tenge)	monthly welfare payments at time of interview (tenge)	monthly income from government assistance at time of interview (tenge)	monthly other income at time of interview (tenge)	monthly total household income at time of interview (tenge)
N	Valid	54	54	54	54	54	54
	Missing	0	0	0	0	0	0
Mean		13722	1593	40574	463	463	56722
Std. Deviation		19123	7503	39034	3402	3402	43822
Minimum		0	0	0	0	0	0
Maximum		80000	52000	160000	25000	25000	200000
Percentiles	25	0	0	0	0	0	25000
	50	0	0	35000	0	0	50000
	75	27000	0	60000	0	0	84000

Table 28. Monthly patient and household income at the time of the interview, stratified by source of income, for patients on category IV treatment

		monthly patient income at time of interview (tenge)	monthly income by other household members at time of interview (tenge)	monthly welfare payments at time of interview (tenge)	monthly income from government assistance at time of interview (tenge)	monthly other income at time of interview (tenge)	monthly total household income at time of interview (tenge)
N	Valid	94	94	94	94	94	94
	Missing	0	0	0	0	0	0
Mean		9479	1911	45766	745	585	51423
Std. Deviation		15691	6112	66277	3592	4138	34223
Minimum		0	0	0	0	0	0
Maximum		85000	26000	600000	20000	35000	150000
Percentiles	25	0	0	20000	0	0	24750
	50	0	0	30000	0	0	50000
	75	20000	0	62500	0	0	70000



Table 29. Reported monthly income before diagnosis with TB for the patient and entire household, and the differences in monthly income at the time of interview compared to before TB diagnosis, for patients on category I-III treatment.

		Monthly patient income before TB illness (tenge)	Monthly patient income at time of interview (tenge)	Percentage patient income decline	Percentage income change among patients with an income before TB illness	Monthly total household income before TB illness (tenge)	Monthly total household income at time of interview (tenge)	Percentage household income decline
N	Valid	54	54	54	47	54	54	54
	Missing	0	0	0	0	0	0	0
Mean		36741	13722	55%	63%	73778	56722	21%
Std. Deviation		22531	19123	45%	43%	47504	43822	94%
Minimum		0	0	0%	0%	0	0	-614%
Maximum		90000	80000	100%	100%	205000	200000	100%
Percentiles	25	25000	0	0%	14%	42500	25000	0%
	50	35000	0	56%	100%	72500	50000	30%
	75	50000	27000	100%	100%	105000	84000	53%

Table 30. Reported monthly income before diagnosis with TB for the patient and entire household, and the differences in monthly income at the time of interview compared to before TB diagnosis, for patients on category IV treatment

		Monthly patient income before TB illness (tenge)	Monthly patient income at time of interview (tenge)	Percentage patient income decline	Percentage income change among patients with an income before TB illness	Monthly total household income before TB illness (tenge)	Monthly total household income at time of interview (tenge)	Percentage household income decline
N	Valid	94	94	94	61	94	94	94
	Missing	0	0	0	0	0	0	0
Mean		34798	9479	43%	66%	75915	51423	26%
Std. Deviation		42711	15691	44%	39%	44843	34223	72%
Minimum		0	0	0%	0%	0	0	-567%
Maximum		300000	85000	100%	100%	245000	150000	100%
Percentiles	25	0	0	0%	33%	47500	24750	0%
	50	30000	0	33%	100%	72500	50000	27%
	75	50000	20000	100%	100%	100000	70000	62%



### 6.17 Suggestions on how to ease the financial burden of TB illness

At the end of the questionnaire, we asked patients which government services they would prefer to ease the financial burden of TB on themselves and their households.

Table 31. Suggestions on how to ease the financial burden of TB illness

	Count	Column N %
How to ease the burden of TB illness	transport vouchers	6 4%
	food package/voucher	4 2%
	more efficient service	32 21%
	money	71 48%
	housing	11 7%
	Other*	26 17%
	Total	149 100%

\* car (n=2), coal (n=2), job placement (n=7), land (n=2)

### 6.18 Summary on patient costs and financial impact of TB illness

In the following two tables and figure, a summary is provided on patients costs and on the financial impact of TB illness, using all results detailed in this chapter.





Table 32. Summary of direct and indirect patient costs, in Kazakhstan tenge

	TB					MDR-TB				
	n	mean	SD	median	IQR	n	mean	SD	median	IQR
<b>Subtotal direct pre-/diagnosis costs</b>	<b>41</b>	<b>1,932</b>	<b>3,151</b>	<b>720</b>	<b>(105-2,000)</b>					
Administrative charges		141	648	0	(0-0)					
Tests		0	0	0	(0-0)					
X-ray		129	399	0	(0-0)					
Drugs		329	1292	0	(0-0)					
Transport		792	1026	450	(25-100)					
Food		297	599	0	(0-400)					
Accommodation		0	0	0	(0-0)					
<b>Subtotal direct treatment costs<sup>#</sup></b>	<b>54</b>	<b>49,810</b>	<b>23,534</b>	<b>26,610</b>	<b>(13,288-59,669)</b>	<b>94</b>	<b>248,456</b>	<b>328,681</b>	<b>132,686</b>	<b>(53,730-365,250)</b>
Hospitalization (intensive phase)	41	4	28	0	(0-0)	62	630	3,403	0	(0-0)
Food supplements*										
Intensive phase	41	11,122	19,313	0	(0-11,000)	62	77,484	148,237	18,000	(0-80,000)
Continuation phase	13	26,538	36,221	1,5000	(4,000-26,500)	32	148,425	184,701	72,000	(2,400-240,000)
Treatment of adverse events										
Intensive phase	41	0	0	0	(0-0)	62	1,024	5,168	0	(0-0)
Continuation phase	13	0	0	0	(0-0)	32	188	738	0	(0-0)
DOT visits (continuation phase)	13	12,146	10,406	9,288	(9,288-11,610)	32	20,705	32,849	4,644	(0-27,864)
Follow-up test costs (continuation phase)	13	0	0	0	(0-0)	32	0	0	0	(0-0)
<b>Subtotals direct treatment costs per phase</b>										
intensive phase	41	11,126	19,325	0	(0-11,000)	62	79,139	148,048	24,500	(0-80,250)
continuation phase	13	38,684	36,809	26,610	(13,288-48,669)	32	169,317	180,633	108,186	(53,730-285,000)
<b>Subtotal indirect pre-/diagnosis costs</b>	<b>41</b>	<b>688</b>	<b>837</b>	<b>379</b>	<b>(169-724)</b>					
<b>Subtotal indirect treatment costs</b>	<b>54</b>	<b>89,889</b>	<b>38,371</b>	<b>75,392</b>	<b>(55,445-33,638)</b>	<b>94</b>	<b>333,253</b>	<b>474,487</b>	<b>260,983</b>	<b>(0-445,626)</b>
Hospitalization (intensive phase)	41	73,805	47556	60,000	(45,000-100,000)	62	304,000	401,273	228,000	(0-400,000)
DOT visits (continuation phase)	13	16,084	9,401	15,392	(10,445-23,638)	32	49,958	44,187	32,983	(0-45,626)
<b>Sum of subtotals indirect diagnostic and treatment costs<sup>#</sup></b>	<b>54</b>	<b>89,889</b>	<b>38,371</b>	<b>21,771</b>	<b>(55,614-123,912)</b>					
<b>Total (direct+indirect) costs<sup>#</sup></b>	<b>54</b>	<b>90,577</b>	<b>39,208</b>	<b>102,802</b>	<b>(68,923-185,517)</b>					
<b>Sum (direct+indirect) diagnostic costs</b>	<b>41</b>	<b>41</b>	<b>2,228</b>	<b>800</b>	<b>(190-2,210)</b>					
<b>Sum (direct+indirect) treatment costs<sup>#</sup></b>	<b>54</b>	<b>54</b>	<b>13,9699</b>	<b>102,002</b>	<b>(68,733-183,307)</b>	<b>94</b>	<b>383,063</b>	<b>498,021</b>	<b>393,669</b>	<b>(53,730-810,876)</b>

\* most money for supplements was spent on fruits and drinks

# Totals are based on adding up medians and/or means from different patients, and therefore must be interpreted with caution

