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TB CARE I

Costs faced by multi-drug resistant tuberculosis patients during diagnosis and treatment. Report from a pilot study in Ethiopia.

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Abstract

Ethiopia has a high prevalence of tuberculosis (TB) and is one of the 22 highest TB burden countries in the world. It is also one of the countries where many people who develop TB every year do not get treated. One of the reasons why infected people delay or do not seek diagnosis and treatment is economic access – the cost to patients and their families. Delays in seeking care and interruptions in treatment can result in transmission of the infection to other people and interruptions in treatment can also result in multi-drug resistant TB.

A study of MDR-TB patient costs in March 2013 indicated that the average total out-of-pocket cost for an MDR-TB patient to get diagnosis and treatment was US$ 1,341 and each patient lost, on average, US$ 293 of income due to time spent seeking and receiving care (excluding income losses due purely to inability to work). Of the 169 MDR-TB patients that were interviewed, 82% were hospitalized at some stage and on average each patient spent 80 days in hospital. To get a correct diagnosis, it took patients an average of 3 visits with each visit taking an average of 22 hours.

The impact on patient employment and on overall patient and family income was catastrophic. Of the 169 MDR-TB patients, 121 (72%) reported losing their jobs and 133 (79%) reported an average income reduction of 100% for themselves and 33% for their families. The average out-of-pocket cost of US$ 1,341 represented over 2 years of the annual post-illness family income.

Patients financed the costs in various ways. Sixty five (38%) of the MDR-TB patients sold some type of property, 12 (7%) leased out property and 69 (41%) took out loans from family or friends. Of the 148 MDR-TB patients under treatment, 108 (73%) received vouchers funded through donor assistance, mostly for food, transport and house rental costs. The average total value of these vouchers was US$ 33 per MDR-TB patient, which appears to be very low compared with the patient costs.

The hospital reports indicated that an estimated 29% of the patients diagnosed with MDR-TB did not start treatment and 3% of the patients who started treatment defaulted. This study indicates that unaffordable patient costs with limited or no social support could be a contributing factor, along with geographical access issues.

In a national workshop held to discuss the findings, several key mitigation recommendations were agreed upon. These included ensuring that the policy of free care for all MDR-TB services is fully implemented, that services are brought closer to patients, and that the provision of social support to patients is improved.

Recommendations were also made for further research. These include interviewing more DS-TB patients across the country, reviewing the norms to see if the numbers of MDR-TB visits and length of stay in hospital can be reduced, and assessing the distribution and availability of MDR-TB diagnostic services. In addition, it will be important to gather data from people MDR-TB who are not receiving care since these are, presumably, the people who have the greatest problems with access. Finally it is worth looking at the feasibility of collecting patient access and cost data routinely through short interviews in facilities and by including questions in patient satisfaction surveys.

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Key Words

TB, MDR-TB, Ethiopia, patient costs.

Disclaimer

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Contents

Acronyms

ACSM	Advocacy, Communication, and Social Mobilization
AIDS	Acquired Immune Deficiency Syndrome
ATM	HIV/AIDS, Tuberculosis, and Malaria
AusAID	Australian Agency for International Development
DOTS	Directly Observed Therapy, Short-course *(the Internationally Recommended Standard for Tuberculosis Control)*
DS-TB	Drug-Susceptible Tuberculosis
GFATM	Global Fund to Fight AIDS, TB and Malaria
HIV	Human Immunodeficiency Virus
HR	Human Resources
KNCV	*KoninklijkeNederlandseCentraleVereniging tot bestrijding der Tuberculosis*
PMDT	Programmatic Management of Drug Resistant Tuberculosis
M&E	Monitoring and Evaluation
MDGs	Millennium Development Goals
MDR-TB	Multi-Drug Resistant Tuberculosis
MOH	Ministry of Health
MSH	Management Sciences for Health
MT-NDP	Medium Term National Development Plan
NTP	National Tuberculosis Control Program
SOW	Scope of Work
TB	Tuberculosis
TB CAP	Tuberculosis Control Assistance Program
TB CARE I	Tuberculosis CARE I Program
TBCTA	Tuberculosis Coalition for Technical Assistance
TORG	Tuberculosis Operations Research Group (NTP)
USAID	United States Agency for International Development
WHO	World Health Organization
XDR-TB	Extremely Drug-Resistant Tuberculosis

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Executive summary

Ethiopia has a high prevalence of tuberculosis (TB) and is one of the 22 highest TB burden countries in the world. TB is a costly disease for the health system and also for the patients, their families and society. A recent study in Indonesia estimated that the total economic burden of TB to society is over US$ 8 per capita (0.2% of GDP) (Collins et al., 2013).

A major issue identified in the 2013 Global Tuberculosis Report (World Health Organization) is the estimated high number of people who develop TB every year but who do not get treated – around 3 million worldwide in 2012. About 75% of these persons were estimated to be in 12 countries, one of which is Ethiopia. Another major issue highlighted in the WHO report is the increase in the number of MDR-TB cases which have higher death rates and place a greater burden on the health system. A recent study in Indonesia indicated that the costs of detection and treatment of MDR-TB can be as much as US$ 10,000 per new case, almost 50 times the cost of US$ 228 for drug-susceptible tuberculosis (DS-TB) (Jarrah et al.).

One of the reasons why infected people delay or do not seek diagnosis and treatment is economic access – the cost to patients and their families for seeking and completing care. Delays in seeking care and interruptions in treatment can result in transmission of the infection to other people and interruptions in treatment can also result in multi-drug resistant TB.

TB patients not only have to pay to access health services (i.e. registration fees, transport fees, and food costs) but also have income losses due to their inability to work. 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. They also lose more income because patients are unable to work for long periods. MDR-TB is more prevalent in high risk populations, such as the homeless, that are often economically more vulnerable and thus more likely to discontinue treatment if costs are too high.

In Ethiopia, starting from 2009, more than 1,250 patients were diagnosed with MDR-TB and 890 patients reportedly started on second line treatment. Of the patients diagnosed 29% did not start treatment and of the patients who started treatment, 24 (3%) defaulted. In both cases patient costs could have been a reason.

Policy makers such as Ministries of Health and National Tuberculosis Control Programs need to understand the problems of 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. With this in mind, TB CARE I developed a tool for estimating MDR-TB patient costs (building on a TB patient costing tool developed previously by USAID's TB CAP Project). The tool has been piloted in Ethiopia, Kazakhstan and Indonesia and this report presents the results from Ethiopia.

In March, 2013, a total of 169 MDR-TB patients and 25 TB patients were interviewed at St. Peter's Hospital and ALERT Hospital in Addis Ababa and at Gondar University Hospital. The findings indicated that the average direct (out-of-pocket) costs for an MDR-TB patient related to getting diagnosis and treatment were significant, with a total of US$ 1,341 comprising US$ 68 for pre-/diagnosis costs, US$ 639 for intensive phase costs and US$ 634 for continuation phase costs. In addition, MDR-TB patients lost an average of US$ 293 of income due to time spent seeking and receiving care. Companions (family members or friends who

assisted MDR-TB patients to seek and receive care) incurred additional direct costs of US$ 50 and income losses of US$ 39.

Due to time constraints it was only possible to interview a small number of DS-TB patients. The findings are, therefore, not robust but they are indicative of the types of problems that these patients suffer. On average a DS-TB patient incurred direct costs of US$ 198, made up of US$ 14 for pre-/diagnosis costs, US$ 104 for intensive phase costs and US$ 80 for continuation phase costs. On average the DS-TB patients did not report income losses. However, their companions suffered direct costs of US$ 48 and income losses of US$ 46.

It should be noted that the figures for income losses do not include losses due to inability to work because people were ill, only the income lost due to time taken for seeking and receiving care.

MDR-TB total direct patient costs were almost 7 times the total costs for DS-TB patients. This is due to the longer time period for the treatment and more frequent travel requirements (since treatment only occurs in one central and one regional location). The largest share of the MDR-TB and DS-TB patient costs was incurred for nutritional supplements.

MDR-TB costs averaged US$ 1,634 in Addis Ababa, which was much higher than the total of US$ 906 in Gondar. Also MDR-TB patients with lower income levels incurred fewer costs than other patients – an average of US$ 909 for the lowest income group, US$ 1,437 for the middle income group, and US$ 2,210 for the highest income group. The poorer group spent less on most elements, notably food, transport, supplementary diet and relocation. This suggests that patients will spend more on such items such as diagnoses, tests and supplemental food if they have more disposable income.

The income lost by patients as a result of getting a proper diagnosis and receiving treatment varies with factors such as the time spent in hospital, the distance from home to the facility, the method of travel, the numbers of outpatient visits and the waiting time. Of the 169 MDR-TB patients, 82% were hospitalized and on average each spent 80 days in hospital. Significant time was spent on getting a diagnosis – 3 visits with an average time spent per visit of 22 hours.

The impact on patient employment and on overall patient and family income was catastrophic for MDR-TB patients. Of the 169 MDR-TB patients, 121 (72%) of them reported losing their jobs and 133 (79%) reported an average income reduction of 100% for themselves and 33% for their families as a whole. The total direct cost of US$ 1,341 for an MDR-TB patient represented over 2 years of annual median post-illness family income.

Patients financed the costs in various ways. Sixty-five (38%) of the MDR-TB patients sold some type of property to cover the costs of seeking and obtaining treatment, 12 (7%) leased out property and 69 (41%) took out loans. Almost all the loans were without interest, indicating that they were from family or friends.[1]

Health insurance is not generally available in Ethiopia and only one of the MDR-TB patients interviewed had coverage.

Of the 148 MDR-TB patients under treatment, 108 (73%) received vouchers funded through donor assistance, mostly for food, transport and house rent. The average value of these was US$ 33 per patient. The average value of the vouchers per patient for the period under treatment was US$ 7.76 per month for

[1] In Ethiopia there is a culture of supporting sick people in the community.

the patients in the intensive phase and US$ 1.39 per month for the patients in the continuation phase. The value of the vouchers appears to be very low compared with the average of one month's total direct patient cost of US$ 54. Fifty (30%) of the MDR-TB patients who received vouchers also sold property or took loans, providing additional evidence that the value of the vouchers might have been insufficient. When asked if and how the government could assist with vouchers, both the patients replied that they would like assistance with house rent and with finding work after they are cured.

As noted earlier, an estimated 29% of the patients diagnosed with MDR-TB did not start treatment and 3% of the patients who started treatment defaulted. Unaffordable patient costs with limited or no social support could be a contributing factor, along with geographical access. This study did not, unfortunately, have the resources to try to find these patients and determine why they did not seek or continue treatment so a relationship between these factors remains theoretical.

In a national workshop held to discuss the findings, several key mitigation recommendations were agreed upon. These included ensuring that the policy of free care for all MDR-TB services is fully implemented, that services are brought closer to patients, and that the provision of social support to patients is improved.

Recommendations were also made for further research. These include interviewing more DS-TB patients across the country, reviewing the norms to see if the numbers of MDR-TB visits and length of stay in the hospital can be reduced, and assessing the distribution and availability of MDR-TB diagnostic services. In addition, it would be important to gather data from people with MDR-TB who are not receiving care since these are, presumably, the people who have the greatest problems with access. Finally it is worth looking at the feasibility of collecting patient access and cost data routinely through short interviews in facilities and by including questions in patient satisfaction surveys.

1. Introduction

Ethiopia has a high prevalence of tuberculosis (TB) and is one of the 22 highest TB burden countries in the world. TB is a costly disease for the health system and also for patients, their families and society in general. A recent study in Indonesia estimated the total economic burden of TB to society as over US$ 8 per capita (0.2% of GDP) (Collins et al., 2013).

