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

## Report from a pilot study in Indonesia

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## 2 Abbreviations

CSR	Corporate social responsibility
DOT	Directly observed treatment
IDR	Indonesian Rupiah (during the data collection period, 10,000 Rupiah was equivalent to 1 USD)
IQR	Interquartile range (usually presented as 25 <sup>th</sup> to the 75 <sup>th</sup> percentile of the frequency distribution)
MDR	Multidrug resistant (i.e., resistance to rifampicin and isoniazid)
MoH	Ministry of Health
NGO	Non-governmental organization
NTP	National tuberculosis control program
PMDT	Programmatic management of MDR TB
<i>Puskesmas</i>	<i>Pusat kesehatan masyarakat</i> (community health center)
SD	Standard deviation
TB	Tuberculosis
UPIC	Unique patient identification code
USD	US dollar
WHO	World Health Organization



### 3 Executive summary

#### **Background**

Indonesia is one of the 22 countries with the highest burden of tuberculosis (TB) countries in the world. Tuberculosis is a costly disease for the health system and also for patients and families and society in general. For Indonesia, it was recently estimated that health services, household costs and productivity losses totalled over 8 USD per capita (0.2% of GDP).

Economically vulnerable populations have a higher risk of TB infection and progression to disease. One of the main reasons why these people remain undetected is that they cannot afford the costs of seeking diagnosis and starting and completing treatment. Delaying seeking care contributes to continued transmission of (MDR) TB and increased mortality from the disease. TB patients face income loss because of charges for health services, costs for transport, accommodation, nutrition and inability to work. During treatment, patients with MDR TB face 5-20 times higher costs than patients with susceptible TB, mainly due to relocation costs and longer pre-diagnosis and treatment periods involving more visits and procedures. MDR TB is more prevalent in high risk populations, like the homeless, which are often also economically more vulnerable.

Policy makers such as Ministries of Health and National Tuberculosis Control Programs need to understand patient costs to identify and mitigate potential bottlenecks in access and adherence to (MDR) TB treatment and the negative impact on the economic status of patients and their families.

#### **Project aims**

We adapted the existing TBCAP Tool to Estimate Patients' Costs to also cover costs of MDR TB patients. The adapted questionnaire was used in Ethiopia, Kazakhstan and Indonesia and this report presents the results from Indonesia. The patient cost tool itself will be further improved using the experience obtained in these countries, and the input from the workshops on mitigation options in all three countries.

#### **Methods**

We collected data on the direct (out of pocket) and indirect (loss of income) costs of patients and their families related to the diagnosis and treatment of (MDR) TB through interviews for patients in different stages of treatment. Direct costs included costs for hospitalization, follow-up tests, food supplements, and costs related to health care visits for directly observed treatment (DOT) and picking up drugs (transport, food, other costs). Calculation of indirect costs was based on time needed for diagnosis and treatment. We assumed that after the interview, hospitalization or treatment of adverse events was not needed (again) within the patient's current treatment phase. Costs were extrapolated over the patient's total treatment phase, taking internationally recommended phase durations. Medians, interquartile ranges (IQR), means with standard deviations (SD) and ranges were calculated for all cost components.

We recruited (MDR) TB patients from Persahabatan hospital and five of its satellite community health centers in Jakarta, and from Dr Moewardi hospital in Solo, Central Java province, in February and March 2013.

#### **Results**

A total of 118 TB and 143 MDR TB patients were included in this study, with a median total household income (including welfare payments) of 2 million IDR (equivalent to 206 US dollar (USD)) per month before the diagnosis of (MDR) TB. This is lower than the estimated minimum income for Jakarta (2.2 million IDR).

The reported median costs for diagnosis of TB and MDR TB were similar, being 339,000 and 450,000 Indonesian Rupiah (IDR), respectively, which corresponds to approximately 35 and 46 USD. Medical expenses (mainly administration fees and cost of laboratory tests) formed the main cost component of TB diagnosis, whereas non-medical expenses (transport and food) were the main component of costs of an MDR TB diagnosis.



The reported patient's costs of TB treatment were 509,000 IDR for the intensive phase and 790,000 IDR for the continuation phase (corresponding to 53 and 82 USD, respectively). Reported patient costs for treatment of MDR were around 15 times higher, being 10,453,000 and 11,893,000 IDR for the intensive and continuation phase of MDR TB treatment, respectively. Corresponding amounts in USD are 1,079 and 1,227 USD. These equal 0.8, respectively 18 months of post-diagnosis household income.

Patient costs were usually not covered by vouchers, health insurance or other reimbursement systems. Only 22% of the TB patients and 34% of the MDR TB patients reported to have received any form of assistance (including insurance), but mostly this was not in cash money, as most reimbursement schemes directly pay the health facility for services provided to the patient. Among the 34 patients who had received cash money (3 (3%) TB patients and 31 (22%) MDR TB patients), values received were 80,000, 1,400,000 and 7,000,000 among the TB patients whereas the median value received by MDR TB patients was 400,000 IDR. The amounts reimbursed were not related to treatment duration or socio-economic status.

As expected, the financial impact of MDR TB was higher than that of TB, although the latter was also perceived as high by the patients. The financial impact was perceived as 'important' or 'extraordinary' by 50% of the TB patients and 77% of the MDR TB patients. MDR TB patients more often lost their job due to TB than TB patients (53% vs. 26%). To cover the expenses of the disease, more often than TB patients, MDR TB patients sold assets (21%, vs. 3% among TB patients) and took on loans with interest (8%, vs. 0% among TB patients).

When asked for preferred government services to relieve the financial burden of TB, the most often mentioned option by TB patients was more efficient health services (62%, vs. only 19% among MDR TB patients), while MDR TB patients preferred transport vouchers (36% vs. 14%).

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

### ***Results policy workshop***

During a national workshop, participants representing different Ministries (including the Ministry of Health), Universities, hospitals, NGO's, and MDR TB patients formulated and prioritized a list of policy options for mitigating patient costs due to (MDR) TB. Options with the highest priority score were 1) make diagnosis and treatment really free of charge or refundable, 2) bring services closer to the patient, 3) prevent or forbid the use of unnecessary or substandard tests, 4) reinforce diagnosis and treatment standards, and 5) provide convenient shelters or housing for MDR TB patients and their families. A group of cured MDR TB patients of Persahabatan hospital listed bringing services closer to the patient in order to reduce transport costs as first priority, but other prioritized options related to social protection rather than TB service improvements: installation of a (MDR) TB hotline available 24/7 for patients, provision of social support in case of depression, job security and job opportunities for (ex) TB patients, and provision of economic support (living allowance). This illustrates that program staff may have a different view on strategies to reduce economic burden of TB than the patients themselves. Recommendations with each option are provided in Chapter 9 of this report. Note that these recommendations are not mutually exclusive – it may be necessary to provide more than one at the same time.

We recommend that the list will be used to prepare an action plan for mitigating patient costs under the guidance of NTP, indicating main stakeholders, and with whom, how and when the option can be worked out into a strategy, and when and how this strategy can be implemented.

### ***Conclusion***

From the results presented in this report, it becomes clear that while TB patients face financial impact of TB, this impact is extraordinary to MDR TB patients and their families. Such high financial



burden may cause patients to default from treatment, and die from (MDR) TB. This is accompanied with continued transmission of (MDR) TB to already vulnerable household members.

To reduce transmission and mortality, it should be a priority of the Indonesian government to relieve the financial burden especially for MDR TB patients.

It is clear that some of the options listed above to mitigate these costs may provide solutions to problems occurring in the short term, while others are solutions to long-term problems. Top priorities are ensuring that current policies for payment of tests and type of tests conducted are obeyed, acceleration of expansion of PMDT services (which includes expansion of MDR TB diagnosis, both geographically and to more MDR TB risk groups), and compensation of transport costs.



## 4 Introduction

### 4.1 Background of the project

A major issue identified in the 2013 Global Tuberculosis Report (World Health Organization, 2013) is the estimated high number of people who develop TB every year who do not get treated – around 3 million worldwide in 2012. About 75% of these persons were in 12 countries, one of which is Indonesia. Partly, missed patients will self-cure before seeking health care. Another reason why infected people delay or do not seek diagnosis and treatment is the cost to patients and their families for seeking and completing care. Delays in seeking care can result in infection of others and interruptions can result in multi-drug resistance. Another major issue highlighted in the report is the increase in the number of multi-drug resistant tuberculosis (MDR-TB) which has higher death rates and places 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 10,000 US dollar per new case, almost 50 times the cost for drug-susceptible TB (Jarrah *et al.*, 2013). Although from published literature little data are available, the data on hand indicate that, during treatment, patients with MDR TB face 5-20 times higher costs than patients with susceptible TB, due to relocation costs and longer pre-diagnosis and treatment periods involving more visits and procedures (Kang *et al.*, 2006; Rouzier *et al.*, 2010). Additionally, Rouzier *et al.* found the indirect costs due to inability to work to be much higher for MDR TB compared to non-MDR TB patients (Rouzier *et al.*, 2010). Moreover, MDR TB is more prevalent in high risk populations, like the homeless, which are often also economically more vulnerable (Danilova *et al.*, 1999). With programs for the programmatic management of drug-resistant TB (PMDT) rolling out, it is important for policy makers, like Ministries of Health and National Tuberculosis Programs (NTPs), to use patient costing data to describe financial hardship and to identify and tackle bottlenecks in access to and continuation of MDR TB treatment.

TBCAP/USAID has funded the development of a generic TB patient costing tool, the Tool to Estimate Patients' Costs (hereafter referred to as 'The Tool'), which was piloted in Kenya and then implemented in 3 countries at different continents (Mauch *et al.*, 2011). This 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 very few (or no) MDR TB cases were included in countries using the Tool thus far. The Tool is designed to assess direct (out of pocket) and indirect (opportunity) costs 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, and the impact of TB on food expenditures, and the welfare of the household.

In Kenya, where the Tool was used, as a result of the findings (showing substantial costs related to diagnosis and treatment of TB and a medical poverty trap), TB treatment services were further decentralized to reduce patient costs and improve access to treatment, other health programs were approached for nutritional support of TB patients and sputum sample transport and a national TB and poverty sub-committee was convened to develop a comprehensive pro-poor approach (Mauch *et al.*, 2011).

The Tool to Estimate Patients' Costs enables a thorough insight into patient costs. However, the Tool does not cover MDR TB patient costs and cannot be used among these patients without adaptation. In the current project, the Tool was simplified and shortened where possible to measure TB patient costs. At the same time, additional questions for MDR TB patients were added.



With this project, using the questionnaire, we aimed to collect data on the costs of (MDR) TB diagnosis in 3 countries for use in policy workshops that will focus on relieving the financial burden of diagnosis and treatment for (groups of) (MDR) TB patients. We collected data in Ethiopia, Indonesia and Kazakhstan. This report summarizes the patient cost information that was obtained from MDR TB and non-MDR TB patients in two PMDT sites and their satellite health centers in Indonesia: Persahabatan hospital in Jakarta and Dr Moewardi hospital in Solo, Central Java.

## 4.2 (Multidrug) resistant tuberculosis in Indonesia

According to the World Health Organization (WHO), there are about 450,000 (95% confidence interval, 370,000 to 540,000) newly diagnosed TB patients each year in Indonesia. The case detection rate of TB in Indonesia in 2012 was estimated to be 72% (95% confidence interval, 61–87%) suggesting that almost one third of TB patients is missed (WHO, 2013a). For 2012, WHO estimated that there were a total of 6,900 (95% CI, 5,200-8,500) MDR TB patients in Indonesia, of which 5,800 (95% CI, 4,300-7,700) were new TB patients (WHO, 2013b). However, only a fraction of these is diagnosed as only about 1% of new TB patients and 9% of previously treated cases was tested for MDR TB in 2011. This has changed after the introduction of Xpert MTB/RIF in the main PMDT centers: in Persahabatan and Dr Moewardi hospitals, 62% and 64% of all MDR TB suspects has received an Xpert test since the introduction of the machines in March 2012 (out of 9 different suspect groups, the main suspect groups receiving an Xpert test were TB patients with a relapse and those with category 2 TB treatment failure since patients of these two groups could be put on MDR TB treatment without awaiting conventional drug susceptibility test results), although according to project protocols, all MDR TB suspects in these centers should have been tested for MDR TB using Xpert which should reduce both delay for receiving appropriate treatment and costs for the patient.

### *MDR TB diagnosis and treatment in Persahabatan and Dr Moewardi hospitals*

Persahabatan hospital in Jakarta is the main MDR TB treatment site of Indonesia, enrolling patients in its PMDT program since August 2009. It includes MDR TB patients from all over Indonesia. In 2012, 161 MDR TB patients were newly enrolled in the PMDT program of the hospital. In its annual report of 2013 to NTP, Persahabatan hospital reported to have diagnosed 620 MDR TB patients. Of the patients having been diagnosed up to January 2013 (n=512), 367 (72%) was enrolled in the PMDT program. There are several reasons why patients are not enrolled, such as early death and comorbidities, but also patients are known to refuse treatment because of fear of stigma and job loss, and inability to afford the costs associated with treatment (Annual report Persahabatan hospital, 2013). According to the same report, of 311 patients with known treatment outcomes, 95 (31%) defaulted during treatment. The reason that was most often mentioned for stopping MDR TB treatment was costs (mentioned by 57% as the main reason for defaulting).

Dr Moewardi hospital in Solo serves as the TB referral center in Central Java province since end 2010 and started its PMDT program in April 2011. In 2012, it enrolled 49 MDR TB patients in its program.

### *Costs and reimbursement schemes*

A recent study in Indonesia estimated the total economic burden of TB to the society as over 8 USD per capita, which is equivalent to 0.2% of the gross domestic product (GDP; Collins *et al.*, 2013).

In public health centers and hospitals under the NTP, sputum examinations for diagnosis of TB using direct smear microscopy among those coughing at least two weeks, and (MDR) TB treatment are for free. Xpert MTB/RIF testing is offered for free to those suspected of having MDR TB. Despite this, seeking diagnosis and treatment of (MDR)TB may be expensive, especially for poor families, since patients usually face other costs, such as registration fees, costs of X-ray, additional tests, and supplements, and transportation costs.



Different insurance schemes exist in Indonesia, such as Askes (for civil servants), Jamsostek (for workers with a formal job), Jamkesmas (national-level scheme for those being registered as poor), and Jamkesda (province/district-level scheme mostly for poor people who are not registered through Jamkesmas). As from 1 January 2014, Indonesia has started a new scheme, called *Jaminan Kesehatan Nasional* (JKN) which combines 3 schemes (Askes, Jamsostek, and Jamkesmas) into one overall nationwide scheme. Jamkesda will be incorporated gradually in this new scheme and will continue to exist in its current form.

Until January 2012, MDR TB patients were provided with vouchers (value 400,000 IDR per month) through TBCARE. However, lack of funds caused this program to end. Although provincial and local initiatives exist up to now, no there is no national strategy to relieve the financial burden of (MDR) TB.



## 5 Methods

### 5.1 Study aims

The study aimed to adapt an existing tool that identifies the components causing the highest financial burden for (MDR) TB patients in order to encourage countries to formulate interventions to relieve this burden. Specific objectives were to:

develop a tool to assess main cost components of (MDR) TB diagnosis and treatment for patients including direct and indirect costs and income lost;

- estimate the costs for (MDR) TB patients, and identify major costs components incurred by (MDR) TB patients in all three participating countries;
- formulate recommendations for policy development and develop action plans with steps to decrease the economic burden of (MDR) TB among patients based on consensus workshops in each of the three countries discussing the questionnaire's outcomes.

Thus, rather than giving a precise estimate of all direct and indirect costs of diagnosis and treatment of (MDR) TB, we aimed to identify the main financial bottlenecks that can be addressed through policy changes.

With the study, we tried to answer the following question: Do diagnosis and treatment costs cause financial hardship to TB patients and their families?

### 5.2 Study design

We conducted a cross-sectional survey in two PMDT sites and their satellite sites on Java Island, Indonesia, in which (MDR) TB patients were interviewed once before or during (MDR) TB treatment in the health facility. We did not aim to collect longitudinal data of patients during the course of diagnosis and treatment, since this would make data collection an lengthy and complicated undertaking which is not suitable for local programs. To minimize recall bias, we collected data on the patient's current treatment status (with a recall period of 3 months).

### 5.3 Study population

We included (MDR) TB patients seeking TB diagnosis and TB treatment at public facilities. Costs related to TB diagnosis and treatment may prevent TB cases from seeking care and treatment but with this study, we were not able to identify TB cases not seeking TB care at such facilities due to financial and logistical constraints. Also, because of logistical challenges, we did not include those seeking diagnosis but interrupting the diagnostic process and treatment because of the associated costs.

We enrolled patients in the PMDT site (Persahabatan hospital) and five of its satellite sites in DKI Jakarta and in the PMDT site of Central Java province (Dr Moewardi hospital), Indonesia (Figure 1). In 2013, Jakarta province counted just over 9.5 million inhabitants, while 32.3 million people were living in Central Java province (of which around 550,000 were living in Solo) <sup>1</sup>.

After diagnosis of MDR TB, patients living in Jakarta are encouraged to be treated at the satellite centre in their area of residence, if existing. However, patients with severe side effects of (MDR) TB treatment are hospitalized and remain under the control of clinicians of Persahabatan hospital until all symptoms have resolved. Also, some patients living outside Jakarta remain under treatment of Persahabatan hospital while some patients prefer to receive their treatment in Persahabatan hospital. Apart from Persahabatan hospital itself, we recruited TB and MDR TB patients in the five satellite community health centres in Jakarta that had the most MDR TB patients on treatment in

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<sup>1</sup> See [http://www.datastatistik-indonesia.com/portal/index.php?option=com\\_staticxt&staticfile=depan.php&Itemid=17](http://www.datastatistik-indonesia.com/portal/index.php?option=com_staticxt&staticfile=depan.php&Itemid=17). Accessed on 20 January 2014.



January 2013, to obtain a sample of non-MDR TB patients that is similar to MDR TB patients with respect to socioeconomic status.

Jakarta is the capital of Indonesia. As such, it is not representative with respect to costs of living to other cities on Java. Therefore, we also included patients in Solo, which is a provincial town in Central Java. In Solo, Dr Moewardi hospital has a PMDT program since April 2011.



**Figure 1.** Location of study sites on Java Island (Jakarta and Solo) and within Jakarta

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

1. TB patients who completed at least one month of treatment and were within last month of the intensive phase of the standard first-line drug treatment and (i.e. standard treatment and retreatment regimens also known as category I and II treatment) (recall period: last three months including pre-treatment period; but including all major coping costs outside the 3-month period);
2. TB patients who started at least 3 months ago with the continuation phase of first line TB treatment (recall period: last three months i.e. covers a part of the continuation phase; but including all major coping costs outside the 3-month period);
3. diagnosed as MDR TB patient within the month before the interview (recall period: last three months before diagnosis of MDR TB; but including all major coping costs outside the 3-month period)



4. MDR TB patients who started at least 3 months ago with the intensive phase of MDR TB treatment (recall period: last three months i.e. covers a part of the intensive phase; but including all major coping costs outside the 3-month period);
5. MDR TB patients who started at least 3 months ago with the continuation phase of MDR TB treatment (recall period: last three months i.e. covers a part of the continuation phase; but including all major coping costs outside the 3-month period).

We aimed to include a total of 50 patients in each of these 5 groups although we expected this to be challenging especially for group 3.

We excluded patients younger than 21 years and patients not consenting to the study or those not able to answer the questions in the interview. Also, we excluded patients who died or transferred out while on treatment because of logistic difficulties. Furthermore, we excluded bedridden patients as these could not be interviewed in a private environment, and those not agreeing to participate. The latter were asked for reasons of non-participation.

## 5.4 Definitions

TB patients were divided into MDR TB and non-MDR TB patients (referred to as TB patients in this report).

A TB patient was defined as any person diagnosed with tuberculosis and being currently on standard first-line TB treatment (i.e. standard regimens for new and previously treated TB patients).

We defined an MDR TB patient as any person diagnosed with tuberculosis resistant against rifampicin and isoniazid by phenotypic or genotypic drug susceptibility testing or with rifampicin resistance according to Xpert MTB/RIF testing and no drug susceptibility test result ruling out MDR TB (according to prevailing (inter)national guidelines). We aimed to include only MDR TB patients who were diagnosed in the month before the interview, and MDR TB patients currently on MDR TB treatment.

Those just diagnosed with MDR TB either had just started with MDR TB treatment or were still on first-line treatment or did not yet receive treatment (the latter two are referred to as the pre-treatment period, which is the period from being earmarked as a MDR TB suspect until start of MDR TB treatment).

The intensive phase of treatment was defined as the first phase of treatment, in accordance with WHO definitions and local guidelines. Usually, this is a 2-3 month period for TB and a 6-8 month period for MDR TB.

The continuation phase of treatment was the second phase of treatment, in accordance with WHO definitions and local guidelines. This period usually lasts 4-6 months for TB and 12-18 months for MDR TB.

Cost definitions were applied as follows:

- Direct costs: out-of-pocket costs linked to seeking diagnosis and treatment including medical expenses, fees, transport, accommodation and food expenditures.
- Indirect (opportunity) costs: these include the cost of foregone income due to the inability to work because of the illness and loss of time due to visits to health facilities, time spent on the road to and at health facilities, lost productivity and loss of job.
- Coping costs: household costs to meet daily requirements despite extra expenditures or loss of income. These include the sale of assets, taking up debt, saving on food or other items, taking a child out of school to care for the patient or taking up a job, or taking up another job.
- Medical costs: any costs made in the health care facilities related to the TB diagnosis or TB treatment, such as hospital registration fees, costs of drugs and tests, hospitalization costs, etc.
- Non-medical costs: any costs made but not directly related to TB diagnosis or treatment, i.e. costs not made in the health care facility (transportation, accommodation), and costs



made in the facility that were not obligatory to get the diagnosis and treatment (i.e., costs of food).

- Diagnostic costs: All medical, non-medical and indirect costs related to getting a diagnosis of (MDR) TB.
- Treatment costs: All medical, non-medical and indirect costs related to (MDR) TB treatment.
- Other costs: (in)direct costs made by or for accompanying persons (attendants)

## 5.5 Sampling

Since with this study, we did not aim to test an *a priori* hypothesis, we did not do sample size calculations. However, to obtain sufficient precision in the estimates and catch the variation existing within each group of patients, we aimed to include a minimum of 50 patients in each group, so that the total sample size is 250 per country. As explained above, these patients were drawn from two different hospitals with a PMDT program and their satellite health centres. Apart for reasons of obtaining enough patients per group, we also did this to obtain enough information about sites located outside Jakarta, which is seen as a non-representative province of Indonesia, and Persahabatan hospital still receives MDR TB suspects from all over Indonesia.

In Persahabatan hospital, there were more than 50 patients on (MDR) TB treatment. Therefore, in this hospital, we applied consecutive sampling, inviting all patients coming for treatment in February and March 2013 to participate in the study up to a maximum of 50 patients per group (see below).

In Dr Moewardi hospital, all consenting patients available during the data collection period were consecutively enrolled in the study.

## 5.6 (Modifications to the) generic patient cost questionnaire

The questionnaire of the "Tool to Estimate Patients' Cost"<sup>2</sup> described above was used as the basis for a new generic questionnaire. It was shortened, while new specific questions for (MDR) TB patients were included (Annex 2). After translation of the questionnaire from English into Indonesian, the questionnaire was adapted to the local context on some questions (e.g. insurance types, type of health care facility, reimbursement schemes). After this, the questionnaire was translated back from Indonesian into English by another staff member to check for translation and interpretation errors. After correcting translation errors, the questionnaire was pretested on 5 patients (one patient of each of the 5 patient groups included) in Persahabatan hospital to check its clarity for patients and interviewers. After the pretest, the questionnaire was further adapted and reprinted for use in training of interviewers and in the interviews.

## 5.7 Organization of the study in Indonesia

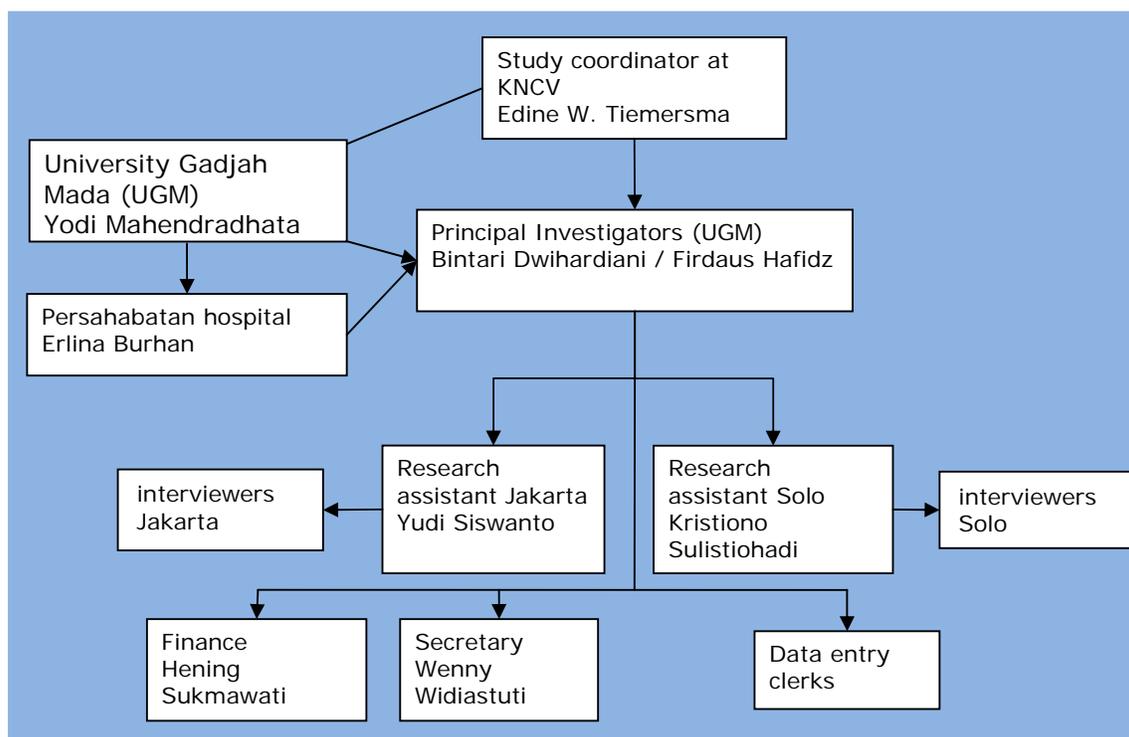
Since KNCV Tuberculosis foundation in Indonesia was overburdened with other work, the study coordinator at KNCV involved Dr Yodi Mahendradhata, senior faculty member at Gadjah Mada University (UGM) in the conduct of the study. Dr Mahendradhata appointed Ms. Bintari Dwiwardiani as principal investigator for the data collection in Indonesia, and, after her leave, Mr. Firdaus Hafidz took her place. The principal investigator was responsible for obtaining the necessary study approvals, preparation of the study sites, the selection, training and supervision of the interviewers, and for data entry and management. The principal investigators were supported and supervised by Dr Mahendradhata for the site in Solo and by Dr Burhan in Jakarta. The principal investigators appointed research assistants in both sites who were responsible for the selection of patients in that site, the organization of the interviews, and supervision of interviewers, including conducting

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<sup>2</sup> Available at [http://www.stoptb.org/wg/dots\\_expansion/tbandpoverty/spotlight.asp](http://www.stoptb.org/wg/dots_expansion/tbandpoverty/spotlight.asp)



checks on filled questionnaires. Regular progress reports on the progress of patient enrolment and data collection were sent to the overall coordinator at KNCV.