Table 33. Summary of financial impact of TB illness

	n/N or median	% or (IQR)	n/N or median	% or (IQR)
<b>Patients who were primary income earner</b>	33/54	61%	50/94	53%
<b>Patients who lost their job</b>				
intensive phase	11/39	28%	20/61	33%
continuation phase	5/12	42%	18/32	56%
<b>Patients who reduced work by &gt;=8 hours per day</b>				
intensive phase	29/39	74%	37/61	61%
continuation phase	4/12	33%	23/32	72%
<b>Patients hospitalized for TB</b>	53/54	98%	94/94	100%
duration of hospitalization (months)	3	(2-4)	7	(6-8)
<b>Time spent per DOT visit (minutes)</b>	45	(33-50)	35	(30-40)
<b>Monthly individual income</b>				
before onset of TB*	3500	(2500-5000)	3000	(0-5000)
after onset of TB	0	(0-2700)	0	(0-2000)
<b>% income change</b>	<b>56%</b>	<b>(0%-100%)</b>	<b>33%</b>	<b>(0%-100%)</b>
<i>for those with an income before onset of TB*</i>	<i>100%</i>	<i>(0%-100%)</i>	<i>100%</i>	<i>(0%-100%)</i>
<b>Patients who received assistance from the government or other organizations</b>	<b>9</b>	<b>17%</b>	<b>25</b>	<b>27%</b>
transport vouchers	2	4%	6	6%
food packages	4	7%	17	18%
monthly allowances	3	6%	4	4%
other reimbursements	3	6%	5	5%
<b>subtotal of reimbursements (tenge)</b>	<b>0</b>	<b>(0-0)</b>	<b>0</b>	<b>(0-1,500)</b>
<b>Coping costs</b>				
donations	31/54	57%	62/94	66%
patients who sold property	0		1/94	1%
patients who took out loans with interest	0		4/94	4%
with interest	-		0	
<b>Patients with health insurance</b>	<b>0</b>	<b>0%</b>	<b>1/94</b>	<b>1%</b>
patients who received reimbursements	0		1	

\* 13% (7/54) of patients on category I-III patients and 35 % (33/94) of patients on category IV treatment reported not to have an income before TB illness



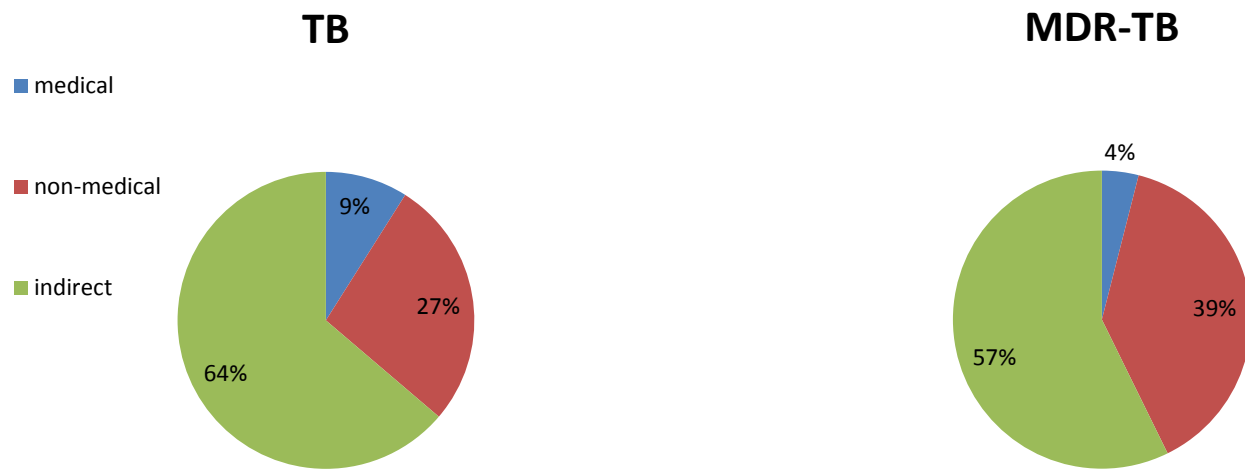


Figure 5. Distribution of direct medical, direct non-medical and indirect costs associated with TB illness, for MDR-TB and other TB patients.



## 7 Discussion including cost mitigation options

### *Main findings*

The data collected in this study in Kokshetau, Akmola oblast, Kazakhstan showed that the financial impact of TB illness on the family was significant for most patients, especially for MDR-TB patients. Indeed, the estimated costs of MDR-TB patient treatment were almost 4 times greater than those for other TB patients, mainly due to the longer time period for treatment.

The median direct costs for diagnosis of TB were 720 (IQR 105-2000) KZT, and transport costs contributed most to these costs. The median number of diagnostic visits needed was 2 (IQR 2-3) and associated median indirect costs were 379 (169-724) KZT.

The median direct treatment costs for TB patients during the intensive phase were 0 (0-11,000) KZT and during the continuation phase 26,610 (13,288-48,669) KZT. The median indirect treatment costs for TB patients during the intensive phase were 60,000 (45,000-100,000) KZT and during the continuation phase 15,392 (10,445-23,638) KZT.

For MDR-TB patients, treatment costs were higher. The median direct treatment costs for MDR-TB patients during the intensive phase were 24,500 (0-80,250) KZT and during the continuation phase 108,186 (53,730-285,000) KZT. The median indirect treatment costs for MDR-TB patients during the intensive phase were 228,000 (0-400,000) KZT and during the continuation phase 32,983 (0-45,626) KZT.

Indirect treatment costs constituted the major cost component. Still, for most patients they are an underestimate of the true income lost. Loss of income in our analysis was calculated based on time needed for obtaining diagnosis and treatment, a macro-economic perspective. As in general patients are hospitalized during the intensive phase of treatment in Kazakhstan, full-time inability to work was included only in the cost calculations for the intensive phase. Loss of income for diagnosis and during the continuation phase of treatment was estimated only as a result of time spent obtaining diagnosis and outpatient treatment. However, in reality, many patients did not work during the continuation phase and actual loss of income may be much higher. Thus, indirect costs during the continuation phase are underestimated in this study. In our estimations we assumed treatment durations in accordance with internationally recommended minimum durations for the standard treatment regimens. However, in Akmola we observed longer treatment durations in this study. This is an additional factor leading to underestimation of indirect costs.

Patients not working while being on ambulatory treatment may be due to two reasons: loss of job due to TB and not having received permission from the central committee (yet) to restart work.

The percentage of patients who had lost their job during TB illness was 41% among MDR-TB patients and 31% among other TB patients. The median percentage of income reduction was 33% for MDR-TB patients and 56% for other TB patients. Note that this percentage is higher for patients who had an income before TB illness. For those that did have an income before TB illness, the median reduction in income was 100%, both for MDR-TB and other TB patients. Before TB illness, 33/94 (35%) MDR-TB patients and 7/54 (13%) other TB patients did not earn any income. During the interview, this had changed to 32/54 (59%) and 62/94 (66%), respectively. The indirect costs presented here do not include costs after the end of treatment, especially further loss of income for those who have lost their jobs or who have developed disabilities not allowing them to do the work they did before.

Only a small proportion of patients had access to other means of finances during treatment to compensate for their own loss of income, but in some households family members started to work (more). As a result, the household income decreased slightly less patient income: the median patient income went down to zero, from 30,000 tenge for MDR-TB patients and 35,000 tenge for other TB patients (note: the average value of 1 USD in 2012 was 148.350 tenge); the median household income went down by 22,500 tenge for both patient groups.



The proportion of patients who reported to receive assistance from the government or other organizations was 27% for MDR-TB patients and 17% for other patients. Most of that assistance was not cash though, but food packages and transport vouchers.

TB diagnosis and treatment is supposed to be for free according to the DOTS strategy adopted in Kazakhstan. In accordance with the DOTS strategy, indeed diagnostic tests, except for X-ray for some patients, were reported to be for free as well as hospitalization, anti-TB drugs and drugs to treat adverse reactions to anti-TB treatment. In general, costs related to TB diagnosis were not high, and mostly associated with transport costs.