A major issue identified in the 2013 Global Tuberculosis Report (World Health Organization) is the estimated high number of people who develop TB every year and who do not receive treatment – around 3 million worldwide in 2012. About 75% of these persons were estimated to be in 12 countries, one of which is Ethiopia. One of the reasons why infected people delay or do not seek diagnosis and treatment is economic access – the cost to patients and their families for seeking and completing care. Delays and interruptions in receiving care can result in the infection of other people and interruptions can also result in multi-drug resistant TB (MDR-TB). The issue of increasing numbers of MDR-TB cases is also highlighted in the WHO report, partly because it has higher death rates and places a much greater burden on families and the health system. A recent study in Indonesia indicated that the costs of detection and treatment of MDR-TB can be as much as US$ 10,000 per new case, almost 50 times the cost of US$ 228 for drug-susceptible tuberculosis (DS-TB) (Jarrah et al.).

In almost all cases TB patients have to pay to access health services (e.g. registration fees, transport fees, and food costs) but also suffer income loss due to their inability to work. Patients with MDR-TB face 5-20 times higher costs than patients with susceptible TB. This is mainly due to relocation costs, longer pre-diagnosis and treatment periods which involve more visits and procedures, and inability to work for long periods. MDR-TB is more prevalent in high risk populations, such as the homeless, that are often economically more vulnerable and thus more likely to discontinue treatment if costs are too high.

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.

2. Statement of Problem

According to the WHO 2013 Global TB Report the prevalence and incidence rates of TB in Ethiopia are 224 and 247 cases per 100,000, respectively, which is slightly higher than the average for the 22 high-burden countries. The estimated incidence of MDR-TB cases is also high, with 1.6% of new cases and 12% of retreatment cases, amounting to an estimated 2,080 new cases in 2012.

Ethiopia is one of 12 countries with high numbers of undetected TB cases – with a reported case detection rate of 64% in 2013 (all forms of TB).[2] The number of untreated MDR-TB cases is also estimated to be high with only 284 MDR-TB cases confirmed and started treatment – 14% of the total of 2,080 estimated new cases.

[2] WHO. Global TB Report 2013.

Starting from 2009, more than 1250 MDR-TB patients were diagnosed throughout the country with the support of EXPAND TB Project (Source: FIND consultant at National Reference laboratory) and 890 patients started on second line treatment (Table 1). These services are provided at three public hospitals: St. Peter's and ALERT in Addis Ababa and Gondar University Hospital in Gondar. Reportedly, as many as 29% of the patients diagnosed with MDR-TB may not have started treatment and 24 (3%) of the 890 patients who started MDR-TB treatment may have defaulted.

Table 1. Total numbers of MDR-TB treatments accumulated through June 2013[3]

No. of	St. Peter's	ALERT	Gondar
MDR-TB Patients started on second line treatment	627	123	140
MDR-TB patients successfully treated (Cured + treatment completed)	171	0	16
MDR-TB patients defaulted their treatment	14	6	4
MDR-TB patients died while on treatment	70	9	11
MDR-TB patients currently on treatment	372	108	109
MDR-TB Patients HIV co-infected	115	18	33
Data source	St. Peter's annual performance report	Dr Hiwot	Dr Ermias

3. MDR-TB Patient Costing tool

In 2008 a tool was developed under USAID's TB CAP Project to estimate TB patient costs (Tool to Estimate Patients' Costs[4]). The Tool was tested in Kenya and then used in three countries – Ghana, Vietnam and the Dominican Republic and was made available for use by countries.

The original Tool is a comprehensive package of a generic questionnaire to be adapted to local circumstances and guidelines for all parts of its implementation, and is freely available at http://www.tbcare1.org/ publications/toolbox/hss/. The Tool includes all TB patients irrespective of type of treatment that they receive and thus there were no or very few MDR-TB cases included in countries using the Tool thus far.

The Tool is designed to assess direct (out of pocket) and indirect costs (income losses) incurred by TB patients at two distinct phases: 1) before and during diagnosis and 2) during treatment. Also, this Tool includes questions on TB patient information, previous TB treatment episodes, health-seeking behavior and delays, costs to the guardian/treatment supporter of the patient, health facility visit costs, social impact of the disease on the family including children, the impact of TB on food expenditures, and the welfare of the household.

The Tool to Estimate Patients' Costs does not cover MDR-TB patient costs and could not be used among these patients without adaptation. In 2012 a project was, therefore, developed under USAID's TB CARE I project to adapt the TB Tool for use to estimate MDR-TB patient costs. The Tool was simplified and

[3] Source: FMOH progress report presented to this year Green Light Committee (GLC). These figures are provisional and may be revised when the data for the fiscal year ended on June 30, 2013 is finalized at Ministry of Health.

[4] http://www.stoptb.org/wg/dots_expansion/tbandpoverty/assets/documents/Tool%20to%20estimate%20Patients'%20Costs.pdf

shortened to more-efficiently measure TB patient costs and additional questions for MDR-TB patients were added. The adapted tool was piloted in 3 countries – Kazakhstan, Indonesia and Ethiopia.[5] [6]

4. Data Collection

A study protocol was developed and was approved by the AHRI/ALERT Ethics Review Committee on December 10, 2012, with comments that were addressed later. Letters of collaboration were also received from the participating hospitals. The interviews were conducted by hospital staff working in the MDR-TB programs in the three hospitals. All participants received a unique patient identification code (UPIC) and all data of the participants were electronically stored using the UPIC only. Name and address of participants were not recorded in any document used in this study. The study only involved one interview per patient which took around 30 minutes.

The main focus was on MDR-TB patients and but some TB drug sensitive (DS) patients were included for comparison purposes. The intended sample size of the study was 250 patient interviews, with fifty interviews from each of the five TB patient groups. The five patient groups were:

- DS-TB patients who completed at least one month of treatment and now are (or should be, in case of default,) within the last month of the intensive phase of category I, II, and III TB treatment;
- DS-TB patients who started at least 3 months ago with the continuation phase of category I, II, and III TB treatment;
- Patients diagnosed with MDR-TB within the month before the interview;
- MDR-TB patients who started at least 3 months ago with the intensive phase of MDR-TB treatment; and
- MDR-TB patients who started at least 3 months ago with the continuation phase of MDR-TB treatment.

A draft questionnaire had been developed for all 3 countries before they were visited. The questionnaire was reviewed in Ethiopia and translated from English into Amharic. Some questions were modified to fit the local context. After this, the questionnaire was translated back into English to check for translation and interpretation errors. The questionnaire was then pretested in Ethiopia and further adapted where necessary.

The data collection took place in March 2013 at the three hospitals that provide MDR-TB services: St. Peters and ALERT in the capital city of Addis Ababa and University of Gondar Hospital in Gondar, a city in Amhara Region, northwest Ethiopia[7]. These are all public hospitals. Given the short amount of time allocated for data collection it was realized early on that it would not be feasible to reach the overall target of 250 patients and the interviews were focused on reaching the target of 150 MDR-TB patients. None of these sites were using Xpert for diagnosis at the time of the study.

The patient cost questions were grouped into four sections: 1) pre- and during diagnosis; 2) intensive (DOTS) treatment; 3) continuation treatment; and 4) other direct and indirect costs such as hospitalization,

[5] The reports for Kazakhstan and Indonesia are referenced under van den Hof and Tiemersma in Annex 1 – References.
[6] The tool will be available on the TB CARE I and MSH web sites and can also be obtained by contacting the lead authors of the country studies.
[7] At the time of this analysis, eight MDR-TB treatment initiating centers were functional in the country. Except for St. Peter's, ALERT and Gondar, the rest opened in the year that ended on June 30, 2013.

follow-up tests, food supplements, relocation costs, adverse events, and companion costs. They were grouped in this way because patients were in one of three different phases and different methods of aggregating costs were used for each group. In addition it was important to understand the time frames when costs are incurred. An additional section called "Coping" was included to cover sources of financing used by patients to cover the costs. Direct costs refer to expenses incurred for food, travel, accommodation and medical fees while indirect costs refer to loss of income incurred during diagnostic visits and treatment.

The standards for treatment duration in Ethiopia are as follows:[8]

- DSTB new cases - minimum of 8 weeks of intensive treatment and 4 months continuation
- DSTB Previously treated – 8 weeks plus 4 weeks of intensive treatment, 5 months continuation
- MDR-TB Intensive – minimum 6 months and 4 months of treatment after culture conversion
- MDR-TB Continuation – minimum 14 months of treatment (18 months total less on average 4 months under intensive phase after conversion)

Based on information from the participating doctors the length of the intensive phase generally follows the above standards.

Table 2 shows the methods used to collect and estimate each type of cost. Note that the grouping of the figures in the output tables is different.

Table 2: Data collection methods

Type of Cost	Description	Collection method
Pre- and during diagnosis	Admin fees, tests, X-rays, medicines, travel, food, accommodation, loss of income, insurance reimbursement and companion costs during visits	Costs any time before the patient was diagnosed and during the diagnosis visit
Intensive (DOTS) treatment	Travel and food [9]	Cost of one round trip at time of interview and the number of trips
Continuous Treatment	Travel, food, facility admin fees, and accommodation costs	Cost of one round trip at time of interview and the number of trips
Other Direct and Indirect costs	Follow-up checks and tests, hospitalization, relocation, diet supplements and treatment of adverse events (including ancillary medicines)	1. Follow-up tests and related companion costs during last 3 months 2. Hospitalization and relocation and related companion costs at any time during illness prior to interview 3. Diet (nutrition) supplements during the last 30 days 4. Adverse events during last 3 months
Coping	Sources of funding for patient costs, borrowing, sales of assets, leasing of assets	During whole period of diagnosis and treatment until the time of interview

[8] Guidelines for Clinical and Programmatic Management of TB, Leprosy and TB/HIV in Ethiopia, 5th edition, April 2012.Federal Democratic Republic of Ethiopia, Ministry of Health.

[9] Questions on companion costs related to the Intensive and Continuous Treatment phases were not included in the Questionnaire.

5. Sample characteristics

During the four weeks of data collection in March 2013, a total of 194 interviews were conducted (see Table 3). Half were conducted at St. Peter's Hospital in Addis Ababa and the remaining half were conducted at the other two hospitals - 28% and 22% at Gondar University and ALERT hospitals, respectively. These numbers are representative of the numbers of patients being served at each hospital.

In total, 169 MDR-TB patients were interviewed, of which 21 were newly diagnosed, 85 were in the intensive phase, and 63 were in the continuation phase. In addition, 25 patients with DS-TB were interviewed and these were evenly divided between those in the intensive phase and those in the continuation phase. More MDR-TB patients were interviewed because that was the priority. Greater numbers of MDR-TB patients were interviewed in the intensive and continuous phases because they were inpatients in the former case and regular attendees in the latter case. There were fewer patients in the diagnostic phase to choose from.

We excluded patients younger than 21 years of age and patients not consenting to the study or those not able to answer the questions in the interview.

Some of the answers were obtained from the patients while some, such as the number of months under treatment, were extracted from the patient records.

Table 3: Interviews conducted, by site and city

Sites	**City**	**# Interviews**	**%**
ALERT	Addis Ababa	43	22%
St Peter's	Addis Ababa	96	50%
Gondar University	Gondar	55	28%
Total Interviews		**194**	**100%**
Patient Groups			
1. Intensive phase of DS-TB new or retreatment		12	6%
2. Continuous phase of DS-TB new/retreatment		13	7%
3. Just diagnosed MDR-TB		21	11%
4. Intensive MDR-TB		85	43%
5. Continuous MDR-TB		63	33%

Table 4 shows the characteristics of the population sampled. The population sampled was predominantly male (55%) and between the ages of 18 and 29 years (57%). The most common ethnic group was Amharic (51%). Most were educated to the secondary level (29%) or primary level (25%) while many had no schooling (23%).

Only 25 of the persons interviewed were DS-TB patients. This was sufficient to test the tool and the resulting figures are useful for comparisons with the MDR-TB figures. But the sample of DS-TB patients is too small for the results to be used to determine any levels of social support by themselves. Of the 25 persons on DS-TB treatment, three were being retreated.

Patients were at varying stages of treatment at the time they were interviewed.The DS-TB patients in the intensive phase were almost all in the second month, the ones in the continuation phase were also mostly

in the second month. The MDR-TB patients in intensive treatment ranged from 1 - 11 months with the majority between 4 - 10 months. The MDR-TB patients in continuation treatment ranged from 3 - 14 months with the majority between 3 - 7 months.