**Figure 2.** Study organogram depicting lines of supervision in the Indonesian part of the project.

## 5.8 Data collection

Data were collected between in February and March 2013. Eleven trained interviewers conducted the face-to-face interviews with patients or DOT supporters using pre-structured questionnaires (5 interviews were conducted by the two principal investigators and 7 interviews were done by the two research assistants). This questionnaire collected data on direct and indirect costs and income loss due to the illness, diagnosis and treatment of (MDR) TB patients, as well as background information of the patients (age, sex, treatment type and phase, socioeconomic status, ethnicity and distance to health facilities) was collected in using a pre-structured questionnaire in a private area at the healthcare facility where they received diagnosis and/or treatment for (MDR) TB. If possible, the patient him/herself was interviewed. If this was not possible, the DOTS supervisor was interviewed. All interviews were conducted in a separate, private room, or outside if such a room was (temporarily) not available.

During the data collection period, the interviewers visited the participating sites (apart from Persahabatan hospital, five communal health centers were included, see Figure 1) on pre-selected days, and interviewed all available patients consecutively, until the number of 50 patients per group was reached, or until the end of the data collection period, whichever came first.

Eligible patients were invited to participate in the interview by the doctor or nurse they were seeing during their scheduled visit to the health care facility. After this visit, those patients wishing to participate in the study were sent to a separate room where they were interviewed by the study staff (i.e., not the doctors and the nurses of the health care centers). Before the start of the interview, written informed consent was asked. After having obtained informed consent, the participants were asked to recall costs made and income losses over the last three-month period



(for MDR TB patients who were just diagnosed with MDR TB: over the last three months before diagnosis of MDR TB) and major coping costs since start of TB symptoms.

## 5.9 Ethical issues

The study protocol was assessed for ethical acceptability and scientific merit by the institutional review board of Gadjah Mada University in Yogyakarta, and of the ethical review boards of Persahabatan and Dr Moewardi hospital. Interviews were conducted by trained interviewers who were not accountable in any way to the hospital staff. All participants received a consecutive 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. As compensation, the patients received a free hygiene kit after the interview.

Interviewers wore N95 respirators during the interviews with smear-positive TB patients and MDR-TB patients.

## 5.10 Data entry and analysis

Data were entered in a pre-designed EpiData data entry sheet ([www.epidata.dk](http://www.epidata.dk)). Randomly, 10% of the questionnaires was double entered. The rate of discrepancies remained below 2% and therefore, no full double data entry was conducted.

Data analysis was performed in Stata/SE 11.1 for Windows (Stata Corp., College Station, Texas, USA; [www.stata.com](http://www.stata.com)).

**Table 1.** Methods used to estimate different types of costs for TB diagnosis and treatment.

Type of cost	Elements included in cost type	Methods used to calculate costs
Diagnostic (groups 1¥ and 3 only)	Food, travel, accommodation, medical costs, and loss of income during visits	Summed direct and indirect costs of visits Indirect costs (income loss) as given by patient and as calculated from total time spent x income/time
Treatment (excluding group 3)	DOT and drug collection visits, hospitalization‡, follow-up tests, treatment of adverse events*, supplements‡, food, travel and loss of income, and loss of income during visits	Summed direct costs and indirect costs multiplied by number visits/week, weeks/month, and internationally defined duration of treatment phase, or current duration of treatment phase if longer than this
Other Costs	Loss of household income after TB diagnosis (in)direct costs of accompanying persons/ attendants	Difference in income before TB diagnosis and at the time of the interview. Summed costs calculated as specified above (diagnostic for groups 1 and 3 and treatment for groups 1, 2, 4 and 5)
Coping strategies	Amount borrowed, assets sold	Summed costs

¥ Groups as defined in paragraph 5.3; in short: group 1 – in intensive phase of TB treatment; group 2 – in continuation phase of TB treatment; group 3 – just diagnosed with MDR TB; group 4 – in intensive phase of MDR TB treatment; group 5 – in continuation phase of MDR TB treatment.

\*Assuming that all costs for these elements had been made before the time of the interview (hence, costs were not extrapolated to the treatment phase) ;

‡Summed costs over last month x internationally defined duration of treatment phase

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



1. Since the distributions of almost all costs were highly skewed towards higher values, we choose to present median with 25<sup>th</sup> and 75<sup>th</sup> percentiles, as well as minimum and maximum for all costs.

#### *Costs for a diagnosis of (MDR) TB*

Costs were obtained per diagnostic visit. Direct costs included all out-of-pocket payments that the patient had to make, such as paying administration fees, paying for laboratory tests, X-ray, and drugs, for food and accommodation, and for transportation to and from the hospital. Direct cost items are listed in Table 1. Direct costs were summed up per cost item over all visits, after which the sums of the cost items were summed up in a total of direct costs per patient.

Patients reported their estimated loss of income. Since we suspected underreporting of loss of income, we calculated the loss of income by multiplying the total number of minutes spent on diagnostic visits by the patient's income before diagnosis of TB per minute and compared this to the income loss reported by the patient. For companions, we used the reported costs only as we had no information about the companion's income.

#### *Costs for (MDR) TB treatment*

Cost items for (MDR) TB treatment included costs made because of taking or picking up drugs at the health care centre, costs for follow-up tests, supplements, hospitalization, and treatment of adverse events (Table 1).

Costs for taking or picking up drugs were reported for a typical visit to take or pick up drugs. To get the total costs per month, individual cost items per visit were summed up and the total costs per month were calculated by multiplying these costs with the number of times per week that drugs were taken/picked up and the number of weeks per month (4.3).

Indirect costs were calculated by multiplying the turn-around-time in minutes for a typical visit with the number of times per week that drugs were taken/picked up, the patients' income per minute, and 4.3 weeks per month.

These monthly costs were subsequently extrapolated over the complete treatment phase using the internationally defined durations of the different treatment phases, as lined out below. Indonesia follows the WHO TB treatment guidelines, with a standard regimen for new TB patients of 2HRZE/4HR<sup>3</sup>, and a retreatment regimen for previously treated patients of 2HRZES/1HRZE/5HRE (WHO, 2010). Standardized MDR TB treatment is Km-(E)-Eto-Lfx-Z-Cs/(E)-Eto-Lfx-Z-Cs<sup>4</sup>, with the intensive phase lasting at least 8 months and a total treatment duration of at least 20 months as according to prevailing WHO guidelines (WHO, 2011). Thus, to obtain total treatment costs, we multiplied the reported costs by 2 or 3 for patients in the intensive phase of the new TB, respectively retreatment regimen (group 1); by 4 or 5 for patients in the continuation phase of the new or retreatment regimen (group 2); by 8 for patients in the intensive phase of MDR TB treatment (group 4); and by 12 for patients in the continuation phase of MDR TB treatment. However, for MDR-TB patients who had already been in the intensive phase for longer than 8 months or in the continuation phase for more than 12 months at the time of the interview, we assumed that they were in the last month of the respective phase during the interview.

Costs for follow-up tests were reported from the start of TB treatment till the interview. Since it was assumed that in a typical TB treatment phase, only one or two follow-up tests would be needed, no extrapolation was applied to obtain the costs per treatment phase for patients being treated with TB regimens. To calculate the costs per treatment phase for MDR TB patients, the total costs were multiplied by the internationally defined duration of the treatment phase of the patient, divided by the number of months that the patient had been in that treatment phase. For patients who had been in the treatment phase for longer than the 'typical' duration, it was

<sup>3</sup> 2HRZE/4HR= 2 months daily isoniazid (H), rifampicin (R), pyrozinamid (Z) and ethambutol (E) for the intensive phase, followed by a 4-month continuation phase of H and R thrice weekly.

<sup>4</sup> The standardized MDR TB regimen contains kanamycin(Km), ethambutol, Etonamide (Eto), Levofloxacin (Lfx), pyrozinamid, and cycloserin in the intensive phase, and etonamid, levofloxacin, pyrazinamid and cycloserin in the continuation phase.



assumed that these were in the final month of their treatment phase, and no extrapolation was applied.

Costs for supplements were reported over the past month. To obtain the total cost per month, individual cost items were summed up. Extrapolation to the total treatment phase was applied by multiplying the costs per month with the internationally defined typical duration of the patient's treatment phase.

In Indonesia, TB patients are not hospitalized for getting TB treatment. Since 1 January 2012, in principle also MDR TB patients are not hospitalized, unless they face severe side effects that need hospitalization. Therefore, we assumed that after the interview, hospitalization did not occur and we did not extrapolate the costs of hospitalization to the complete treatment phase.

Similarly, we considered adverse events needing treatment unlikely to occur and did not apply extrapolation of the costs to the complete treatment phase.

#### *Other costs*

As outlined in Table 1, other costs included costs reported for the patient's companion.

Companion costs consisted of income loss due to time spent on visits for accompanying a patient taking or picking up drugs, costs for hospitalization of the patient (this included costs for accommodation, food, transportation and loss of income), and costs for a companion due to the treatment of adverse events (direct and indirect costs combined). Costs made by a companion for a (MDR) TB patient's diagnosis were calculated as explained above (see *Costs for a diagnosis of (MDR) TB*). Costs made by a companion who accompanied a (MDR) TB patient during his/her treatment were calculated and extrapolated as explained under *Costs for (MDR) TB treatment*.

#### *Coping costs*

Coping with the financial impact of TB treatment involves multiple strategies, such as borrowing money, asking for donations from family and friends, using savings, selling assets costs and cutting down other expenses. We asked patients for the financial impact of their disease on their family and the coping strategies used. Costs were defined as loss of household income after TB diagnosis (indirect costs), amounts borrowed, and market value of assets sold (both defined as direct costs). We did not extrapolate any of these costs since reduction in household income was reported as monthly reduction in income and it remained unknown when the income had changed. Besides, we assumed that borrowing money and selling assets were one-off actions.

#### *Sensitivity analysis*

Though we aimed to include patients who were at least three months in their current phase of treatment (except for patients in the intensive phase of first line TB treatment since the intensive phase of the regimen for new TB patients lasts only 2 months, and patients just diagnosed with MDR TB), also patients who had been in their current treatment phase for less than 3 months were included. Since changing from intensive to continuation phase of first-line TB treatment usually results in changes in frequency of visiting health care facilities (WHO, 2011), these patients might have reported mixed costs of intensive and continuation phase of treatment. Therefore, we conducted a sensitivity analysis excluding these patients and compared the results of this analysis to the analysis of all patients.



## 6 Results

### 6.1 Summary of main results

The main results of 261 (MDR) TB patients (118 TB patients and 143 MDR TB patients) are summarized in Tables 2 and 3. In the following paragraphs, these main results are discussed in more detail. Annex 1 presents detailed data and is referred to in the following paragraphs.

In Table 2, we approximated the total cost of an episode of TB and of an episode of MDR TB. Since all patients were only interviewed once, and they were asked about costs made during the past three months, they were expected to only report over their current phase: (pre-)diagnosis, intensive phase and continuation phase of (MDR) TB treatment. Consequently, to estimate the costs of a total episode, the means and medians of different patient groups had to be added up which does yield an indication rather than a good estimate of total patient costs.

Total approximated median patient costs for diagnosis and treatment of TB were around 1.5 million Indonesian Rupiah (IDR), corresponding with approximately 150 USD. Total approximated median patients costs for diagnosis and treatment of MDR TB were 15 times higher at around 22 million IDR, corresponding to about 2,200 USD (Table 2). In general, direct costs were much higher than indirect costs: only 10-20% of the costs were due to lost income. However, as will be explained in Chapter 7, it should be noted that income loss was probably underestimated in this study. Details of costs made for getting a diagnosis of (MDR) TB are described in paragraph 6.3, while more details for the costs of (MDR) TB treatment can be found in paragraph 6.4. Paragraph 6.5 discusses the costs made by/for persons accompanying the (MDR) TB patient.

Table 3 summarizes the financial impact of (MDR) TB in several statistics, which are discussed in more detail in section 6.7 of this report. As can be concluded from the Table, patients with MDR TB experienced a higher economic impact of their disease than TB patients: more often they lost their job, their personal income more often dropped to 0 and their household income dropped more significantly, and more often than TB patients, they were obliged to sell property or take on loans with an interest rate. While MDR TB patients more often received any type of support from government or other organizations, this support remained very limited (median amount reimbursed, 0 IDR; see paragraph 6.6.). TB patients lost more time per visit for picking up drugs than MDR TB patients per DOT visit, but it should be noted that TB patients usually only collect their drugs once or twice per month, while MDR TB patients visit the health facility on a daily basis for DOT. Although MDR TB patients more often reported to have lost their job than TB patients, they were less often absent from work due to their illness. This can be explained by the fact that MDR TB services are provided 24/7 while TB patients can only receive services during limited hours on working days. On the other hand, hospitalization was more often needed for MDR TB than for TB patients, and the median duration of hospitalization was longer (Table 3).



**Table 2.** Summary of direct and indirect patient costs, x 1,000 Indonesian Rupiah\*.

	TB					MDR-TB				
	n	mean	SD	median	IQR	n	mean	SD	median	IQR
<b>Total direct (pre-)diagnosis costs</b>	<b>62</b>	<b>432</b>	<b>449</b>	<b>322</b>	<b>(85-617)</b>	<b>29</b>	<b>586</b>	<b>1,114</b>	<b>382</b>	<b>(116-613)</b>
Administrative charges		73	126	37	(0-105)		57	128	6	(0-40)
Tests		117	146	56	(0-180)		59	128	0	(0-28)
X-ray		107	259	15	(0-100)		44	65	0	(0-85)
Drugs		43	122	0	(0-0)		45	105	0	(0-0)
Transport		57	99	30	(12-48)		205	383	52	(25-225)
Food		13	33	0	(0-20)		36	49	20	(3-50)
Accommodation		0	0	0	(0-0)		3	19	0	(0-0)
<b>Total direct treatment costs‡</b>	<b>118</b>	<b>2,363</b>	<b>8,334</b>	<b>504</b>	<b>(128-1,274)</b>	<b>114</b>	<b>9,739</b>	<b>7,876</b>	<b>7,435</b>	<b>(4,168-12,636)</b>
Intensive phase	62	2,287	10,249	393	(80-1,050)	55	8,142	7,321	5,774	(3,311-10,028)
Continuation phase	56	2,448	5,591	573	(160-2,170)	59	11,227	8,142	9,458	(5,406-15,351)
Hospitalization	118	1,314	7,470	0	(0-0)	143	1,833	4,340	0	(0-1,250)
Food supplements										
Intensive phase	58	285	534	100	(0-300)	54	1,145	1,731	320	(0-1,600)
Continuation phase	56	749	3,345	2	(0-400)	58	2,207	2,851	1,140	(0-3,000)
Treatment of adverse events										
Intensive phase	62	12	45	0	(0-0)	55	2	14	0	(0-0)
Continuation phase	56	8	31	0	(0-0)	59	10	43	0	(0-0)
DOT visits (MDR TB)										
Intensive phase						54	5,576	5,393	3,732	(2,408-6,140)
Continuation phase						59	7,047	5,641	6,140	(2,528-9,030)
Picking up drugs (TB)										
Intensive phase	62	150	200	80	(34-188)					
Continuation phase	56	233	433	120	(40-263)					
Follow up tests										
Intensive phase	62	38	96	0	(0-0)	54	26	101	0	(0-0)
Continuation phase	13	143	403	0	(0-169)	58	6	48	0	(0-0)
<b>Total indirect (pre-) diagnosis costs**</b>	<b>62</b>	<b>91</b>	<b>350</b>	<b>34</b>	<b>(0-85)</b>	<b>29</b>	<b>90</b>	<b>187</b>	<b>27</b>	<b>(6-60)</b>
<b>Total indirect treatment costs‡</b>	<b>118</b>	<b>720</b>	<b>2,562</b>	<b>95</b>	<b>(0-438)</b>	<b>114</b>	<b>6,017</b>	<b>12,377</b>	<b>2,806</b>	<b>(379-6,082)</b>
Intensive phase	62	655	2,813	95	(0-384)	55	6,266	7,594	3,053	(1,482-8,217)
Continuation phase	56	793	2,274	84	(0-551)	59	5,785	15,641	2,463	(0-4,886)
<b>Sum (direct+indirect) diagnostic costs</b>	<b>62</b>	<b>523</b>	<b>610</b>	<b>339</b>	<b>(155-664)</b>	<b>29</b>	<b>676</b>	<b>1,256</b>	<b>450</b>	<b>(159-794)</b>
<b>Sum (direct+indirect) treatment costs§</b>		<b>6,183</b>		<b>1,145</b>			<b>31,420</b>		<b>20,748</b>	
<b>Total (direct+indirect) costs§</b>		<b>6,706</b>		<b>1,484</b>			<b>32,096</b>		<b>21,198</b>	

\* Diagnostic costs were calculated for patients in the intensive phase of TB treatment and just diagnosed with MDR TB (groups 1 and 3). Treatment costs were calculated including all groups, except MDR TB patients just diagnosed with MDR TB. At the time of data collection, 10,000 Rupiah were equivalent to approximately 1 US dollar. Abbreviations used in this table: TB-tuberculosis, MDR-multidrug resistant, SD-standard deviation, IQR-interquartile range; ‡ These totals are a from mixes of patients in different treatment phases and should be interpreted with caution; \*\* calculated from the time spent on getting a (MDR) TB diagnosis in minutes multiplied by the patient's income per minute before TB diagnosis; § These sums are based on adding up medians and/or means from different patient groups, and therefore must be interpreted with caution.



**Table 3.** Summary of financial impact of TB illness.

	TB		MDR TB	
	n/N or median	% or (IQR)	n/N or median	% or (IQR)
<b>Patients earning an income before diagnosis of TB</b>	84/116	72%	112/143	78%
Patients who were primary income earner	51/116	44%	34/141	24%
<b>Patients who were still earning an income at time of interview</b> (of primary income earners)	40/51	78%	21/34	62%
<b>Patients who lost their job</b>				
intensive phase	14/62	23%	43/81*	53%
continuation phase	17/55	31%	31/58	53%
<b>Ever absent from work due to TB</b> (of those earning an income before TB diagnosis and not having lost their job during TB treatment)	36/57		16/44	
Among those: days absent due to TB¥				
intensive phase	15	(6-42)	160	(56-160)
continuation phase	24	(5-40)	120	(96-360)
<b>Patients hospitalized for TB</b>	39/118	33%	87/141	62%
duration of hospitalization (days; among those having been hospitalized)	7.5	(6-14)	10	(6-15)
<b>Time spent per visit:</b>				
per DOT visit (minutes)	NA‡		90	(60-150)
per drug collection visit (minutes)	150	(60-240)	NA‡	
<b>Monthly individual income x 1,000 IDR</b>				
before onset of TB	1,300	(0-2,000)	1,000	(200-2,000)
after onset of TB	0	(0-1,800)	0	(0-375)
<b>% income change for those with an income before onset of TB</b>	<b>25%</b>	<b>(0%-100%)</b>	<b>100%</b>	<b>(60%-100%)</b>
<b>% household income change (overall)</b>	<b>0%</b>	<b>(0-49%)</b>	<b>33%</b>	<b>(0%-60%)</b>
<b>Patients who received assistance from the government or other organizations</b>	26/118	22%	49/143	34%
transport vouchers	1	1%	21	15%
food packages	1	1%	1	1%
other types of vouchers	1	1%	11	8%
other reimbursements	2	2%	8	6%
<b>subtotal of reimbursements, x 1,000 IDR</b>	<b>0</b>	<b>(0-0)</b>	<b>400</b>	<b>(0-400)</b>
<b>Coping costs</b>				
Donations	38/118	32%	61/143	43%
patients who sold property	4/118	3%	30/143	21%
patients who took out loans	11/118	9%	38/143	27%
with interest	0/9	0%	12/32	38%
median interest rate (%)			2%	(2%-10%)
<b>Patients with health insurance</b>	<b>25/118</b>	<b>22%</b>	<b>36/143</b>	<b>25%</b>
patients who received reimbursements	2/23	9%	8/34	24%

\* Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant, IQR – interquartile range, IDR – Indonesian Rupiah (10,000 IDR being equivalent to approximately 1 US dollar).

¥ extrapolated to the complete treatment phase for those having a job at time of interview (NB this assumes that these patients will not lose their jobs later during the current treatment phase); ‡ TB patients do not take DOT in the health facility while MDR TB patients do not pick up drugs.



## 6.2 Characteristics of the study population

Data were collected of 261 patients; most of these (n=187, 72%) were recruited in Jakarta. From Dr Moewardi hospital in Solo, 74 patients were recruited (Table 4). Unfortunately, the staff inviting patients for the interview did not keep lists of patients who were invited, whereas anecdotal evidence suggests that there were patients who refused participation because they considered this too time-costly, as well as patients who had agreed to participate but did not show up at the interview location. Therefore, a response rate cannot be calculated, and it remains unknown whether those patients not interviewed differed from the participants to this study.

We aimed to interview patients, and only if this was not possible, to interview the DOT supporter of the patient. We were able to interview 251 (96%) patients and 10 DOT supporters. The DOT supporters disclosed information of the patient and not of themselves.

**Table 4.** Sampling of patient groups.

Category	Persahabatan hospital		Dr Moewardi hospital	
	Number of patients available*	Number of patients enrolled (% of total)	Number of patients available* or eligible**	Number of patients enrolled (% of total)
Group A: in last month of intensive phase of cat I-II treatment	125	52 (41.6)	10**	10 (NA)
Group B: in continuation phase of cat I-II treatment	199	46 (23.1)	10**	10 (NA)
Group C: just diagnosed with MDR TB	28	11 (39.3)	18**	18 (NA)
Group D: in intensive phase of MDR TB treatment	102§	38† (37.3)	39*	17
Group E: in continuation phase of MDR TB treatment	101§	40‡ (39.6)	25*	19

Abbreviations used cat – category, NA – not available, MDR – multidrug resistant, TB – tuberculosis. \* Note that though available, not all of these patients were eligible since some patients were in the treatment phase for less than 3 months; \*\*Note that these were the patients actually being invited to the study because they were visiting the hospital while the study team was available, rather than the total number of patients available per treatment phase, since the latter numbers were not available for these groups; § For patients enrolled between April 2012 and September 2012, the number of patients in a phase was estimated since these were not yet available in the electronic system, assuming that the intensive phase took 8 months; † Four of these patients were enrolled in one of the satellite sites of Persahabatan hospital; ‡ Thirteen of these patients were enrolled in one of the satellite sites of Persahabatan hospital.

Four of the 5 groups enrolled included more than the 50 patients that we intended to enroll. Only in group 3 (those just diagnosed with MDR TB), 29 patients were enrolled. As specified in the definitions, we aimed to include patients who were at least three months in their current phase of treatment (except for patients in the intensive phase of cat I/II treatment since this generally lasts only 2 months, and patients just diagnosed with MDR TB). However, because of a misunderstanding in the protocol, 19 (34%) of 56 patients in the continuation phase of cat I/II treatment had been in this phase for less than 3 months (Table 5). Other patients who should not have been included in the study were 2 patients who had been diagnosed with MDR TB longer than 1 month ago, 3 patients who were in the intensive phase of cat IV treatment for less than 3 months, and 2 patients who had been in the continuation phase of cat IV treatment for less than 3 months. Sensitivity analyses were done excluding these 25 patients (see paragraph 6.9).



**Table 5.** Number of patients per treatment phase, by number of months in that treatment phase.

Months on treatment in current phase	intensive phase TB treatment	continuation phase TB treatment	just diagnosed with MDR TB	intensive phase MDR TB treatment	continuation phase MDR TB treatment	Total
0			18	1	1	20
1	3	11	9		1	24
2	51	8	2	1	1	63
3	8	8		18	6	40
4		16		15	8	39
5		7		10	3	20
6		2		4	3	9
7				3	2	5
8		3		2	8	13
9					2	2
10				1	4	5
11					2	2
12					6	6
13		1			1	2
14					3	3
15					3	3
17					4	4
19					1	1
<b>Total</b>	<b>62</b>	<b>56</b>	<b>29</b>	<b>55</b>	<b>59</b>	<b>261</b>

Table 6 summarizes the general characteristics of the patients. Of the 187 patients recruited in Jakarta, 22 (12%) were recruited in one of the five satellite health centers of Persahabatan hospital. Of all enrolled patients, 143 (55%) had MDR TB while the others were treated for TB. Patients were between 21 and 73 years old (mean age  $39.6 \pm 12.7$  years); 53% of the patients was of male sex. Three percent of the TB patients included in this study was infected with HIV. Most patients lived within 30 minutes travel distance from their DOT facility, where as almost 10% of the patients had to travel for more than 2 hours. The median household income before diagnosis of TB was 2 million IDR. Although there was no information on sex, age and other general characteristics for some individuals, these numbers were generally small (Table 6).

There were 10 previously treated patients who had defaulted previous treatment; 9 of these had MDR TB. Three of the defaulters had defaulted because they had no money to continue the treatment. The other most often mentioned reason ( $n=3$ ) was that the patient felt cured.

Tables 1A, 1B and 1C in Annex 1 present the general characteristics of the study population by (MDR) TB status, by site, and by household income class.

MDR TB patients usually had a longer travel time to the nearest public health center than TB patients (medians and IQRs were respectively 40 (20-120) minutes and 20 (10-60) minutes,  $p=0.002$ ), whereas the reported time to their own DOT center was similar (medians and IQRs respectively 35 (20-90) minutes for MDR TB patients and 30 (25-60) minutes for TB patients; Table 1A, Annex 1).

In Jakarta, proportionally less MDR TB patients were enrolled than in Solo (Table 1B, Annex 1). This is probably due to the fact that the study sites in Jakarta included five community health centers, whereas in Solo, only patients visiting Dr Moewardi hospital (a referral site for MDR TB patients) were enrolled. In Solo, only patients of Javanese ethnicity were enrolled, whereas different ethnicities were enrolled in Jakarta ( $p<0.0001$ ), which may both reflect the population of the country's capital and the fact that Persahabatan hospital is regarded as a national reference center for MDR TB whereas Dr Moewardi hospital serves its region. The same reason may also explain the fact that the patients enrolled in Solo more often were registered with smear-positive TB than those enrolled in Jakarta (85% vs 55%,  $p,0.0001$ ). Longer travel times to the DOT facility in Jakarta may also reflect the latter difference (27% of the patients in Jakarta reported travel



times of over 1 hour versus 14% in Solo), though this may also be due to the traffic in Jakarta, which is much more intense than in Solo. Median patient income did not differ between the two cities (Table 1B, Annex 1).