We were not able to estimate costs for MDR-TB patients as only two just diagnosed MDR-TB patients had been interviewed, but it can be expected that the direct costs are not (much) higher than for other TB patients, given the fact that culture and DST in principle is done for all TB patients and is free of charge. However, direct costs while on first-line drug treatment and especially associated indirect costs are assumed to be high, due to the reported delays in diagnosis of MDR-TB: the median delay was 6 (IQR 5-7) months. Consequently, the true costs for MDR-TB diagnosis are expected to be similar to the full costs for diagnosis and treatment reported by patients in category I treatment (assumed to be 6 months). With implementation of Xpert MTB/RIF, diagnostic delays and consequently diagnostic costs related to MDR-TB are expected to decline significantly.

The major direct treatment cost components were food supplements and transport costs for DOT during ambulatory treatment. Most costs for food supplements were also reported during outpatient treatment. We do not know whether these supplements (mostly fruits and (energy) drinks) were recommended or prescribed by physicians, but patients reported them as costs they otherwise would not have made. Transport costs to reach the DOT facility may be small, but may add up to a substantial amount if made every day during ambulatory treatment. With roll-out of full outpatient care, the DOT-related costs will increase for TB patients. For some patients, these costs can be brought down by bringing DOT facilities closer to the patients' homes.

Direct patients costs were very similar for patients from different socio-economic background, as determined by the household income before TB illness. The relative burden of these direct costs however, is higher for patients with low income levels, as these costs constitute a higher proportion of the total income. On the other hand, indirect cost estimates were based on patients' reported income before TB illness. Indirect costs associated with TB therefore are higher for patients with higher income levels.

#### *Limitations*

This study has several limitations. Most importantly, due to limitations in time and budget, only patients being on (MDR) TB treatment were included in the study. By only including patients who were diagnosed with (MDR) TB, most of whom initiated treatment, the study results may have been biased towards the less socio-economically vulnerable groups, as the very poor might have less good access to TB diagnosis and treatment<sup>1</sup>.

We had to rely on self-reported costs and therefore, recall and reporting bias cannot be excluded. We limited recall bias through interviewing patients from different treatment stages, thus limiting the recall period. The questionnaire included cross-checks and the interviewers were trained to double-check unusually high costs when reported by the patients.

Treatment cost data were collected during an interview and extrapolated over the treatment phase. As costs were estimated per phase and not per patient, it means that this study did not yield total costs of (MDR) TB treatment incurred *per patient*. We did add median costs per stage, thus assuming that patients interviewed per stage were representative of all patients of each other.



Our intention was to interview a total of 250 patients. It was not possible to reach the target for four out of the five patient groups. It is not clear in how far selection bias through selective non-participation has biased our results.

As in-hospital treatment in Akmola oblast is diversified between different TB hospital facilities, our sample of patients was not representative of all TB patients. Most importantly, smear-negative and relapse patients in the intensive phase were not included, as well as MDR-TB patients on compulsory and palliative care. Patient costs may be different for these patients.

It is important to keep in mind that we aimed to capture the major cost components, not the exact costs of (MDR) TB treatment. We chose to take this focus since we wanted to develop a tool that is simple enough to be used by local NTPs and research institutions and that gives a quick enough answer to major questions of policy makers. Capturing the total costs per patient requires follow-up of a sample of patients during their treatment, which may take more than two years for MDR TB patients and takes at least 6 months for non-MDR TB patients. To get an exact estimate of total costs incurred, other methods than (repeated) interviews would have been required, such as patient diaries. However, it is known that it is difficult to motivate patients to keep diaries for a longer time period and this may lead to selective dropout of the less well educated and socially engaged patients.

With the current method involving only one interview per patient, the study did reveal major cost components and a rough estimate of the costs incurred per treatment phase, which may give enough information to develop reimbursement policies. More specific information from a more specific group of patients can then be collected if required.

#### *Previous results of the patient cost tool and policy options to mitigate costs*

A study using the previous version of the patient cost tool compared the costs of TB drug sensitive (DS) treatment for the three countries of Ghana, Vietnam and the Dominican Republic<sup>2</sup>. The overall study findings were that 27-70% of TB patients stopped working and experienced reduced income, 5-37% sold property and 17-47% borrowed money due to TB. They also found that hospitalization and supplementary food items were the largest costs during treatment. The average total patient costs, which ranged from US\$538 to US\$1,268) came to approximately one year of individual income.

In a Dominican Republic study<sup>3</sup> that was part of the three country report mentioned above, a total of 198 patients were interviewed in 2009 of whom 20 had MDR-TB. For most respondents, direct and indirect costs increased while income decreased. Total costs amounted to a median of US\$ 908 for new patients, US\$ 432 for retreatment patients, and US\$ 3,557 for MDR-TB patients. The proportion of patients without a regular income increased from 1% to 54% because of falling ill with TB.

The purpose of this study was to identify the burden of MDR-TB patient costs and the financial impact on their lives and the results are intended to help policy makers find ways to reduce this burden so that people with MDR-TB seek and complete treatment and are not driven into poverty by so doing.

The recommendations based on the studies in the three countries<sup>2</sup> were similar: bringing services closer to patients, reducing expenditures on transport and invested time, increasing efforts to find cases early to reduce indirect costs related to inability to work, informing health care workers and the public about TB diagnosis and treatment to reduce costs unrelated to TB, and including TB-related out-patient costs in social protection schemes. That study reported that each country took action to implement one or more of the identified solutions.

In Ghana, policy makers agreed to include TB care interventions as part of its pro-poor strategies in the delivery of health care. The Nutrition Department of the MoH also developed nutrition guidelines to address the specific needs of TB patients. The evidence generated from the study



findings was key in informing and developing the successful Global Fund Round 10 TB proposal. Given the identified high burden for female TB patients in Ghana, the NTP focused on addressing gender-sensitive challenges of poor TB patients. Also the parliamentary sub-committee on health has increased insurance coverage for all TB patients for health-related costs other than (free) anti-tuberculosis treatment.

In Vietnam, the NTP in Viet Nam decided to increase the involvement of the private sector in public-private-mix projects focusing on reducing travel, accommodation and hospitalization costs for TB patients and guardians. Second, the study contributed to the decision to switch from the 8-month to the 6-month anti-tuberculosis treatment regimen, which will help reduce the treatment time and travel costs for follow-up tests. Third, the NTP worked on the expansion of its NTP network to provide TB services at provincial general hospitals, all major public non-MoH hospitals and private hospitals. Fourth, the NTP started planning for a way to provide social and economic support to TB patients in each district. Finally, the NTP started to mobilize support for TB patients by organizations such as farmers and womens' unions.

In the Dominican Republic the Ministry of Health decided in 2011 to move forward with allocating public funds for food supplements for TB patients and including in- and outpatient TB services in the national health insurance schemes.

Within Central Asia, only Tajikistan has reported results on patient cost studies in the international literature<sup>4,5</sup>. This study was done before the patient cost tool had been developed. They also showed that during treatment, income loss constituted more costs than direct costs while this was the other way around before diagnosis. They also showed that the total costs were much higher during treatment than before diagnosis: the mean total costs during treatment were 901 USD of which 57% constituted indirect costs; the mean costs before diagnosis were 293 USD of which 48% due to indirect costs<sup>4</sup>.

#### *Policy options to mitigate patient costs in Kazakhstan*

Several mitigation recommendations were identified by TB health professionals involved in providing (MDR)TB services and KNCV consultants, during a national workshop (on outpatient treatment, 20-22 November in Astana) where the key results of this study were presented. These recommendations are not mutually exclusive – it may be necessary to provide more than one at the same time. The recommendations are separated into two areas: service delivery and social protection:

#### **3. TB service improvements:**

- a. Reduce hospitalization.** Kazakhstan has moved in recent years from full in-patient treatment to partial outpatient treatment, usually in the continuation phase. Akmola is a pilot site for further reduction of hospitalization, and the country plans to move towards full outpatient care. This has the potential to greatly reduce indirect costs.
- b. Ensure that policy of free care for all (MDR)TB services is fully implemented.** Currently some TB services such as tomography are either unavailable at designated diagnostic TB health facilities while physicians prescribe them. As a result patients sometimes have to go to other health facilities and pay for these tests. Agreements between the TB program and public health facilities need to be in place so that presumed TB patients can make use of these diagnostic tools for free.
- c. Bring services closer to patients.** TB services are to be integrated into primary health care in Kazakhstan. However, this task shifting has not been completed yet, and may require coordination by the Ministry of Health. Such integration of diagnostic and DOT services should reduce patient expenditures on transport and patient time and should reduce detection and treatment delays. For areas where there is no public transport, arrangement of transport for patients or home visits should be arranged. Other options for bringing services closer to patients are DOT at school and at the work place.