The majority of the MDR-TB patients (72%) had experienced 2 - 3 TB episodes, with the figure ranging from 0 - 7. Most of them (77%) had retreatment failure. Only one patient reported having defaulted due to side effects. On average, patients were 15 months on Category IV treatment after having been diagnosed with MDR-TB.

Ninety one percent of the interviewees were pulmonary smear positive, 21% were HIV positive and 2% had diabetes. Separate cost data related specifically to HIV/AIDS or diabetes were not included.

Table 4: Characteristics of Sample

	Description	Frequency	Percent
Demographic Characteristics			
Gender	Male	107	55%
	Female	87	45%
Age Group	18-29	110	57%
	30-39	49	25%
	40-49	20	10%
	50+	15	8%
Ethnic Group	Amhara	99	51%
	Oromo	32	17%
	Tigray	14	7%
	Southern Nations	47	24%
	Other (Somali)	2	1%
Education	No schooling	44	23%
	Primary	49	25%
	Secondary	56	29%
	University	20	10%
	Vocational	24	12%
	Other (Church)	1	1%
	Missing	1	1%
Characteristics of TB			
Type of TB	Pulmonary smear +	176	91%
	Pulmonary smear –	4	2%
	Extra-pulmonary	13	7%
	Missing	1	1%
Treatment Regimen	New Treatment	22	11%
	Retreatment	3	2%
	MDR-TB	159	82%
	Missing	10	5%
How long on treatment (months)	TB Intensive phase	2-8	N/A*
	TB Continuation phase	3-5	N/A
	MDR-TB intensive phase	3-11	N/A
	MDR-TB continuation phase	3-14	N/A
Co-Morbidity			
HIV	Positive	41	21.1
	Negative	146	75.3
	Not tested	2	1.0
	Missing	5	2.5
Diabetes/Hypertension	Positive	4	2.1
	Negative	187	96.4
	Missing	3	1.5

*N/A = not applicable

6. Data entry and analysis

Data entry clerks entered the data into EpiData (www.epidata.dk) and used double data entry to ensure accuracy. The original analysis was done in SPSS and a later analysis was done in Microsoft Excel.

Since the data was collected at a single point in time (one interview), costs were extrapolated as shown below:

- Pre-diagnosis and diagnosis direct costs and income losses for patients and companions as well as insurance reimbursements for patients related to diagnosis: the totals were sums of the figures for all visits.
- Intensive treatment phase: the average cost for a visit in the last 3 months was multiplied by the reported number of visits during that period and the total was multiplied by the normative minimum number of months of treatment. For DS-TB this was the cost per visit times 6 visits per week times 8 weeks (2 months). For MDR-TB this was the cost per visit times 5 visits per week times 44 weeks (10 months).
- Continuation treatment phase: the average cost for a recent visit was multiplied by the reported number of visits during that period and the total was multiplied by the normative minimum number of months of treatment. For DS-TB this was the cost per visit times 4 visits per month times 4 months. For MDR-TB this was the cost per visit times 1 visit per month times 14 months.
- Follow-up treatment: the cost per visit during the last 3 months times the number of visits in that period. This total was extrapolated over 6 months for DS-TB patients which assumed that each patient would make 2 visits over the whole treatment period. For MDR-TB the total was extrapolated over 24 months for MDR-TB patients which assumed that each patient would make 8 visits over the whole treatment period.
- Companion income losses related to intensive, continuation and follow-up tests: the total income loss reported in the interviews extrapolated to the full treatment period for DS-TB and for MDR-TB.[10]
- Hospitalization (patient and companion): the total of the reported costs (no extrapolation).[11]
- Relocation costs: the total of the reported costs (no extrapolation).
- Nutrition supplements: the total reported for the last 30 days extrapolated over the full periods of treatment.
- Adverse events: the total amount reported for the last 3 months. Not extrapolated because it was assumed that adverse events do not recur.
- Insurance reimbursements: none were reported.
- Vouchers: figures reported through date of interview. Not extrapolated because there is no system in place that would ensure that they would continue.
- Loans, property sales: figures reported to date of interview. Assumed will not recur after interview but also impossible to estimate if assumed would recur.
- Patient income losses for intensive and continuation phases: average minutes per visit times average patient income per minute prior to contracting disease.[12][13].

[10] The question did not specify if the income loss was per visit or in total for the 3 months, but based on the reported amounts we assumed they were 3 month totals.

[11] Not all patients reported having companions while in hospital.

- Reduction in income was calculated by deducting the reported income after infection from the income before infection.

For the analysis, the patient TB costs were stratified by patient group, facility location and income levels. The figures are shown by diagnosis and treatment phases and other elements as grouped in the questionnaire.

Zero figures were included in the calculations of the means and medians. This assumes that a zero answer to a cost question, for example, means that nothing was spent. Blank answers were, however, not included, assuming that the answer was not relevant or not known. Excluding the blank answers means that the means and medians are drawn from a sample that was less than the total number of patients interviewed.

We show the mean and median costs for the patients who incurred a particular type of cost. For example, 22 of the 169 MDR-TB patients relocated and we calculated the median (US$ 78) and IQM (US$ 102) for the 22 patients since this provides an average cost for a patient who needs relocation. To calculate the average cost over the whole sample of patients, the total cost for the patients who incurred that cost must be divided by the full sample of patients interviewed. For example, the total cost for the 22 patients would be divided by the 169 patients.

For each type of cost we show four indicators: the inter-quartile mean (IQM)[14], the median, the inter-quartile range (IQR) and the number of responses. The IQM was used instead of the arithmetic mean to eliminate the outliers in the bottom 25% and top 25% of the figures, which, given the presence of many zeros and some abnormally high costs makes the results more robust.

The figures in this report are shown in US$ and were converted using an exchange rate of 18.60 Birr to 1 US$.

[12] This is based on the patient's estimate of income. Higher income levels will therefore be reflected in higher estimated costs.

[13] The questionnaire used did not attempt to get information on the loss of income due to the total length of time not working due to the illness. It is worth noting that such a figure can reflect an underestimate of the total income loss because some persons lose their jobs and it may take much longer to be re-employed.

[14] The inter-quartile mean (IQM) is the arithmetic mean of the range of figures between the 25% and 75% quartiles. The IQM is a trimmed mean which is a more robust measure of central tendency than an arithmetic mean. For example, a small fraction of anomalous measurements with abnormally large deviation from the center may change the mean value substantially. A trimmed mean is more stable in the presence of abnormal extreme values, which get "trimmed" away. The degree of trimming can vary, for example from 5% to 25%.
http://www.statistics.com/index.php?page=glossary&term_id=866

7. Findings – direct costs

MDR-TB direct patient costs

The median direct costs for MDR-TB were US$ 68 (IQM US$ 100) during the pre-/diagnosis phase, US$ 639 (IQM US$ 640) during the intensive phase and US$ 634 (IQM US$ 731) during the continuation phase (Table 5). The sum of the median figures is US$ 1,341 and the sum of the IQMs is US$ 1,471).[15] [16] The pre-/diagnosis figures include the costs of hospitalization and dietary supplements reported by patients in that phase. The intensive and continuation phase costs include the costs of hospitalization, adverse events, relocation, follow-up tests and dietary supplements during each phase. As can be seen from the table the median figure for pre-/diagnosis is the least robust of the three because the sample size was smaller (21 patients compared with 85 and 63) and the range is wider. The IQM figure of US$ 100 for pre-/diagnosis is higher than the median cost of US$ 68.

Table 5. MDR-TB direct costs by phase, 2013 (US$)

	Number in sample	Inter-quartile mean	Median	Median IQR 25%	Median IQR 65%
Direct pre-/diagnosis costs	21	100	68	35	191
Direct intensive phase costs	85	640	639	259	968
Direct continuation phase costs	63	731	634	458	1,048
Sum of direct costs		**1,471**	**1,341**		

A breakdown of the direct patient costs by type of expenditure (e.g., health service costs, transport costs), as shown in Table 6, is useful for policy-making since different approaches can be used to mitigate these costs. Unlike the figures in Table 5, these figures are the averages for the patients who incurred them and not the averages for the whole sample of patients.[17]

The highest median cost element was US$ 768 (IQM US$ 833) for dietary supplements, which was incurred by 95% of all MDR-TB patients interviewed. This cost is shown separately from regular patient food as this supplementary diet makes an important nutritional contribution to the patient's recovery. The second highest cost group is patient food where the sum of the median costs was US$ 210 (IQM US$ 310). Within that group the highest single median cost was US$ 105 for food bought by the 78% of the patient who were hospitalized.

Another high cost was for follow-up tests which were undergone by 30% of all MDR-TB patients and which had median cost of US$ 125 for each of these patients. This amount, however, includes US$ 116 for "Other" Follow-up test costs, which may include transport and food costs. If that is the case, the remaining cost of health services is low, which should be the case since the policy is that these services are free of charge in public facilities and currently MDR-TB services are only provided in public facilities. Twenty two patients

[15] Sums of medians and means are not very robust and are best used as indicative figures.
[16] These figures are the averages across for the whole sample of 169 patients.
[17] To estimate the overall costs or set budgets for these elements it is best to use both the frequency rates and average costs – for example, 13% of MDR-TB patients would require relocation and the median cost per each of those patients would be US$ 78.

stated that they relocated and the median cost of the relocation among the 22 patients was US$78 (IQM US$ 102).

Table 6: Direct MDR-TB patient costs by expenditure type – 2013 (US$)

Direct patient costs	MDR-TB					
	Inter-quartile mean (US$)	Median US$)	Median IQR 25% (US$)	Median iQR 75% (US$)	Number of responses	Responses as % of sample group
Medical services						
Patient direct pre-/diagnosis costs						
Administrative fees	0	0	0	1	17	81%
Tests	0	-	-	-	17	81%
X-rays	1	-	-	1	20	95%
Medicines	2	-	-	3	21	100%
Hospitalization	7	3	-	16	134	79%
Adverse event fees	-	-	-	-	5	6%
Adverse event medicines	2	-	-	5	5	6%
Follow-up fees, tests and drugs	143	125	24	268	50	30%
Sum - medical services	**155**	**128**				
Transport						
Transport – pre-/diagnosis	12	6	3	28	20	95%
Transport – intensive treatment visits	56	59	-	118	45	53%
Transport - continuation treatment phase	49	23	11	102	60	95%
Transport - adverse events	6	-	-	15	5	6%
Sum - transport	**123**	**88**				
Food						
Food related to pre-/diagnosis visits	14	10	1	27	20	95%
Food while hospitalized	109	105	28	186	132	78%
Food related to intensive treatment visits	149	71	-	355	39	46%
Food related to continuation treatment visits	38	24	11	75	60	95%
Sum - food	**310**	**210**				
Accommodation						
Accommodation – pre-/diagnosis	7	1	-	17	17	81%
Accommodation – continuation treatment	98	94	68	128	13	21%
Accommodation - adverse events	-	-	-	-	5	6%
Sum - accommodation	**105**	**95**				
Other						
Supplementary diet	833	768	387	1,290	160	95%
Other costs for adverse events	1	-	-	3	5	6%
Patient relocation	102	78	59	130	22	13%
Numbers of patients in sample groups						
MDR-TB just diagnosed					21	
MDR-TB intensive treatment					85	
MDR-TB continuation treatment					63	
Total count					**169**	

The direct MDR-TB patient costs were analyzed by city to see if there were significant differences that might be important from a policy perspective. At the time of the study MDR-TB services were only provided in two cities – Addis Ababa and Gondar. The analysis shows that total MDR-TB direct patient costs were roughly twice as high in Addis Ababa than in Gondar, with a median total cost of US$ 1,634 in Addis Ababa and US$ 906 in Gondar (Table 7). Costs were higher in Addis Ababa for almost all expenditure types, especially patient food, transport, accommodation and supplementary diet. Patient relocation costs were, however, higher in Gondar, which may reflect the distance that some patients have to travel to that city. 28% of all Gondar patients relocated whereas only 7% of Addis Ababa patients relocated. Note that the sample size was smaller in Gondar, especially for pre-/diagnosis patients.