**Table 6.** General characteristics of the study population (N=261)

<b><i>Patient characteristic</i></b>	<b>N‡</b>	<b>%*</b>
<b>Patient group</b>		
Intensive phase of standard (re)treatment regimen	62	23.8
Continuation phase of standard (re)treatment regimen	56	21.5
Just diagnosed with MDR TB	29	11.1
Intensive phase of MDR TB treatment	55	21.1
Continuation phase of MDR TB treatment	59	22.6
<b>TB regimen</b>		
standard regimen for new TB patients	93	35.6
retreatment regimen	25	9.6
MDR TB regimen	143	54.8
<b>Type of TB</b>		
Pulmonary smear positive	166	63.6
Pulmonary smear negative	72	27.6
Extrapulmonary	16	6.1
No information	7	2.7
<b>Type of TB: susceptibility</b>		
TB (i.e., not diagnosed with MDR TB)	118	45.2
MDR TB	143	54.8
<b>Recruited at site</b>		
Persahabatan hospital, Jakarta	165	63.2
Satellite of Persahabatan hospital, Jakarta	22	8.4
Dr Moewardi hospital, Solo	74	28.4
<b>Sex</b>		
Male	138	52.9
Female	120	46.0
No information	3	1.2
<b>Age</b>		
Median age (25th, 75th percentile)	39 (30, 49)	
Age group		
21-29	62	23.8
30-39	71	27.2
40-49	66	25.3
50+	61	23.4
No information	1	0.4
<b>Ethnic group</b>		
Betawi	51	19.5
Jawa	145	55.6
Sumatera	37	14.2
Tionghoa	4	1.5
East Indonesian	6	2.3
Sundanese	9	3.5
Other, specify	7	2.7
No information	2	0.8

\* Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant, DOT – directly observed treatment, USD – US dollar.

‡ Unless otherwise specified.



**Table 6, continued.** General characteristics of the study population (N=261).

<i>Patient characteristic</i>	N*	%*
<b>Highest education completed</b>		
No schooling	4	1.5
Primary school	53	20.3
Secondary school	171	65.5
Bachelor	32	12.3
Other	1	0.4
<b>HIV status according to patient card</b>		
Positive	8	3.1
Negative	128	49.0
not tested	109	41.8
not indicated on card	14	5.4
no information in database	2	0.8
<b>Travel time to health facilities</b>		
Median time to nearest public health facility, minutes (25th, 75th percentile)	30 (15, 60)	
0-15 minutes	80	30.7
16-30 minutes	70	26.8
31-60 minutes	48	18.4
61-120 minutes	40	15.3
>120 minutes	23	8.8
Median time to DOT facility, minutes (25th, 75th percentile)	30 (20, 60)	
0-15 minutes	51	19.5
16-30 minutes	86	33.0
31-60 minutes	63	24.1
61-120 minutes	37	14.2
>120 minutes	23	8.8
No information	1	0.4
<b>Household income per month before TB was diagnosed</b>		
Median household income, million Rupiah (25th, 75th percentile)	2.00 (1.25, 3.00)	
0 - 1.5 million Rupiah (0-154 USD)	90	34.5
1.51 - 2.6 million Rupiah (155-275 USD)	84	32.2
2.7 - 102 million Rupiah (276-10,500 USD)	87	33.3

\* Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant, DOT – directly observed treatment, USD – US dollar.

‡ Unless otherwise specified.

As expected, education level was associated with household income level (Table 1C, Annex 1): patients in the highest income class more often had obtained a bachelor degree (22%) than those in the middle (12%) and lowest income class (3%;  $p=0.001$ ). Betawi, the original inhabitants of Jakarta, more often fell in the lowest household income tertile than other groups (Table 1C, Annex 1). Compared to patients of Sumatran and East Indonesian origin, their average household income was lower (2.1 vs. 3.5 million IDR ( $p=0.06$ ), respectively vs. 21.6 million IDR ( $p<0.001$ ). It should be noted however, that there were only six persons of East Indonesian origin in this study population and that these do not necessarily reflect the total population of (MDR) TB patients of East Indonesian origin living in Jakarta. The different household income classes did not differ with respect to other general characteristics (Table 1C, Annex 1).



## 6.3 Diagnosis of (MDR) TB

### 6.3.1 Number of visits needed to get a diagnosis of (MDR) TB

The median number of visits needed to get a (MDR) TB diagnosis was 3 (Table 7). TB patients needed a maximum of 7 visits, while there were 3 patients who needed more than 7 visits among the MDR TB patients. While TB patients in Jakarta needed 3 (interquartile range (IQR) 2-3) visits, those in Solo needed 4 (2-5) visits to get a diagnosis ( $p=0.007$ ). Contrary, MDR TB patients needed 4 (2-8) visits in Jakarta while they needed only 2 (2-3) visits if diagnosed in Dr Moewardi hospital in Solo ( $p=0.01$ ).

The total time needed for getting a diagnosis was 360 minutes (averaging to 120 minutes per visit; Table 7), and though slightly longer among those diagnosed with MDR TB (390 minutes) than among those diagnosed with TB (355 minutes), this difference was not statistically significant ( $p=0.66$ ).

**Table 7.** Number of visits and time needed to get a diagnosis.

TB group	Item	number of visits to get a diagnosis	total time lost to get a diagnosis (minutes)	average time per visit (minutes)
<b>Overall</b>	N patients	91	91	91
	median	3	360	120
	p25	2	180	65
	p75	4	600	200
<b>Intensive phase standard regimen</b>	N patients	62	62	62
	median	3	355	120
	p25	2	130	53.3
	p75	4	600	180
<b>just diagnosed with MDR TB</b>	N patients	29	29	29
	median	3	390	156.7
	p25	2	210	90
	p75	4	720	260

### 6.3.2 Time from start of TB treatment to diagnosis of MDR TB

Out of 143 MDR TB patients, 61 (43%) patients reported to have been on any type of TB treatment before the diagnosis of MDR TB, for a median of 7 months (IQR, 6-11 months). More than half of these patients (54%) had been on treatment for more than 6 months (Table 1D, Annex 1).

### 6.3.3 Patient costs for getting a diagnosis of (MDR) TB

Table 8 (next page) summarizes the costs involved in getting a (MDR) TB diagnosis, both for patients and companions. Out of 62 patients with a TB diagnosis, only nine reported any indirect costs due to loss of income while visiting health facilities, whereas 27 patients had a paid job. This suggests underreporting of income loss. Therefore, we compared indirect costs (loss of income) reported by the patients with costs calculated by multiplying the total time spent on diagnostic visits with the patient's income per minute. Indeed, the calculated median indirect costs of getting a diagnosis were much higher than the reported median indirect costs (Table 2A, Annex 1), but since direct costs were at least 10 times higher than indirect costs, there was not much difference between the total costs of getting a (MDR) TB diagnosis calculated by the two methods. In Table 8, only the costs calculated from using the second method are presented.



**Table 8.** Costs of getting a (MDR) TB diagnosis x 1,000 Indonesian Rupiah\*.

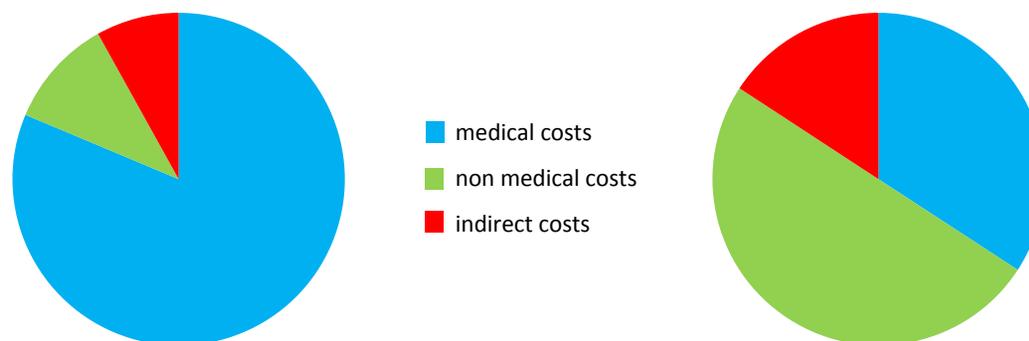
Costs of getting a TB diagnosis	Overall (n=91)			Intensive phase standard TB regimen (n=62)			Just diagnosed with MDR-TB (n=29)			P-value‡
	mean	median (IQR)†	range	mean	median (IQR)	range	mean	median (IQR)	range	
total direct costs	481	322 (110-617)	0; 6,160	432	322 (85-617)	0; 2,220	586	382 (116-613)	12; 6,160	0.66
loss of income **	91	30 (0-74)	0; 2,761	91	34 (0-85)	0; 2,761	90	27 (6-60)	0; 818	0.29
total costs¥	572	350 (155-736)	0; 6,978	523	339 (155-664)	0; 3,511	676	450 (159-794)	29; 6,978	0.46
reimbursements received	10	0 (0-0)	0; 700	11	0 (0-0)	0; 700	6	0 (0-0)	0; 180	0.58

\* This analysis includes only patients in the intensive phase of TB treatment and patients just diagnosed with MDR TB. At the time of data collection, 10,000 Indonesian Rupiah corresponded to approximately 1 US dollar. Abbreviations used in this table: TB – tuberculosis; MDR – multidrug resistant; IQR – interquartile range (25<sup>th</sup> and 75<sup>th</sup> percentiles of frequency distribution).

‡ p-values for the difference in costs between TB and MDR TB patients as calculated from K-sample equality-of-medians test.

\*\*Loss of income was calculated by multiplying the number of minutes spent for getting a diagnosis with the patient's income per minute.

¥ Includes loss of income calculated as specified above (see \*\*) and excludes reimbursements received.



**Figure 3.** Relative contribution of medical, non-medical and indirect costs to the total costs of seeking a diagnosis of TB (left) or MDR TB (right). Proportional cost shares were calculated for each patient, after which these were summarized into median proportions over the two patient groups (TB and MDR TB). The proportional cost shares were subsequently corrected to total 100%.



Patients diagnosed with MDR TB paid slightly more than patients with TB (medians 449,682 IDR vs. 338,960 IDR), but due to the high range of costs in both groups, these medians were not statistically significantly different. Distributions were highly skewed towards high costs for both groups, and this is reflected in higher means than medians: 523,125±609,838 IDR for a TB diagnosis vs. 675,891±1,256,369 IDR for an MDR TB diagnosis.

#### *6.3.4 Costs for (MDR) TB diagnosis by city and household income class*

Tables 2B and 2C present the costs for getting a TB diagnosis by city of enrolment and household income class, respectively.

While overall costs for getting a (MDR) TB diagnosis were similar, patients in Jakarta paid more health facility registration costs than those in Solo (Table 2B, Annex 1). This was especially the case for MDR TB patients (median and IQR for MDR TB patients in Jakarta vs. MDR TB patients in Solo 40,000 (6,000-219,000) and 2,500 (0-7,500) IDR respectively ( $p=0.04$ ). Also, patients in Jakarta paid more for (laboratory) tests than patients in Solo (Table 2B, Annex 1), and again, this difference was clearest for MDR TB patients, with median costs of 80,000 (0-300,000) IDR in Jakarta and of 0 (0-0) IDR in Solo ( $p=0.03$ ). On the other hand, patients in Solo paid slightly more on transportation and food than those in Jakarta (Table 2B, Annex 1). TB patients paid more for drugs in Solo than in Jakarta (median costs (IQR) 0 (0-0) and 25,000 (0-275,000) IDR respectively).

Not surprisingly, the (calculated) indirect costs of getting a TB diagnosis were associated with total household income: the patients in the highest income tertile lost significantly more income than those in the lower two tertiles (Table 2C, Annex 1). There were no other differences in diagnostic costs between patients in different household income classes.

#### *6.3.5 Diagnostic cost components*

Individual cost items are shown in Table 2A in Annex 1. The medians of the direct cost items are much lower than the medians for the total costs. This is due to the skewed distributions of costs for all components and the fact that 3 patients only provided a relatively high lump sum of direct costs (of 600,000, 700,000 and 4,000,000 IDR, respectively) because they were not able to split the reported costs into individual cost items. One of these patients only reported the total costs for all visits together.

We calculated the contribution of cost components specified as medical (i.e., all costs paid for getting health care, including administrative charges, and costs for tests and drugs), non-medical (i.e., costs of travel, food and accommodation specifically spent for getting a (MDR) TB diagnosis) and indirect costs (i.e., loss of income) to the total diagnostic costs. We calculated the proportional contributions of these cost components to the total diagnostic costs for each patient separately and summarized these into median proportions per patient group. TB patients paid relatively more on medical costs than MDR TB patients. Loss of income had an equal cost share at around 10% (Figure 3).

The direct costs made up for around 90% of the total costs of getting a (MDR) TB diagnosis. Main cost shares were for laboratory tests (median 56,200 IDR), followed by administrative fees (median costs 37,000 IDR) and travel (median costs 29,500 IDR) among TB patients, and for travel (52,000 IDR) followed by food (20,000 IDR) and administrative fees (6,000 IDR) among MDR TB patients just diagnosed with MDR TB. The differences between TB and MDR TB patients may be explained by the fact that MDR TB patients more often were already registered as a TB patient at the time of starting the diagnostic process for MDR TB. Moreover, the Xpert MTB|RIF test is provided free of charge for MDR TB suspects and X-rays were less often done or charged among these patients than among TB patients.



## 6.4 Treatment of (MDR) TB

### 6.4.1 Costs for (MDR) TB treatment

Costs for (MDR) TB treatment are summarized in Table 9 (next page). Detailed breakdowns of costs, both per month and extrapolated for the complete treatment phase, can be found in Annex 1 (respectively in Tables 3A and 3B). Since patients were only interviewed once, no costs for complete treatment can be provided. We approximated the total costs for (MDR) TB treatment by adding up medians and means from the different patient groups in Table 2. However, these totals should be treated with caution (see discussion in paragraph 7.2).

Costs of treatment per month were higher for MDR TB than for TB patients (Table 9), as was expected, since MDR TB patients have to make more visits to the health facility than TB patients. This is especially reflected in the much higher direct and indirect costs for taking visits related to DOT as reported by MDR TB patients compared with costs for picking up drugs reported by TB patients (Tables 3A and 3B, Annex 1). MDR TB patients also paid more for hospitalization than TB patients (Table 3A, Annex 1), probably because they were more often hospitalized at the start of treatment and/or for side effects than TB patients (WHO, 2013a).

When extrapolated to the total treatment phase, costs of MDR TB treatment were at least 15 times higher than costs of TB treatment, depending on the treatment phase and type of costs (Table 9). Especially the estimated indirect costs were higher, due to the fact that MDR TB patients have to visit the health facility more frequently than TB patients (e.g., in the intensive phase, TB patients usually visit the clinic once per week or once per two weeks, whereas MDR TB patients visit the clinic on a daily basis); besides, the treatment phases of MDR TB treatment last much longer than the phases of TB treatment.

Reimbursements were hardly received and remained restricted to a few individual patients. Median amounts received were 0 IDR for both TB and MDR TB patients (Table 9).

### 6.4.2 Taking drugs (DOT visits) and picking up drugs

Almost all TB patients took their TB drugs at home, only 3 (3%) of them reported to take DOT in the health facility. Contrarily, MDR TB patients almost all took DOT in the health facility, only one (0.7%) patient reportedly took his drugs at home. It is thus not surprising that almost none of the TB patients reported costs for taking drugs, while relatively high costs were reported by MDR TB patients (Table 10 and Table 3A, Annex 1).

Table 10 displays monthly costs for patients in different phases of (MDR) TB treatment. As expected, the direct costs of taking DOT were similar for MDR TB patients in the intensive and in the continuation phase of treatment. However, the indirect costs for MDR TB patients in the intensive phase were higher than for MDR TB patients in the continuation phase. This may be explained because patients in the intensive phase earned more income than patients in the continuation phase of MDR TB treatment and spent more time per DOT visit (however, both differences were not statistically significant).

TB patients reported 10-15 times lower costs for picking up drugs because they had to travel much less often, and consequently spent less on transport and food, and lost less income (Table 10).

Main cost components for both TB and MDR TB patients were travel and indirect costs.

### 6.4.3 Follow-up tests

Patients were asked for the total number of follow-up tests received from the start of TB treatment until the interview; 176 reported having had any follow-up test since the start of (MDR) TB treatment (range: 1-18 follow-up tests done). For 16 patients, no information on follow-up tests was obtained; 15 of these were just diagnosed with MDR TB. MDR TB patients more often reported that they had had at least one follow-up test than TB patients (58% vs. 84%,  $p < 0.001$ ).



**Table 9.** Direct, indirect and total costs of (MDR) TB treatment and reimbursements received, extrapolated to the treatment phase x 1,000 Indonesian Rupiah.\*

cost item	TB				MDR-TB				Ratio median costs TB: MDR TB
	N	mean (SD)	median (IQR)	range	N	mean (SD)	median (IQR)	range	
<i>Direct costs</i>									
Intensive phase	62	2,287 (10,249)	393 (80 – 1,050)	12 ; 80,620	55	8,142 (7,321)	5,774 (3,311 – 10,028)	0 ; 28,840	14.7
Continuation phase	56	2,448 (5,591)	573 (160 – 2,170)	0 ; 33,077	59	11,227 (8,142)	9,458 (5,406 – 15,351)	0 ; 36,012	16.5
<i>Indirect costs</i>									
Intensive phase	62	655 (2,813)	95 (0 – 384)	0 ; 22,091	55	6,266 (7,594)	3,053 (1,482 – 8,217)	0 ; 32,252	32.1
Continuation phase	56	793 (2,274)	84 (0 – 551)	0 ; 13,781	59	5,785 (15,641)	2,463 (0 – 4,886)	0 ; 117,095	29.3
<i>Total costs</i>									
Intensive phase	62	2,942 (10,671)	509 (169 – 1,298)	24 ; 81,596	55	14,408 (11,149)	10,453 (5,812 – 22,272)	52 ; 46,470	20.5
Continuation phase	56	3,241 (7,511)	790 (248 – 2,770)	0 ; 38,596	59	17,012 (20,771)	11,893 (7,073 – 17,884)	1,020 ; 149,600	15.1
Total amount reimbursed									
Intensive phase	62	124 (892)	0 (0 – 0)	0 ; 7,000	55	74 (244)	0 (0 – 0)	0 ; 1,600	NA
Continuation phase	56	1.4 (11)	0 (0 – 0)	0 ; 80	59	304 (1,222)	0 (0 – 400)	0 ; 8,600	NA

\* This analysis excludes patients just diagnosed with MDR TB (n=29). At the time of data collection, 10,000 Indonesian Rupiah corresponded to approximately 1 US dollar. Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant, SD – standard deviation, IQR – interquartile range (25<sup>th</sup> and 75<sup>th</sup> percentiles of frequency distribution), NA – not applicable (division by 0).



**Table 10.** Costs of taking DOT and picking up drugs per month x 1000 Indonesian Rupiah.\*

	<b>DOT visits‡</b>		<b>Picking up drugs§</b>	
	Intensive phase	Continuation phase	Intensive phase	Continuation phase
Frequency of visits	7/week	7/week	2/month	1/month
<b>Costs</b>				
<i>Travel</i>				
Mean (SD)	447 (485)	372 (321)	37 (62)	34 (84)
Median (IQR)	301 (135-602)	301 (135-602)	20 (10-40)	10 (5-40)
<i>Food</i>				
Mean (SD)	226 (315)	185 (330)	14 (26)	16 (27)
Median (IQR)	151 (0-301)	0 (0-301)	0 (0-20)	5 (0-25)
<i>Administration</i>				
Mean (SD)	NA	NA	17 (33)	6 (17)
Median (IQR)	NA	NA	0 (0-0)	0 (0-0)
<i>Other</i>				
Mean (SD)	0.7 (3)	0.2 (0.8)	NA	NA
Median (IQR)	0 (0-0)	0 (0-0)	NA	NA
<b>Total direct costs</b>				
Mean (SD)	709 (674)	562 (457)	67 (91)	56 (108)
Median (IQR)	482 (301-768)	512 (166-722)	40 (17-90)	30 (10-61)
<b>Indirect costs</b>				
Mean (SD)	744 (932)	443 (1,239)	107 (582)	28 (47)
Median (IQR)	342 (144-1,0226)	171 (0-376)	24 (0-45)	11 (0-33)
<b>Total costs</b>				
Mean (SD)	1,461 (1,252)	1,005 (1,548)	174 (582)	84 (121)
Median (IQR)	958 (506-1,991)	708 (278-1,081)	76 (38-149)	46 (17-81)

\* This analysis excludes patients just diagnosed with MDR TB (n=29). At the time of data collection, 10,000 Indonesian Rupiah corresponded to approximately 1 US dollar. Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant, SD – standard deviation, IQR – interquartile range (25<sup>th</sup> and 75<sup>th</sup> percentiles of frequency distribution), NA – not applicable (because of lack of data, since only 3 TB patients conducted DOT visits and only 1 MDR TB patient was picking up drugs). Accommodation costs were not reported by any of the patients and are therefore not displayed in this table.

‡ MDR TB patients only.

§ TB patients only.

MDR TB patients in the intensive phase of treatment reported most follow-up tests per month, while those in both phases of TB treatment had the least tests per month (medians 0.82 vs. 0.17, Table 3E, Annex 1). This means that most TB patients will have had less than 1 follow-up test at the end of each treatment phase, since first-line TB treatment phases usually involve 5 months or less. Therefore, we extrapolated the costs for follow-up tests for MDR TB patients only. Costs for follow-up tests, even when extrapolated to the complete treatment phase, contributed little to the total treatment costs; only MDR TB patients in the intensive phase of MDR TB treatment reported median costs above 10,000 IDR (34,000 IDR, Table 3B, Annex 1).

#### 6.4.4 Hospitalization

Patients were requested to report any costs associated with hospitalization due to TB, also if it occurred before the start of TB treatment. Since patients usually start the treatment very soon after admission, in this report, we regarded these costs as treatment costs. We assumed that hospitalization occurred rarely and therefore did not extrapolate hospitalization costs to the complete treatment phase. Therefore, hospitalization costs reported in Table 3A and 3B of Annex 1 are identical.

Table 11 shows the length and costs of hospitalization for those patients who had been hospitalized by group. Thirty-nine (33%) of the TB patients and 87 (61%) of the MDR TB patients reported



having been hospitalized due to TB ( $p < 0.0001$ ). Among those reporting hospitalization, the median length of stay was 7.5 (IQR, 6-14) days for TB patients, and 10 (IQR, 6-15) days for MDR TB patients. Apparently, most patients had been presented with a lump sum bill for hospitalization and were not able to mention individual cost components; median costs for each component were 0 IDR, while the median total costs were almost 1.3 million IDR overall. Taking only those patients into account who reported hospitalization, the median total costs of hospitalization were slightly higher for TB than for MDR TB patients: 2,263,637 (IQR, 306,818-5,572,727) IDR versus 1,022,727 (545,455-5,113,637) IDR, but this difference was not statistically significant ( $p = 0.34$ ). Loss of income accounted for 20% (TB) to 40% (MDR TB) of all hospitalization costs.

**Table 11.** Costs of hospitalization x 1000 Indonesian Rupiah for those patients reporting hospitalization, by (MDR) TB status. Mean and median costs of hospitalization irrespective of whether hospitalization occurred are shown in Table 3B of Annex 1.\*

	TB		Just diagnosed	MDR TB	
	Intensive phase	Continuation phase		Intensive phase	Continuation phase
n/N (%)	24/62 (39%)	15/56 (27%)	23/29 (79%)	25/53 (47%)	39/59 (66%)
<b>Days hospitalized</b>					
Median	7	9	8	10	10
(IQR)	(5-12)	(7-15)	(7-13)	(6-14)	(5-15)
Mean (SD)	8.4 (5.1)	13.9 (14.2)	9.2 (4.6)	11.6 (7.4)	13.8 (14.2)
<b>Costs of stay</b>					
<i>Direct</i>					
Median	775	2,000	900	1,250	300
(IQR)	(0-2,390)	(320-5,000)	(130-7,000)	(0-5,000)	(0-2,200)
Mean (SD)	4,678 (16,100)	2,851 (2,497)	3,656 (5,131)	3,079 (4,005)	2,590 (6,035)
<i>Indirect</i>					
Median	480	477	318	532	307
(IQR)	(36-932)	(182-955)	(82-636)	(114-1,023)	(0-636)
Mean (SD)	1,027 (2,223)	973 (1,468)	455 (546)	827 (924)	389 (429)
<b>Total costs</b>					
Median	1,320	2,955	1,091	2,014	682
(IQR)	(127-4,135)	(502-6,364)	(603-7,000)	(1,000-5,445)	(273-2,519)
Mean (SD)	5,704 (16,300)	3,824 (3,526)	4,110 (5,145)	3,905 (4,049)	2,979 (6,276)

\* At the time of data collection, 10,000 Indonesian Rupiah corresponded to approximately 1 US dollar. Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant, SD – standard deviation, IQR – interquartile range (25<sup>th</sup> and 75<sup>th</sup> percentiles of frequency distribution).

#### 6.4.5 Relocation

Six (5.1%) TB and 28 (19.6%) MDR TB patients reported that they had moved to another house to be able to receive TB treatment ( $p < 0.0001$ ). One TB and one MDR TB did not disclose costs of relocation. Among those moving, the median relocation costs for these patients 300,000 IDR (IQR, 10,000-650,000 IDR). MDR TB patients paid slightly, but not statistically significantly, more than TB patients for relocation (medians (IQRs) 130,000 (0-15,000) for TB and 400,000 (20,000-700,000) IDR for MDR TB).



#### 6.4.6 Supplements

Overall, 63% of the interviewed patients reported taking supplements (60% of the TB patients and 67% of the MDR TB patients,  $p=0.26$ ). Fruits were the most popular type of supplement (67%) consumed, followed by special drinks (57%). Consumption of meat and vitamins as supplements was more often reported by TB than by MDR TB patients (respectively, 19% vs. 7%,  $p=0.03$  and 34% vs. 19%,  $p=0.03$ ). Milk was often reported as a supplement other than drinks, and use was reported by 14 patients (12 of which were MDR TB patients).

Estimated median costs for supplements varied between 2,000 IDR for TB patients in the continuation phase of TB treatment and 1.14 million IDR for MDR TB patients in the continuation phase of MDR TB treatment (Table 3B, Annex 1).

#### 6.4.7 Adverse events

Adverse events were common: 57 (48%) of the TB patients and 111 (77%) of the MDR TB patients reported having experienced at least one adverse event. Adverse events were more common among MDR TB than among TB patients ( $p<0.0001$ ). Of 168 patients experiencing any adverse event, 40 (24%) needed treatment for this event. Though this percentage was similar for TB (28%) and MDR TB (22%) patients ( $p=0.35$ ), the costs of treatment of such adverse events were significantly higher for TB patients than for MDR TB patients: among the patients who reported that they needed treatment for adverse events, the median total costs were 57,500 IDR (IQR: 10,450-128,500) for TB patients, and 0 IDR (IQR: 0-21,000) among MDR TB patients ( $p=0.004$ ) (data not shown in Tables). Reported costs were mainly spent on drugs.