- d. **Detect and treat MDR-TB cases earlier.** Especially detection of drug-resistant TB should reduce the time to appropriate treatment, and thus reduce direct and indirect treatment costs for patients, especially the amount of income lost due to inability to work during initial first-line drug treatment. Full implementation of new diagnostics such as Xpert MTB/RIF should reduce time to diagnosis and thus patient costs.
  - e. **Involve local NGO's and civil society organizations** to improve (MDR)TB treatment adherence.
- 4. Social protection improvements.**
- a. **Include direct (transport, food support) costs in social support schemes provided through TB services.** Such incentives and enablers should reduce direct costs associated with TB treatment and improve treatment adherence.
  - b. **Include indirect (sick leave allowance) costs in social protection schemes.** Review, standardize and expand current social protection mechanisms and schemes by the government. Social protection schemes, including temporary disability allowances, should be made available to those (MDR)TB patients who need it, from the moment they are diagnosed. Include social protection for (MDR)TB under disability policy strategies while ensuring that the protection is provided from the time of confirmed diagnosis to those who are risk of becoming poor or not seeking or completing treatment. Professional guidance by health care workers or social workers for submitting applications for social support is needed for many patients. Possibilities for agreements on delaying or waiving payments (e.g. mortgage loans, school fees) are to be investigated.
  - c. **Improve employment protection.** Advocate for regulations and policies that mandate that private employers pay employees (a portion of) their salary while they are unable to work. Also advocate for patients to be able to return to previous positions once they are fully cured and clinically fit to perform their assignments.
  - d. **Assure continuation of education.** When rendered non-infectious, children and students need to be able to continue their education.
  - e. **Increase re-socialization and employment possibilities.** Develop mechanisms to involve socially vulnerable patients in different re-socialization activities provided e.g. through temporary, assisted living facilities. Develop mechanisms to involve patients in income generating activities and advocate government to support this, for example through microfinance.
  - f. **Reduce stigma and acceptance of outpatient treatment.** Improve education to the public on TB and MDR-TB, e.g. through primary level services, in order to reduce stigma of (MDR)TB and reduce fear of transmission during outpatient treatment.

Based on the above analysis, it is clear that some of the options open to the Government of Kazakhstan to address the issues identified are short term and others are long term. The most important place to start in the short term seem to be to accelerate the expansion of outpatient treatment in order to reduce income loss, including acceleration of expansion of DOT services closer to the patients, and to analyze and improve the existing social support system. It would be useful to repeat a patient cost study again in the future to assess effects of implementation of Xpert MTB/RIF and full outpatient treatment on the economic burden of (MDR)TB in Akmola.





## 8 Literature

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## Annex 1. Additional tables

### Diagnostic costs

Annex Table 1. Sum of time, direct costs and indirect costs for all diagnostic visits related to TB illness, as reported by patients in the intensive phase of category I-III treatment

		Count	Column N %
sum of time needed for diagnostic visits (minutes) <i>median (IQR): 120 (78-273)</i>	<2h	18	44%
	2-4h	11	27%
	4-8h	6	15%
	>=8h	6	15%
sum of direct and indirect costs related to diagnostic visits (tenge) <i>median (IQR): 800 (190-2210)</i>	0	7	17%
	1-499	8	20%
	500-999	8	20%
	1000-1999	4	10%
	2000-9999	11	27%
	10000-49999	3	7%
50000+	0	0%	
sum of direct costs related to diagnostic visits (tenge) <i>median (IQR): 720 (105-2000)</i>	0	9	22%
	1-499	8	20%
	500-999	7	17%
	1000-1999	4	10%
	2000-9999	10	24%
	10000-49999	3	7%
50000+	0	0%	
sum of indirect costs related to diagnostic visits (tenge) <i>median (IQR): 379 (169-724)</i>	0	6	15%
	1-499	20	49%
	500-999	6	15%
	1000-1999	5	12%
	2000-9999	4	10%
	10000-49999	0	0%
50000+	0	0%	



Annex Table 2. Sum of all diagnostic costs for all diagnostic visits related to TB illness, as reported by patients in the intensive phase of category I-III treatment, stratified by type of costs, and sum of reimbursements

		Count	Column N %
sum of administrative costs paid during diagnostic visits (tenge)	0	38	93%
	1-499	0	0%
	500-999	1	2%
	1000-1999	1	2%
	2000-9999	1	2%
	10000-49999	0	0%
	50000+	0	0%
sum of costs for X-ray during diagnostic visits (tenge)	0	36	88%
	1-499	0	0%
	500-999	2	5%
	1000-1999	2	5%
	2000-9999	1	2%
	10000-49999	0	0%
	50000+	0	0%
sum of costs for drugs paid during diagnostic visits (tenge)	0	38	93%
	1-499	0	0%
	500-999	0	0%
	1000-1999	0	0%
	2000-9999	3	7%
	10000-49999	0	0%
	50000+	0	0%
sum of costs for travel dor diagnostic visits (tenge)	0	10	24%
	1-499	11	27%
	500-999	10	24%
	1000-1999	4	10%
	2000-9999	6	15%
	10000-49999	0	0%
	50000+	0	0%
sum of costs for food during diagnostic visits (tenge)	0	27	66%
	1-499	7	17%
	500-999	3	7%
	1000-1999	2	5%
	2000-9999	2	5%
	10000-49999	0	0%
	50000+	0	0%
sum of costs for accomodation of accompanyng person during diagnostic visits (tenge)	0	41	100%
	1-499	0	0%
	500-999	0	0%
	1000-1999	0	0%
	2000-9999	0	0%
	10000-49999	0	0%
	50000+	0	0%
sum of reimbursements for costs related to diagnostic visits (tenge)	0	41	100%
	1-499	0	0%
	500-999	0	0%
	1000-1999	0	0%
	2000-9999	0	0%
	10000-49999	0	0%
	50000+	0	0%



Annex Table 3. Costs for accompanying persons during diagnostic visits

	Count	Column N %
0	36	88%
1-499	1	2%
sum of costs for travel of		
accompanying person	2	5%
during diagnostic visits		
(tenge)		
1000-1999	1	2%
2000-9999	1	2%
10000-49999	0	0%
50000+	0	0%
0	41	100%
sum of costs for		
accommodation for		
accompanying person		
during diagnostic visits		
(tenge)		
1-499	0	0%
500-999	0	0%
1000-1999	0	0%
2000-9999	0	0%
10000-49999	0	0%
50000+	0	0%
0	39	95%
1-499	0	0%
sum of income lost by		
accompanying person		
during diagnostic visits		
(tenge)		
500-999	0	0%
1000-1999	1	2%
2000-9999	1	2%
10000-49999	0	0%
50000+	0	0%
0	35	85%
1-499	1	2%
total costs for diagnostic		
visits by accompanying		
person		
500-999	2	5%
1000-1999	0	0%
2000-9999	3	7%
10000-49999	0	0%
50000+	0	0%



## Hospitalization

Annex Table 4. Costs associated with hospitalization. Selected are those patients who have been hospitalized at least once during treatment.

		Count	Column N %
Fee for hospitalization	0	127	100.0%
Fee for sheets during hospitalization	0	127	100.0%
Costs for food not provided by the hospital*	0	121	95.3%
	90	1	.8%
	180	1	.8%
	9000	1	.8%
	10000	1	.8%
	25000	1	.8%
	40000	1	.8%
Fee for transport to and from the hospital	0	127	100.0%
Fee for drugs during hospitalization	0	126	99.2%
	5000	1	.8%
Fee for tests during hospitalization	0	127	100.0%
Other fees during hospitalization	0	127	100.0%
Total costs during hospitalization	0	121	94.5%
	90	1	.8%
	180	1	.8%
	5000	1	.8%
	9000	1	.8%
	10000	1	.8%
	25000	1	.8%
	40000	1	.8%

\* note that there may be overlap between costs for food reported here and costs for supplements to diet



Annex Table 5. Stay of family or friends during hospitalization. Selected are those patients who have been hospitalized at least once during treatment.