Table 7: MDR-TB direct patient costs by city by expenditure type, 2013 (US$)

Direct patient costs by location	MDR-TB							
	Addis Ababa				Gonder			
	Inter-quartile mean (US$)	Median (US$)	Number of responses	Responses as % of sample group	Inter-quartile mean (US$)	Median (US$)	Number of responses	Responses as % of sample group
Patient health care costs - sum	**$ 228**	**$ 184**			**$ 146**	**$ 126**		
Sum patient direct pre-/diagnosis costs - sum	**$ 4**	**$ 0**			**$ 7**	**$ 1**		
Administrative charges	$ 0	$ 0	15	100%	$ 1	$ 0	6	100%
Tests	$ -	$ -	11	73%	$ 3	$ -	6	100%
X-rays	$ 1	$ -	14	93%	$ 1	$ 1	6	100%
Medicines	$ 2	$ -	15	100%	$ 2	$ -	6	100%
Hospitalization	**$ 6**	**$ 1**	**109**	**89%**	**$ 10**	**$ 9**	**25**	**54%**
Sum Adverse events and follow-up tests	**$ 218**	**$ 183**			**$ 129**	**$ 117**		
Adverse event fees	$ -	$ -	3	13%	$ -	$ -	2	9%
Adverse event medicines	$ 4	$ -	3	13%	$ -	$ -	2	9%
Follow-up fees, tests and drugs	$ 215	$ 183	14	11%	$ 129	$ 117	36	78%
Patient transport - sum	**$ 205**	**$ 115**			**$ 22**	**$ 9**		
Transport – pre-/diagnosis	$ 19	$ 7	14	93%	$ 10	$ 6	6	100%
Transport – intensive treatment visits	$ 104	$ 71	24	39%	$ 6	$ -	21	91%
Transport - continuation treatment phase	$ 73	$ 38	45	98%	$ 5	$ 2	15	88%
Transport - adverse events	$ 9	$ -	3	13%	$ 1	$ 1	2	9%
Patient food - sum	**$ 478**	**$ 392**			**$ 113**	**$ 53**		
Food related to pre-/diagnosis visits	$ 19	$ 10	14	93%	$ 12	$ 10	6	100%
Food while hospitalized	$ 122	$ 108	107	87%	$ 59	$ 43	25	54%
Food related to intensive treatment visits	$ 283	$ 237	18	29%	$ 38	$ -	21	91%
Food related to continuation treatment visits	$ 54	$ 38	45	98%	$ 3	$ -	15	88%
Patient accommodation - sum	**$ 107**	**$ 94**			**$ 7**	**$ 4**		
Accommodation – pre-/diagnosis	$ 10	$ -	11	73%	$ 7	$ 4	6	100%
Accommodation – continuation treatment	$ 98	$ 94	13	28%				0%
Accommodation - adverse events	$ -	$ -	3	13%	$ -	$ -	2	9%
Other								
Supplementary diet	$ 908	$ 774	119	97%	$ 655	$ 619	41	89%
Other costs for adverse events	$ 2	$ -	3	13%	$ -	$ -	2	9%
Patient relocation	$ 75	$ 75	9	7%	$ 132	$ 94	13	28%
Sum direct patient costs	**$ 2,003**	**$ 1,634**	**123**	100%	**$ 1,075**	**$ 906**	**46**	100%
Sample groups								
Just diagnosed			15				6	
Intensive treatment			62				23	
Continuation treatment			46				17	
Total sample			**123**				**46**	

The direct MDR-TB patient costs were also analyzed to see if there were differences across lower, middle and higher income groups (Table 8). The responses were sorted into these groups based on the reported total family income before catching TB and the median figures were used for the comparison. The sum of the median direct patient costs was lowest for the lower income group (US$ 909) followed by the middle income group (US$ 1,437) and the higher-income group (US$2,210) (Table 8). The poorer group spent less on most elements, notably food, transport, supplementary diet and relocation. Again when we break the figures down among three groups the sample size for any one cost element can be small and so the results are only indicative. For example, the cost of medicines for adverse events for the higher-income group is based on responses from 2 patients.

Table 8: Median MDR-TB direct patient costs by income level, 2013 (US$)[18]

Direct patient costs by income group	MDR-TB								
	Lower income			Middle income			Higher income		
	Median	Number of responses	Responses as % of sample group	Median	Number of responses	Responses as % of sample group	Median	Number of responses	Responses as % of sample group
Patient health care costs - sum	**$ 101**			**$ 134**			**$ 139**		
Sum patient direct pre-/diagnosis costs	**$ 0**			**$ -**			**$ 0**		
Administrative charges	$ 0	4	100%	$ -	5	100%	$ 0	7	64%
Tests	$ -	4	100%	$ -	5	100%	$ -	7	64%
X-rays	$ -	4	100%	$ -	5	100%	$ -	10	91%
Medicines	$ -	4	100%	$ -	5	100%	$ -	11	100%
Hospitalization	**$ 2**	**48**	**86%**	**$ 4**	**44**	**80%**	**$ 9**	**41**	**73%**
Sum Adverse events and follow-up tests - sum	**$ 99**			**$ 131**			**$ 129**		
Adverse event fees	$ -	1	3%	$ -	2	6%	$ -	2	11%
Adverse event medicines	$ -	1	3%	$ 5	2	6%	$ -	2	11%
Follow-up fees, tests and drugs	$ 99	7	13%	$ 125	26	47%	$ 129	16	29%
Patient transport - sum	**$ 47**			**$ 99**			**$ 91**		
Transport – pre-/diagnosis	$ 5	4	100%	$ 6	5	100%	$ 10	10	91%
Transport – intensive treatment visits	$ 12	8	25%	$ 41	22	67%	$ 65	14	74%
Transport - continuation treatment phase	$ 30	20	100%	$ 38	15	88%	$ 15	25	96%
Transport - adverse events	$ -	1	3%	$ 13	2	6%	$ 1	2	11%
Patient food - sum	**$ 109**			**$ 189**			**$ 552**		
Food related to pre-/diagnosis visits	$ 2	4	100%	$ 26	5	100%	$ 13	10	91%
Food while hospitalized	$ 81	47	84%	$ 54	43	78%	$ 161	41	73%
Food related to intensive treatment visits	$ -	7	22%	$ 83	18	55%	$ 355	13	68%
Food related to continuation treatment visits	$ 26	20	100%	$ 26	15	88%	$ 23	25	96%
Patient accommodation - sum	**$ 77**			**$ 106**			**$ 121**		
Accommodation – pre-/diagnosis	$ -	4	100%	$ 16	5	100%	$ 8	7	64%
Accommodation – continuation treatment	$ 77	4	20%	$ 90	5	29%	$ 113	4	15%
Accommodation - adverse events	$ -	1	3%	$ -	2	6%	$ -	2	11%
Other									
Supplementary diet	$ 516	52	93%	$ 839	52	95%	$ 1,032	55	98%
Other costs for adverse events	$ -	1	3%	$ 3	2	6%	$ -	2	11%
Patient relocation	$ 59	5	9%	$ 67	10	18%	$ 275	7	13%
Sum direct patient costs	**$ 909**	**56**	**100%**	**$ 1,437**	**55**	**100%**	**$ 2,210**	**56**	**100%**
Sample groups									
MDR just diagnosed		4			5			11	
MDR intensive treatment		32			33			19	
MDR cont		20			17			26	
Total sample		56			55			56	

DS-TB direct patient costs

As stated earlier, it was only possible to interview 25 drug-susceptible (DS) TB patients due to the need to focus on MDR-TB patient costs. And for some questions there were only 3 or 4 responses. While the DS-TB results are, therefore, not robust, they are, nevertheless, useful for indicating possible challenges and for comparing with the MDR-TB results. Due to the small sample size we did not analyze the costs by location or income group.

The sum of the median direct costs for DS-TB patients was US$ 198 (IQM US$ 270) (Table 9).[19] Patients in the intensive phase suffered the highest cost, with a median of US$ 104 (IQM US$ 122).

[18] The IQM figures are not necessary for this comparison and are not shown due to lack of space.

[19] 5 of the 25 patients interviewed also provided information on pre-/diagnosis costs and these figures were included in the results.

Table 9. DS-TB direct costs by phase – 2013 (US$)[20]

	Number in sample	Inter-quartile mean	Median	Median IQR 25%	Median IQR 65%
Direct pre-/diagnosis costs	5	48	14	4	109
Direct intensive phase costs	12	122	104	10	231
Direct continuation phase costs	13	100	80	34	156
Sum of direct costs		**270**	**198**		

The DS-TB costs were also grouped by expenditure type (Table 10). This analysis shows that the highest cost group was again for supplementary diet (median US$ 226 and IQM US$ 224). The next highest group was patient food (median US$ 106 and IQM US$ 127). As in the case of MDR-TB patients, follow-up tests had a high cost (median US$ 84 and IQM US$ 75) but this may be because the figures may include some food and transport costs. Three of the 25 patients relocated (all attending Gondar) with a median cost of US$ 47 (IQM US$ 101).

[20] Five of the 25 patients in the intensive phases also provided information on diagnostic costs, which we included.

Table 10. Direct DS-TB patient costs by expenditure type – 2013 (US$)

Direct patient costs	DS-TB					
	Inter-quartile mean	Median	Median IQR 25%	Median iQR 75%	Number of responses	Responses as % of sample group
Medical services						
Patient direct pre-/diagnosis costs						
Administrative fees	$ 1	$ 0	$ 0	$ 3	5	42%
Tests	$ 3	$ 3	$ 0	$ 7	4	33%
X-rays	$ 2	$ 1	$ -	$ 6	5	42%
Medicines	$ 10	$ 1	$ -	$ 28	4	33%
Hospitalization	$ 34	$ 27	$ -	$ 85	9	36%
Adverse event fees						
Adverse event medicines						
Follow-up fees, tests and drugs	$ 75	$ 84	$ 23	$ 125	11	44%
Sum medical services	**$ 126**	**$ 117**				
Transport						
Transport – pre-/diagnosis	$ 11	$ 3	$ 2	$ 23	5	42%
Transport – intensive treatment visits	$ 25	$ 25	$ 8	$ 42	6	50%
Transport - continuation treatment phase	$ 11	$ 9	$ 3	$ 320	11	85%
Transport - adverse events						
Sum transport	**$ 46**	**$ 36**				
Food						
Food related to pre-/diagnosis visits	$ 24	$ 8	$ 2	$ 63	4	33%
Food while hospitalized	$ 47	$ 40	$ 19	$ 94	8	32%
Food related to intensive treatment visits	$ 47	$ 52	$ 13	$ 71	8	67%
Food related to continuation treatment visits	$ 9	$ 6	$ -	$ 19	9	69%
Sum food	**$ 127**	**$ 106**				
Accommodation						
Accommodation – pre-/diagnosis	$ 5	$ 5	$ -	$ 10	4	33%
Accommodation – continuation treatment						
Accommodation - adverse events						
Sum accommodation	**$ 5**	**$ 5**				
Other						
Supplementary diet	$ 224	$ 226	$ 103	$ 339	21	84%
Other costs for adverse events						
Patient relocation	$ 101	$ 47	$ 18	$ 240	3	12%
Sample group						
TB Intensive					12	
TB Continuous					13	
Total group					**25**	

Direct companion costs

DR-TB and MDR-TB patients often need support from a family member or friend and the direct costs to these companions can be significant (Table 11). Only a few of the DS-TB patients reported having companion assistance, and this was mainly when the patients were hospitalized. For MDR-TB, 67% of patients reported having companion assistance during the pre-/diagnostic phase, 29% during hospitalization and 24% while suffering from adverse effects. The median cost per DS-TB patient companion was US$ 121 and the median cost per MDR-TB patient companion was US$ 120. For both DS-TB and MDR-TB the highest cost element was for hospital attendants. It should be noted that information on companion costs may not be very reliable since it was generally provided by patients who may not have been aware of all the costs incurred by companions.