#### 6.4.8 Costs for (MDR) TB treatment by city and household income class

Costs per treatment phase for the different sites and different classes of household income can be found in Tables 3C and 3D in Annex 1, respectively.

Costs of treatment were generally higher in Jakarta than in Solo (Figure 4 and Table 3C, Annex 1), except for TB patients in the intensive phase of TB treatment, while reimbursements were lower in Jakarta than in Solo (medians 0 (IQR: 0-0) IDR vs. 40,000 (IQR: 0-400,000) IDR). The most pronounced difference between the two cities was the difference in total costs for MDR TB patients in the intensive phase of treatment: for the intensive phase of MDR TB treatment, patients paid a median of 16 million (IQR: 8-6 million) IDR in Jakarta, versus 7 million (IQR: 4-9 million) IDR in Solo. This was both due to higher direct and higher indirect (i.e., more income lost) costs experienced by patients in Jakarta.

In terms of household income classes, not surprisingly, those in the highest household income class experienced the highest income losses (Table 3D, Annex 1). However, this trend was not reflected in the total costs of (MDR) TB treatment: though these rose with household income level, there was no significant trend (Figure 4 and Table 3D, Annex 1).

#### 6.4.9 Main cost components

Costs of supplements and of travel formed the main direct cost components for both TB and MDR TB patients (Table 3B, Annex 1).

When divided in medical, non-medical and indirect cost components, the main cost share for TB patients were medical costs (i.e. costs spent at the hospital or health center), whereas the main cost share for MDR TB patients was for non-medical costs. Indirect costs were similar for TB and MDR TB patients (Figure 5).



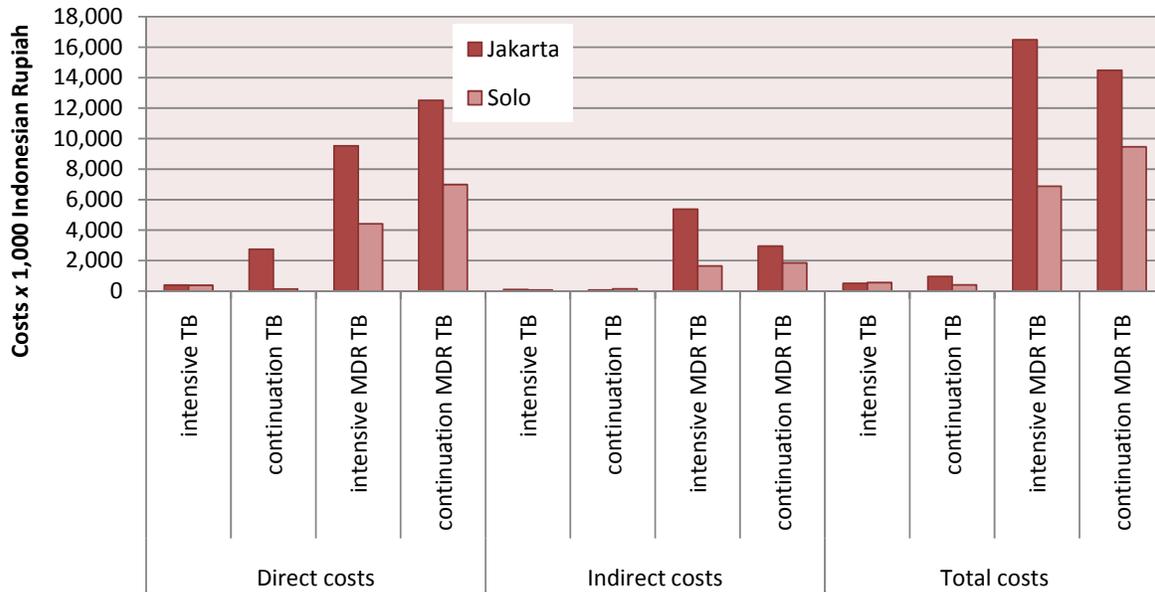


Figure 4A

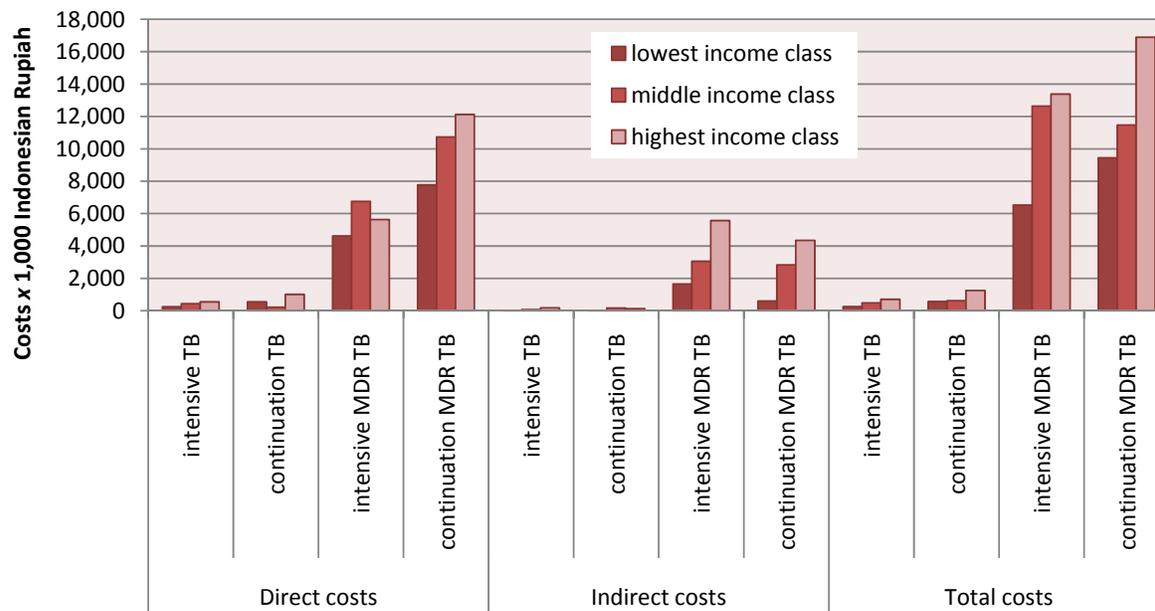


Figure 4B

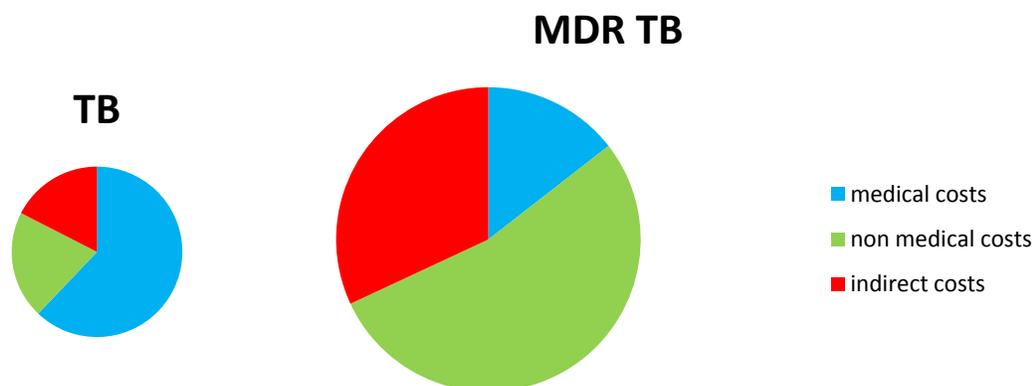
Figure 4. Direct, indirect and total costs of (MDR) TB treatment by city (figure 4A) and household income level (figure 4B) x 1,000 Indonesian Rupiah. See Tables 3C and 3D, Annex 1, for details.

## 6.5 Companion costs

### 6.5.1 Companion costs for pre-diagnosis visits

Seventy-one percent of the patient reported to have brought a companion on any pre-diagnosis visit (Table 12). Total costs of the companion were higher (but not statistically significantly so) for companions of MDR TB patients than for those accompanying TB patients, and this was mainly due to higher travel costs reported (Table 4A, Annex 1).





**Figure 5.** Median costs per type of costs for TB treatment (left chart) and MDR TB treatment (right chart). Proportional cost shares were calculated for each patient, after which these were summarized into median proportions over the two patient groups (TB and MDR TB). The proportional cost shares were subsequently corrected to total 100%.

Tables 4C and 4D in Annex 1 display companion costs by city and household income tertile. In Solo, higher income losses were reported for companions than in Jakarta, and this resulted in higher total costs for companions in Solo than in Jakarta. This is in contrast with patient costs being reported for diagnosis of (MDR) TB, which were higher in Jakarta than in Solo (see paragraph 6.3).

#### 6.5.2 Companion costs related to TB treatment

While most patients reported involvement of a companion somewhere during treatment (70%), the mean and median reported companion costs were low (Table 12). Probably, this is partly due to the questionnaire itself since it inquires about loss of income due to accompanying the patient on visits related to DOT, picking up drugs and follow-up tests, about direct costs and loss of income for a companion staying in the hospital with the patient, and any costs made by the guardian for the treatment of adverse events. Loss of income for the companion was probably underestimated, as was loss of income for the patient him/herself (see paragraph 6.3.3). Hospitalization was a rare event in both TB and MDR TB patients. This is reflected in the low means and the zero-medians for direct costs.

Sixty-one percent of the TB patients and 39% of the MDR TB patients was accompanied by someone on at least one of the visits related to DOT, picking up drugs or follow-up tests ( $p=0.001$ ). Most accompanied patients seemed to have been accompanied on all visits. However, most of these patients (76% of the TB patients and 61% of the MDR TB) patients did not report any income loss for the companion, and this resulted in low indirect companion costs (Table 4B, Annex 1).

Almost all of the patients (89.6%) had a family member who stayed with them in the hospital, and most of them (87.3%) made any additional costs. The most important reported cost component for the companion during hospitalization of the TB patient was costs of food.

The questionnaire did not include a question on whether or not a companion was brought on a visit for the treatment of adverse events, so it remains unclear how many patients did bring a companion on such visits. Of 40 patients reporting treatment of adverse events, only one reported costs for a companion. The costs were 10,000 IDR (Table 4B, Annex 1).

Tables 4C and 4D in Annex 1 display companion costs by city and household income tertile. While patient costs for TB treatment were higher in Jakarta than in Solo (see paragraph 6.4), the reported companion costs were significantly higher in Solo than in Jakarta. This finding is not the result of the higher proportion of patients bringing a companion in Solo compared with Jakarta, as the association remained after restricting the analysis to those bringing a companion.



**Table 12.** Direct, indirect and total costs of (MDR) TB treatment reported for companions of (MDR) TB patients x 1,000 Indonesian Rupiah.\*

	Overall			TB			MDR TB		
	Mean (SD)	Median (IQR)	range	Mean (SD)	Median (IQR)	range	Mean (SD)	Median (IQR)	range
<b>Companion costs related to diagnosis of MDR (TB) ‡</b>									
N bringing companion on any visit (% of total number of patients)	N=65 (71%)			N=44 (71%)			N=21 (72%)		
<i>Direct costs</i>	76 (442)	5 (0-30)	0; 4,200	26 (55)	0 (0-30)	0; 305	184 (777)	14 (0-50)	0; 4,200
<i>Indirect costs</i>	49 (143)	0 (0-0)	0; 1,000	46 (156)	0 (0-0)	0; 1,000	55 (113)	0 (0-50)	0; 450
<b>Total costs</b>	124 (500)	5 (0-60)	0; 4,550	70 (177)	0 (0-36)	0; 1,010	239 (841)	24 (0-105)	0; 4,550
<b>Companion costs related to (MDR) TB treatment ‡,¥</b>									
N bringing companion on any occasion (% of total number of patients)	N=159 (68%)			N=86 (73%)			N=73 (64%)		
Intensive phase				N=45 (73%)			N=33 (60%)		
Continuation phase				N=41 (73%)			N=40 (68%)		
<i>Direct costs</i>	183 (533)	0 (0-160)	0; 5,000						
Intensive phase				73 (212)	0 (0-0)	0; 1,037	187 (381)	0 (0-280)	0; 2,000
Continuation phase				143 (406)	0 (0-0)	0; 2,250	346 (877)	0 (0-290)	0; 5,000
<i>Indirect costs</i>	441 (2,045)	0 (0-160)	0; 19,200						
Intensive phase				74 (177)	0 (0-100)	0; 1,000	1,047 (3,657)	0 (0-400)	0; 19,200
Continuation phase				207 (519)	0 (0-0)	0; 2,400	592 (2,262)	0 (0-200)	0; 12,200
<b>Total costs</b>	686 (2,142)	100 (0-500)	0; 19,200						
Intensive phase				214 (348)	0 (0-300)	0; 1,300	1,373 (3,748)	240 (0-1,000)	0; 19,200
Continuation phase				360 (713)	0 (0-220)	0; 2,730	987 (2,353)	210 (0-500)	0; 12,200

\* At the time of data collection, 10,000 Indonesian Rupiah corresponded to approximately 1 US dollar. Abbreviations used in this table: SD, standard deviation; IQR, interquartile range; ‡ The results in this table are restricted to those patients bringing a companion on any occasion. ¥ Indirect costs were extrapolated to the complete treatment phase. As direct costs only included costs for hospitalization and for treatment of adverse events, and both were assumed not to occur anymore after the interview, these were not extrapolated. Total costs included extrapolated indirect costs plus direct costs.



## 6.6 Reimbursements

All patients were asked whether they had received any reimbursements or other type of financial assistance, such as vouchers, related to their TB illness. Since this included reimbursements for TB diagnosis, this question was also asked to patients just diagnosed with MDR TB. Twenty-two percent of the TB and 34% of the MDR TB patients said they had received any type of assistance, either through, reimbursements, vouchers, food packages, or living allowances. Only one patient (in the continuation phase of MDR TB treatment) had been reimbursed for the diagnosis of MDR TB and had also received one transport vouchers. No other patient had received money or items from more than one source.

Of the 261 patients, 200 had no insurance scheme and of the 61 with any insurance scheme, 47 had not (yet) received any reimbursements (this information was not available for 4 patients with an insurance scheme). Strikingly, of the 10 patients who indicated that they had received any reimbursements, three indicated that the amount was 0 IDR while one did not disclose any information. It is possible that these patients were not reimbursed themselves, but instead they did not have to pay for specific services, as the scheme directly pays the health facility for specific medical services (which is the case for e.g. Jamkesmas). For the only six patients who indicated the amount that they had received, the reimbursements varied between 130,000 and 95,000,000 IDR. Three of them did only provide a lump sum, while the other three specified the type of costs being reimbursed. This was for treatment (1 person), for transportation (1 person) and for other type of costs (not further specified, for 1 person).

Twenty-two patients reportedly had received one or more transport- or food vouchers; 19 of them only had received one voucher. The maximum number of vouchers received was 4 (transport vouchers). Of these 22 patients, 20 had MDR TB. All patients who had received vouchers had either received food or transport vouchers; 18 of them had received transport vouchers (Table 13). The total value of vouchers ranged between 80,000 and 400,000 IDR.

**Table 13.** Assistance received by (MDR) TB patients, either through insurance scheme or vouchers\*.

	TB		MDR TB		p-value§
	n/N	% or median (IQR)	n/N	% or median (IQR)	
Receives any assistance	26/118	22%	49/143	34%	0.03
Has an insurance scheme	25/118	22%	36/143	25%	0.45
Among those: received reimbursements through scheme	2/23‡	9%	8/34‡	24%	0.15
<b>Total amount reimbursed through insurance, median x 1,000 IDR</b>	<b>2</b>	<b>350 (0-700)</b>	<b>7¥</b>	<b>130 (0-4,000)</b>	<b>0.86</b>
Vouchers or other assistance outside insurance	2/97	2%	24/131	18%	<0.0001
Transport vouchers	1		17		
Food vouchers	1		1		
Other vouchers	0		3		
Type not specified	0		3		
<b>Total value of vouchers received, median x 1,000 IDR</b>	<b>2</b>	<b>3,540 (80-7,000)</b>	<b>24</b>	<b>400 (400-400)</b>	<b>0.08</b>

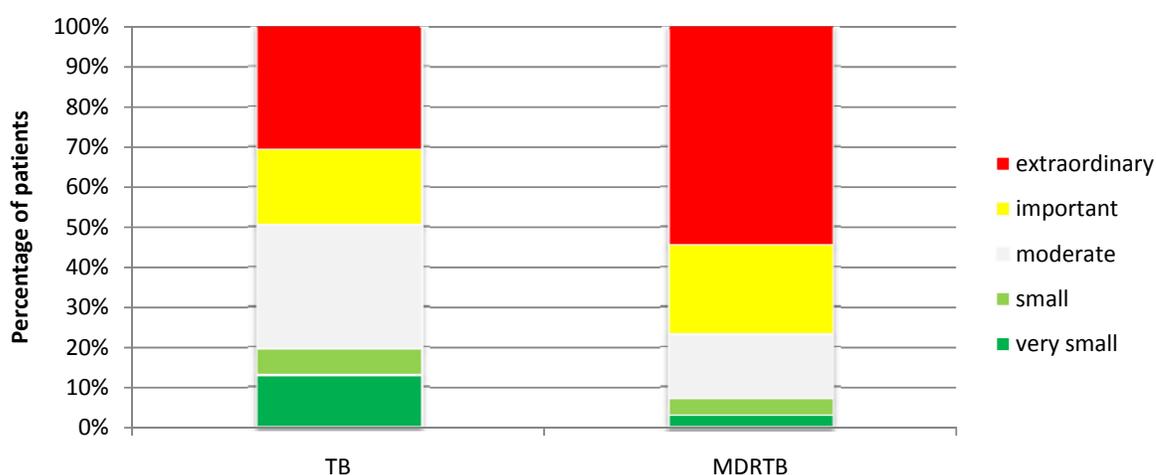
\* Abbreviations used in this table: IDR – Indonesian Rupiah, IQR – interquartile range; ‡ No information for 2 patients; ¥ no information about amount received for 1 patient; § for comparison of cell counts, Chi-square test was used, while for comparison of medians, K-sample equality-of-medians test was used.



## 6.7 Coping

### 6.7.1 Financial impact of TB disease

Patients were asked to rate how they experienced the financial impact of their disease on the household. There was no difference in rating between the two sites ( $p=0.23$ ) and surprisingly, also not between household income groups ( $p=0.16$ ), although slightly less patients in the highest income group said that TB had importantly or extraordinarily affected their family financially (57% vs. 69% and 68% for the highest compared to the middle and lowest income groups). Details are provided in Table 5A (Annex 1). As can be concluded from Figure 6, there was a difference between TB and MDR TB patients in the perception of the financial impact of their disease: among TB patients, 50% said that the financial impact of TB was at least important, while the same was said by 77% of the MDR TB patients ( $p<0.0001$ ).



**Figure 6.** Perceived financial impact of (MDR) TB by the respondents, by (MDR) TB status.

Patients reported to use up to five different strategies to pay for expenses due to their disease (Table 14). The most commonly mentioned sources were asking from donations from friends and family (mentioned by 99 (38%) of 261 patients), followed by using savings ( $n=85$  patients, 33%), and borrowing money ( $n=49$ , 19%). Most MDR TB patients (53%) used two or more strategies concurrently, while most TB patients (64%) used only one strategy to pay for expenses due to TB ( $p=0.009$ ).

### 6.7.2 Borrowing money

MDR TB patients significantly more often reported to have borrowed money and sold assets than TB patients ( $p<0.0001$ ). Among those who borrowed money, MDR TB patients borrowed more money than TB patients (1,500,000 vs. 400,000 IDR,  $p=0.02$ ). Of the 49 patients having borrowed money, most borrowed money from family ( $n=19$ ) or friends and neighbors ( $n=20$ ). Three patients did not disclose information about their loan.

Ninety percent of the TB patients took on a loan from within their personal network (i.e., from family, friends or neighbours) versus 77% of the MDR TB patients ( $p=0.66$ ). Four patients took a loan with a private bank. All of these were MDR TB patients. Twelve MDR TB patients reported that they had to pay a loan interest. Loans with an interest were higher than loans without interest, but not statistically significantly so ( $p=0.17$ ). Loan interests were sometimes requested by neighbors/friends (5 out of 20), private banks and cooperations, and interest rates varied between



1 and 30%. Amounts borrowed from neighbors or friends were lower than amounts borrowed from family or other sources (p=0.04) (Table 5B, Annex 1).

**Table 14.** Type and number of coping strategies used to pay for expenses due to TB.\*

	TB (n=118) %	MDR TB (n=143) %	Total (n=261) %	p- value§
<i>Type of strategy used</i>				
Regular household's income	9.3	8.4	8.8	0.79
Health insurance	11.0	4.2	7.3	0.04
Employer covers expenses	14.4	11.9	13.0	0.55
Reducing other expenses	9.3	14.0	11.9	0.25
Using savings	31.4	33.6	32.6	0.70
Borrowing money	9.3	26.6	18.8	<0.0001
Selling assets	3.4	21.0	13.0	<0.0001
Asking for donations	32.2	42.7	37.9	0.08
Taking on extra job	0.8	0.7	0.8	0.89
<i>Number of strategies concurrently used to cover expenses due to TB‡</i>				0.002
1	71.2	47.6	55.6	
2	23.7	36.4	33.3	
3	4.3	13.3	9.6	
4	0.9	1.4	0.8	
5	0	1.4	0.8	

\* This analysis includes all interviewed patients. Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant.

§ Calculated by chi-square test.

‡ This includes all strategies listed above in this table, except paying from regular household's income.

### 6.7.3 Selling property

Of the 34 patients who reported to have sold property, 30 were MDR TB patients. The most often reported types of property sold were jewelry (38%), household assets (18%) and transportation means (15%; Table 5C, Annex 1). One person sold two different types of property: his market stall and gold. Table 5C in Annex 1 gives details of the types and value of property sold. Most of the property was sold for less than 10 million IDR (76%). While all patients reported a value range, only 11 patients were able and willing to report the market value of the property sold. The median market value of the property sold, if indicated, was 2,000,000 IDR (IQR, 500,000-13,300,000). The median value received for the property by the same persons was similar to the median market value (2,000,000 IDR; IQR, 600,000-15,000,000). Of these 11 persons, 3 had received more money than the estimated market value, while 2 had received less money than that (Table 5E, Annex 1). The other 13 person only indicated a range of the market value and the money received for the property sold. In terms of ranges, 3 persons reported that they had received a lower amount range than the estimated price range while one person reported that he had received an amount in a higher range than the estimated market value (Table 5D, Annex 1).

### 6.7.4 Inability to work

Table 15 summarizes information related to the work situation of TB and MDR TB patients. Thirty-three percent of the patients reported to be the main income earner in the household; patients with TB were more often earning the main income than MDR TB patients (44% vs. 24%, p=0.001). Forty-nine percent of the TB patients and 31% of the MDR TB patients was working at the time of



the interview ( $p=0.003$ ). Twenty three of those still working did not earn an income from that work (probably because this concerned house work). Strikingly, 17 patients who said not to be working currently still reported that they earned an income at the time of the interview. Possibly, these patients had a job as civil servant or alike, and were on sick leave at the time of the interview. However, we cannot verify this as we did not ask the patients for their type of job.

Most patients with a job were paid in cash (56% among TB patients and 66% among MDR TB patients) or through bank transfers (35% vs. 16%). Nineteen percent of the TB patients and 30% of the MDR TB patients reportedly had to change jobs because of their TB illness (Table 15).

MDR TB patients significantly more often lost their job due to TB: of those reporting to have an income before TB disease ( $n=196$ ), 64% of the MDR TB patients reported to have lost their job, versus 37% of the TB patients ( $p=0.001$ ). Only 1 (TB) patient dropped out of school due to TB (Table 15).

Seventeen patients reported to have stopped their informal work at any moment during TB disease, most of them (81%) for a maximum of 3 months (Table 15). Only one person reported that he/she had hired a person to do their informal work, but did not provide the amount paid to this person.

**Table 15.** Indicators related to (in)formal work, by (MDR) TB status\*.

	TB		MDR TB		p-value§
	n/N or median	% or IQR	n/N or median	% or IQR	
<b>Current situation related to job</b>					
Main earner (currently)	51/116	44%	34/141	24%	0.001
Bread winner‡	37/118	32%	40/143	28%	0.69
Currently working**	57/116	49%	44/141	31%	0.003
Currently earning an income	56/116	48%	38/143	27%	<0.0001
<b>Changes in job/school due to TB</b>					
Lost job due to TB	31/117	27%	74/139	53%	<0.0001
Changed job due to TB (among those currently working)	11/57	19%	13/44	30%	0.23
Dropped out of school due to TB	1/117	1%	0/139	0%	0.28
Daily wages reduced	2/117	2%	2/139	1%	0.86
Stopped with informal work at any time due to TB,					
for a median period of:	1.5 months	(1-3.5)	3 months	(1-3)	0.32
<b>Absence from work</b>					
Days absent, median	1 days	(0-6)	0 days	(0-7.5)	
among those currently working	4 days	(0-24)	0 days	(0-12)	0.005
Median income loss related to absence among those currently working	115,152 IDR	(0-681,818)	0 IDR	(0-600,000)	

\* Abbreviations used in this table: IQR – interquartile range, IDR – Indonesian Rupiah.

‡ Defined as the only income earner in household (before diagnosis of (MDR) TB – note that for 1 household of a TB patient and 4 households of MDR TB patients, the total household income was 0 IDR.

\*\* includes non-formal work, such as house work.

The median number of days per month that the patient was absent due to TB disease was 0 days (IQR, 0-7.5) for MDR TB patients and 1 (IQR, 0-6) for TB patients. The likely explanation for this difference is that MDR TB patients can receive DOT services 24/7, while clinic opening hours for TB



patients are usually limited to a few hours in the mornings of working days only. We calculated that this inability to work due to TB was associated with a median loss of income of 65,152 (IQR, 0-727,273) IDR per treatment phase. We did not add this amount to the total of indirect costs to prevent double counting, since we assumed that the days that the patient was unable to work were actually the days that he/she had to pick up TB drugs.

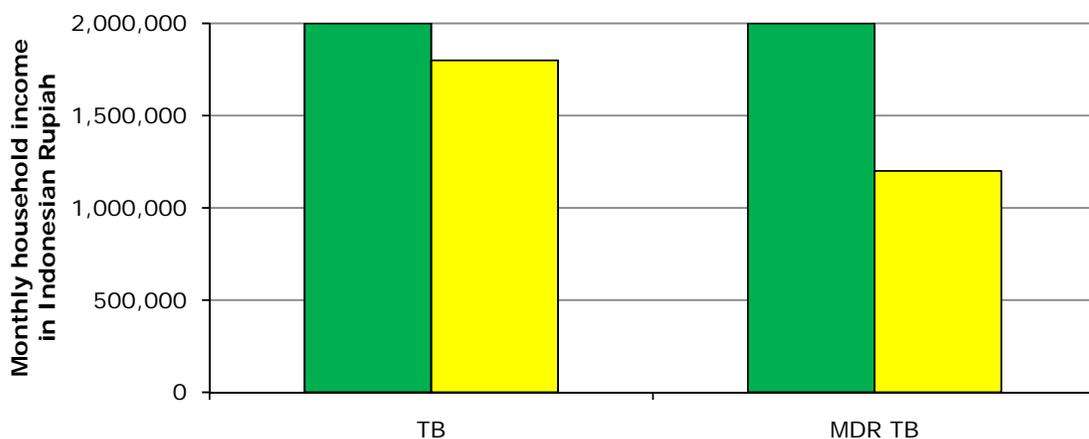
Only two MDR TB patients reported that someone had to stay at home specifically to take care of them, for a period of 12, respectively 16 months. One of these caretakers was paid for this job by the patient or his family (amount paid was not specified), while the other care taker stopped working.