		Count	Column N %
		9	6%
Did someone stay with patient during hospital stay	no	138	93%
	yes	2	1%
If yes, number of days	2	1	100%
Costs for accompanying person		141	95%
	no	7	5%
	yes	1	1%
Cost for accommodation (tenge)	0	1	100%
Cost for food (tenge)	15000	1	100%
Cost for transport (tenge)	30000	1	100%
Income loss (tenge)	0	149	100%
Other costs (tenge)	0	1	100%
Total costs (tenge)	45000	1	100%



Annex Table 6. Other visitors during hospitalization. Selected are those patients who have been hospitalized at least once during treatment.

		Count	Column N %
did other family/friends visit you	no	36	24%
	yes	113	76%
accomodation costs for visitors	0	111	99%
	1-499	0	0%
	500-999	0	0%
	1000-1999	0	0%
	2000-9999	1	1%
	10000-49999	0	0%
	50000+	0	0%
food costs for visitors	0	15	13%
	1-499	26	23%
	500-999	2	2%
	1000-1999	21	18%
	2000-9999	44	39%
transport costs for visitors	10000-49999	6	5%
	50000+	0	0%
	0	19	17%
	1-499	0	0%
	500-999	1	1%
income loss for visitors	1000-1999	5	4%
	2000-9999	58	51%
	10000-49999	31	27%
	50000+	0	0%
	0	146	98%
other costs for visitors	1-499	0	0%
	500-999	0	0%
	1000-1999	1	1%
	2000-9999	2	1%
	10000-49999	0	0%
total costs for visitors	50000+	0	0%
	0	107	94%
	1-499	0	0%
	500-999	0	0%
	1000-1999	0	0%
total costs for visitors	2000-9999	4	4%
	10000-49999	3	3%
	50000+	0	0%
	0	42	28%
	1-499	1	1%
total costs for visitors	500-999	2	1%
	1000-1999	6	4%
	2000-9999	56	38%
	10000-49999	41	28%
	50000+	1	1%



## Time and costs for directly observed TB treatment

Annex Table 7. Time and costs involved related to DOT, for patients in the continuation phase of category I-III treatment. Costs are shown in Kazakh tenge (10 USD  $\approx$  1500 Kazakh tenge).

	Count	Column N %	
time needed to reach DOT facility (minutes)	0 min	0	0%
	1-29	7	54%
	30-59	6	46%
	60-89	0	0%
	90-119	0	0%
	120+	0	0%
	0	2	15%
direct costs DOT over treatment phase (tenge)	1-499	0	0%
	500-999	0	0%
	1000-1999	0	0%
	2000-9999	6	46%
	10000-49999	5	38%
	50000+	0	0%
	0	1	8%
indirect costs DOT over treatment phase (tenge)	1-499	0	0%
	500-999	0	0%
	1000-1999	0	0%
	2000-9999	2	15%
	10000-49999	10	77%
	50000+	0	0%
	0	0	0%
total (direct and indirect) costs DOT over treatment phase (tenge)	1-499	0	0%
	500-999	0	0%
	1000-1999	0	0%
	2000-9999	0	0%
	10000-49999	12	92%
	50000+	1	8%
	0	0	0%





Annex Table 8. Time and costs involved related to DOT, for patients in the continuation phase of category IV treatment. Costs are shown in Kazakh tenge (10 USD ≈ 1500 Kazakh tenge).

	Count	Column N %	
time needed to reach DOT facility (minutes)	0 min	0	0%
	1-29	20	74%
	30-59	7	26%
	60-89	0	0%
	90-119	0	0%
	120+	0	0%
direct costs DOT over treatment phase (tenge)	0	13	48%
	1-499	0	0%
	500-999	0	0%
	1000-1999	0	0%
	2000-9999	1	4%
	10000-49999	10	37%
indirect costs DOT over treatment phase (tenge)	50000+	3	11%
	0	7	26%
	1-499	0	0%
	500-999	0	0%
	1000-1999	0	0%
	2000-9999	0	0%
total (direct and indirect) costs DOT over treatment phase (tenge)	10000-49999	17	63%
	50000+	3	11%
	0	3	11%
	1-499	0	0%
	500-999	0	0%
	1000-1999	0	0%
	2000-9999	1	4%
	10000-49999	12	44%
	50000+	11	41%



## Supplements

Annex Table 9. Purchase of supplements in the last month because of TB illness, stratified by patient group

		purchase of supplements for diet because of TB illness			
		no		yes	
		Count	Row N %	Count	Row N %
TB patient group	intensive phase Cat I-III	22	55%	18	45%
	continuation phase Cat I-III	3	21%	11	79%
	just diagnosed with MDR	1	50%	1	50%
	intensive phase Cat IV	27	44%	35	56%
	continuation phase Cat IV	8	25%	24	75%
	Total	61	41%	89	59%

\* note that there may be overlap between costs for supplements reported here and costs for food not provided by the hospital

Annex Table 10. Sort of supplements purchased in the last month, by patient group

		TB patient group				
		intensive phase Cat 1-3	continuation phase Cat 1-3	just diagnosed with MDR	intensive phase Cat 4	continuation phase Cat 4
		Count	Count	Count	Count	Count
fruit		22	3	1	27	6
	no	2	0	0	3	6
	yes	17	10	1	32	20
(energy) drinks		22	3	1	27	6
	no	3	2	0	11	6
	yes	16	8	1	24	20
vitamins		22	3	1	27	6
	no	9	7	1	16	9
	yes	10	3	0	19	17
meat		22	3	1	27	6
	no	13	5	0	25	11
	yes	6	5	1	10	15
other supplements		22	3	1	28	6
	no	17	10	1	32	24
	yes	2	0	0	2	2



Annex Table 11. Costs for supplements per month, stratified by TB patient group.

	TB patient group									
	intensive phase Cat I-III		continuation phase Cat I-III		just diagnosed with MDR		intensive phase Cat IV		continuation phase Cat IV	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
costs of supplements 0 in last month (tenge)	22	54%	3	23%	1	50%	26	43%	8	25%
1000-1999	1	2%	0	0%	0	0%	0	0%	0	0%
10000-49999	9	22%	2	15%	0	0%	19	31%	12	38%
2000-9999	9	22%	8	62%	1	50%	14	23%	10	31%
500-999	0	0%	0	0%	0	0%	0	0%	1	3%
50000+	0	0%	0	0%	0	0%	2	3%	1	3%
<b>Total</b>	<b>41</b>	<b>100%</b>	<b>13</b>	<b>100%</b>	<b>2</b>	<b>100%</b>	<b>61</b>	<b>100%</b>	<b>32</b>	<b>100%</b>



Annex Table 12. Costs for supplements by TB patient group, extrapolated to the treatment phase

	TB patient group									
	intensive phase Cat I-III		continuation phase Cat I-III		just diagnosed with MDR		intensive phase Cat IV		continuation phase Cat IV	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
costs of supplements over treatment phase (tenge)	22	54%	3	23%	1	100%	27	44%	8	25%
0	22	54%	3	23%	1	100%	27	44%	8	25%
1-499	0	0%	0	0%	0	0%	0	0%	0	0%
1000-1999	0	0%	0	0%	0	0%	0	0%	0	0%
10000-49999	6	15%	7	54%	0	0%	14	23%	2	6%
2000-9999	8	20%	1	8%	0	0%	0	0%	1	3%
500-999	0	0%	0	0%	0	0%	0	0%	0	0%
50000+	5	12%	2	15%	0	0%	21	34%	21	66%
Total	41	100%	13	100%	1	100%	62	100%	32	100%