Table 11: TB and MDR-TB direct companion costs – 2013 (US$)

Companion costs - direct	DS-TB				MDR-TB			
	Inter-quartile mean	Median	Number of responses	Responses as % of sample group	Inter-quartile mean	Median	Number of responses	Responses as % of sample group
Direct								
Diagnosis travel	$ 11	$ 11	1	7%	$ 11	$ 7	14	67%
Diagnosis food and accommodation	$ 21	$ 21	1	7%	$ 24	$ 16	14	67%
Hospital attendant	$ 98	$ 89	7	47%	$ 89	$ 97	49	29%
Adverse events companion	$ -	$ -	0	0%	$ 2	$ -	5	24%
Sum Direct Costs	**$ 131**	**$ 121**			**$ 127**	**$ 120**		

8. Income losses

The income lost by patients as a result of getting a proper diagnosis and receiving treatment varies with factors such as the time spent in hospital, the distance from home to the facility, the method of travel, the numbers of outpatient visits and the waiting time. As can be seen from Table 12 a significant amount of time was spent by both TB and MDR-TB patients.

Of the 169 MDR-TB patients, 138 (82%) were hospitalized at some stage and on average each spent 80 days in hospital. And significant time was spent on getting a diagnosis – an average of 3 visits with an average 22 hours spent per visit of. The longest times were generally reported by patients at Gondar and the shortest by patients at ALERT.

Although the sample of TB patients was too small to draw firm conclusions, it is worth noting that 36% of patients were hospitalized at some stage and on average they each spent 40 days in hospital. Again, significant time was spent on getting a diagnosis – 3 visits with an average time spent per visit of 43 hours. Of the 5 responses on diagnosis visits, 4 responses were from Gondar and these had the longest times (perhaps indicating the large catchment area and the long distance some people had to travel).

Table 12. Time spent seeking and receiving diagnosis and treatment

Time spent on diagnosis and treatment	DS-TB		MDR-TB	
	Data	Number of responses	Data	Number of responses
Total interviewed	25		169	
Number of visits to get diagnosis	3	6	3	27
Average (IQM) hours per diagnosis visit	43	5	22	21
Number of patients hospitalized	9	9	138	138
% of patients hospitalized	36%		82%	
Days spent in hospital (median)	40	9	80	138
Number of visits per week (intensive treatment)	6	15	4	71
Hours per visit (intensive treatment)	1.5	8	1.3	1.3
Number of visits per month (continuation treatment)	3	12	2	62
Hours per visit (continuation)	1.3	11	4	62
Number of follow-up visits per month	1.4	16	1.1	117

Patients suffered losses of income related to the time that they spent seeking diagnosis and receiving treatment (Table 13). The median costs were US$ 0 for DS-TB, US$ 220 for the intensive phase of MDR-TB

and US$ 73 for the continuation phase of MDR-TB.[21] The greatest income losses were due to hospitalization.

It should be noted that these figures do not include income losses related to illness (periods of time when the person is too ill to be productive).

Table 13. Median patient income losses due to seeking and receiving care phase – DS-TB and MDR-TB, 2013 (US$)

	DS-TB			MDR-TB		
	Median	**Median IQR 25%**	**Median IQR 75%**	**Median**	**Median IQR 25%**	**Median IQR 75%**
Indirect pre-/diagnosis costs	-	-	30	-	-	8
Indirect treatment costs						
Intensive phase	-	-	34	220	89	374
Continuation phase	-	-	4	73	1	375
Sum of indirect costs by phase	**-**			**293**		

Patient income losses were less for the lower income group than for the middle and higher income groups. However, these estimates were based on the level of income reported by each patient and it is therefore, logical, that the poorer patients suffer smaller losses.

Companions can also suffer significant losses of income while accompanying patients (Table 14). The median income loss for the companions of the DS-TB patients who reported having this assistance was US$ 158 (IQM US$ 201) and the loss for the companions of the MDR-TB patients who reported this assistance was US$ 213 (IQM US$ 331).

Table 14. Companion income losses – 2013 (US$)

Companion income losses	**DS-TB**				**MDR-TB**			
	Inter-quartile mean	**Median**	**Number of responses**	**Responses as % of sample group**	**Inter-quartile mean**	**Median**	**Number of responses**	**Responses as % of sample group**
Indirect								
Diagnosis income loss	$ 31	$ 31	1	4%	$ 7	$ 6	11	52%
Treatment income loss (intensive, continuation and follow-on)	$ 72	$ 38	6	24%	$ 302	$ 206	15	10%
Hospitalization	$ 98	$ 89	7	28%	$ 22	$ -	40	24%
Sum Indirect Costs	**$ 201**	**$ 158**			**$ 331**	**$ 213**		

Information was also collected on the impact of DS-TB and MDR-TB on patient employment and on overall patient and family income (Table 15). Of the 25 DS-TB patients interviewed, 19 (76%) reported losing their jobs and 23 (92%) reported an average income reduction of 100% for themselves and 50% for their families.[22] Of the 169 MDR-TB patients, 121 (72%) reported losing their jobs and 133 (79%) reported an average income reduction of 100% for themselves and 33% for their families.

[21] These figures were based on the income levels reported by the patients before becoming ill from TB. Since income levels were much lower after becoming ill, and in many cases were reduced to zero, using those figures would reduce the income loss considerably and inappropriately.
[22] The median of the reported pre-illness income figures was lower for MDR-TB patients than for TB patients, which may indicate that MDR-TB patients were generally poorer than TB patients at the time of infection. However, the sample of TB patients was too small to draw any conclusions.

Table 15. Impact of DSTB and MDR-TB on jobs and income

Impact on jobs and income	DSTB	MDR-TB
Number of interviews	25	169
Number of patients who lost their jobs due to TB	19	121
% of patients who lost their jobs due to TB	76%	72%
Number of patients who left school due to TB	1	10
Number of patients who reported income change	23	133
% of patients who reported income change	92%	79%
Monthly IQMpatient income before TB	$43	$54
Monthly median patient income at time of interview	$0	$0
Monthly median total income before TB	$75	$81
Monthly median total income at time of interview	$38	$54
% patient income change due to TB	-100%	-100%
% total income change due to TB	-50%	-33%

9. Coping mechanisms

Patients financed the costs in various ways. As can be seen in Table 16, six (24%) of the DS-TB patients sold property, 3 (12%) leased out property and 14 (56%) took out loans. Sixty-five (38%) of the MDR-TB patients sold some type of property to pay for treatment, 12 (7%) leased out property and 69 (41%) took out loans.[23] In both cases almost all the loans were without interest, indicating that they were from family or friends.[24]

One of the MDR-TB patients had health insurance but did not report reimbursement because the interview was done during the diagnostic stage which was possibly too early to process any claim.

Six (24%) of the 25 DS-TB patients and 108 (73%) of the 148 MDR-TB patients under treatment received vouchers funded through donor assistance, mostly for food, transport and house rent. The DS-TB patients received an average of US$ 76 in vouchers and the MDR-TB patients received an average of US$ 33. The difference is because the food vouchers for DS-TB patients had an average value of US$ 32 whereas the food vouchers for MDR-TB patients had an average value of US$ 10. We did not extrapolate the reported value of the vouchers across the whole treatment period as they were donor funded and it was not guaranteed that they would continue across the whole period.

The total direct cost of US$ 198 for a DS-TB and US$ 1,341 for an MDR-TB patient represents 44% and 208% of the annual median post-illness family income.

[23] Some of percentages overlap as in some cases the same patients sold property, took out loans and leased out property.
[24] It is worth noting that the family and friends of poor people are generally also poor which mean that they also have to make sacrifices.

Table 16. Financing mechanisms – 2013 (currency in US$)

Financing mechanisms	DSTB		MDR-TB	
	N /Value	% of total sample	N /Value	% of total sample
Number of interviews	25		169	
Patients who sold property	6	24%	65	38%
House	6	24%	6	4%
Farm	6	24%	4	2%
Livestock	6	24%	38	22%
Other	6	24%	12	7%
Patients who leased out property	3	12%	12	7%
House	3	12%	2	1%
Livestock	3	12%	2	1%
Land	3	12%	7	4%
Other	3	12%	0	0%
Patients who took out loans	14	56%	69	41%
Number of patients with Health insurance	0	0%	1	1%
Number of patients reimbursed by health insurance	0	0%	0	0%
Number of patients who received vouchers	6	24%	108	73%
Average value of vouchers per patient	$ 76		$ 33	
Patients who received vouchers and who sold property and/or took loans	4	16%	50	30%
Annual median family income post TB onset	$ 452		$ 645	
Total mean direct patient cost	$ 198		$ 1,341	
Total direct patient cost as a % of annual family income	44%		208%	

The MDR-TB patients in the intensive phase had been on average 5.9 months under treatment when they were interviewed. Those in the continuation phase had been in on average 6.3 months under treatment in that phase when they were interviewed. Assuming the continuation phase patients had already completed 10 months of intensive treatment that would be a total of 16.3 months under treatment. The question on vouchers did not specify if the response should just be for the continuation phase or the combined intensive and treatment phase. For the purposes of estimating, we assumed that the value of the vouchers covers the whole treatment phase up to the interview. On that basis the average value of the vouchers per patient for the period under treatment was US$ 7.76 per month for the MDR-TB patients in the intensive phase and US$ 1.39 per month for the MDR-TB patients in the continuation phase. If, instead, we assume that the total value of the vouchers only relates to the continuation phase the average per month would be US$ 3.62. In either case the value of the vouchers appears to be very low compared with the average of one month's total direct patient cost for an MDR-TB patient of US$ 56.

Four (16%) of the TB patients and 50 (30%) of the MDR-TB patients who received vouchers also sold property or took loans, providing additional evidence that the value of the vouchers might have been insufficient.

When asked if and how the government could assist with vouchers both the TB and MDR-TB patients replied that they would like assistance with house rental costs and money to start work.

From the reported figures it appears that the voucher schemes differ across the 3 hospitals and according to patient circumstances. While this initial analysis is indicative – especially as they are not broken out by length of time under treatment and the questions did not define the time period to be used - an evaluation of the system would be important, including a review of why only 25% of TB patients and 73% of MDR-TB patients reported receiving vouchers and why the total value of vouchers for TB patients was higher than the figure for MDR-TB patients.

10. Summary of findings

The key findings are summarized in Table 17 and described in the narrative. These show clearly that the economic impact on MDR-TB patients and their families is much higher than on DS-TB patients and that the impact on MDR-TB patients is catastrophic. When reviewing the figures it is important to remember that these should be regarded as estimates due to the study limitations described in the next section.

Table 17. Key findings

	DS-TB Median	MDR-TB Median
Direct patient costs	US$ 198	US$ 1,341
Direct companion costs	US$ 48	US$ 50
Income lost by patients while seeking care	US$ 0	US$ 293
Income lost by companions while accompanying patients	US$ 46	US$ 39
Patients who lost jobs	76%	72%
Patients who suffered reduction in income	92%	79%
Reduction in patient income after getting TB	100%	100%
Reduction in family income after patient got TB	50%	33%
Direct patient costs as % of annual family income	44%	208%

The direct costs to MDR-TB patients for diagnosis and treatment were significant, with a median direct patient cost of US$ 1,341. Additional median direct costs of US$ 50 were incurred by companions. The direct costs to DS-TB patients were much less, with a median of US$ 198. An additional median cost of US$ 46 was incurred by companions.

The MDR-TB direct costs were almost 7 times the direct costs for DS-TB patients due to the longer time period for the treatment and greater travel requirements (since treatment only occurs in one central and one regional locations).

The sum of the median direct patient MDR-TB costs was US$ 1,634 in Addis Ababa, much higher than the figure of US$ 906 in Gondar.[25] Costs were higher in Addis Ababa in all categories, especially patient food, transport, accommodation and supplementary diet, except for relocation which was higher in Gondar, presumably because more patients lived far from that city.