### 6.7.5 Impact of TB disease on household income and patient income

Overall, the median household income dropped from 2 million IDR (IQR, 1.25 – 3 million IDR) to 1.5 million IDR (IQR, 750,000 – 2.7 million) per month. Of 258 respondents with information, 168 (65%) reported a different total household income at time of interview compared to before diagnosis of TB; for 141 (84%), this change in income was due of TB. The median income difference for these 141 patients' households was -900,000 IDR (IQR, -400,000 – -1,5 million IDR). One hundred fifty seven respondents (92%) reported a lower income at time of interview than before the diagnosis of TB, while 11 (8%) reported that the income had increased.

When dividing respondents into tertiles of household income (based on the distribution in income before diagnosis of TB), at the time of the interview, 54% of the patients fell into the lowest household income tertile (compared to 35% of patients before TB diagnosis), 21% fell in the middle tertile (compared to 32% before diagnosis) and 25% fell into the highest tertile (compared to 33% before diagnosis). The largest shift was seen among those in the middle tertile before diagnosis of TB: almost half of these shifted to the lower tertile, whereas 7% shifted to the highest tertile (Table 5F, Annex 1).

Details on total monthly household income by (MDR) TB status are provided in Table 5G (Annex 1). Ninety-seven (69%) of the MDR TB patients experienced a change in household income due to TB, for all but 11, the income dropped, versus 44 (38%) TB patients ( $p < 0.0001$ ). The median income dropped from 2 to 1.2 million IDR per month among MDR TB patients, and from 2 to 1.8 million IDR per month among TB patients (Figure 7). Among those who reported that the income change was due to TB, the drop in income was actually similar among TB (median drop -900,000 IDR (IQR -500,000 to -1.6 million)) and MDR TB patients (median drop -1 million IDR (IQR -360,000 to -1.5 million)). Thus, the larger drop in median household income among MDR TB patients was the result of the much higher percentage of MDR TB patients than TB patients experiencing a drop in income (Table 5F, Annex 1).



**Figure 7.** Median total monthly household income before diagnosis of (MDR) TB (green) and at the time of interview (yellow).



## 6.8 Options for government relief mentioned by patients

All respondents were also asked what kind of service they would like to receive if the government could provide them with any service to ease their (households) financial burden of (MDR) TB; 254 (97%) of the respondents answered this question. The most frequently mentioned options were more efficient services (98 patients), followed by provision of transport vouchers (66 patients) and provision of cash money (43 patients; Table 16). Further decentralization of MDR TB services was mentioned by only one patient, although other patients wished to have better health care including more doctors. Not surprisingly, TB patients wanted more efficient services (62%, vs. only 19% among MDR TB patients), while MDR TB patients opted more frequently for transport vouchers (36% vs. 14%) and food vouchers (10% vs. 3%) than TB patients. Also, it was not surprising that MDR TB patients more frequently mentioned that they would like to receive cash money than TB patients (22% vs. 11%).

**Table 16.** Services that the government could provide to mitigate the financial burden of (MDR) TB, as mentioned by 254 patients.\*

Service mentioned	TB (n=115)		MDR TB (n=139)		Total	
	N	%	N	%	N	%
More efficient service	71	61.7%	27	19.4%	98	38.6%
Transport vouchers	16	13.9%	50	36.0%	66	26.0%
Cash money	13	11.3%	31	22.3%	43	16.9%
Food vouchers	4	3.5%	14	10.1%	18	7.1%
All services/treatment free of charge	5	4.4%	3	2.6%	9	3.1%
Better/more health facilities	0	0.0%	4	2.9%	4	1.6%
(Staple) foods and/or dietary supplements	0	0.0%	3	2.2%	3	1.6%
Convenient shelter near to treatment center	0	0.0%	3	2.2%	3	1.2%
Health insurance	2	1.7%	0	0.0%	2	0.8%
Schooling and support for patient's children	1	0.8%	1	0.7%	2	0.8%
Other‡	3	2.6%	3	2.2%	6	1.2%

\* Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant

‡ The following options were all mentioned once: cheap loans and more doctors by TB patients; decentralized management of MDR TB, service centers for MDR TB, good or better health facilities, starting capital business, job, and “the best” by MDR TB patients. For 1 TB and 1 MDR TB patient, the preferred service was not further specified.

## 6.9 Outcome of sensitivity analyses

Table 17 shows the number of patients excluded from the analysis because they were in their current treatment phase for less than 3 months or because they were diagnosed with MDR TB more than one month before the interview. We compared the data of 235 patients to those of all 261 patients, and to those of the 26 excluded patients by TB group on overall, direct and indirect diagnostic and treatment costs. No important and no statistically significant differences were found (see Table 6A, Annex 1). Therefore, all 261 patients were included in the main analyses.



**Table 17.** Number of patients excluded from the sensitivity analysis.\*

TB group	months in current phase				total include d	total excluded	total
	0	1	2	>=3			
in intensive phase of TB treatment§	0	3	51	8	62	0	62
in continuation phase of TB treatment	0	11	8	37	37	19	56
just diagnosed with MDR TB‡	18	9	2	0	27	2	29
in intensive phase of MDR TB treatment	1	0	1	53	53	2	55
in continuation phase of MDR TB treatment	1	1	1	56	56	3	59
<b>Total</b>					<b>235</b>	<b>26</b>	<b>261</b>

\* The general rule for inclusion was that patients had to be in their current treatment phase for at least 3 months. Abbreviations used in this table: TB – tuberculosis; MDR – multidrug resistant.

§ Since the intensive phase of standard first-line TB treatment takes only 2 months, we wanted to include patients at the end of the intensive phase, but since this was not a clear criterion, those being on treatment for at least one month were also considered eligible.

‡ those just diagnosed with MDR TB should have been diagnosed not longer than 1 month before the interview, and could thus have been on treatment for 1 month at the time of the interview.



## 7 Discussion

### 7.1 Main results of the study

In this study, we found that TB patients and MDR TB patients experience similar costs for the diagnosis of (MDR) TB (Table 18). The direct costs of TB diagnosis made up for 90% of the total costs. Main direct cost components for TB patients were medical costs related to administration charges and laboratory tests, while main direct cost shares among MDR TB patients were non-medical costs for transport and food.

While diagnostic costs were comparable between TB and MDR TB patients, the costs related to MDR TB treatment were much higher (around 15 times more) than costs for TB treatment (Table 18). Indirect costs formed an important cost component for MDR TB patients because of the time involved in daily travel to the health clinic for DOT. Indeed, costs were mainly spent on receiving DOT and buying supplements, which was similar to TB patients, who spent the costs mainly to picking up drugs and buying supplements. Hospitalization costs were also high.

The estimated total costs of TB were 1.5 million IDR (~150 USD), while the total costs of MDR TB were estimated at 21 million IDR (~2200 USD). This is equivalent to approximately 18 months of total household income after the diagnosis of TB for MDR TB patients (i.e. equivalent to almost the full duration of MDR TB treatment lasting 20-24 months usually), and to one month household income after diagnosis of TB for TB patients.

It was uncommon to be reimbursed or to receive allowances or vouchers, both among TB and MDR TB patients. Considering the above results, it is not surprising that the financial impact of (MDR) TB was much higher among MDR TB than among TB patients. Not only were the costs of MDR TB treatment much higher, also more MDR TB than TB patients lost their jobs (53% vs. 26%), thereby further increasing the financial burden of their disease. Not surprisingly, 77% of MDR TB patients perceived the financial impact of MDR TB on their household as 'important' or 'extraordinary' (versus 50% of TB patients). MDR TB patients more often sold property and took on loans than TB patients.

**Table 18.** Summary of median costs for diagnosis and treatment in Indonesian Rupiah (IDR) and US dollar (USD).

Costs of:	Tuberculosis (TB)		Multidrug resistant TB	
	x 1,000 IDR	USD	x 1,000 IDR	USD
<b>Diagnosis</b>				
Direct	322	33.23	382	39.42
Indirect	34	3.51	27	2.79
<b>Total</b>	<b>339</b>	<b>34.99</b>	<b>450</b>	<b>46.44</b>
<b>Treatment</b>				
Direct				
Intensive phase	393	40.56	5,774	595.88
Continuation phase	573	59.13	9,458	976.07
Indirect				
Intensive phase	95	9.80	3,053	315.07
Continuation phase	84	8.67	2,463	254.18
<b>Total</b>				
Intensive phase	<b>509</b>	<b>52.53</b>	<b>10,453</b>	<b>1,078.76</b>
Continuation phase	<b>790</b>	<b>81.53</b>	<b>11,893</b>	<b>1,227.37</b>
Total estimated costs for a (MDR) TB episode*	1,484	153.15	21,198	2,187.65

\* Sums are based on adding up medians from different groups of patients, and therefore must be interpreted with caution.



## 7.2 Limitations

This study faced several limitations. Most importantly, due to limitations in time and budget, only patients being on (MDR) TB treatment in the two selected public hospitals (and the satellite community health centers of one of these) were included in the study. This implies that those (MDR) TB patients not seeking diagnosis, those being diagnosed with (MDR) TB but not starting (MDR) TB treatment, and those defaulting from (MDR) TB treatment before the interview were missed by this study. Thus, the study results are likely to be biased towards the less socio-economically vulnerable groups, as the very poor might have no access to TB diagnosis and treatment (see e.g. Hossein *et al.*, 2012). The extent of this bias will depend on the country. Since Indonesia will do a TB prevalence survey in the same time period, it might be possible to assess this bias in Indonesia.

Another important limitation is that respondents were only interviewed once, so that costs could be extrapolated per stage and to the total (MDR) TB episode, which means that this study did not yield total costs of (MDR) TB treatment incurred *per patient*. Capturing the total costs per patient requires follow-up of a sample of patients during their treatment, which may take more than 2 years for MDR TB patients and takes at least 6 months for non-MDR TB patients. However, this study revealed the major cost components and a rough estimate of the costs incurred per treatment phase, which may give enough information to develop reimbursement policies. More specific information from a more specific group of patients can be collected if required.

All studies using questionnaires suffer from recall bias and this study is not an exception. It is difficult to say in which way recall bias may have influenced the study results, as respondents may have failed to mention lower or routine costs – or contrarily may have been more accurate in recalling these costs as they know prices of food and transportation very well. On the other hand, major one-off costs are likely to be remembered, whereas this might not be the case for other one-off or infrequently occurring costs.

To overcome the problem of recall bias, we only asked the respondents about costs made in the past three months, and about major one-off costs. Consequently, the costs reported in this study must be regarded as rough estimates, not as the exact costs of specific components, nor as a precise estimate of the total patient costs of (MDR) TB.

To get an exact estimate of total costs incurred, other methods than (repeated) interviews are required, such as patient diaries. However, it is known that it is difficult to motivate patients to keep diaries for a longer time period and this may lead to selective dropout of the less well educated and socially engaged patients.

The costs reported in this report are likely to underestimate the true costs for several reasons:

- patients may have failed to remember all items that cost money, especially with respect to costs that fell in the category 'other costs';
- missing costs (e.g. because the respondent did not remember the costs, because the question was skipped, or because the respondent did not want to disclose cost information) were assumed to be 0 (zero);
- Reported costs concern costs for a specific stage of (MDR) TB diagnosis and treatment, not for the total episode of (MDR) TB. Obviously, these costs are much higher than the costs of a single stage. Though we attempted to come up with a cautious and rough estimate for the cost of a total (MDR) TB episode (Table 2, Table 18), it should be noted that this is the result of adding up medians of different groups of patients. Cost patterns and amounts may change over the course of the episode, making it very difficult to forecast total costs of an (MDR) TB episode for a specific patient.
- As we did not know when a (MDR) TB patient who lost his/her job did lose the job, we could not calculate the indirect costs due to loss of income. Considering that 26% of the TB patients and 53% of the MDR TB patients lost their job, apparently often already in the



- intensive phase of (MDR) TB treatment, this lost income must cause an important financial burden to the (household of the) (MDR) TB patient.
- Extrapolation was applied to the internationally minimum recommended phase duration (2 and 3 months respectively for the intensive phase of TB treatment of new and previously treated patients, 4 and 5 months respectively for TB treatment continuation phase, 8 months for the intensive phase of MDR TB treatment and 12 months for the continuation phase of MDR TB treatment (the latter to come to the minimum recommended duration of 20 months)). If a patient was in the current phase for more than the minimum recommended duration, we assumed that this patient must be in the last month of that treatment phase. However, it is known that MDR TB patients frequently are treated for longer than 20 months.

Another limitation is that costs may not directly correspond with the experienced financial burden of (MDR) TB. Patients with higher incomes consequently lose more income and thus experience higher indirect costs of (MDR) TB, while this may not affect the experienced burden of (MDR) TB. On the other hand, the financial impact of (MDR) TB did not vary by household income class – possibly because patients with higher incomes also have a more expensive expenditure pattern (e.g., use more expensive transportation means).

We did not collect information on the type of job of the patients while this may be important. Civil servants, for example, may report time lost while no income was lost because their employer is insured and they can take sick leave, while those being self-employed or being paid on a daily basis may suffer direct income loss for each day that they are not able to work.

Finally, in this study we only included two PMDT sites in Indonesia, which are both located on Java Island. The results are probably not representative for Indonesia as a country. Results of other provinces on other islands are needed to come to a reliable estimate for the financial burden of (MDR) TB in Indonesia. However, we hypothesize that our main conclusions (listed in Chapter 9) will be applicable to Indonesia as a country.

### 7.3 Previous results of the patient cost tool

A study using the previous version of the patient cost tool compared the costs of TB treatment for the three countries of Ghana, Vietnam and the Dominican Republic (Mauch *et al.*, 2013a). 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 their TB disease. Main cost shares of TB treatment were for hospitalization and supplementary food items. The average total patient costs, which ranged from 538 to 1,268 USD) were equivalent to approximately one year of individual income.

In a Dominican Republic study 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 (Mauch *et al.*, 2013b). Over the course of their TB episode, for most respondents, direct and indirect costs increased while income decreased. Total costs amounted to a median of 908 USD for new patients, 432 USD for retreatment patients, and 3,557 USD for MDR TB patients. The proportion of patients without a regular income increased from 1% to 54% because of TB.

The results reported for the three countries differed from each other and they are also different from the results that we report here for Indonesia (Mauch *et al.*, 2013a). The direct costs of TB diagnosis were much lower (reported medians between 8 USD (Vietnam and Dominican Republic) and 14 USD) than in this patient population in Indonesia (46 USD). In contrast, the indirect costs were much higher (reported medians, 170 for Ghana to 721 USD for Vietnam, versus 36 USD for Indonesia). There are two potential explanations for these differences. First, unlike the three-country study, the population of TB patients included in our study is probably not representative for all TB patients in Indonesia, as we included TB patients (mainly visiting TB referral hospitals) in



Jakarta and Solo. Such patients may (be willing to) pay higher costs for diagnosis or may have been more difficult to diagnose with TB than patients getting a diagnosis at an average community health center. Second, we did not include the indirect costs due to inability to work in the diagnostic costs. However, even if we would have included this (based on the average number of days per month that patients had been absent from formal work over the past 3 months), this would not have led to an increase in indirect costs, as the medians were 0 days for both TB and MDR TB patients (IQRs respectively 0-6 and 0-0 days). Direct treatment costs reported from the three-country study were also lower than those we reported (73 USD for Vietnam to 114 USD for Ghana (Mauch *et al.* 2013a), versus 240 USD for Indonesia), while indirect costs were higher (median costs 12-69 USD (Mauch *et al.*, 2013a) versus 9 USD for Indonesia). However, it should be stressed that our study did not aim to estimate the exact costs of (MDR) TB diagnosis and treatment; rather it aimed to give an indication of the cost burden and the main costs components to provide information for action.

The recommendations based on the three-countries study were: bringing services closer to patients, reducing expenditures on transport and invested time, increasing efforts to find cases early to reduce indirect costs related to inability to work, informing health care workers and the public about TB diagnosis and treatment to reduce costs unrelated to TB, and including TB-related out-patient costs in social protection schemes. The study reported that each country took action to implement one or more of the identified solutions (Mauch *et al.*, 2013a).

In Vietnam, the NTP in Viet Nam decided to increase the involvement of the private sector in public-private-mix projects focusing on reducing travel, accommodation and hospitalization costs for TB patients and guardians. Second, the study contributed to the decision to switch from the 8-month to the 6-month anti-tuberculosis treatment regimen, which will help reduce the treatment time and travel costs for follow-up tests. Third, the NTP worked on the expansion of its NTP network to provide TB services at provincial general hospitals, all major public hospitals not reporting to NTP and private hospitals. Fourth, the NTP started planning for a way to provide social and economic support to TB patients in each district. Finally, the NTP started to mobilize support for TB patients by organizations such as farmers and Women's Unions.

In Ghana, the Ministry of Health included TB care interventions as part of its pro-poor strategies in the delivery of health care. The Nutrition Department of the Ministry of Health also developed nutrition guidelines to address the specific needs of TB patients. The study generated key evidence in informing and developing the successful Global Fund Round 10 TB proposal. Given the identified high burden for female TB patients in Ghana, the NTP focused on addressing gender-sensitive challenges of poor TB patients. Also the parliamentary sub-committee on health has increased insurance coverage for all TB patients for health-related costs other than (free) anti-tuberculosis treatment.

In the Dominican Republic the Ministry of Health decided in 2011 to move forward with allocating public funds for food supplements for TB patients and including in- and outpatient TB services in the national health insurance schemes (Mauch *et al.*, 2013).

## **8 Policy options**

### **8.1 Workshop**

A national workshop was held in Jakarta on 13 and 14 November 2013 to discuss the findings of the study in Indonesia and to generate options for mitigating patient costs and formulate an action list. The workshop scope and agenda can be found in Annex 3. Invitees from different Ministries, governmental working groups, international NGOs (including MSH and KNCV), universities, PMDT sites, and from the first MDR TB patient organization participated in the workshop (see Annex 3 for invited organizations).



During the workshop, the results of this study were presented and discussed. Subsequently, policy options for mitigating the financial burden of (MDR) TB were discussed, listed, and prioritized. Also, participants from other provinces were invited to present the mitigation options that they implemented. In Dr Soetomo hospital, after stopping the monthly living allowances (400,000 IDR, provided through TBCARE) due to lack of funding, the hospital started reimbursing this amount of money from its own resources to all MDR TB patients asking for this assistance; up until half November 2013, the total costs for the hospital amounted to 289 million Indonesian Rupiah. In staff's experience, only the very poor patients opt to use these services. In this study, we indeed found that reimbursements were more common among MDR TB patients being treated in Solo than in Jakarta (Table 3C, Annex 1). Besides, in Central Java province, the governor has undersigned a decree that states that all non medical costs of MDR TB patients (i.e., costs of food and transport) should be reimbursed to MDR TB patients.

## 8.2 Mitigation options

During the first day of the workshop, participants formulated a list of policy options. During the second day, this list was prioritized in 8 multi-disciplinary groups of participants (each group of participants contained civil servants from different ministries, staff of (international) NGO's, medical doctors from different PMDT sites, and ex MDR TB patients), using rank scores from 10 (option with highest priority) to 1 (option with lowest priority). Feasibility scores were also given, but these are not included in this report (see below). The prioritized list of mitigation options is shown in Table 19. Since the (ex) MDR TB patients present at the workshop felt that this list was not fully meeting their needs, they prepared a separate list of options (Table 20). Part of these options was also mentioned during the workshop (Table 19). Not surprisingly, participants of the workshop, which were mainly civil servants working at the Ministry of Health and representatives of local and international NGO's, mainly prioritized TB service improvements (TBS), while the representatives of the patient organization preferred measures to improve social protection (SP).

Table 21 provides a matrix (adapted from the Policy Briefing Paper after the workshop for this project in Ethiopia, prepared by D. Collins) with challenges and solutions to the economic burden of MDR TB. Though it does not list all options provided in Tables 19 and 20, it gives a broad overview of opportunities to reduce the financial burden of patients due to MDR TB.

## 8.3 Recommendations

We formulate the following recommendations per (group of) option(s) listed in Tables 19 and 20, which are not mutually exclusive – it may be necessary to provide more than one mitigation strategy at the same time. In this section, the recommendations (in italic font) are separated into two areas: service delivery and social protection:

### 1. **TB service improvements:**

- a. **Ensure that policy of free care for all (MDR) TB services is fully implemented.** TB services for the diagnosis of smear-positive TB are provided free of charge in all community health centers. However, diagnosis at other places (general hospitals, private sector) usually comes at (high) costs. Also, administrative fees are charged to TB patients. Currently some TB services such as X-ray are not free of charge while physicians prescribe them, sometimes also when X-ray is not needed (in the case of smear-positive TB). As a result patients sometimes pay high costs for X-ray. *Official local government decrees need to be in place so that presumed TB patients can make use of the necessary diagnostic tools for free.*



**Table 19.** Prioritized list of mitigation options made during national workshop on patient costs of (MDR) TB\*.

<b>Category</b>	<b>Description</b>	<b>Priority score (0-80) ‡</b>
TBS service improvement	Service closer to the patient (further decentralization/mobile clinics) / Improve downward referral	46/12
TBS	Empowerment of community health workers (also for administration of drugs)	24
SP	Diagnosis and treatment free of charge or refundable	49
TBS	Reinforce treatment standards / Forbid the use of unnecessary/substandard tests	32/39
TBS regulation	Obligatory treatment for MDR TB patients (to protect community)	21
SP	Strengthen regulations for community health workers (including incentives)	14
SP	Introduce ID card for poor patients	13
SP	Convenient shelters for patient and family	28
SP	Include TB (and other diseases) in social support programs <sup>§</sup>	24
SP	Secure or advocate for job protection <sup>§</sup>	20/7
SP social protection	Free sponsored transportation schemes <sup>§</sup>	17
SP	Develop disability insurance programs <sup>§</sup>	15
SP	Introduce small business scheme for (MDR) TB patients who lost their job due to TB <sup>§</sup>	11
SP	Empowerment of patient peer groups	25
SP patient information	Patient education by health staff/patient peer groups about reimbursement schemes	17
TBS/empowerment	Involve local NGO's and/or community organizations to improve MDR TB treatment adherence	17
TBS program budgeting	Better planning and awareness about possibilities for donor funding of patient support programs	20
SP community awareness rising	Inform community about importance of TB treatment and government support	9

\* Abbreviations used in this table: (MDR) TB – (multidrug resistant) tuberculosis, TBS – TB service improvements, SP – social protection improvements, NGO – non-governmental organization. Although feasibility was also scored (from 0 for least feasible to 10 for most feasible option), we do not present these here as the ranking were not uniformly applied by the eight working groups, and it therefore becomes impossible to calculate a meaningful overall rank.

‡ All 8 groups were asked to pick the 10 options with highest priority from a list 22 options (and to add extra options if this was felt necessary) and to rank these 10 options with minimum 0 (for the option that was considered to have least priority) to maximum 10 points (for the option with highest priority).

§ This was summarized as "social security net for TB patients" by one of the eight working groups.

**Table 20.** Mitigation strategies according to representatives of the MDR TB patient organization in Persahabatan hospital\*.

<b>category</b>	<b>mitigation strategy</b>
SP	reimbursement of travel costs
TBS	bring services closer to patient
SP	(MDR) TB hotline available 24h for patients
SP	social support in case of depression
SP	job security and opportunities
SP	economic support (living allowance)

\* Abbreviations used in this table: (MDR) TB – (multidrug resistant) tuberculosis, TBS – TB service improvements, SP – social protection improvements.