## Employment and Income

Annex Table 13. Changes in nonformal work due to TB

		Count	Column N %	Count	Column N %	Count	Column N %
stop nonformal work due to TB	no	18	33%	28	30%	46	31%
	yes	36	67%	66	70%	104	69%
duration of stopping nonformal work due to TB	less 1 month	7	19%	0	0%	8	7%
	1 month	7	19%	4	6%	11	10%
	2-3 months	12	33%	11	16%	23	21%
	4-5 months	6	17%	19	28%	26	24%
	more 6 months	4	11%	35	51%	39	36%
someone else has taken over nonformal work	yes, member household	33	66%	52	58%	85	60%
	yes, other person	0	0%	2	2%	2	1%
	no	17	34%	35	39%	54	38%
payment for this person	yes	3	6%	4	4%	7	5%
did someone stay at home to take care of patient	yes	8	15%	23	24%	31	21%
did this person quit an income-earning job	yes	3	6%	8	9%	11	7%
payment for person taking care of patient	yes	0	0%	1	1%	1	1%
did anyone in household have to start work (more) to finance costs due to TB illness	yes	1	2%	14	15%	15	10%

Annex Table 14. Monthly amount of sources of income before TB illness and at the time of the interview, by patient group

Annex Table 14a. Patient income before TB illness

		TB patient group											
		intensive phase Cat I-III		continuation phase Cat I-III		just diagnosed with MDR		intensive phase Cat IV		continuation phase Cat IV		Total	
		Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %
monthly patient	0	6	14%	1	2%	2	5%	24	57%	9	21%	42	100%
income before TB illness	10000-49999	21	31%	10	15%	0	0%	18	27%	18	27%	67	100%
(tenge)	50000+	14	34%	2	5%	0	0%	20	49%	5	12%	41	100%

Annex Table 14b. Patient income at the time of the interview

		TB patient group											
		intensive phase Cat I-III		continuation phase Cat I-III		just diagnosed with MDR		intensive phase Cat IV		continuation phase Cat IV		Total	
		Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %
monthly patient	0	30	31%	2	2%	2	2%	52	54%	10	10%	96	100%
income at time of interview	10000-49999	9	19%	9	19%	0	0%	9	19%	21	44%	48	100%
(tenge)	50000+	2	33%	2	33%	0	0%	1	17%	1	17%	6	100%

Annex Table 14c. Income by other members of the household before TB illness

		TB patient group										Total	
		intensive phase Cat I-III		continuation phase Cat I-III		just diagnosed with MDR		intensive phase Cat IV		continuation phase Cat IV			
		Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %
monthly income by other household members before TB illness (tenge)	0	39	27%	13	9%	2	1%	60	42%	30	21%	144	100%
	10000-49999	2	33%	0	0%	0	0%	2	33%	2	33%	6	100%

Annex Table 14d. Income by other members of the household at the time of the interview

		TB patient group										Total	
		intensive phase Cat I-III		continuation phase Cat I-III		just diagnosed with MDR		intensive phase Cat IV		continuation phase Cat IV			
		Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %
monthly income by other household members at time of interview (tenge)	0	38	29%	11	9%	2	2%	56	43%	22	17%	129	100%
	1000-1999	0	0%	1	14%	0	0%	0	0%	6	86%	7	100%
	10000-49999	2	25%	0	0%	0	0%	3	38%	3	38%	8	100%
	2000-9999	0	0%	1	20%	0	0%	3	60%	1	20%	5	100%
	50000+	1	100%	0	0%	0	0%	0	0%	0	0%	1	100%

Annex Table 14e. Welfare income before TB illness

		TB patient group										Total	
		intensive phase Cat I-III		continuation phase Cat I-III		just diagnosed with MDR		intensive phase Cat IV		continuation phase Cat IV			
		Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %
monthly welfare payments before TB illness (tenge)	0	10	50%	1	5%	0	0%	6	30%	3	15%	20	100%
	10000-49999	15	25%	4	7%	1	2%	29	48%	12	20%	61	100%
	2000-9999	0	0%	0	0%	0	0%	1	100%	0	0%	1	100%
	50000+	16	24%	8	12%	1	1%	26	38%	17	25%	68	100%

Annex Table 14f. Welfare income at the time of the interview

		TB patient group										Total	
		intensive phase Cat I-III		continuation phase Cat I-III		just diagnosed with MDR		intensive phase Cat IV		continuation phase Cat IV			
		Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %
monthly welfare payments at time of interview (tenge)	0	12	34%	3	9%	0	0%	11	31%	9	26%	35	100%
	10000-49999	15	26%	3	5%	2	4%	29	51%	8	14%	57	100%
	2000-9999	0	0%	0	0%	0	0%	1	100%	0	0%	1	100%
	50000+	14	25%	7	12%	0	0%	21	37%	15	26%	57	100%



Annex Table 14g. Other government assistance income before TB illness

		TB patient group										Total	
		intensive phase Cat I-III		continuation phase Cat I-III		just diagnosed with MDR		intensive phase Cat IV		continuation phase Cat IV			
		Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %
monthly income from government assistance before TB illness (tenge)	0	41	28%	13	9%	2	1%	61	41%	32	21%	149	100%
	10000-49999	0	0%	0	0%	0	0%	1	100%	0	0%	1	100%

Annex Table 14h. Other government assistance income at the time of the interview

		TB patient group										Total	
		intensive phase Cat I-III		continuation phase Cat I-III		just diagnosed with MDR		intensive phase Cat IV		continuation phase Cat IV			
		Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %
monthly income from government assistance at time of interview (tenge)	0	40	28%	13	9%	2	1%	59	41%	31	21%	145	100%
	10000-49999	1	20%	0	0%	0	0%	3	60%	1	20%	5	100%

Annex Table 14i. Income from other sources before TB illness

	TB patient group												
	intensive phase Cat I-III		continuation phase Cat I-III		just diagnosed with MDR		intensive phase Cat IV		continuation phase Cat IV		Total		
	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	
monthly other income before TB illness (tenge)	0	41	28%	13	9%	2	1%	61	41%	31	21%	148	100%
	10000-49999	0	0%	0	0%	0	0%	1	50%	1	50%	2	100%

Annex Table 14j. Income from other sources at the time of the interview

	TB patient group												
	intensive phase Cat I-III		continuation phase Cat I-III		just diagnosed with MDR		intensive phase Cat IV		continuation phase Cat IV		Total		
	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	
monthly other income at time of interview (tenge)	0	41	28%	12	8%	2	1%	61	41%	31	21%	147	100%
	10000-49999	0	0%	1	33%	0	0%	1	33%	1	33%	3	100%

Annex Table 14k. Total household income before TB illness

		TB patient group											
		intensive phase Cat I-III		continuation phase Cat I-III		just diagnosed with MDR		intensive phase Cat IV		continuation phase Cat IV		Total	
		Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %
monthly total	0	5	50%	0	0%	0	0%	5	50%	0	0%	10	100%
household	10000-	9	30%	2	7%	1	3%	15	50%	3	10%	30	100%
income before	49999												
TB illness	50000+	27	25%	11	10%	1	1%	42	38%	29	26%	110	100%
(tenge)													

Annex Table 14l. Total household income at the time of the interview

		TB patient group											
		intensive phase Cat I-III		continuation phase Cat I-III		just diagnosed with MDR		intensive phase Cat IV		continuation phase Cat IV		Total	
		Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %
monthly total	0	8	47%	0	0%	0	0%	9	53%	0	0%	17	100%
household	10000-	12	23%	4	8%	2	4%	25	47%	10	19%	53	100%
income at	49999												
time of	2000-	0	0%	0	0%	0	0%	1	100%	0	0%	1	100%
interview	9999												
(tenge)	50000+	21	27%	9	11%	0	0%	27	34%	22	28%	79	100%

## Annex 2. Patient Cost Questionnaire

Tool to estimate patients' costs

**Questionnaire**

Name of interviewer : .....

Patient registration number in facility TB register : .....

Date of Interview (dd/mm/yy)	Oblast	Rayon	Place of interview (facility name)
<b>Category of Facility</b>	1. Tuberculosis dispensary      2. Medical center (polyclinic)      3. District hospital 4. Sanatoria      5. Other, point out.....		

Introduction to the patient:

My name is ..... The organization I am working for, TB CARE, is interested in the costs that people face because of tuberculosis illness. Therefore, we would like to inquire how much people spend on healthcare, and more specifically on tuberculosis before and during diagnosis and during treatment. We request you to provide us with information on the past three months plus major costs related to TB that were made longer ago.