The analysis of costs by income level indicated that, in general, MDR-TB patients with lower income levels incurred fewer costs than other patients. The total of the median direct patient costs was lowest for the lower income group (US$ 909) followed by the middle income group (US$ 1,437) and the higher-income group (US$ 2,210, Table 8). The poorer group spent less on most elements, notably food, transport, supplementary diet and relocation. This suggests that patients will spend more on such items such as diagnoses, tests and supplemental food if they have more disposable income. For example, one patient from Gondar indicated that rather than wait a lengthy period to get a TB diagnosis, he had traveled to Addis Ababa and stayed there until he received a diagnosis.

[25]The analyses by city and by income group were not done for DS-TB patients as the sample was too small to have meaningful results when split.

The income lost by patients as a result of getting a proper diagnosis and receiving treatment varies with factors such as the time spent in hospital, distance from home to the facility, method of travel, numbers of outpatient visits and waiting time. Of the 169 MDR-TB patients, 82% were hospitalized and on average each spent 80 days in hospital. Significant time was spent on getting a diagnosis – 3 visits with an average time spent per visit of 22 hours. Although the sample of TB patients was too small to draw firm conclusions, it is worth noting that 36% of patients were hospitalized at some stage and on average they each spent 40 days in hospital. Again, significant time was spent on getting a diagnosis – 3 visits with an average time spent per visit of 43 hours. Of the 5 responses on diagnosis visits 4 were from Gondar and these had the longest times (perhaps indicating the large catchment area and the long distance some people had to travel).

Patients suffer losses of income related to the time that they have to spend seeking diagnosis and receiving treatment. The median income loss for the 25 DS-TB patients was zero while the median loss for the 169 MDR-TB patients was US$ 293. The greatest cause of income loss was hospitalization. It should be noted that these figures do not include income losses related to illness.

The impact on patient employment and on overall patient and family income was catastrophic. Of the 25 DS-TB patients, 19 (76%) reported losing their jobs and 23 (92%) reported an average income reduction of 100% for themselves and 50% for their families. Of the 169 MDR-TB patients, 121 (72%) of them reported losing their jobs and 133 (79%) reported an average income reduction of 100% for themselves and 33% for their families.

Patients financed the costs in various ways. Six (24%) of the TB patients sold property, 3 (12%) leased out property and 14 (56%) took out loans. Sixty five (38%) of the MDR-TB patients sold some type of property to pay for treatment, 12 (7%) leased out property and 69 (41%) took out loans. In both cases almost all the loans were without interest, indicating that they were from family or friends.

One of the MDR-TB patients had health insurance but did not report reimbursement because the interview was done during the diagnostic stage which was possibly too early to process any claim.

Six (24%) of the 25 DS-TB patients and 108 (73%) of the 148 MDR-TB patients under treatment received vouchers funded through donor assistance, mostly for food, transport and house rent. The DS-TB patients received an average of US$ 76 in vouchers and the MDR-TB patients received an average of US$ 33. The difference is because the food vouchers for DS-TB patients had an average value of US$ 32 whereas the food vouchers for MDR-TB patients had an average value of US$ 10. The average value of the vouchers per patient for the period under treatment was US$ 7.76 per month for the patients in the intensive phase and US$ 1.39 per month for the patients in the continuation phase. The value of the vouchers appears to be very low compared with the average of one month's total direct patient cost of US$ 54).

The total direct cost of US$ 198 for a DS-TB and US$ 1,341 for an MDR-TB patient represented 44% and 208% of the annual median post-illness family income. Although the values of the vouchers cannot be compared directly with the costs because they relate to different time periods it is noticeable that in the case of MDR-TB the average total value of US$ 33 is less than an average of one month's total direct patient cost of US$ 56. Four (16%) of the TB patients and 50 (30%) of the MDR-TB patients who received vouchers also sold property or took loans, providing additional evidence that the value of the vouchers might have been insufficient. When asked if and how the government could assist with vouchers both the TB and MDR-TB patients replied that they would like assistance with house rental costs and money to start work.

As noted in the introduction, an estimated 29% of the patients diagnosed with MDR-TB did not start treatment and 3% of the patients who started treatment defaulted. Unaffordable patient costs with limited or no social support could be a contributing factor, along with geographical access. This study did not, unfortunately, have the resources to try to find these patients and determine why they did not seek or continue treatment so a relationship between these factors remains theoretical.

11. Limitations

This study faced several limitations. Most importantly, due to limitations in time and budget, only patients on DS-TB and MDR-TB treatment who attended the three public hospitals that provide MDR-TB services were included in the study. The study, therefore, excluded patients who were not present at the hospital when the interviews were conducted – persons who were not seeking diagnosis, patients diagnosed with MDR-TB who had not started treatment, and patients who had defaulted from treatment. To interview these patients would require finding them in their homes which would be beyond the resources available for this study. Unfortunately, however, these are the very patients most likely to have had economic barriers to access.

Another important limitation is that all interviews were conducted during a short period of time and respondents were only interviewed once. The results had to be extrapolated over the treatment periods to arrive at an average total cost per patient. This may be less precise than capturing the total costs for an individual patient but that would require follow-up of a sample of patients during their full treatment period, which may take more than 2 years for MDR-TB patients. Such lengthy studies would significantly delay the identification and implementation of mitigation options.

All studies using questionnaires suffer from recall bias. To partly address this problem we only asked the respondents about costs made in the past three months, and about major one-off costs. Patients may still, however, have failed to remember some costs especially under the category 'other costs' and in some cases questions may have been skipped or respondent may not have wanted to answer.

The methodology may cause some inaccuracies in the estimates, for example:

- Cost patterns that were reported at one point in time may change over the course of treatment period (for example a person who paid for housing at the time of the interview may move in with a friend later);
- It was not possible to identify periods of reduced income because the points of time at which the patients lost their jobs were not identified.
- Extrapolation was applied using the Ethiopian norms for minimum recommended treatment. Additional time periods for patients who were under treatment for longer periods were not taken into account.
- Patients with higher levels of income spent more. Although the use of inter-quartile means removed some outliers, the costs could still have been influenced by the costs of these patients.
- The figures for income losses were based on patients' estimates of their income levels. These costs are, therefore, greater for patients with higher income levels. This would need to be taken into account if the figures are to be used to determine support payments to patients.

- We did not collect information on the type of jobs held by the patients. This could have been useful since civil servants, for example, may not lose income because they can take sick leave.
- Data was not sought out on the time lost from work due to the illness – only the time spent in accessing diagnosis and treatment. While comparisons of income before and after becoming ill are feasible the period of lost work was not ascertained.
- The intention of the study was to interview a total of 250 patients, 100 with DS-TB and 150 with MDR-TB. Due to time constraints it was decided to focus on MDR-TB patients to ensure that at least 150 were interviewed. This was achieved with a total of 169 MDR-TB patients interviewed, exceeding the target by 19 patients. However, there was only time to interview 25 DS-TB patients and these results should, therefore, be used with caution.
- It was also not possible to reach the target of 50 MDR-TB patients who were just diagnosed as there were insufficient numbers of patients in that category during the limited time available for the interviews. The targets for the other two categories of MDR-TB patients were, however, exceeded.
- In some cases, like relocation, only a small number of the 169 MDR-TB patients had that experience and the average costs were, therefore, estimated from a smaller sample.
- Some of the one-off costs assume that the related event will not reoccur. For example, hospitalization costs assume that the status at the time of the interview will not change later. If a patient was not hospitalized it was assumed that he or she would not be hospitalized later and if the patient was hospitalized it was assumed that he or she would not be admitted again. This is the same for some income items (e.g., insurance) and coping mechanisms.
- Costs related to co-morbidity (e.g., AIDS) are not included.
- There were only 3 retreatment cases out of the sample of 25 DS-TB patients and we did not, therefore, adjust or separate the length of treatment for these patients.
- Despite quality control procedures over the completion of the questionnaires it became apparent during the analysis that some data was not corrected and some had errors. Where this was identified this data were not included in the analysis.

12. Comparisons with other studies

We reviewed some other recent studies from Ethiopia and other countries to try to compare results. However, in many cases it is difficult as the situations and methodologies are often different. The studies reviewed were as follows:

a) A study on the costs of patients with TB and human immunodeficiency virus (TB-HIV) in Ethiopia was published in 2010 (Vassall et al.)[26]. This study included an estimate of the mean total pre-treatment cost for persons with TB but without HIV, which was US$ 129 (median US$ 15). This amounted to 35% of the household mean annual income. Total mean treatment costs for patient with only smear-positive TB came to US$ 225 for out-patients and US$ 327 for in-patients (49% and 71%, respectively, of the monthly household income).
b) An unpublished study of TB patient costs in Ethiopia involved interviews with 222 patients at 12 health centers in Addis Ababa in 2011. The total median cost (direct and indirect) of TB Patient was

[26] A separate study was conducted of TB patient costs in Addis Ababa in 2011 but has not yet been published.

4682.5 Birr (US$ 272) which was 26 % of the patient's median individual annual income. The cost during TB diagnosis and treatment was higher than during pre-diagnosis. The median patient monthly income decreased by 33.3% after catching TB and the total household income decreased by 72%.

c) A study (Mauch, Bonsu et al., in 2013) compared the costs of TB drug sensitive (DS) treatment for Ghana, Vietnam and the Dominican Republic[27]. 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.

d) In a Dominican Republic study (Mauch, Melgen et al., 2013) 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 retreatmentpatients, 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.

e) The corresponding pilot studies in Kazakhstan and Indonesia, which used the same methodology, had similar findings. Total costs were much higher in both countries but fewer patients lost their jobs and suffered income losses, and fewer patients had to sell property or take loans. However, fewer patients received assistance from government of other organizations in those two countries.[28]

Apart from the corresponding pilot studies, it is not possible to accurately compare the results of this study with the results of those listed above, but it can be seen that the costs and losses of income are in a similar range as those found in the other studies.

13. Policy options

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.

Mitigation recommendations from other studies

The previous studies referenced here made several recommendations to alleviate the problems identified for TB patients. The three-country report (Mauch, Bonsu et al., 2013) recommended:

- 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 including TB-related out-patient costs in social protection schemes

In terms of actions taken, it is reported that in Ghana:

[27] The studies were carried out in 2009/10.
[28] A report comparing the findings of the three countries will be published in the future.

- Policy makers agreed to include TB care interventions as part of its pro-poor strategies in the delivery of health care;
- Nutrition guidelines were developed for TB patients;
- Study findings were key in developing the successful Global Fund Round 10 TB proposal;
- The NTP focused more on gender-sensitive challenges of poor TB patient; and
- The Parliamentary sub-committee on health has increased insurance coverage for all TB patients for health-related costs other than (free) anti-tuberculosis treatment.

Vietnam, reportedly, decided on some different approaches:

- 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;
- Switch from the 8-month to the 6-month anti-tuberculosis treatmentregimen, which will help reduce the treatment time and travel costs for follow-up tests;
- Expand TB services network to provincial general hospitals, all major public non-MOH hospitals and private hospitals;
- Plan ways to provide social and economic support to TB patients in each district; and
- Mobilize support for TB patients from organizations such as farmers and women's unions.

Finally, in the Dominican Republic the Ministry of Health decided in 2011 to:

- Allocate public funds for food supplements for TB patients; and
- Include in- and outpatient TB services in the national health insurance schemes.

Based on the above examples, it is clear that there are several options open to the Government of Ethiopia to address the issues identified in the study once it has reviewed and accepted them. Important places to start in the short term would include a review of the expansion of access to MDR-TB services and an analysis of the existing voucher system.

Mitigation options and recommendations for Ethiopia

In November, 2013, a workshop was held in Addis Ababa to review the Ethiopia MDR-TB patient costs, discuss mitigation options and make recommendations on which options would be suitable for Ethiopia. Following the workshop the results were presented to the Director – Infectious Diseases and team members including the NTP Manager.