- b. Bring services closer to patients.** MDR TB services are being rolled out in Indonesia, though this roll out is slower than expected due to a range of challenges.
- i. *Further decentralization should reduce patient expenditures on transport and patient time and therefore is expected to reduce detection and treatment delays.*
  - ii. *For areas where no public transport exists, transport for patients, reimbursement of transport fees, or home visits by clinic staff should be arranged.*
  - iii. *Patients may be given various alternatives for the place where they wish to receive their treatment, as acceptance of decentralized care in community health centers varies over the country (e.g., only 11% of MDR TB patients from Persahabatan hospital is being treated in a community health center currently). Low acceptance of decentralized care is related to limited opening hours of community health centers, perceived low standards of care, and fear of stigma among patients when being treated in their own residential area.*
  - iv. *Currently, TB and HIV services are being integrated at primary health care level and implementation is being scaled up gradually. At present, this integration remains restricted to voluntary counseling and HIV testing (VCT). We recommend that these services should be further integrated with priority.*
- c. No unnecessary or substandard tests.** As indicated under option 1a, some tests are being prescribed by physicians that are not needed (e.g., X-ray for diagnosis of smear-positive TB patients). Private laboratories sometimes use substandard tests (e.g., Microdot, and other serological tests, and IS6110 based PCR for detection of *Mycobacterium tuberculosis*). Such tests are not only unnecessary, but also may importantly increase the costs of (MDR) TB diagnosis. Especially detection of drug-resistant TB should reduce the time to appropriate treatment, and thus reduce direct and indirect treatment costs for patients. *Reinforcement of current policies for diagnosis of TB outlined in the PNPk document (Standards for Clinical Practice, 2013) should include advocacy to all private providers). Full implementation of new diagnostics such as Xpert MTB/RIF should reduce time to diagnosis and thus patient costs.*
- d. Obligatory treatment for MDR TB patients** may be needed in parts of the country where a large proportion of MDR TB patients refuses MDR TB treatment, due to lack of knowledge or support, to protect the community against the spread of MDR TB. MDR TB patients may fear the costs and side effects related to MDR TB treatment. *Patient education, installation of patient organizations (as is starting up now in different hospitals), and provision of living allowances may help to remove some of these obstacles.*
- e. Better planning and awareness about possibilities for donor funding** of patient support programs. Global Fund provides opportunities for funding of patient support programs, but these are not optimally used. *Sustainable solutions should be developed for domestic funding, such as corporate social responsibility (CSR) programs, support by local NGO's and social services support..*
- f. Involve local NGO's and civil society organizations** and empower community health workers in provision of (MDR) TB drugs to improve (MDR) TB treatment adherence, since this will increase the population that can be targeted. *KNCV and WHO are currently developing a service package for delivery of services by (local) NGOs.*
- g. Improve downward referral** from national or provincial MDR TB treatment centers to local community health centers to reduce transport costs and time for



MDR TB patients on treatment. At present, decentralization is being set up. However, as was shown for Persahabatan hospital (Persahabatan annual report 2013), although decentralized treatment is available, this is not being exploited optimally. This is due to several factors, amongst which lack of knowledge and experience with MDR TB treatment (side effects) among local health staff, limited opening hours of community health centers, lack of trust of the patient in the local health staff, and problems with monitoring of remote community health centers. *However, we recommend that decentralization will be continued up to a feasible level (at least in each province, MDR TB diagnosis and treatment services should be available), and that other solutions (such as the provision of free and convenient transport) should be provided in those cases where decentralization is not feasible.*

## **2. Social protection improvements.**

- a. Provide convenient lodging** to those MDR TB patients who cannot travel back and forth for receiving DOT. Since MDR TB treatment roll-out is still ongoing distances that MDR TB patients have to travel for receiving DOT can be long in Indonesia and this may mean that patients need to move to a shelter close to the PMDT site. It is expected that the number of patients needing such lodging possibility will decrease with the roll-out of the PMDT program. Meanwhile, *we recommend that MDR TB patients and their families should be provided with cheap and convenient shelters close to the DOT site for themselves and their companions (families).*
- b. Empower patient groups** that can support MDR TB patients in a practical way during MDR TB treatment. Being a new development in Indonesia, MDR TB peer educator groups are being set up by ex MDR TB patients. The first group has been established in Persahabatan hospital, and new groups have started in other hospitals in Java province recently. MDR TB peer educator groups provide information and moral support to MDR TB patients regarding side effects, reimbursements systems, etc., and thus serve as a valuable and easily accessible information point to MDR TB patients. *We recommend that formation of such patient support groups should be actively encouraged and facilitated by community based organizations and local health facilities.*
- c. Include direct (transport, food support) costs in social support schemes provided through Social Services.** Such incentives and enablers should reduce direct costs associated with TB treatment and improve treatment adherence.
- d. Include indirect (sick leave allowance) costs in social protection schemes.** *Review, standardize and expand current social protection mechanisms and schemes by the government.* Social protection schemes, including temporary disability allowances, should be made available to those (MDR) TB patients who need it, from the moment they are diagnosed. Include social protection for (MDR) TB under disability policy strategies while ensuring that the protection is provided from the time of confirmed diagnosis to those who are at risk of becoming poor or not seeking or completing treatment. Professional guidance by health care workers or social workers for submitting applications for social support is needed for many patients. *Possibilities for agreements on delaying or waiving payments (e.g. mortgage loans, school fees) are to be investigated by the national and provincial authorities in cooperation with the health facilities, patient organizations and local NGOs.*
- e. Improve employment protection.** *Advocate for regulations and policies that mandate that private employers pay employees (a portion of) their salary while they are unable to work. Also advocate for patients to be able to return to previous positions once they are fully cured and clinically fit to perform their assignments.*



- f. **Increase re-socialization and employment possibilities.** Local facilities, assisted by (local) NGO's and patient groups, should develop mechanisms to involve patients in income generating activities and advocate to the government to support these, for example through microfinance systems.
- g. **Reduce stigma and acceptance of outpatient treatment.** *Improve education to the public on TB and MDR TB, e.g. through primary level services, in order to reduce stigma of (MDR) TB and reduce fear of transmission during outpatient treatment.*

Table 21 summarizes these options. Based on the above analysis, it is clear that some of the options open to the Government of Indonesia to address the issues identified are short term and others are long term. The most important place to start in the short term seem to be to accelerate the expansion of outpatient treatment in order to reduce income loss, including acceleration of expansion of DOT services closer to the patients, and to analyze and improve the existing social support system.

We trust that the results of this study are useful to further guide the development of policies to relieve financial hardship for (MDR) TB patients and hereby potentially improve treatment outcomes.

## 8.4 Next steps

Next, stakeholders should be identified for each mitigation option, and a plan of action should be made with NTP, the Ministry of Health and other stake holders on whether, with whom, how and when to implement these options. Feasibility should be assessed more thoroughly than was possible during the workshop.

**Table 21.** Challenges and solutions regarding MDR TB patient economic burden.

PROBLEM AND IMPACT			
<b>Problem</b>	Poverty prevents seeking health care; Poverty makes people more vulnerable for TB-related complaints	Delays in seeking correct diagnosis and treatment and non-adherence to treatment; Continued transmission.	
<b>Impact</b>		Increased illness, death and disease transmission. Increased service delivery costs due to inefficiency and reduced potential for sustainability.	Families become poorer and more susceptible to TB infection. Children leave school prematurely.
<b>BROAD CHALLENGE</b>	<b>DETAILED CHALLENGE</b>	<b>IMPACT</b>	<b>RECOMMENDED SOLUTION</b>
Health services not all free	Additional tests (e.g. X-ray) are done even when not necessary; not in all health centers, TB services are for free.	Increased service costs and diagnostic delays when trying to obtain services or funds.	Improve correct implementation of national guidelines, also in health centers not under Ministry of Health.
Services far from patients	MDR TB diagnostic and treatment services not available in all provinces and to all MDR TB suspects and patients	Increased transport, food and accommodation costs and reduced income.	Expand MDR TB diagnostic and treatment capacity, transport of test samples. Further decentralisation of treatment services, Community Health Nurses
Detection and	Lack of early	Increased transport,	Expand ability of community



treatment slow	recognition of symptoms, seeking of diagnosis and initiation of treatment at primary health care levels, unnecessary testing.	food and accommodation costs and reduced income.	health workers, health extension and facility-based health staff to recognize TB symptoms and get diagnosis and support treatment. Improve upward and downward referral system.
Social protection not available for all patient costs	Fragmented and limited social protection program, existence and criteria of insurance schemes often unknown to patients and health staff.	Inadequate income replacement.	Standardize social protection program and guarantee funding from government while allowing donors to continue to contribute.
Little employment protection	Some employers may not allow employees to take time off for diagnosis and treatment, or fire patients out of fear (stigma). Patients cannot get back their old jobs when they are cured.	Reduced income because some employers do not provide partial salary when an employee is ill or because of loss of job.	Advocate against stigma. Advocate employers to follow the law on paying the legally required benefits to sick employees. Advocate employers to allow cured patients to recover their old jobs.
Lack of employment opportunities after cured	Persons who remain poor after being cured are at risk of recurrence of MDR-TB.	Long-term reduced income possibilities can keep families in the poverty trap.	Look for income generating possibilities for affected families, including access to micro-credit.

## 9 Conclusion and recommendations

With the study, we tried to answer the following question: Do diagnosis and treatment costs cause financial hardship to TB patients and their families? From the results presented in this report, it becomes clear that while TB patients face a considerable financial impact due to their disease, this impact is extraordinary to MDR TB patients and their families. A too high financial burden may cause patients to default from treatment, and die from (MDR) TB. This results in continued transmission of (MDR) TB to already vulnerable household members.

Indeed, 3 of the 9 patients with MDR TB who had defaulted previously had done so because of the costs of treatment. Thus, to reduce transmission and mortality, it should be a priority of the Indonesian government to relieve the financial burden especially for MDR TB patients.

Based on the above, it is clear that some options address issues may provide solutions to problems occurring in the short term, while others are solutions to long-term problems. Acceleration of expansion of PMDT services – this includes diagnosis of MDR TB, also of the lower risk groups has the highest priority, followed by making sure that current policies for payment for tests and type of tests conducted are followed.

## 10 Literature

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## 11 Annexes

Annex 1. Additional tables with details of data analysis not presented in the main text

Annex 2. Questionnaire

Annex 3. Details of the national workshop on costs faced by (MDR) TB patients during diagnosis and treatment (in Indonesian)



## Annex 1. Additional tables.

**Annex Table 1A.** General patient characteristics by type of tuberculosis (TB or MDR TB)\*.

Patient characteristic	TB (N=118)		MDR TB (N=143)		p-value§
	N‡	%	N‡	%	
<b>Type of TB</b>					0.06
Pulmonary smear positive	70	59.3	96	67.1	
Pulmonary smear negative	34	28.8	38	26.6	
Extrapulmonary	12	10.2	4	2.8	
No information	2	1.7	5	3.5	
<b>Recruited at site</b>					<0.0001
Persahabatan hospital, Jakarta	96	81.4	69	48.3	
Satellite of Persahabatan hospital, Jakarta	2	1.7	20	14.0	
Dr Moewardi hospital, Solo	20	17.0	54	37.8	
<b>Sex</b>					0.1
Male	71	60.2	67	46.9	
Female	46	39.0	74	51.8	
No information	1	0.9	2	1.4	
<b>Age</b>					0.051
Age group					
21-29	36	30.5	26	18.2	
30-39	24	20.3	47	32.9	
40-49	28	23.7	38	26.6	
50+	29	24.6	32	22.4	
No information	1	0.9	0	0.0	
Median age (25 <sup>th</sup> , 75 <sup>th</sup> percentile)	38	(28, 49)	39	(30, 49)	0.97
<b>Ethnic group</b>					0.06
Betawi	26	22.0	25	17.5	
Jawa	53	44.9	92	64.3	
Sumatera	23	19.5	14	9.8	
Tionghoa	2	1.7	2	1.4	
East Indonesian	3	2.5	3	2.1	
Sundanese	6	5.1	3	2.1	
Other, specify	3	2.5	4	2.8	
No information	2	1.7	0	0.0	
<b>Highest education completed</b>					0.15
No schooling	0	0.0	4	2.8	
Primary school	20	17.0	33	23.1	
Secondary school	80	67.8	91	63.6	
Bachelor	17	14.4	15	10.5	
Other	1	0.9	0	0.0	
<b>HIV status according to patient card</b>					<0.001
positive	7	5.9	1	0.7	
negative	33	28.0	95	66.4	
not tested	72	61.0	37	25.9	
not indicated on card	5	4.2	9	6.3	
no information in database	1	0.9	1	0.7	
<b>Travel time to nearest health facility</b>					0.001
0-15 minutes	50	42.4	30	21.0	
16-30 minutes	30	25.4	40	28.0	
31-60 minutes	21	17.8	27	18.9	
61-120 minutes	10	8.5	30	21.0	
>120 minutes	7	5.9	16	11.2	
Median time to nearest public health facility (25 <sup>th</sup> , 75 <sup>th</sup> percentile)	20	(10, 60)	40	(20, 120)	0.002

\* Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant, USD – US dollar

‡ Unless specified that the median is presented

§ for counts, chi-square test was used, for medians, K-sample equality-of-means test was used

**Annex Table 1A, continued.** General patient characteristics by type of tuberculosis (TB or MDR TB).

Patient characteristic	TB (N=118)		MDR TB (N=143)		p-value§
	N‡	%	N‡	%	
<b>Travel time to DOT facility</b>					
0-15 minutes	23	19.5	28	19.6	0.52
16-30 minutes	43	36.4	43	30.1	
31-60 minutes	30	25.4	33	23.1	
61-120 minutes	12	10.2	25	17.5	
>120 minutes	10	8.5	13	9.1	
No information	0	0.0	1	0.7	
Median time to DOT facility (25 <sup>th</sup> , 75 <sup>th</sup> percentile)	30	(25, 60)	35	(20, 90)	0.34
<b>Household income per month before TB was diagnosed</b>					
0 - 1.5 million Rupiah (0-154 USD)	38	32.2	52	36.4	0.47
1.51 - 2.6 million Rupiah (155-275 USD)	36	30.5	48	33.6	
2.7 - 102 million Rupiah (276-10,500 USD)	44	37.3	43	30.1	
Median household income, million Indonesian Rupiah (25 <sup>th</sup> , 75 <sup>th</sup> percentile)	2.0	(1.5, 3.3)	2.0	(1.1, 3.0)	0.87

\* Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant, USD – US dollar

‡ Unless specified that the median is presented

§ for counts, chi-square test was used, for medians, K-sample equality-of-means test was used

**Annex Table 1B.** General patient characteristics by city of enrollment (Persahabatan hospital and satellite sites in Jakarta or Dr Moewardi hospital in Solo).

Patient characteristic	Jakarta (N=187)		Solo (N=74)		p-value§
	N*	%	N*	%	
<b>Patient group</b>					
Intensive phase of standard (re)treatment regimen	52	27.8	10	13.5	<0.0001
Continuation phase of standard (re)treatment regimen	46	24.6	10	13.5	
Just diagnosed with MDR TB	11	5.9	18	24.3	
Intensive phase of MDR TB treatment	38	20.3	17	23.0	
Continuation phase of MDR TB treatment	40	21.4	19	25.7	
<b>TB regimen</b>					
standard regimen for new TB patients	77	41.2	16	21.6	0.001
retreatment regimen	21	11.2	4	5.4	
MDR TB regimen	89	47.6	54	73.0	
<b>Type of TB</b>					
Pulmonary smear positive	103	55.1	63	85.1	<0.0001
Pulmonary smear negative	67	35.8	5	6.8	
Extrapulmonary	14	7.5	2	2.7	
No information	3	1.6	4	5.4	
<b>Type of TB: susceptibility</b>					
TB	98	52.4	20	27.0	<0.0001
MDR TB	89	47.6	54	73.0	
<b>Sex</b>					
Male	103	55.1	35	47.3	0.25
Female	81	43.3	39	52.7	
No information	3	1.6	0	0	

\* Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant, USD – US dollar

‡ Unless specified that the median is presented

§ for counts, chi-square test was used, for medians, K-sample equality-of-means test was used

**Annex Table 1B, continued.** General patient characteristics by city of enrolment.

Patient characteristic	Jakarta (N=187)		Solo (N=74)		p-value§
	N‡	%	N‡	%	
<b>Age</b>					
Age group					0.04
21-29	50	26.7	12	16.2	
30-39	45	24.1	26	35.1	
40-49	52	27.8	14	18.9	
50+	40	21.4	21	28.4	
No information	0	0.0	1	1.4	
Median age (25 <sup>th</sup> , 75 <sup>th</sup> percentile)	39	(29, 48)	39	(31, 51)	0.9
<b>Ethnic group</b>					
					<0.0001
Betawi	51	27.3	0	0.0	
Jawa	71	38.0	74	100	
Sumatera	37	19.8	0	0.0	
Tionghoa	4	2.1	0	0.0	
East Indonesian	6	3.2	0	0.0	
Sundanese	9	4.8	0	0.0	
Other, specify	7	3.7	0	0.0	
No information	2	1.1	0	0.0	
<b>Highest education completed</b>					
					<0.0001
No schooling	2	1.1	2	2.7	
Primary school	28	15.0	25	33.8	
Secondary school	125	66.8	46	62.2	
Bachelor	31	16.6	1	1.4	
Other	1	0.5	0	0.0	
<b>HIV status according to patient card</b>					
					0.02
positive	7	3.7	1	1.4	
negative	85	45.5	43	58.1	
not tested	82	43.9	27	36.5	
not indicated on card	13	7.0	1	1.4	
no information in database	0	0.0	2	2.7	
<b>Travel time to nearest health facility</b>					
					0.003
0-15 minutes	48	25.7	32	43.2	
16-30 minutes	47	25.1	23	31.1	
31-60 minutes	37	19.8	11	14.9	
61-120 minutes	37	19.8	3	4.1	
>120 minutes	18	9.6	5	6.8	
Median time to nearest public health facility (25 <sup>th</sup> , 75 <sup>th</sup> percentile)	30	(15, 90)	25	(15, 40)	0.001
<b>Travel time to DOT facility</b>					
					0.02
0-15 minutes	29	15.5	22	29.7	
16-30 minutes	60	32.1	26	35.1	
31-60 minutes	48	25.7	15	20.3	
61-120 minutes	32	17.1	5	6.8	
>120 minutes	18	9.6	5	6.8	
No information	0	0.0	1	1.4	
Median time to DOT facility (25 <sup>th</sup> , 75 <sup>th</sup> percentile)	45	(30, 90)	30	(15, 60)	0.008
<b>Household income per month before TB diagnosis</b>					
					0.56
0 - 1.5 million Rupiah (0-154 USD)	63	33.7	27	36.5	
1.51 - 2.6 million Rupiah (155-275 USD)	58	31.0	26	35.1	
2.7 - 102 million Rupiah (276-10,500 USD)	66	35.3	21	28.4	
Median household income, million Rupiah (25 <sup>th</sup> , 75 <sup>th</sup> percentile)	2.0	(1.3, 3.3)	1.9	(1.2, 2.7)	0.34

\* Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant, USD – US dollar

‡ Unless specified that the median is presented

§ for counts, chi-square test was used, for medians, K-sample equality-of-means test was used

**Annex Table 1C.** General patient characteristics by income level (tertiles of million (M) Indonesian Rupiah (IDR)).

Patient characteristic	Patient income group						p-value§
	0-1.5 M IDR (N=90)		1.51-2.6 M IDR (N=84)		2.7-102 M IDR (N=87)		
	N‡	%	N‡	%	N‡	%	
<b>Patient group</b>							0.75
Intensive phase of standard (re)treatment regimen	19	21.1	19	22.6	24	27.6	
Continuation phase of standard (re)treatment regimen	19	21.1	17	20.2	20	23.0	
Just diagnosed with MDR TB	14	15.6	7	8.3	8	9.2	
Intensive phase of MDR TB treatment	16	17.8	21	25.0	18	20.7	
Continuation phase of MDR TB treatment	22	24.4	20	23.8	17	19.5	
<b>TB regimen</b>							0.78
standard regimen for new TB patients	31	34.4	28	33.3	34	39.1	
retreatment regimen	7	7.8	8	9.5	10	11.5	
MDR TB regimen	52	57.8	48	57.1	43	49.4	
<b>Type of TB</b>							0.54
Pulmonary smear positive	55	61.1	60	71.4	51	58.6	
Pulmonary smear negative	26	28.9	19	22.6	27	31.0	
Extrapulmonary	5	5.6	4	4.8	7	8.1	
No information	4	4.4	1	1.2	2	2.3	
<b>Type of TB: susceptibility</b>							0.47
TB	52	57.8	48	57.1	43	49.4	
MDR TB	38	42.2	36	42.9	44	50.6	
<b>Recruited at site</b>							0.29
Persahabatan hospital, Jakarta	55	61.1	48	57.1	62	71.3	
Satellite of Persahabatan hospital, Jakarta	8	8.9	10	11.9	4	4.6	
Dr Moewardi hospital, Solo	27	30.0	26	31.0	21	24.1	
<b>Sex</b>							0.74
Male	46	51.1	45	53.6	47	54.0	
Female	42	46.7	39	46.4	39	44.8	
No information	2	2.2	0	0.0	1	1.2	
<b>Age</b>							0.6
Age group							
21-29	17	18.9	20	23.8	25	28.7	
30-39	28	31.1	22	26.2	21	24.1	
40-49	20	22.2	23	27.4	23	26.4	
50+	25	27.8	18	21.4	18	20.7	
No information	0	0.0	1	1.2	0	0.0	
Median age (25 <sup>th</sup> , 75 <sup>th</sup> percentile)	39.5	(30, 50)	39	(30, 49)	38	(29, 47)	0.92
<b>Ethnic group</b>							0.05
Betawi	26	28.9	14	16.7	11	12.6	
Jawa	46	51.1	49	58.3	50	57.5	
Sumatera	9	10.0	16	19.1	12	13.8	
Tionghoa	2	2.2	0	0.0	2	2.3	
East Indonesian	1	1.1	0	0.0	5	5.8	
Sundanese	2	2.2	4	4.8	3	3.5	
Other	3	3.3	0	0.0	4	4.6	
No information	1	1.1	1	1.2	0	0.0	

\* Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant, USD – US dollar

‡ Unless specified that the median is presented

§ for counts, chi-square test was used, for medians, K-sample equality-of-means test was used

**Annex Table 1C, continued.** General patient characteristics by income level, *continued*

Patient characteristic	Patient income group						p-value§
	0-1.5 M IDR (N=90)		1.51-2.6 M IDR (N=84)		2.7-102 M IDR (N=87)		
	N‡	%	N‡	%	N‡	%	
<b>Highest education completed</b>							0.008
No schooling	2	2.2	1	1.2	1	1.2	
Primary school	26	28.9	16	19.1	11	12.6	
Secondary school	58	64.4	57	67.9	56	64.4	
Bachelor	3	3.3	10	11.9	19	21.8	
Other	1	1.1	0	0.0	0	0.0	
<b>HIV status according to patient card</b>							0.22
positive	5	5.6	0	0.0	3	3.5	
negative	41	45.6	38	45.2	49	56.3	
not tested	36	40.0	42	50.0	31	35.6	
not indicated on card	7	7.8	3	3.6	4	4.6	
no information in database	1	1.1	1	1.2	0	0.0	
<b>Travel time to nearest health facility</b>							
0-15 minutes	28	31.1	28	33.3	24	27.6	0.76
16-30 minutes	19	21.1	25	29.8	26	29.9	
31-60 minutes	19	21.1	13	15.5	16	18.4	
61-120 minutes	13	14.4	12	14.3	15	17.2	
>120 minutes	11	12.2	6	7.1	6	6.9	
Median time to nearest public health facility (25 <sup>th</sup> , 75 <sup>th</sup> percentile)	30	(15, 90)	30	(15, 60)	30	(15, 60)	0.35
<b>Travel time to DOT facility</b>							
0-15 minutes	12	13.3	19	22.6	20	23.0	0.48
16-30 minutes	32	35.6	30	35.7	24	27.6	
31-60 minutes	24	26.7	17	20.2	22	25.3	
61-120 minutes	10	11.1	13	15.5	14	16.1	
>120 minutes	11	12.2	5	6.0	7	8.1	
No information	1	1.1	0	0.0	0	0.0	
Median time to DOT facility (25 <sup>th</sup> , 75 <sup>th</sup> percentile)	40	(30, 60)	30	(20, 60)	30	(20, 60)	0.45

\* Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant, USD – US dollar

‡ Unless specified that the median is presented

§ for counts, chi-square test was used, for medians, K-sample equality-of-means test was used

**Annex Table 1D. Number of months of previous TB treatment, among MDR TB patients.**

Number of months on TB treatment before MDR TB diagnosis	N	Percent
2	1	1.64
4	5	8.2
5	1	1.64
6	21	34.43
7	3	4.92
8	3	4.92
9	5	8.2
10	6	9.84
11	2	3.28
12	6	9.84
13	1	1.64
14	1	1.64
15	1	1.64
16	2	3.28
19	1	1.64
21	1	1.64
28	1	1.64
Total	61/143 (43%)	100

**Annex Table 2A.** Total costs to get TB diagnosis for patient and companion, among patients in intensive phase of TB treatment and just diagnosed with MDR TB (x 1,000 Indonesian Rupiah).\*

Item	Overall (N=91)			Intensive phase standard TB treatment (N=62)			just diagnosed with MDR TB (N=29)			p-value for difference between TB and MDR TB§
	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Max¶	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Max¶	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Max¶	
<b>Direct costs</b>	481 (727)	322 (110 – 617)	6,160	432 (449)	322 (85 – 617)	2,220	586 (1,114)	382 (116 – 613)	6,160	0.66
registration/consult	68 (126)	10 (0 – 90)	687	73 (126)	37 (0 – 105)	687	57 (128)	6 (0 – 40)	594	0.13
(laboratory) tests	98 (143)	0 (0 – 180)	680	117 (146)	56 (0 – 180)	680	59 (128)	0 (0 – 28)	500	0.048
X-ray	87 (219)	0 (0 – 100)	1,625	107 (259)	15 (0 – 100)	1,625	44 (65)	0 (0 – 85)	200	0.28
drugs	44 (116)	0 (0 – 0)	600	43 (122)	0 (0 – 0)	600	45 (105)	0 (0 – 0)	400	0.84
travel	104 (239)	30 (14 – 75)	2000	57 (99)	30 (12 – 48)	600	205 (383)	52 (25 – 225)	2,000	0.04
food	20 (40)	0 (0 – 23)	230	13 (33)	0 (0 – 20)	200	36 (49)	20 (3 – 50)	230	0.001
accommodation	1 (10)	0 (0 – 0)	100	0 (0)	0 (0 – 0)	0	3 (19)	0 (0 – 0)	100	0.14
<b>Indirect costs</b>										
using reported income loss	26 (73)	0 (0 – 0)	500	22 (58)	0 (0 – 0)	300	35 (99)	0 (0 – 0)	500	0.26
using calculated income loss**	91 (306)	30 (0 – 74)	2,761	91 (350)	34 (0 – 85)	2,761	90 (187)	27 (6 – 60)	818	0.29
<b>Total diagnostic costs</b>										
using reported income loss	507 (770)	322 (116 – 658)	6,660	453 (450)	322 (105 – 622)	2,220	621 (1,201)	384 (120 – 658)	6,660	0.46
using calculated income loss**	572 (865)	350 (155 – 736)	6,978	523 (610)	339 (155 – 664)	3,511	676 (1,256)	450 (159 – 794)	6,978	0.46
<b>Reimbursements for diagnosis</b>	10 (76)	0 (0 – 0)	700	11 (89)	0 (0 – 0)	700	6 (33)	0 (0 – 0)	180	0.58

\* Only patients in intensive phase of TB treatment and patients just diagnosed with MDR TB are included. At the time of data collection, 10,000 Indonesian Rupiah corresponded to approximately 1 USD. Abbreviations used: TB – tuberculosis, MDR – multidrug resistant, SD – standard deviation,

§ Calculated using K-sample equality-of-medians test for differences between medians.

¶ Only maximums are given as minimums were 0 except for total direct and total diagnostic costs (minimums 12,000, 12,000 and 29,000 IDR respectively for total direct costs, total costs using income loss given by patient and total costs using income loss calculated).

\*\*Loss of income was calculated by multiplying the time spent for getting a diagnosis (minutes) with the patient's income per minute.



**Annex Table 2B.** Costs to get TB diagnosis among patients in intensive phase of TB treatment and just diagnosed with MDR TB (x 1,000 Indonesian Rupiah), by city.\*

Item	Jakarta (N=63)			Solo (N=28)			p-value for difference between cities§
	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Range	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Range	
<b>Direct costs</b>	448 (443)	322 (120 – 692)	0; 2,220	606 (1,160)	341 (93 – 617)	10; 6,160	0.70
registration/consult	86 (145)	37 (0 – 111)	0; 687	26 (48)	3 (0 – 12)	0; 180	0.002
(laboratory) tests	129 (156)	128 (0 – 180)	0; 680	30 (69)	0 (0 – 20)	0; 300	0.03
X-ray	103 (257)	0 (0 – 100)	0; 1,625	49 (73)	0 (0 – 105)	0; 217	0.38
Drugs	31 (97)	0 (0 – 0)	0; 570	72 (149)	0 (0 – 55)	0; 600	0.31
Travel	59 (102)	28 (10 – 52)	0; 600	205 (389)	53 (25 – 255)	5; 2,000	0.07
Food	18 (43)	0 (0 – 20)	0; 230	27 (31)	15 (0 – 48)	0; 106	0.02
Accommodation	0 (0)	0 (0 – 0)	0; 0	4 (19)	0 (0 – 0)	0; 100	0.13
<b>Indirect costs</b>							
using reported income loss	20 (56)	0 (0 – 0)	0; 300	35 (103)	0 (0 – 23)	0; 500	0.22
using calculated income loss**	97 (353)	34 (0 – 74)	0; 2,761	78 (160)	27 (8 – 74)	0; 818	0.20
<b>Total diagnostic costs</b>							
using reported income loss	468 (440)	322 (120 – 772)	0; 2,220	594 (1,233)	341 (93 – 616)	10; 6,660	0.94
using calculated income loss**	544 (597)	362 (165 – 794)	0; 3,511	633 (1,292)	314 (100 – 681)	29; 6,978	0.70
<b>Reimbursements for diagnosis</b>	14 (91)	0 (0 – 0)	0; 700	0 (0)	0 (0 – 0)	0; 0	0.24

\* Only patients in intensive phase of TB treatment and patients just diagnosed with MDR TB are included. At the time of data collection, 10,000 Indonesian Rupiah corresponded to approximately 1 USD. Abbreviations used: TB – tuberculosis, MDR – multidrug resistant, SD – standard deviation,

§ Calculated using K-sample equality-of-medians test for differences between medians.