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 refuse. If you refuse, there will be no consequence for you and you will receive whatever 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 choose to participate, I would like to stress that you will not receive any reimbursements for the costs that you have made and tell us about during the interview.

If you choose to participate in this study you need to know that you may 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 and the income of your household. We will NOT provide this information to any tax or welfare authorities, also not after the end of the study.

This survey will take ca. 30 minutes.

**Do you have any questions? Do you want to participate? (circle) Yes / No**

**Signature of interviewee:** .....

If Yes: Thank you!

If No: Is there a reason why not? (circle) 1. Language not good enough    2. Time constraint  
 3. Not comfortable      4. Other, specify .....

To be filled in by interviewer <b>(MDR) TB patient group (circle)</b>	<b>1 in last month of intensive phase of cat I-III treatment</b> <b>2. in continuation phase of cat I-III treatment</b> <b>3. just diagnosed with MDR-TB</b> <b>4. in intensive phase of cat IV treatment</b> <b>5. in continuation phase of cat IV treatment</b>
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**Patient Information** (to be filled in by Interviewer, where needed with the help of patient card; fill in also if interview is refused for non-response analysis )

Interviewee	1. Patient 3. Other -> do not interview
1. a) Gender    1. male    2. female	1b. Age of patient: ..... years
2. What is your nationality	1. Kazakh      2. Russian      3. Ukrainian 4. Uzbek      5. Kyrgyz      6. other

<b>3. What is your highest level of education?</b>	
1. did not study/ illiterate      2. elementary education      3. secondary education      4. incomplete secondary education 5. secondary vocational education      6. incomplete higher education      7. complete higher education/diploma 8. Other, .....	
<i>For question 4-7, fill in from patient card if patient does not know</i>	
<b>4. Type of TB</b> (circle)	1. pulmonary smear +      2. pulmonary smear -      3. Extra-pulmonary
<b>5. Treatment Regimen</b> (circle)	1. Cat I (new Pulmonary)      2. Cat II (retreatment) 3. Cat III (new SS- or Extra-Pulmonary)      4. Cat IV (chronic, MDR)
<b>6. In which phase and how long on treatment are you currently?</b>	<i>Fill number of months here – check with patient's treatment card</i> 1. .... Months in intensive phase of Cat I/II/III 2. .... Months in continuation phase of Cat I/II/III 3. .... Months in intensive phase of Cat IV 4. .... Months in continuation phase of Cat IV
<b>7. HIV status</b> (as indicated on card!)	1. positive      2. negative      3. not tested      4. not indicated on card
<b>8. How far is the nearest government facility where TB can be diagnosed?</b>	..... minutes walking/cycling ..... minutes with own motorized or public transport
<b>9. How far is your DOT facility (where you receive your current TB treatment)</b>	..... minutes walking/cycling ..... minutes with own motorized or public transport

**MDR-TB** (only ask these questions to MDR-TB patients in group 3-5)

<b>10. a) How long had you been on TB treatment before you were diagnosed with MDR-TB?</b>	.... Months
<b>10 b). If on MDR-TB treatment with second-line drugs, what was the duration between diagnosis of MDR-TB and start of MDR-TB treatment?</b>	... months
<b>10 c). If not on MDR-TB treatment with second-line drugs, what was the duration of TB treatment until now?</b>	... months

**DIAGNOSIS** (only for patients in group 1 or 3. For other patients, go to question 13)

<b>11. How many visits related to TB symptoms did you make before you received the diagnosis of (MDR-)TB at this facility (this includes the visit in which you received the diagnosis)</b>	..... visits
<i>Note for interviewer: fill out total number of visits after the table below (Q12) has been filled</i>	

**12. About how much did you spend for each of these visits before you were diagnosed with TB, including the visit when you actually received your diagnosis?**

*For MDR-TB patients, ask only about cost for MDR-TB diagnosis; for other TB patients, ask about costs for TB diagnosis. For all that don't apply, mark N/A; Fill one line per visit*

	Provider	Total Time spent per visit (in minutes, includes travel time)	Administrative Costs (consultative, registration)	Test costs (for sputum or other except X-ray)	Xray costs (includes sending xrays to radiologist, travel & fees)	Drug costs (all kinds total)	Travel Costs (return total)	Food costs (total)	Accommodation Costs (total)	Sub-Total costs per visit	Insurance Reimbursement <i>If yes: amount and for what, if no n/a</i>	Accompanied by someone else (circle correct answer)	Travel costs of accompanying person (return total)	Accommodation costs of accompanying person (total)	Loss of income of accompanying persons
Visit 1												Yes / No			
Visit 2												Yes / No			
Visit 3												Yes / No			
Visit 4												Yes / No			
Visit 5												Yes / No			
Visit 6												Yes / No			
Visit 7												Yes / No			
Visit 8												Yes / No			
Visit 9												Yes / No			
TOTAL	----- -----											Yes / No			

**Total Direct Prediagnostic & Diagnostic costs (sum subtotals) minus costs covered by insurance (KZT) = ..... (to be calculated by interviewer)**

<b>Treatment Costs</b>	
<u>Costs related to DOT</u>	
<b>13. Where do you currently take your TB drugs?</b> <i>If the patient has visited two different DOT places, tick the current place and report costs only for that place. If DOT at home, go to Q Fout! Verwijzingsbron niet gevonden..</i>	
1. Health facility / hospital      2. Home (go to Q18)      3. Community      4. Workplace      5. Dispensary	
<b>b) How many times per week do you go there to take your drugs?</b> ..... times	
<b>14. How long does it take you to get there?</b> (one way)	.... minutes walking      ..... minutes with transport      other:.....
<b>15. How long does one of these visits take on average, including time on the road and waiting time</b> (total turnaround time)?	..... minutes
<b>16. From your home to the DOT place, how much does transportation cost you to visit DOT facility?</b> (both ways)	.....
<b>17. How much do you spend on food on the road, while waiting at DOT facility?</b>	.....

<u>Costs related to check-ups and follow-up test during treatments</u>	
<b>18. a) Did you ever have to go to the health facility for follow up tests since the beginning of treatment?</b> <i>If No, go to Q19</i>	1. Yes      2. No
<b>b) If yes, how many times?</b>	..... Times
<b>c) If yes, did you have to pay any additional costs for follow-up tests during the entire period?</b>	1. Yes      2. No
<b>d) If so, what kind of costs and how much?</b>	
Fees.....      Sputum /lab tests .....      Xray.....	Total: .....
TB Drugs .....      Other Drugs.....      Other.....	

<b>Accompanying person and his/her costs related to DOT, picking up drugs, and follow-up tests during treatment</b>	
<b>19. a) Did someone accompany you on visits related to DOT, picking up drugs, and follow-up test visits or go in your place to collect your TB drugs ?</b> <i>If No, go to Q20</i>	1. Yes      2. No
<b>b) If YES, on how many visits were you accompanied or has someone gone in your place?</b>	..... times
<b>c) Did this accompanying person(s) lose income due to going with you?</b>	1. Yes      2. No If yes, how much in total .....

<b>Hospitalization</b>	
<i>Note to interviewer: if the patient is still hospitalized, ask about situation up to and including time of interview</i>	
<b>20. Have you been hospitalized due to TB?</b> <i>If No, go to Q27</i>	1. Yes      2. No



<b>21. If YES: how many days in total did you stay at the hospital?</b>	..... months
<b>22. How much did you pay in the hospital during your entire stay?</b> Hospital administration fees: ..... Sheets/Linen: ..... Food (not provided by hospital): ..... Transport (return): ..... Drugs: ..... Tests: ..... Other fees: .....	Total: .....
<b>23. Did any family/friend <u>stay</u> with you while you were in hospital? If No, go to Q26</b>	1. Yes      2. No
<b>24. If YES: How many days did he/she/they stay with you ?</b>	..... Days
<b>25. Were there any extra costs for your relative(s)/friend(s) for staying at the hospital?</b> Accommodation (hospital or other): ..... Food: ..... Transport: ..... Loss of Income: ..... Other: .....	Total Costs: .....
<b>26. a) Did any <u>other</u> family/friend visit you while in hospital? If No, go to Q27.</b> <b>b) If yes, what were the costs for the people that visited you?</b> <i>Note: This question aims to get the TOTAL number of visits and associated costs Add all costs of different persons</i> Accommodation : ..... Food: ..... Transport : ..... Loss of earning: ..... Other: .....	Total costs: .....