1. **Ensure that policy of free care for all MDR-TB services is fully implemented**. Currently some services are either unavailable at designated MDR-TB diagnosis and treatment centers or there are interruptions in key supplies, such as diagnostic supplies and ancillary drugs, and so those have to be obtained from the private sector and either patients or supporting partner organizations have to pay.
2. **Bring services closer to patients.** Designated MDR-TB treatment initiation services are presently expanding across regions andout from hospitals to satellite centers which will reduce patient expenditures on transport and patient time and should reduce detection and treatment delays. However, the expansion of diagnostic capacity is not keeping up with that of treatment capacity which results in logistical challenges in specimen transfer and delays in getting results. This applies to initial diagnosis and follow-up testing. Treatment monitoring could be improved and speeded up by greater involvement of health extension workers and community health workers (health development army).
3. **Detect and treat cases earlier**. Detecting cases earlier should to reduce the severity of illness and thus the amount of income lost due to inability to work as well as direct patient costs related to having to spend more time at a hospital rather than at a satellite center. Detection can be made earlier by expanding the role of health extension workers and community health workers more for

active case finding and contact tracing. Increasing and improving active cases can also be achieved by looking for TB signs and symptoms at all health service delivery points including family planning and under-five clinics. Ensure better referral system from health centers and primary hospitals (including the private sector) where patients are first seen as well as feedback to those facilities, using the guidelines. Implement a triage system where suspects are identified at first registration and are then separated from other patients and use a fast track process to make sure diagnosis takes place as quickly as possible.

4. **Raise the awareness of health workers**. Provide education and training of primary level health workers to recognize suspects and ensure speedy diagnosis, and to follow up on cases and contact tracing.
5. **Include out-of-pocket costs (transport, food, etc.) in social protection schemes**. Review, standardize and expand current social protection schemes funded by NGOs and partner organization while seeking to have the schemes taken over by the government in the longer term. Corporate social responsibility is not considered a major option due to limited numbers of large employers but be considered.
6. **Use social health insurance**. Advocate with MOH to incorporate TB services in the future social health insurance system to provide sustainable financing. Also advocate for social protection to be included in the benefits package on the grounds that this will reduce severity of illness and transmission and thus save on treatment costs.
7. **Improve employment protection**. Ensure employers followregulations and policies that mandate pay employees a portion of salary while they are ill. Also advocate for patients to be able to return to previous positions once they are cured. However, ensure that persons in jobs where there is a high transmission risk (e.g. teachers, health workers) do not return to work until fully cured.
8. **Increase employment possibilities**. Develop ideas to involve MDR-TB patients in different income generating activities and advocate government to support, for example through microfinance.
9. **Consistency across social assistance programs and over time.** The data collected on vouchers indicates that the amounts provided are very low compared with the patient costs and taking into account reductions in income. In addition there may be inconsistency in the amounts provided across facilities and over time. It is recommended that the government develop a standard policy that is applied to all facilities and maintained over time.

14. Recommendations

Based on the experiences gained in the process of conducting the study and on the discussions in the workshop a number of recommendations were made.

- The sample of DS-TB patients interviewed in this study was small due to logistical difficulties. Nevertheless the results indicate some issues related to financial access for DS-TB patients and the study should therefore be repeated with a larger sample over a range of facilities that represent the country as a whole. This can be done locally without external technical assistance as the local researchers gained sufficient experience in this area.
- It appears that the number of visits to facilities and the average length of stay in hospitals may be more than proposed in international norms. These should be reviewed to see if they can be reduced which could have a positive impact on patient costs and income.
- Information should be collected on existing social protection systems as background to the study and to better pose questions and analyze answers.
- A key aspect of patient access relates to the availability of MDR-TB diagnostic services. The functionality of services (i.e. stock-outs of test materials), distance from a patient's home to a provider of these services, and time that it takes to get results are important factors in reducing

patient and provider costs and reducing the time that a patient can infect others. Information on these factors would be important background to the study and in the analysis of mitigation options.

- It is important to have better data in regards to: (1) delays in seeking diagnosis; (2) delays or non-seeking of treatment after diagnosed positive; and (3) interruptions and/or defaults from treatment. If possible, interviews with these persons should be collected routinely and, if not, a sample of these persons should be added to annual facility-based interviews.
- As a longer term monitoring process, a few questions on patient costs and mitigation should be included in patient satisfaction surveys and these should be routinely analyzed and reported.
- These studies should be conducted every year as part of the monitoring of access.
- As the MDR-TB services are expanded geographically, the studies should be expanded into those areas.
- An important contribution to the knowledge base would be to conduct follow-up studies in the three countries where TB patient costs were analyzed – Ghana, Vietnam and the Dominican Republic – to see what policy changes were made and what impact they had on those costs as well as on levels of initiation and completion of treatment.

ANNEXES

Annex 1: References

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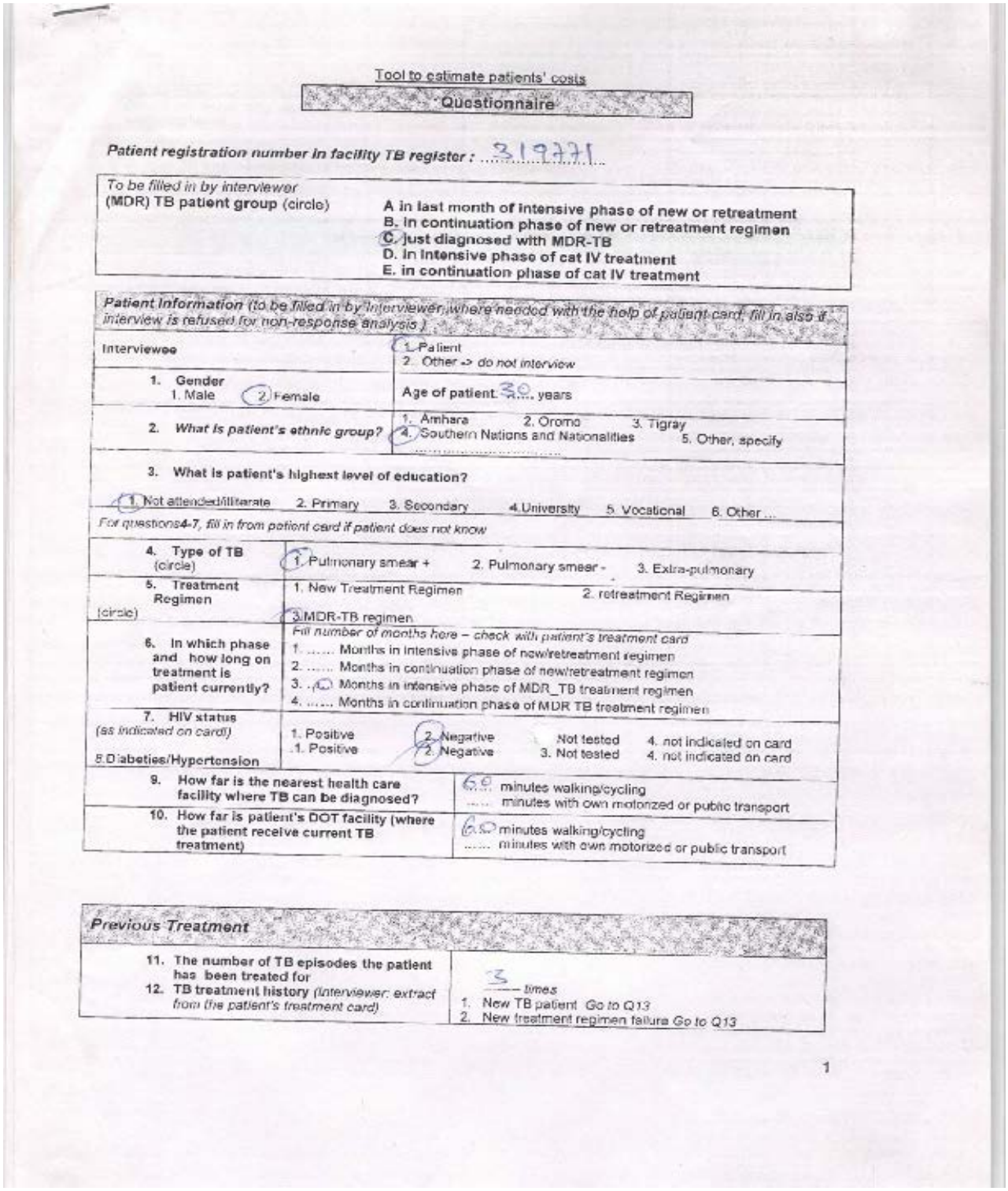
Annex 2. Questionnaire used in Ethiopia



Tool to estimate patients' costs

Questionnaire

Patient registration number in facility TB register : 319771

To be filled in by interviewer	
(MDR) TB patient group (circle)	**A in last month of intensive phase of new or retreatment** **B. in continuation phase of new or retreatment regimen** **C. just diagnosed with MDR-TB** **D. in intensive phase of cat IV treatment** **E. in continuation phase of cat IV treatment**

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 2. Other -> *do not interview*
1. Gender 1. Male (2) Female	**Age of patient:** 30 years
2. *What is patient's ethnic group?*	1. Amhara 2. Oromo 3. Tigray (4) Southern Nations and Nationalities 5. Other, specify .....
3. What is patient's highest level of education? (1) Not attended/illiterate 2. Primary 3. Secondary 4.University 5. Vocational 6. Other ...	
For questions4-7, fill in from patient card if patient does not know	
4. Type of TB (circle)	(1) Pulmonary smear + 2. Pulmonary smear - 3. Extra-pulmonary
5. Treatment Regimen (circle)	1. New Treatment Regimen 2. retreatment Regimen (3) MDR-TB regimen
6. In which phase and how long on treatment is patient currently?	*Fill number of months here – check with patient's treatment card* 1. ..... Months in intensive phase of new/retreatment regimen 2. ..... Months in continuation phase of new/retreatment regimen 3. (4) Months in intensive phase of MDR_TB treatment regimen 4. ..... Months in continuation phase of MDR TB treatment regimen
7. HIV status *(as indicated on card)*	1. Positive (2) Negative Not tested 4. not indicated on card
8.Diabeties/Hypertension	1. Positive (2) Negative 3. Not tested 4. not indicated on card
9. How far is the nearest health care facility where TB can be diagnosed?	60 minutes walking/cycling ..... minutes with own motorized or public transport
10. How far is patient's DOT facility (where the patient receive current TB treatment)	60 minutes walking/cycling ..... minutes with own motorized or public transport

Previous Treatment

11. The number of TB episodes the patient has been treated for	3 times
12. TB treatment history *(interviewer: extract from the patient's treatment card)*	1. New TB patient *Go to Q13* 2. New treatment regimen failure *Go to Q13*

1

	3. Retreatment regimen failure *Go to Q13* 4. treatment after default *Go to Q12a* 5. TB relapse *Go to Q13* 6. Others
a) The treatment card indicated that the patient had default treatment. Why was previous treatment not completed?	1. Lack of money for treatment costs 2. Drug side effects 3. distance to facility 4. Other (specify): .....
b) If on Cat IV treatment, how long has the patient been on TB treatment before being diagnosed with MDR-TB?	18 Months

Questions 13-14 apply to PATIENTS IN THE newly diagnosed phase of new and retreatment regimen and newly diagnosed MDR-TB patient. FOR OTHER PATIENTS, GO TO QUESTION 15.

13. How many visits related to TB symptoms did the patient make before receiving the diagnosis of (MDR-)TB at this facility (this includes the visit in which the patient received the diagnosis) *Note for interviewer: fill out the total number of visits after the table below (Q144) has been filled*	3 visits

2

14. About how much did each of these visits cost before the patient was diagnosed with TB, including the visit when patient actually received the 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

	Health Facility	Total Time spent per visit (in minutes, includes travel time)	Administrative Costs (consultative, registration)	Test costs (for sputum or other except X-ray)	X-ray costs (includes sending x-rays to radiologist, travel & fees)	Drug costs (all kinds total)	Travel Costs (return total)	Food costs (total)	Accommodation Costs (total)	Loss of Income of patient	Sub-Total costs per visit	Insurance Reimbursement (if yes: amount and for what, if no n/a	Accompanied by someone else (circle correct answer)	Travel costs of accompanying person (return total)	Accommodation and food costs of accompanying person (total)	Loss of income of accompanying persons
Visit 1	Health Station	120m	–		120	100	10	20			250		Yes / No			
Visit 2	"	120	–	–	100	–	20	50			170		Yes / No			
Visit 3		120	–	–	–	–	50	100			150		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			

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Treatment Costs (For patient not currently on treatment, go to Q29)

Costs related to DOT (Questions 15 through 19 are for patients at the intensive phase only)

15. a) Where was the patient taking TB drugs the majority of the time during the last three months?