¶ Only maximums are given as minimums were 0 except for total direct and total diagnostic costs (minimums 12,000, 12,000 and 29,000 IDR respectively for total direct costs, total costs using income loss given by patient and total costs using income loss calculated).

\*\*Loss of income was calculated by multiplying the time spent for getting a diagnosis (minutes) with the patient's income per minute.



**Annex Table 2C.** Costs to get TB diagnosis by household income class (in tertiles) among patients in intensive phase of TB treatment and just diagnosed with MDR TB, x 1,000 IDR.\*

Item	0-1.5 M IDR (N=33)			1.51-2.6 M IDR (N=26)			2.7-102 M IDR (N=32)			p-value for difference between TB and MDR TB
	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Max <sup>¶</sup>	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Max <sup>¶</sup>	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Max <sup>¶</sup>	
<b>Direct costs</b>	349 (357)	281 (85 – 430)	1,322	418 (321)	366 (115 – 622)	1,084 <sup>¶</sup>	668 (1,123)	326 (118 – 823)	6,160	0.37
registration/consult	59 (126)	0 (0 – 41)	594	81 (149)	37 (0 – 100)	687	66 (107)	36 (0 – 108)	550	0.17
(laboratory) tests	82 (138)	0 (0 – 153)	500	114 (154)	46 (0 – 180)	680	103 (141)	10 (0 – 180)	580	0.62
X-ray	36 (48)	0 (0 – 85)	132	88 (191)	0 (0 – 115)	970	139 (318)	39 (0 – 100)	1,625	0.83
drugs	39 (112)	0 (0 – 0)	570	36 (94)	0 (0 – 0)	400	54 (137)	0 (0 – 0)	600	0.86
travel	108 (143)	31 (20 – 186)	600	79 (123)	30 (20 – 60)	458	121 (362)	28 (7 – 52)	2,000	0.38
food	24 (43)	7 (0 – 23)	200	20 (46)	5 (0 – 20)	230	16 (31)	0 (0 – 25)	150	0.71
accommodation	0 (0)	0 (0 – 0)	0	0 (0)	0 (0 – 0)	0	3 (18)	0 (0 – 0)	100	0.39
<b>Indirect costs</b>										
using reported income loss	8 (28)	0 (0 – 0)	120	16 (37)	0 (0 – 0)	150	52 (112)	0 (0 – 38)	500	0.23
using calculated income loss**	20 (38)	2 (0 – 24)	196	48 (51)	33 (9 – 74)	182	199 (500)	62 (30 – 101)	818	<0.0001
<b>Total diagnostic costs</b>										
using reported income loss	357 (353)	281 (100 – 430)	1,322	434 (320)	366 (170 – 658)	1,084	720 (1,197)	387 (120 – 860)	6,660	0.33
using calculated income loss**	368 (358)	314 (85 – 450)	1,356	466 (342)	436 (159 – 723)	1,249	868 (1,342)	407 (165 – 1,017)	6,978	0.35
<b>Reimbursements for diagnosis</b>	0 (0)	0 (0 – 0)	0	34 (140)	0 (0 – 0)	700	0 (0)	0 (0 – 0)	0	0.08

\* Only patients in intensive phase of TB treatment and patients just diagnosed with MDR TB are included. At the time of data collection, 10,000 Indonesian Rupiah corresponded to approximately 1 USD. Abbreviations used: TB – tuberculosis, MDR – multidrug resistant, IDR – Indonesian Rupiah, SD – standard deviation,

§ Calculated using K-sample equality-of-medians test for differences between medians.

¶ Only maximums are given as minimums were 0 except for total direct and total diagnostic costs (minimums 12,000, 12,000 and 29,000 IDR respectively for total direct costs, total costs using income loss given by patient and total costs using income loss calculated).

\*\*Loss of income was calculated by multiplying the time spent for getting a diagnosis (minutes) with the patient's income per minute.



**Annex Table 3A.** Costs of (MDR) TB treatment per cost component per month, per (MDR) TB treatment phase (x 1000 Indonesian Rupiah).\*

Cost item	Treatment phase	TB						MDR TB					
		N	mean	(SD)	median (IQR)	range	N	mean (SD)	median (IQR)	range			
<i>Taking drugs</i>													
direct	Intensive	62	0	(0)	0 (0-0)	0 ; 0	54	696 (675)	467 (301-768)	0 ; 2,709			
	Continuation	56	110	(623)	0 (0-0)	0 ; 4,515	59	562 (457)	512 (166-722)	0 ; 2,107			
indirect	Intensive	62	0	(0)	0 (0-0)	0 ; 0	55	730 (929)	342 (143-1,026)	0 ; 3,934			
	Continuation	56	80	(409)	0 (0-0)	0 ; 2,565	59	443 (1,239)	171 (0-376)	0 ; 9,235			
total	Intensive	62	0	(0)	0 (0-0)	0 ; 0	54	1,434 (1,256)	930 (467-1,991)	0 ; 5,787			
	Continuation	56	190	(1018)	0 (0-0)	0 ; 7,080	59	1,005 (1,548)	708 (278-1,081)	0 ; 11,300			
<i>Picking up drugs</i>													
direct	Intensive	62	67	(91)	40 (17-90)	0 ; 600	55	0 (1)	0 (0-0)	0 ; 4			
	Continuation	56	56	(108)	30 (10-61)	0 ; 750	59	0 (0)	0 (0-0)	0 ; 0			
indirect	Intensive	62	107	(582)	24 (0-45)	0 ; 4,602	55	0 (0)	0 (0-0)	0 ; 3			
	Continuation	56	28	(47)	11 (0-33)	0 ; 206	59	0 (0)	0 (0-0)	0 ; 0			
total	Intensive	62	174	(582)	76 (38-149)	0 ; 4,608	55	0 (1)	0 (0-0)	0 ; 7			
	Continuation	56	84	(121)	46 (17-81)	0 ; 750	59	0 (0)	0 (0-0)	0 ; 0			
<i>Follow-up tests†</i>													
direct	Intensive	62	38	(96)	0 (0-0)	0 ; 560	55	14 (59)	0 (0-0)	0 ; 350			
	Continuation	56	143	(403)	0 (0-169)	0 ; 2,800	59	19 (76)	0 (0-0)	0 ; 400			
indirect	Intensive	62	35	(233)	0 (0-5)	0 ; 1,841	55	46 (114)	8 (0-45)	0 ; 784			
	Continuation	56	12	(34)	0 (0-8)	0 ; 205	59	120 (643)	5 (0-31)	0 ; 4,909			
total	Intensive	62	73	(248)	0 (0-17)	0 ; 1,841	55	61 (123)	18 (0-57)	0 ; 784			
	Continuation	56	156	(405)	4 (0-183)	0 ; 2,800	59	139 (644)	10 (0-46)	0 ; 4,909			
<i>Hospitalization**</i>													
direct	Intensive	62	1,811	(10,200)	0 (0-0)	0 ; 80,000	55	1,399 (3,086)	0 (0-1,050)	0 ; 15,000			
	Continuation	56	764	(1,792)	0 (0-0)	0 ; 7,047	59	1,712 (5,039)	0 (0-570)	0 ; 30,000			
indirect	Intensive	62	397	(1,455)	0 (0-182)	0 ; 11,000	55	376 (743)	0 (0-477)	0 ; 3,636			
	Continuation	56	261	(859)	0 (0-0)	0 ; 5,455	59	257 (394)	0 (0-477)	0 ; 2,045			
total	Intensive	62	2,208	(10,400)	0 (0-853)	0 ; 80,900	55	1,775 (3,337)	0 (0-1,909)	0 ; 15,000			
	Continuation	56	1,024	(2,466)	0 (0-153)	0 ; 12,500	59	1,969 (5,276)	273 (0-977)	0 ; 32,000			
<i>Relocation</i>	Both	117	6,667	(49,497)	0 (0-0)	0 ; 500,000	140	170,714 (973,227)	0 (0-0)	0 ; 11,000,000			
<i>Supplements</i>	Intensive	58	129	(227)	50 (0-128)	0 ; 1,000	54	143 (216)	40 (0-200)	0 ; 900			
	Continuation	56	160	(670)	1 (0-100)	0 ; 5,000	58	177 (225)	95 (0-250)	0 ; 900			
<i>Treatment adverse events</i>	Intensive	62	12	(45)	0 (0-0)	0 ; 261	55	2 (14)	0 (0-0)	0 ; 100			
	Continuation	56	8	(31)	0 (0-0)	0 ; 178	59	10 (43)	0 (0-0)	0 ; 300			
<i>Reimbursements‡</i>	Intensive	60	12	(90)	0 (0-0)	0 ; 700	55	0 (0)	0 (0-0)	0 ; 0			
	Continuation	56	0	(0)	0 (0-0)	0 ; 0	59	70 (521)	0 (0-0)	0 ; 4,000			
<i>Vouchers‡</i>	Intensive	62	113	(889)	0 (0-0)	0 ; 7,000	55	74 (244)	0 (0-0)	0 ; 1,600			
	Continuation	56	1.4	(11)	0 (0-0)	0 ; 80	59	234 (1,120)	0 (0-0)	0 ; 8,600			

\* Patients just diagnosed with MDR TB were excluded from this analysis. Abbreviations used in this table: SD – standard deviation, IQR – interquartile range; † follow up tests not per month but from start of Tx till interview; \*\* includes hospitalization due to TB for all groups and may include out-of-treatment hospitalization (n=23 of those just diagnosed with MDR TB reported hospitalization); ‡ 2 patients got reimbursements (1 for transportation, 1 for treatment); both were just diagnosed with MDR TB; ‡ not per month but from start of disease till interview.

**Annex Table 3B.** Costs of (MDR) TB treatment per cost component, extrapolated for the complete treatment phase (x 1,000 Indonesian Rupiah).\*

Item		TB				MDR-TB				p-value
		N	mean (SD)	median (IQR)	min; max	N	mean (SD)	median (IQR)	min; max	
Taking drugs: direct	Overall	118	260 (2153)	0 (0 - 0)	0; 22,600	113	6,344 (5,548)	4,816 (2,408 - 8,428)	0; 25,300	<0.0001
	Intensive	62	0 (0)	0 (0 - 0)	0; 0	54	5,576 (5,393)	3,732 (2,408 - 6,140)	0; 21,700	
	Continuation	56	549 (3,115)	0 (0 - 0)	0; 22,600	59	7,047 (5,641)	6,140 (2,528 - 9,030)	0; 25,300	
Taking drugs: indirect	Overall	118	190 (1,420)	0 (0 - 0)	0; 12,800	114	5,618 (11,800)	2,443 (205 - 5,473)	0; 111,000	<0.0001
	Intensive	62	0 (0)	0 (0 - 0)	0; 0	55	5,843 (7,428)	2,736 (1,140 - 8,209)	0; 31,500	
	Continuation	56	401 (2,044)	0 (0 - 0)	0; 12,800	59	5,407 (14,900)	2,052 (0 - 4,789)	0; 111,000	
Taking drugs: total	Overall	118	451 (3,523)	0 (0 - 0)	0; 35,400	113	12,000 (15,000)	8,055 (4,050 - 15,200)	0; 136,000	<0.0001
	Intensive	62	0 (0)	0 (0 - 0)	0; 0	54	11,500 (10,000)	7,443 (3,738 - 15,900)	0; 46,300	
	Continuation	56	950 (5,091)	0 (0 - 0)	0; 35,400	59	12,500 (18,600)	8,669 (3,342 - 13,500)	0; 181,000	
Picking up drugs: direct	Overall	118	189 (333)	84 (40 - 220)	0; 3,000	114	0.3 (3)	0 (0 - 0)	0; 32	<0.0001
	Intensive	62	150 (200)	80 (34 - 188)	0; 1,200	55	0.6 (4)	0 (0 - 0)	0; 32	
	Continuation	56	233 (433)	120 (40 - 263)	0; 3,000	59	0 (0)	0 (0 - 0)	0; 0	
Picking up drugs: indirect	Overall	118	173 (853)	47 (0 - 123)	0; 9,205	114	0.2 (2)	0 (0 - 0)	0; 20	<0.0001
	Intensive	62	223 (1,163)	50 (0 - 102)	0; 9,205	55	0.4 (3)	0 (0 - 0)	0; 20	
	Continuation	56	118 (206)	46 (0 - 132)	0; 1,031	59	0 (0)	0 (0 - 0)	0; 0	
Picking up drugs: total	Overall	118	363 (910)	181 (73 - 337)	0; 9,217	114	0.5 (5)	0 (0 - 0)	0; 52	<0.0001
	Intensive	62	373 (1,167)	156 (78 - 299)	0; 9,217	55	1 (7)	0 (0 - 0)	0; 52	
	Continuation	56	351 (500)	200 (67 - 376)	0; 3,000	59	0 (0)	0 (0 - 0)	0; 0	
Follow-up tests: direct	Overall	118	88 (289)	0 (0 - 18)	0; 2800	112	16 (79)	0 (0 - 0)	0; 560	<0.0001
	Intensive	62	38 (96)	0 (0 - 0)	0; 560	54	26 (101)	0 (0 - 0)	0; 560	
	Continuation	56	143 (403)	0 (0 - 169)	0; 2800	58	6 (48)	0 (0 - 0)	0; 368	
Follow-up tests: indirect	Overall	118	24 (171)	0 (0 - 7)	0; 1841	112	44 (161)	0 (0 - 19)	0; 1,568	0.84
	Intensive	62	35 (233)	0 (0 - 5)	0; 1841	54	87 (224)	15 (0 - 91)	0; 1,568	
	Continuation	56	9 (29)	0 (0 - 5)	0; 205	58	5 (20)	0 (0 - 0)	0; 146	
Follow-up tests: total	Overall	118	112 (333)	0.6 (0 - 85)	0; 2,800	112	60 (179)	0 (0 - 35)	0; 1,568	0.28
	Intensive	62	73 (248)	0 (0 - 26)	0; 1,841	54	113 (238)	34 (0 - 114)	0; 1568	
	Continuation	56	152 (402)	3 (0 - 181)	0; 2,800	58	11 (68)	0 (0 - 0)	0; 514	
Hospitalization: direct‡	Overall	118	1,314 (7,470)	0 (0 - 0)	0; 80,000	143	1,833 (4,340)	0 (0 - 1,250)	0; 30,000	0.001
	Intensive	62	1,811 (10,200)	0 (0 - 0)	0; 80,000	55	1,399 (3,086)	0 (0 - 1,050)	0; 15,000	
	Continuation	56	764 (1,792)	0 (0 - 0)	0; 7,047	59	1,712 (5,039)	0 (0 - 570)	0; 30,000	
Hospitalization: indirect‡	Overall	118	332 (1,206)	0 (0 - 159)	0; 11,000	143	324 (574)	0 (0 - 500)	0; 3,636	0.002
	Intensive	62	397 (1,455)	0 (0 - 182)	0; 11,000	55	376 (743)	0 (0 - 477)	0; 3,636	
	Continuation	56	261 (859)	0 (0 - 0)	0; 5,455	59	257 (394)	0 (0 - 477)	0; 2,045	
Hospitalization: total‡	Overall	118	1,646 (7,700)	0 (0 - 307)	0; 80,900	143	2,156 (4,538)	300 (0 - 2014)	0; 32,000	<0.0001
	Intensive	62	2,208 (10,400)	0 (0 - 853)	0; 80,900	55	1,775 (3,337)	0 (0 - 1909)	0; 15,000	
	Continuation	56	1,024 (2,466)	0 (0 - 153)	0; 12,500	59	1,969 (5,276)	273 (0 - 977)	0; 32,000	

\* Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant, SD – standard deviation, IQR – interquartile range, min – minimum, max – maximum; ‡ Includes hospitalization due to TB for all groups and may include out-of Tx hospitalization (n=23 of those just diagnosed with MDR TB reported hospitalization); § Calculated using K-sample equality-of-medians test for differences between medians; † Since in the means and medians calculated for all MDR TB patients, also MDR TB patients just diagnosed with MDR TB are included, and these patients reported much lower costs, the mean and median for all MDR TB patients are distinctly different than the means and medians calculated for each treatment phase.

**Annex Table 3B**, continued. Costs of (MDR) TB treatment per cost component, extrapolated for the complete treatment phase (x 1,000 Indonesian Rupiah).

Item		TB				MDR-TB				p-value§
		N	mean (SD)	median (IQR)	min; max	N	mean (SD)	median (IQR)	min; max	
Relocation	Overall	117	7 (49)	0 (0 - 0)	0; 500	140	171 (973)	0 (0 - 0)	0; 11,000	0.001
Supplements	Overall	114	513 (2,376)	74 (0 - 400)	0; 25,000	141	1,346 (2,267)†	48 (0 - 1,800)†	0; 10,800	0.96
	Intensive	58	285 (534)	100 (0 - 300)	0; 3,000	54	1,145 (1,731)	320 (0 - 1,600)	0; 7,200	
	Continuation	56	749 (3,345)	2 (0 - 400)	0; 25,000	58	2,207 (2,851)	1,140 (0 - 3,000)	0; 10,800	
Treatment adverse events	Overall	118	10 (39)	0 (0 - 0)	0; 261	143	5 (29)	0 (0 - 0)	0; 300	0.12
	Intensive	62	12 (45)	0 (0 - 0)	0; 261	55	2 (14)	0 (0 - 0)	0; 100	
	Continuation	56	8 (31)	0 (0 - 0)	0; 178	59	10 (43)	0 (0 - 0)	0; 300	
Reimbursements ¥	Overall	116	6 (65)	0 (0 - 0)	0; 700	140	94 (698)	0 (0 - 0)	0; 7,000	0.25
	Intensive	60	12 (90)	0 (0 - 0)	0; 700	55	0 (0)	0 (0 - 0)	0; 0	
	Continuation	56	0 (0)	0 (0 - 0)	0; 0	59	70 (521)	0 (0 - 0)	0; 4,000	
Vouchers	Overall	118	60 (644)	0 (0 - 0)	0; 7,000	143	126 (738)	0 (0 - 0)	0; 8,600	<0.0001
	Intensive	62	113 (889)	0 (0 - 0)	0; 7,000	55	74 (244)	0 (0 - 0)	0; 1,600	
	Continuation	56	1.4 (11)	0 (0 - 0)	0; 80	59	234 (1,120)	0 (0 - 0)	0; 8,600	

\* Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant, SD – standard deviation, IQR – interquartile range, min – minimum, max – maximum. Includes hospitalization due to TB for all groups and may include out-of Tx hospitalization (n=23 of those just diagnosed with MDR TB reported hospitalization)

§ Calculated using K-sample equality-of-medians test for differences between medians.

¥ 2 patients got reimbursements (1 for transportation, 1 for treatment); both were just diagnosed with MDR TB.

† Since in the means and medians calculated for all MDR TB patients, also MDR TB patients just diagnosed with MDR TB are included, and these patients reported much lower costs, the mean and median for all MDR TB patients are distinctly different than the means and medians calculated for each treatment phase.



**Annex Table 3C.** Costs of (MDR) TB treatment per treatment phase by treatment site, x 1,000 Indonesian Rupiah. Costs are extrapolated to the complete treatment phase.\*

Item	Jakarta			Solo			p-value**
	N	mean	median (25th- 75th percentile)	N	mean	median (25th- 75th percentile)	
<b>Direct costs per phase</b>							
Intensive phase TB treatment	52	2,532	393 (118 - 1,127)	10	1,013	375 (40 - 600)	1
Continuation phase TB treatment	46	2,747	735 (280 - 2,315)	10	1,075	134 (88 - 450)	0.04
Intensive phase MDR TB treatment	38	9,526	7,124 (4,094 - 11,550)	17	5,047	4,412 (2,924 - 5,743)	0.01
Continuation phase MDR TB treatment	40	12,511	10,478 (6,856 - 17,007)	19	8,523	6,990 (4,025 - 11,423)	0.06
<b>Indirect costs per phase</b>							
Intensive phase TB treatment	52	741	101 (0 - 391)	10	211	70 (0 - 153)	0.49
Continuation phase TB treatment	46	900	61 (0 - 591)	10	299	147 (0 - 439)	0.16
Intensive phase MDR TB treatment	38	8,217	5,374 (2,073 - 12,244)	17	1,906	1,650 (28 - 2,513)	0.01
Continuation phase MDR TB treatment	40	7,614	2,956 (409 - 7,340)	19	1,933	1,848 (0 - 3,223)	0.46
<b>Total costs‡ per phase</b>							
Intensive phase TB treatment	52	3,272	509 (215 - 1,782)	10	1,224	552 (48 - 926)	1
Continuation phase TB treatment	46	3,647	963 (378 - 2,899)	10	1,374	406 (166 - 660)	0.04
Intensive phase MDR TB treatment	38	17,743	16,482 (7,947 - 26,300)	17	6,952	6,882 (4,238 - 8,904)	<0.0001
Continuation phase MDR TB treatment	40	20,126	14,480 (8,357 - 24,423)	19	10,456	9,458 (5,497 - 14,834)	0.06
<b>Total amount reimbursed</b>							
Intensive phase TB treatment	52	148	0 (0 - 0)	10	0	0 (0 - 0)	0.53
Continuation phase TB treatment	46	0	0 (0 - 0)	10	8	0 (0 - 0)	0.03
Intensive phase MDR TB treatment	38	0	0 (0 - 0)	17	241	40 (0 - 400)	<0.0001
Continuation phase MDR TB treatment	40	275	0 (0 - 0)	19	365	0 (0 - 400)	0.02

\* This analysis excludes patients just diagnosed with MDR TB. Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant.

\*\* P-value for difference in costs between PMDT sites as calculated by using the K-sample equality-of-medians test.

‡ In this calculation, reimbursements are not taken into account (i.e., are not subtracted from the total costs).



**Annex Table 3D.** Costs of (MDR) TB treatment per treatment phase by household income tertile, x 1,000 Indonesian Rupiah. Costs are extrapolated to the complete treatment phase.

Item	lowest income class			middle income class			highest income class			P-value**
	N	Mean	median (25 <sup>th</sup> - 75 <sup>th</sup> percentile)	N	mean	median (25 <sup>th</sup> - 75 <sup>th</sup> percentile)	N	mean	median (25 <sup>th</sup> - 75 <sup>th</sup> percentile)	
<b>Direct costs</b>										
Intensive phase TB treatment	19	632	245 (60 - 1,054)	19	784	440 (60 - 900)	24	4,786	548 (190 - 2,132)	0.04
Continuation phase TB treatment	19	1,377	543 (88- 2,315)	17	1,520	211 (80 - 1,040)	20	4,254	1,013 (537 - 3,090)	0.08
Intensive phase MDR TB treatment	16	7,627	4,614 (3,541 - 9,153)	21	8,868	6,748 (3,458 – 10,028)	18	7,752	5,636 (2,924 - 11,412)	0.18
Continuation phase MDR TB treatment	22	8,641	7,772 (4,025 - 9,877)	20	10,717	10,732 (5,019 – 15,432)	17	15,174	12,124 (7,224 - 18,024)	0.31
<b>Indirect costs</b>										
Intensive phase TB treatment	19	151	5 (0 - 153)	19	241	68 (0 - 398)	24	1,383	181 (81 - 967)	0.03
Continuation phase TB treatment	19	153	7 (0 - 133)	17	925	172 (32 - 520)	20	1,288	134 (12 - 701)	0.07
Intensive phase MDR TB treatment	16	2,095	1,649 (158 - 2,478)	21	6,133	3,053 (1,687 - 8,217)	18	10,129	5,570 (4,045 - 16,002)	0.003
Continuation phase MDR TB treatment	22	1,931	600 (0 - 3,742)	20	3,416	2,831 (775 - 3,762)	17	13,560	4,347 (2,028 - 9,985)	0.1
<b>Total costs</b>										
Intensive phase TB treatment	19	783	250 (80 - 1,118)	19	1,026	478 (277 - 1,298)	24	6,168	701 (301 - 4,688)	0.24
Continuation phase TB treatment	19	1,531	566 (167 - 2,789)	17	2,445	622 (211 - 1,040)	20	5,542	1,251 (609 - 3,791)	0.25
Intensive phase MDR TB treatment	16	9,722	6,524 (4,333 - 11,745)	21	15,001	12,644 (7,286 - 20,576)	18	17,880	13,379 (7,638 - 24,680)	0.24
Continuation phase MDR TB treatment	22	10,572	9,443 (5,497 - 14,518)	20	14,132	11,461 (6,724 - 17,669)	17	28,733	16,896 (10,326 - 31,439)	0.54
<b>Total amount reimbursed</b>										
Intensive phase TB treatment	19	0	0 (0 - 0)	19	37	0 (0 - 0)	24	292	0 (0- 0)	0.62
Continuation phase TB treatment	19	0	0 (0 - 0)	17	5	0 (0 - 0)	20	0	0 (0- 0)	0.31
Intensive phase MDR TB treatment	16	128	0 (0 - 400,000)	21	76	0 (0 - 0)	18	24	0 (0- 0)	0.02
Continuation phase MDR TB treatment	22	427	0 (0- 0)	20	127	0 (0 - 400)	17	353	0 (0- 400)	0.2

\* This analysis excludes patients just diagnosed with MDR TB. Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant.

\*\* P-value for difference in costs between PMDT sites as calculated by using the K-sample equality-of-medians test.

‡ In this calculation, reimbursements are not taken into account (i.e., are not subtracted from the total costs).