<b>Other Costs</b>	
<b>27. a) Do you buy any supplements for your diet (additional to mentioned in Q22) because of the TB illness, for example vitamins, meat, energy or other drinks, fruits or medicines? If No, go to Q28</b>	1. Yes      2. No
<b>b) If YES: What kind of items? (specify)</b> 1. Fruits      2. Drinks      3. Vitamins/Herbs      4. Meat      5. Other (specify):	
<b>c) How much did you spend on these items in the last 30 days approximately?</b>	.....
<b>28. a) Did you experience any adverse events during the treatment of (MDR-) TB?</b> <i>(Adverse events are any additional health problems that occur during(MDR-) TB treatment and that may be related to the treatment)</i>	1. Yes      2. No <i>If No, go to Q29</i>
<b>b) If YES: Was treatment required of these events? This includes changes in TB drug regimen!</b>	1. Yes      2. No
<b>c) IF YES, How much did you spend on treatment of adverse events and/or changes in the TB drug regimen approximately?</b> Drugs: ..... Additional payments: ..... Transport: ..... Accommodation: ..... Costs made by accompanying person: ..... Other: .....	Total: .....

<b>Insurance, reimbursements and vouchers</b>		
<b>29. a) Do you have any kind of private or government health/medical insurance scheme?</b> <i>If No, go to Q30</i>		1. Yes      2. No
<b>b) If YES: What type?</b> 1. reimbursement scheme      2. monthly medical allowance      3. donor 4. family/community fund      5. Other (specify)		
<b>c) Have you received reimbursement for any costs related to the TB illness?</b> <i>Cross-check with question 12 (table on prediagnostic &amp; diagnostic costs) If No, go to Q 30</i>		1. Yes      2. No
<b>d) If yes, how much have you received as reimbursement?</b>  For diagnosis: ..... For treatment: ..... For transport costs:..... Other: .....		Total: .....
<b>30. Did the government or other organisations provide you with any of the below items?</b> 1 .Transport vouchers      number: ..... value in money per voucher: ..... 2. Food package      number ..... value in money per voucher:..... 3. Monthly allowance      value in money: ..... 4. Other (specify): .....      value in money: .....		Total value: .....

## Coping Costs

<b>31. To what extent has the TB illness affected the family financially?</b> <i>(circle)</i>	1 = little impact 2 3 4 5 = serious impact
<b>32. Where did the money come from to pay for expenses related to TB?</b> <i>(circle, multiple responses allowed)</i>  <i>If no money borrowed or no property sold, go to Q 34</i>	1. Health insurance 2. Employer 3. Cutting down on other expenses 4. Using savings 5. Borrowing 6. Selling assets 7. Asking for donations from friends and relatives 8. Others, specify .....
<b>33. a) If you borrowed money, how much did you borrow?</b>  <b>b) From whom did you borrow (most)? Circle most appropriate</b> 1. Family    2. Neighbors/friends    3. Private bank    4. Cooperative  5. Other (specify): .....	Amount of money borrowed: .....
<b>c) What is the interest rate on the loan? (%)</b>	1. .... % 2. I don't pay any interest 3. I am not expected to pay back the money
<b>34. a) If you sold any of your property to finance the cost of the TB illness, what did you sell? Circle most appropriate</b> 1. Land    2. Livestock    3. Transport/vehicle    4. Household item    5. Farm produce  6. Other (specify): .....	
<b>b) What is the estimated market value of the property you sold?</b>	.....
<b>c) How much did you earn from the sale of your property?</b>	.....

## Socioeconomic Information Individual Situation and Income

<b>35. Who is the primary income earner in the household? Circle most appropriate</b> 1. Patient    2. Other (specify): .....	
<b>36. Are you currently working (includes non-formal work such as housework)?</b>	1. Yes    2. No (go to Q38)
<b>37. How are you usually paid (before TB disease, if this has changed)?</b>  1. cash    2. in kind    3. cash and in kind    4. not paid    5. bank transferred salary    6. Other	
<b>38. Did you have to change jobs when you became ill with TB?</b>	1. Yes    2. No
<b>39. How many hours did you work on average per day BEFORE you became ill with TB?</b>	..... Hours
<b>40. How many hours do you work on average NOW per day?</b>	..... Hours
<i>If answer to Q 40 differs from answer to Q 39 :</i> <b>41. Is the change related to the TB illness?</b>	1. Yes    2. No
<i>If answer to Q40 differs from answer to Q 39:</i> <b>42. Is someone doing the work that you used to do?</b>	1. Yes, member of own household 2. Yes, other person 3. No

<b>43. a) Have you ever stopped doing nonformal (house) work due to TB?</b> <i>If No, go to Q 46.</i>	1. Yes      2. No
<b>b) If YES: for how long?</b>	1. Less than 1 month 2. 1 month 3. 2-3 months 4. 4-5 months 5. more than 6 months
<b>44. Did/does someone do the non-formal work that you used to do?</b>	1. Yes, member of own household ( <i>go to Q46</i> ) 2. Yes, other person ( <i>go to Q45</i> ) 3. No ( <i>go to Q46</i> )
<b>45. In case someone from outside your own household did/does non-formal work for you, do/did you pay to that person to do your housework that you used to do before having TB illness?</b> 1. No    2. Yes, total amount (up until now)?	Total amount: .....
<b>46. a) Did/does someone stay home <u>specifically</u> to take care of you?</b> <i>If NO, go to Q47</i>  <i>If YES:</i> <b>b) For how long?</b> <b>c) Did they quit their income-earning job to stay home and care for you?</b> <b>d) Did you pay for anyone to take care of you?</b> IF yes, what is the value in cash or in value?	1. Yes      2. No  ..... Weeks 1. Yes      2. No 1. Yes      2. No Total value/amount: .....
<b>47. Does anyone in your household (including children or below school age) have to start work or work more to finance costs due to the TB illness?</b>	1. Yes      2. No
<b>48. Has the TB illness caused loss of your job or education?</b>  1. No      2. Loss of Job      3. Dropped out of school      4. Other (specify): .....	

### Household Income and Spending

<b>49. How much do you estimate was the average income of your household per month BEFORE the TB illness ?</b> (for all persons in the house, including patient; includes welfare payments, government assistance or other social support)	
1. income patient: .....	2. income rest of household: .....      3. welfare payments: .....
4. government assistance: .....	5. Other: .....      TOTAL: .....
<b>50. How much do you estimate is the average income of your household per month NOW ?</b>	
1. income patient: .....	2. income rest of household: .....      3. welfare payments: .....
4. government assistance: .....	5. Other: .....      TOTAL: .....
<b>51. If income under 50 is different from 49: Was this change in income the result of TB illness?</b>	1. Yes      2.No

**Socioeconomic Indicators (**

52. Does any member of the household currently own any of the following assets which are in working condition?	Fill in: 1. Yes 2. No	If yes, indicate number, size or value of assets where applicable			
1. Motor car			19. House / Apartment		
2. Motor bike			20. Land for farming		
3. Bicycle			21. Other land		
4. Truck			22. Account with financial institution		
5. Tractor			23. Shares in a company		
6. Furniture			24. Jewellery		
7. Sewing machine			25. Cattle		
8. Refrigerator/Freezer			26. Sheep/Goats		
9. Radio (no cassette/CD)			27. Horses/Donkeys		
10. Radio cassette/CD player			28. Poultry		
11. Television			29. Non-farm business enterprise		
12. Video recorder (DVD)			30. Treasury Bills		
13. Electric/Gas Stove			31. Other .....		
14. Electric Iron					
15. Electric Fan / Airconditioning					
16. Landline Telephone					
17. Mobile Telephone					
18. Internet access at home					

**53. If the government could provide you with some service to ease the financial burden of TB on you and your household, what would you prefer to have? Don't give options unless patient does not bring up answer him/herself. Only choose one.**

1. Transport vouchers      2. Food vouchers      3. More efficient service      4. Other (specify): .....

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

.....  
 .....

**Comments by Interviewer:**

.....  
 .....

**Date      and      Signature by Interviewer**  
 dd/mm/yy

.....      .....