1. Health facility / hospital 2. Home (go to Q20) 3. Community 4. Workplace
If at home, go to Q 29

b) How many times per week does the patient go there to take drugs? .....times

16. How long does it take the patient to get there the majority of the time? (one way)	.... Minutes walking ..... Minutes with transport other:.....
17. How long does one of these visits take on average, including time on the road and waiting time (round trip)?	..... minutes
18. From patient's home to the DOT facility, how much does transportation cost? (round trip)	.....
19. How much does the patient spend on food on the road during the visit to DOT facility?	.....

Costs related to picking up the TB drugs – where drugs are currently picked up(Questions 20 through 26 are for patients at the continuous phase only

20. How often does the patient travel to the health facility / hospital for picking up TB drugs? *If the patient never has to pick up TB drugs, fill out 'zero' and go to Q27*	..... Times / month
21. How long does it take the patient to get there (one way) the majority of the time?	.....minutes walking ..... minutes with own transport ..... minutes with public transport
22. How long does one of these visits take on average, including time on the road and waiting time (round trip)?	..... minutes
23. From patient's home to the facility, how much does transportation cost? (round trip)	.....
24. If the patient goes to a facility to pick up drugs, how much does the patient spend on food on that day? (on the road, while waiting, etc.)	.....
25. a) Does the patient have to pay administration fees when picking up TB drugs? *If No, go to Q26.* b) If YES, how much?	1. Yes 2. No .....
26. a) Does the patient have any accommodation costs when picking up TB drugs? *If No, go to Q27.* b) If YES: how much?	1. Yes 2. No .....

Costs related to check-ups and follow-up tests during treatments

27. a) Did the patient ever have to go to the health facility for follow-up tests during the last three months? *If No, go to Q28.*	1. Yes 2. No
b) If yes, how many times?	..... Times
c) If yes, did the patient have to pay any additional costs for follow-up tests during the entire period?	1. Yes 2. No
d) If so, what kind of tests and how much? Fees..... Sputum /lab tests..... X-ray..... TB Drugs ..... Other Drugs..... Other.....	Total: .....

Guardian Costs related to DOT, picking up drugs, and follow-up tests during treatment	
28. a) Did someone accompany the patient on visits related to DOT, picking up drugs, and follow-up test visits or collect TB drugs during the last three months? *If No, go to Q29.*	1. Yes 2. No
b) *If YES,* on how many visits was the patient accompanied or someone collected the drugs for patient?	..... times
c) Did this accompanying person(s) lose income due to accompanying the patient or collecting drugs for patient?	1. Yes 2. No If yes, how much in total .....

Hospitalization	
Note to interviewer: if the patient is still hospitalized, ask about situation up to and including time of interview	
29. Has the patient been hospitalized at any time before (due to current TB) or during current TB treatment? *If No, go to Q36.*	1. Yes 2. No
30. If YES: how many days in total did the patient stay at the hospital?	..... days
31. How much did the entire hospital stay cost? Hospital administration fees: ..... Sheets/Linen: ..... Food (not provided by hospital): ..... Transport (return): ..... Drugs: ..... Tests: ..... Other fees:	Total: .....
32. Did any attendants stay with the patient while patient was in the hospital? *If No, go to Q 35*	1. Yes 2. No
33. If YES: How many days did he/she/they stay with the patient (sleep at the hospital or nearby)?	..... Days
34. Were there any extra costs for attendants for staying at the hospital? Accommodation (hospital or other): ..... Food: ..... Transport: ..... Loss of income: ..... Other:	1. Yes 2. No Total Costs: .....
35. a) Did any <u>other</u> family/ visit the patient while in hospital? *If No, go to Q 36.* b) If yes, what were the costs for the people that visited the patient? *Note: This question aims to get the TOTAL number of visits and associated costs. Add all costs of different persons* Accommodation: ..... Food: ..... Transport: ..... Loss of earning: ..... Other:	Total costs: .....

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Relocation costs

36. Did the patient have to move to be able to receive (MDR) TB treatment?	1. Yes (2) No
a) If YES: how much did the relocation cost? -Meals and accommodation - Transport	....

Other Costs

37. a) Does the patient buy any supplements for diet because of the TB illness, for example vitamins, meat, energy drinks, soft drinks, fruits or medicines? *If No, go to Q38.*	(1) Yes 2. No
b)If YES: What kind of items?(specify) (1) Fruits (2) Drinks (3) Vitamins/Herbs (4) Meat 5. Other (specify)	
c)How much did the patient spend on these items in the last 30 days approximately?	500
38. a) Did the patient experience any adverse events during the last three months of treatment of MDR-TB? *(Adverse events are any additional health problems that occur during(MDR-) TB treatment and that may be related to the treatment)*	1. Yes (2) No *If No, go to Q37*
b)If YES: Was the treatment required of these events? *This includes changes in TB drug regimen.*	1. Yes (2) No
c) IF YES, How much did the treatment of adverse events and/or changes in the TB drug regimen approximately cost? Drugs. ..... Transport: ..... Costs made by guardian: ..... Fees: ..... Accommodation: ..... Other:	Total: .....

Insurance, reimbursements and vouchers

39. a) Does the patient have any kind of private or government health/medical insurance scheme? *If No, go to Q 40*	1. Yes (2) No
b)If YES: Specify the name of the scheme or program	
c)Has the patient received reimbursement for any costs related to the TB illness? *Cross-check with question 12 (table on costs before and during diagnosis) If No, go to Q 40*	1. Yes (2) No
d) If yes, how much has the patient received as reimbursement? For diagnosis: ..... For transport costs: ..... For treatment: ..... Other:	Total: .....
40. Did the government or other organisations provide the patient with any of the below items? 1. Transport vouchers number: ..... Value in money per voucher: ..... 2. Food vouchers number ..... Value in money per voucher:..... 3. Other (specify): ..... Value in money:	Total value: .....

Coping Costs

41. To what extent has the TB illness affected the patient's family financially? *(circle)*	1 Mild 2 Moderate 3 Severe
42. Where did the money come from to pay for these expenses? *(circle, multiple responses allowed)* *If did not borrow money or did not sell property, go to Q 44*	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 Indana Care
43. a) If borrowed money, how much? b) From whom did the patient borrow (most)? *Circle most appropriate* 1. Family 2. Neighbors/friends 3. Private bank 4. Cooperative 5. Other (specify):	Amount of money borrowed: .....
c) What is the interest rate on the loan? (%)	1. ..... % 2. I don't pay any interest 3. I am not expected to pay back the money
44. a) Has the patient or his/her family sold any property to finance the cost of the TB illness? *If No, go to Q 05.*	1. Yes 2. No
b) If YES: What was sold? *Circle most appropriate* 1. House 2. Livestock 3. Transport/vehicle 4. Household item (specify)..... 5. Farm produce 6. Other (specify):	
c) What is the estimated market value of the property sold?	.....
d) How much did the patient or his/her family earn from the property sale?	.....
45. a) Has the patient or his/her family leased any property to finance the cost of the TB illness? If No, go to Q 46. b) If YES: What was leased? 1) House 2) Livestock 3) Transport/vehicle 4. Household item (specify) 5. Land 6.other (specify).....	1. Yes 2. No

Socioeconomic Information *Individual Situation and Income*

46. Who is the primary income earner in the household? *Circle most appropriate*

1. Patient 2. Other (specify) Her husband

47. Is the patient currently working (includes non-formal work such as housework)?	1. Yes 2. No *(go to Q54)*
48. How the patient is usually paid *(before TB disease)*? 1. cash 2. in kind 3. cash and in kind 4. not paid 5. bank transferred salary 6. Other	
49. Did the patient have to change jobs when became ill with TB?	1. Yes 2. No
50. How many hours did the patient work on average per day BEFORE he/she became ill with TB?	..... Hours

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51. How many hours does the patient work on average NOW per day?	..... Hours
If answer to Q50 differs from answer to Q 51: 52. Is the change related to the TB illness?	1. Yes 2. No
If answer to Q 50 differs from answer to Q 51 53. Is someone doing the work that the patient used to do?	1. Yes, member of own household 2. Yes, other person 3. No
54. a) Has the patient ever stopped doing non-formal (house) work due to TB? *If No, go to Q 56*	1. Yes 2. No
b)If YES: for how long?	1. Less than 1 month 2. 1 month 3. 2-3 months 4. 4-5 months 5. more than 6 months
55. Did/does someone do the non-formal work that the patient used to do?	1. Yes, member of own household *(go to Q54)* 2. Yes, other person *(go to Q 53)* 3. No *(go to Q54)*
56. In case someone from outside patient's household did/does non-formal work, does/did that person get paid to do the housework that the patient used to do before having TB illness? 1. No 2. Yes, total amount (up until now)?	Total amount: .....
57. a) Did/does someone stay home specifically to take care of the patient? *If No, go to Q58* *If YES* b) For how long? c) Did he/she quit their income-earning job to stay home and care for the patient? d) Was he/she paid to take care of the patient? IF yes, how much orwhat is the value?	1. Yes 2. No ..... Weeks 1. Yes 2. No 1. Yes 2. No Total value/amount: .....
58. Does anyone in patient's household (including children or below school age) have to start work or work more to finance costs due to the TB illness?	1. Yes 2. No
59. Has the TB illness caused loss of patient's job or education?	
1. No 2. Loss of Job 3. Dropped out of school 4. Other (specify):	

Household Income and Spending

60. How much was the estimated average income of patient's household per month BEFORE the TB illness? (for all persons in the house, including patient; includes welfare payments, government assistance or other social support)

1. Income from the patient: 1000 2. Income from the rest of the household: 2500
3. Welfare payments: ..... 4. Government assistance: ..... 5. Other: .....
TOTAL: 3500

61. How much is the estimated average income of patient's household per month NOW?

1. Income from the patient: ..... 2. Income from the rest of the household: 200
3. Welfare payments: ..... 4. Government assistance: ..... 5. Other: 800
TOTAL: 1000

62. *If income under 61 is different from 60* Was this change in income the result of TB illness?	1. Yes 2.No

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Socioeconomic Indicators

63. Does any member of the patient's 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	N		17. Mobile Telephone	N	
2. Motor bike	N		18. Internet access at home	N	
3. Bicycle	N		19. House	N	
4. Truck	N		20. Land for farming	N	
5. Tractor			21. Other land	N	
6. Furniture	Yes	5,000	22. Account with financial institution	N	
7. Sewing machine	N		23. Shares in a company	N	
8. Refrigerator/Freezer	N		24. Jewelry	N	
9. Radio (no cassette/CD)	N		25. Cattle	N	
10. Radio cassette/CD player	N		26. Sheep/Goats	N	
11. Television	N		27. Horses/Donkeys	N	
12. Video recorder	N		28. Camels	N	
13. Electric/Gas Stove	N		29. Poultry	N	
14. Electric Iron	N		30. Non-farm business enterprise	N	
15. Electric Fan	N		31. Treasury Bills	N	
16. Landline Telephone	N		32. Other	N	

64. If the government could provide the patient with some services to ease the financial burden of TB on the patient and his/her household, what would the patient prefer to have? *Don't give options unless patient does not bring up answer him/herself. Only choose one. But interviewers can paraphrase the choices available including what are contained in others choice4 such as house rent, hotel accommodation etc*

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

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

.....

.....

Comments by Interviewer:

.....

.....

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Date and Signature by Interviewer
dd/mm/yy

20 17/05

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