**Annex Table 3E.** Number of follow-up tests per month per TB treatment phase and regimen.

Treatment regimen and phase	Number of patients	Average number of follow-up tests per month, over total duration of TB treatment					Median (IQR)
		None N (%)	<1 N (%)	1 N (%)	>1-2 N (%)	>2 N (%)	
Intensive phase cat I/II treatment	62	31 (50.0)	20 (32.2)	8 (12.9)	1 (1.6)	2 (3.2)	0.17 (0.0-0.5)
Continuation phase cat I/II treatment	56	18 (32.0)	36 (64.3)	0 (0.0)	2 (3.5)	0 (0.0)	0.17 (0.0-0.4)
Intensive phase MDR TB treatment	64	10 (15.6)	24 (37.5)	25 (39.1)	3 (4.7)	2 (3.1)	0.82 (0.4-1.0)
Continuation phase MDR TB treatment	59	7 (11.9)	50 (84.7)	2 (3.4)	0 (0.0)	0 (0.0)	0.36 (0.1-0.6)

**Annex Table 4A.** Companion costs related to diagnosis of (MDR) TB. Data are presented including all patients and including only those patients bringing a companion on any visit (x 1,000 Indonesian Rupiah).\*

Item	Overall (N=91)			Intensive phase standard TB treatment (N=62)			just diagnosed with MDR-TB (N=29)			p-value for difference between TB and MDR TB§
	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Max¶	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Max¶	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Max¶	
travel	73 (422)	0 (0 – 30)	4,000	25 (54)	0 (0 – 30)	305	177 (741)	5 (0 – 50)	4,000	0.46
accommodation	3 (21)	0 (0 – 0)	200	0.5 (4)	0 (0 – 0)	30	7 (37)	0 (0 – 0)	200	0.17
total direct costs for companion	76 (442)	5 (0 – 30)	4,200	26 (55)	0 (0 – 30)	305	184 (777)	14 (0 – 50)	4,200	0.31
reported income loss	49‡ (143)	0‡ (0 – 0)	1,000	46¥ (156)	0¥ (0 – 0)	1,000	55 (113)	0 (0 – 50)	450	0.03
total companion costs for diagnosis	124‡ (500)	5‡ (0 – 60)	4,550	70¥ (177)	0¥ (0 – 36)	1,010	239 (841)	24 (0 – 105)	4,550	0.16
<i>Costs restricted to patients bringing companion on any visit</i>	N=65 (71%)			N=44 (71%)			N=21 (72%)			0.89
travel	103 (497)	18 (0 – 50)	4,000	35 (61)	13 (0 – 34)	305	244 (867)	30 (5 – 50)	4,000	0.16
accommodation	4 (25)	0 (0 – 0)	200	1 (5)	0 (0 – 0)	30	10 (44)	0 (0 – 0)	200	0.19
total direct costs for companion	107 (521)	18 (0 – 50)	4,200	36 (62)	13 (0 – 34)	305	254 (910)	30 (5 – 50)	4,200	0.16
reported income loss	69‡ (166)	0‡ (0 – 55)	1,000	66¥ (183)	0¥ (0 – 0)	1,000	76 (128)	15 (0 – 75)	450	0.02
total companion costs for diagnosis	175‡ (587)	30‡ (0 – 132)	4,550	99¥ (205)	20¥ (0 – 105)	1,010	331 (980)	50 (15 – 210)	4,550	0.09

\* Only companions of patients in intensive phase of TB treatment and patients just diagnosed with MDR TB are included. At the time of data collection, 10,000 IDR corresponded to approximately 1 USD. Abbreviations used in this table: TB – tuberculosis, MDR – multidrug resistant, SD – standard deviation, max – maximum.

¶ Only maximums are given as minimums were 0 except for total direct and total diagnostic costs (minimums 12,000, 12,000 and 29,000 IDR respectively for total direct costs, total costs using income loss given by patient and total costs using income loss calculated).

§ p-value was calculated using the K-sample equality-of-medians test

‡ N=90, respectively N=64, as for 1 patient, income loss experienced by companion was unknown.

¥ N=61, respectively N=43, as for 1 patient, income loss experienced by companion was unknown.



**Annex Table 4B.** Companion costs related to the treatment of (MDR) TB. Data are presented including all patients and including only those patients bringing a companion on any visit (x 1,000 Indonesian Rupiah).\*

	TB								MDR TB							
	N	mean	SD	median	p25	p75	min	max	N	mean	SD	median	p25	p75	min	max
<b>Companion costs overall</b>																
<b>Direct costs</b>																
Intensive phase	62	53	183	0	0	0	0	1,037	55	112	307	0	0	21	0	2,000
Continuation phase	56	104	352	0	0	0	0	2,250	59	235	738	0	0	180	0	5,000
<b>Indirect costs§</b>																
Intensive phase	62	54	154	0	0	0	0	1,000	54	640	2,888	0	0	160	0	19,200
Continuation phase	56	151	452	0	0	0	0	2,400	58	408	1,891	0	0	0	0	12,150
<b>Total costs§</b>																
Intensive phase	62	155	311	0	0	150	0	1,300	54	839	2,989	0	0	544	0	19,200
Continuation phase	56	263	629	0	0	95	0	2,730	58	681	2,000	50	0	400	0	12,150
<b>Companion costs per cost item</b>																
<b>Visits for DOT, picking up drugs, follow-up tests (indirect costs only)</b>																
n/N (%) with companion on any visit	72/126		(61%)						54/137**		(39%)					
n/N (%) whose companion lost income	19/72		(26%)						23/54		(43%)					
Intensive phase	38	76	184	0	0	100	0	1,000	25	1,259	4,194	40	0	240	0	19,200
Continuation phase	34	148	496	0	0	0	0	2,400	22	946	3,024	0	0	0	0	12,150
<b>Hospitalization (direct+ indirect)</b>																
n/N (%) having brought a companion	36/39		(92%)						76/87†		(87%)					
n/N (%) reporting costs companion	30/36		(83%)						66/76‡		(87%)					
Direct	26	351	508	205	0	420	0	2250	64	405	731	201	0	463	0	5000
Indirect	26	149	341	0	0	0	0	1400	64	135	247	0	0	170	0	1000
Total	26	631	568	418	200	1000	20	2250	64	648	753	365	203	998	21	5000
<b>Treatment of adverse events (mixed direct and indirect)</b>																
N (%) reporting companion costs	1/16										0/24					
Intensive phase	0	--	--	--	--	--	--	--	0	--	--	--	--	--	--	--
Continuation phase	1	10	--	10	--	--	--	--	0	--	--	--	--	--	--	--

\* This analysis excludes companions of patients who were just diagnosed with MDR TB; § These costs were extrapolated to the total treatment phase; \*\*Information missing for 5 persons just diagnosed with MDR TB and 1 person in the intensive phase of MDR TB treatment; † information was missing for 1 person; ‡ information was missing for 2 persons.



**Annex Table 4C.** Companion costs by city of enrolment. Data are presented including all patients and including only those patients bringing a companion on any visit (x 1,000 IDR).

Item	Jakarta			Solo			p-value for difference between cities§
	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Range	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Range	
<b>TB diagnosis*</b>	N=63			N=28			
travel	18 (38)	0 (0 – 20)	0; 190	198 (752)	25 (5 – 52)	0; 4,000	<0.0001
accommodation	0 (2)	0 (0 – 0)	0; 15	7 (38)	0 (0 – 0)	0; 200	0.17
total direct costs for companion	18 (38)	0 (0 – 20)	0; 190	206 (790)	25 (5 – 52)	0; 4,200	0.03
reported income loss	24¥ (134)	0 (0 – 0)	0; 1,000	104 (150)	45 (0 – 150)	0; 600	<0.0001
total companion costs for diagnosis	41¥ (138)	0¥ (0 - 24)	0; 1,010	310 (854)	78 (5 – 215)	0; 4,550	0.003
<i>Costs restricted to patients bringing companion on any visit</i>	N=40 (63%)			N=25 (89%)			0.01
travel	29 (45)	13 (0 – 31)	0; 190	221 (794)	30 (5 – 54)	0; 4,000	0.17
accommodation	0 (2)	0 (0 – 0)	0; 15	9 (40)	0 (0 – 0)	0; 200	0.30
total direct costs for companion	29 (45)	16 (0 – 31)	0; 190	231 (834)	30 (5 – 54)	0; 4,200	0.17
reported income loss	39¥ (168)	0 (0 – 0)	0; 1,000	116 (155)	60 (0 – 150)	0; 600	<0.0001
total companion costs for diagnosis	65¥ (170)	16¥ (0 - 50)	0; 1,010	347 (899)	105 (30 – 220)	0; 4,550	0.001
<b>TB treatment**</b>	N=176			N=56			
total direct costs for companion	53 (252)	0 (0-0)	0; 2,250	355 (758)	122 (0-408)	0; 5,000	<0.0001
reported income loss	148 (913)	0 (0-0)	0; 9,600	334 (1,078)	55 (0-330)	0; 8,000	<0.0001
total companion costs for diagnosis	251 (1,017)	0 (0-50)	0; 9,600	707 (1,295)	305 (0-1,044)	0; 8,000	<0.0001
<i>Costs restricted to patients bringing companion on any visit</i>	N=112 (64%)			N=47 (84%)			0.01
total direct costs for companion	83 (313)	0 (0-0)	0; 2,250	422 (811)	220 (0-475)	0; 5,000	<0.0001
reported income loss	232 (1,137)	0 (0-0)	0; 9,600	398 (1,167)	200 (0-390)	0; 8,000	<0.0001
total companion costs for diagnosis	395 (1,255)	0 (0-210)	0; 9,600	842 (1,375)	415 (200-1,085)	0; 8,000	<0.0001

\* Only companions of patients in intensive phase of TB treatment and patients just diagnosed with MDR TB are included in calculations of TB diagnosis; \*\* Companions of patients just diagnosed with MDR TB are excluded in calculations of costs of TB treatment; ¥ includes 62, respectively 39 patients as one companion lost income but the amount of income lost was unknown.



**Annex Table 4D.** Companion costs by level of household income. Data are presented including all patients and including only those patients bringing a companion on any visit.

Item	0-1.5 M IDR			1.51-2.6 M IDR			2.7-102 M IDR			p-value for difference between TB and M\$DR TB
	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Max¶	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Max¶	Mean (SD)	Median (25 <sup>th</sup> – 75 <sup>th</sup> percentile)	Max¶	
<b>TB diagnosis*</b>	N=33			N=26			N=32			
travel	22 (41)	5 (0 – 30)	180	43 (93)	6 (0 – 50)	458	152 (705)	0 (0 – 33)	4,000	0.46
accommodation	0 (3)	0 (0 – 0)	15	1 (6)	0 (0 – 0)	30	6 (35)	0 (0 – 0)	200	0.98
<i>total direct costs for companion</i>	22 (41)	5 (0 – 30)	180	44 (95)	6 (0 – 50)	458	158 (740)	14 (0 – 33)	4,200	0.62
income loss given by patient	49 (176)	0 (0 – 0)	1,000	46‡ (127)	0‡ (0 – 0)	600	52 (121)	0 (0 – 0)	450	0.97
<i>total companion costs for diagnosis</i>	71 (181)	8 (0 – 36)	1,010	85‡ (181)	20‡ (0 - 50)	755	210 (805)	24 (0 – 73)	4,550	0.33
<i>Costs restricted to patients bringing companion on any visit</i>	N=21 (64%)			N=20 (77%)			N=24 (75%)			0.46
travel	34 (48)	16 (5 – 35)	180	55 (104)	25 (0 – 55)	458	203 (812)	11 (0 – 50)	4,000	0.82
accommodation	1 (3)	0 (0 – 0)	15	2 (7)	0 (0 – 0)	30	8 (41)	0 (0 – 0)	200	0.99
<i>total direct costs for companion</i>	35 (47)	16 (5 – 35)	180	57 (105)	25 (0 – 55)	458	211 (853)	11 (0 – 50)	4,200	0.82
reported income loss	77 (217)	0 (0 – 75)	1,000	60‡ (143)	0‡ (0 – 50)	600	69 (135)	0 (0 – 38)	450	0.81
<i>total companion costs for diagnosis</i>	112 (219)	30 (14 – 150)	1,010	112‡ (201)	46‡ (5 - 73)	755	280 (923)	11 (0 – 152)	4,550	0.77
<b>TB treatment**</b>										
<i>total direct costs for companion</i>	157 (447)	0 (0-0)	2,250	143 (594)	0 (0-0)	5,000	81 (243)	0 (0-0)	1,700	0.94
reported income loss	82 (218)	0 (0-0)	1,050	177 (1,098)	0 (0-0)	9,600	315 (1,208)	0 (0-0)	8,000	0.53
<i>total companion costs for diagnosis</i>	252 (533)	0 (0-205)	2,490	372 (1,263)	0 (0-210)	9,600	457 (1,330)	0 (0-300)	8,000	0.49
<i>Costs restricted to patients bringing companion on any visit</i>	N=44 (58%)			N=56 (73%)			N=59 (75%)			0.05
<i>total direct costs for companion</i>	266 (563)	0 (0-215)	2,250	197 (690)	0 (0-124)	5,000	108 (277)	0 (0-100)	1,700	0.72
reported income loss	142 (273)	0 (0-200)	1,050	243 (1,285)	0 (0-0)	9,600	422 (1,384)	0 (0-200)	8,000	0.42
<i>total companion costs for diagnosis</i>	435 (644)	190 (0-563)	2,490	511 (1,461)	85 (0-363)	9,600	611 (1,510)	100 (0-600)	8,000	0.61

\* Only companions of patients in intensive phase of TB treatment and patients just diagnosed with MDR TB are included in calculations of TB diagnosis; \*\* Companions of patients just diagnosed with MDR TB are excluded in calculations of costs of TB treatment; ¶ Only maximums are given as minimums were 0 except for total direct and total diagnostic costs (minimums 12,000, 12,000 and 29,000 IDR respectively for total direct costs, total costs using income loss given by patient and total costs using income loss calculated); § chi-square tests used for comparison of counts, K-sample equality-of-medians test used for comparing means; ‡ N=25, respectively N=19, as one companion lost income but the amount was unknown.

**Annex Table 5A.** Financial impact of (MDR) TB on the family, by household income group, treatment site and (MDR) TB status.

	Very small N	Small N	Moderate N	Important N	Extra-ordinary N	Total N	p-value*
<b>household income (tertile)</b>							0.16
0-1.5 million IDR	6	5	18	14	47	90	
1.51-2.6 million IDR	7	3	16	26	32	84	
2.7-102 million IDR	6	6	25	14	35	86	
Total	19	14	59	54	114	260	
<b>Site</b>							0.23
Persahabatan	15	10	38	35	89	187	
Dr Moewardi	4	4	21	19	25	73	
Total	19	14	59	54	114	260	
<b>(MDR) TB status</b>							<0.0001
TB	15	8	36	22	36	117	
MDRTB	4	6	23	32	78	143	
Total	19	14	59	54	114	260	

\* Chi square test; \*\* Abbreviations used in this table: IDR, Indonesian Rupiah; TB, tuberculosis; MDR, multidrug resistant.

**Annex Table 5B.** Amount of money borrowed x 1,000 Indonesian Rupiah, by (MDR) TB status, source of the loan and interest rate, among those having borrowed money (n=49).\*

	N with infor- mation	N no infor- mation	Mean	SD	Median	p25	p75	Mini- mum	Maxi- mum	p§
<b>Total</b>	45	4	2,877	7,534	1,000	200	3,000	20	50,000	
<b>TB</b>	8	3	568	658	400	88	750	70	2,000	0.02
<b>MDR TB</b>	37	1	3,376	8,237	1,500	200	3,000	20	50,000	
<b>Source of loan:</b>	44	5								
family	14		1,962	1,312	2,000	1,000	3,000	70	5,000	0.04
neighbors/ friends	20		759	960	350	63	1,200	20	3,000	
private bank	4		1,295	1,267	990	340	2,250	200	3,000	
cooperation	1		8,000	NA	8,000	8,000	8,000	8,000	8,000	
other, specify	5		14,700	20,100	8,000	5,000	10,000	500	50,000	
<b>Paid interest</b>	39**	10								0.17
Yes	12		7,475	13,800	3,000	1,450	8,000	100	50,000	
No	26		1,363	1,485	1,000	75	2,000	20	5,000	
<b>Interest rate</b>	12	0								
1%	2				4,700			1,400	8,000	
2%	5				3,000			1,500	50,000	
5%	1				8,000			8,000	8,000	
10%	2				3,000			3,000	3,000	
20%	1				100			100	100	
30%	1				200			200	200	

\* Abbreviations used in this table: (MDR) TB – (multidrug resistant) tuberculosis, SD – standard deviation, p25 - 25<sup>th</sup> percentile, p75 – 75<sup>th</sup> percentile.

§ p-values calculated using chi-square test.

\*\* One person was not expected to pay back the loan and is not included in this specific analysis.

**Annex Table 5C.** Types and value of property sold to cover up expenses due to TB, by (MDR) TB status.

Type of TB	Most appropriate type of property sold	Value received for sold property in Indonesian Rupiah				Total
		<1 million	>1-<10 million	>10-<50 million	>50 million	
		N	N	N	N	
<b>TB</b>	livestock	0	1	1	0	2
	household asset	2	0	0	0	2
<b>Subtotal TB</b>		<b>2</b>	<b>1</b>	<b>1</b>	<b>0</b>	<b>4</b>
<b>MDRTB</b>	land	0	0	1	1	2
	livestock	0	2	0	0	2
	car/other transport means	0	3	2	0	5
	household asset	4	0	0	0	4
	farm products	2	1	0	0	3
	jewelry	1	10	2	0	13
	house	0	0	1	0	1
<b>Subtotal MDR TB</b>		<b>7</b>	<b>16</b>	<b>6</b>	<b>1</b>	<b>30</b>
<b>Total</b>		<b>9</b>	<b>17</b>	<b>7</b>	<b>1</b>	<b>34</b>

**Annex Table 5D.** Estimated market value of sold property and money received for the sold property for 32 patients who provided information\*.

estimated market value of sold property	money received for the sold property				Total
	<1M	>1-<10 Million	>10-<50 Million	>50M	
< 1 Million Rupiah	6	0	0	0	6
>1-<10 Million Rupiah	2	16	1	0	19
>10-<50 Million Rupiah	0	0	5	0	5
>50 Million Rupiah	0	0	1	1	2
<b>Total</b>	<b>8</b>	<b>16</b>	<b>7</b>	<b>1</b>	<b>32</b>

\* Values displayed in cells are counts. Abbreviations used: M – million,

**Annex Table 5E.** Details for patients who received either more (indicated with green color) or less (indicated with orange) for the property they sold than the estimated market value\*.

Type of TB	Phase	Market value	Value received	Market value range**	Range of value received**
TB	Continuation	13250000	15000000		
TB	Intensive	300000	500000		
MDR TB	Continuation			>1-<10M Rp	>10-<50M Rp
MDR TB	intensive	500000	900000		
MDR TB	just diagnosed MDR TB	1000000	600000		
MDR TB	continuation	30000000	20000000		
MDR TB	continuation			>1-<10M Rp	< 1M Rp
MDR TB	continuation			>50M Rp	>10-<50M Rp

\* Abbreviations used: M – million, Rp – Indonesian Rupiah.

\*\*given only for those who did not give the exact values.

**Annex Table 5F.** Household income before and after TB, in tertiles (based on the distribution of income before TB).

		Household income after TB in tertiles			Total
		0-1.5M IDR	1.51M-2.6M IDR	2.7M-102M IDR	
Household income before TB in tertiles					
0-1.5M IDR	N	86	4	0	90
	%	33.0%	15.3%	0.0%	34.5%
1.51M-2.6M IDR	N	41	37	6	84
	%	15.7%	14.2%	2.3%	32.2%
2.7M-102M IDR	N	13	14	60	87
	%	5.0%	5.4%	23.0%	33.3%
Total		140	55	66	261
		53.6%	21.1%	25.3%	100.0%

\* Abbreviations used: M – million, IDR – Indonesian Rupiah

**Annex Table 5G.** Household income before the diagnosis of TB and at the time of the interview, and difference between these two, x 1,000 Indonesian Rupiah\*.

	TB						MDR TB					
	N	p50	p25	p75	min	max	N	p50	p25	p75	min	max
Household income before diagnosis of TB	118	2,000	1,500	3,300	0	102,000	143	2,000	1,100	3,000	0	30,000
Household income at time of interview	118	1,800	800	3,000	0	102,000	143	1,200	550	2,000	0	20,000
Income difference	118	0	0	-800	-6,000	1,800	143	-500	0	-1,500	-23,000	3,000
Income difference among households with a difference due to TB only	44	-900	-500	-1,550	-3,000	-100	97	-1,000	-360	-1,500	-23,000	2,800
Households with income dropping to 0 IDR	9	-1,500	-1,000	-2,000	-3,000	-800	11	-1,200	-800	-2,500	-4,000	-80
Among all patients:												
patient income before diagnosis of TB	118	1,300	0	2,000	0	81,000	143	1,000	200	2,000	0	23,000
patient income at time of interview	116	0	0	1,800	0	81,000	143	0	0	375	0	4,300
Among patients with an income before diagnosis of TB:												
patient income before diagnosis of TB	84	1,800	1,000	2,500	200	81,000	112	1,500	775	2,000	30	23,000
patient income at time of interview	83	1,000	0	2,000	0	81,000	112	0	0	500	0	4,300

\* Abbreviations used: TB – tuberculosis, MDR – multidrug resistant, p50 – median, p25 – 25<sup>th</sup> percentile, p75 – 75<sup>th</sup> percentile, min – minimum, max – maximum, IDR – Indonesian Rupiah.



**Annex Table 6A.** Results of sensitivity analysis, comparing direct, indirect and total costs between eligible and ineligible (MDR) TB patients\*. Costs should be multiplied by 1,000 Indonesian Rupiah.

	Eligible						Ineligible						p-value §
	N	mean	SD	median	p25	p75	N	mean	SD	median	p25	p75	
<b>Cost of getting (MDR) TB diagnosis</b>													
<i>Direct costs</i>	27	564	1,153	281	115	610	2	886	4	886	883	888	0.13
<i>Indirect costs</i>	27	94	193	27	6	60	2	37	52	37	0	74	0.96
<i>Total costs</i>	27	658	1,302	393	142	736	2	922	49	922	888	957	0.13
<b>Treatment costs</b>													
<i>Direct costs per phase</i>													
Continuation phase TB treatment	37	2,020	4,443	538	128	1,274	19	3,282	7,410	1,040	450	3,000	0.4
Intensive phase MDR TB treatment	53	8,411	7,321	5,812	3,771	10,028	2	1,016	1,392	1,016	32	2,000	0.16
Continuation phase MDR TB treatment	56	11,463	8,276	9,484	5,409	15,432	3	6,824	2,906	6,502	4,093	9,877	0.57
<i>Indirect costs per phase</i>													
Continuation phase TB treatment	37	2,018	4,444	538	123	1,274	19	3,282	7,410	1,040	450	3,000	0.4
Intensive phase MDR TB treatment	53	6,450	7,672	4,045	1,647	8,217	2	1,378	1,920	1,378	20	2,736	0.16
Continuation phase MDR TB treatment	56	5,868	16,043	2,417	0	4,777	3	4,229	3,569	3,742	929	8,016	0.53
<i>Total costs per phase</i>													
Continuation phase TB treatment	37	2,915	6,956	616	196	1,736	19	3,872	8,659	1,245	500	3,000	0.16
Intensive phase MDR TB treatment	53	14,784	11,170	10,501	6,166	22,272	2	2,394	3,312	2,394	52	4,736	0.16
Continuation phase MDR TB treatment	56	17,011	21,390	11,210	6,741	18,781	3	11,053	3,348	10,806	7,835	14,518	0.57
<i>Total amount reimbursed</i>													
Continuation phase TB treatment	37	2	13	0	0	0	19	0	0	0	0	0	0.47
Intensive phase MDR TB treatment	53	77	248	0	0	0	2	0	0	0	0	0	0.52
Continuation phase MDR TB treatment	56	320	1,253	0	0	400	3	0	0	0	0	0	0.28

\* Those in the intensive phase of TB treatment were not included in this sensitivity analysis since by definition none of these patients was considered ineligible. Abbreviations used: TB – tuberculosis, MDR – multidrug resistant, p50 – median, p25 – 25<sup>th</sup> percentile, p75 – 75<sup>th</sup> percentile.

§ Calculated using K-sample equality-of-medians test.



## Annex 2. Data collection tool

Tool to estimate patients' costs

### Questionnaire

Name of interviewer : .....

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

Date of Interview (dd/mm/yy)	Name of Province	Name of District/City	Name of commune	Name of health facility where interview was conducted
Type of Facility	<b>1. Health Post    2. Health center/clinic    3. RSUD/District Hospital    4. Other, specify</b>			

Introduction to the patient:

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

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

If you choose to participate in this study you need to know that you may withdraw from the study at any stage without giving any explanation for your withdrawal. Your answers will be kept confidential. At some point I will ask you about your personal income and the income of your household. We will NOT provide this information to any tax or welfare authorities, also not after the end of the study.

This survey will take ca. 30 minutes.

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

Signature of interviewee: .....

If Yes: Thank you!

If No: Is there a reason why not? (circle)

- |                             |                         |
|-----------------------------|-------------------------|
| 1. Language not good enough | 2. Time constraint      |
| 3. Not comfortable          | 4. Other, specify ..... |

To be filled in by interviewer

**(MDR<sup>5</sup>) TB patient group (circle)**

- A. in last month of intensive phase of cat I-II treatment**
- B. in continuation phase of cat I-II treatment**
- C. just diagnosed with MDR-TB**
- D. in intensive phase of cat IV treatment**
- E. in continuation phase of cat IV treatment**

<sup>5</sup> MDR = Multi drug resistant tuberculosis

**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. DOT <sup>6</sup> supporter / guardian living in same household as the patient
1. Gender    1. male    2. female	Age of patient: ..... years
2. To which ethnic group do you count yourself?	1. Betawi (original from Jakarta)    2. Javanese    3. Sumatran 4. Tionghoa (Chinese)    5. East Indonesian <sup>7</sup> #    6. Other: .....
3. What is your highest level of education? 1. No educational degree    2. Elementary school    3. Secondary school    4. 3 years University/Bachelor degree 5. Other, specify: .....	
4. Type of TB (circle)	1. pulmonary smear +    2. pulmonary smear -    3. Extra-pulmonary
5. Treatment Regimen (circle)	1. Cat I (new case)    2. Cat II (retreatment) 3. Cat IV (chronic, MDR)
6. In which phase and how long on treatment are you currently?	<i>Fill number of months here – check with patient’s treatment card</i> 1. .... Months in intensive phase of Cat I/II 2. .... Months in continuation phase of Cat I/II 3. .... Months in intensive phase of Cat IV 4. .... Months in continuation phase of Cat IV
7. HIV status (as indicated on card!)	1. positive    2. negative    3. not tested    4. not indicated on card
8. How far is the nearest public health facility where TB can be diagnosed?	..... minutes walking/cycling ..... minutes with own motorized or public transport
9. How far is your DOT facility (where you receive your current TB treatment)	..... minutes walking/cycling ..... minutes with own motorized or public transport

**Previous Treatment**

10. TB treatment history (interviewer: extract from the patient’s treatment card)	1. not previously treated for TB → Go to Q11 2. Cat I treatment failed → Go to Q11 3. Cat II treatment failed → Go to Q11 4. transfer to cat IV during non-MDR treatment → Go to Q10b 5. treatment after default → Go to Q10a 6. TB relapse → Go to Q11 7. Other, specify .....
a) Your treatment card indicated that you had default treatment. Why was previous treatment not completed?	1. Not enough money for treatment 2. Drug side effects 3. Distance to facility 4. Other (specify): .....
b) If on Cat IV treatment, how long have you been on TB treatment before you were diagnosed with MDR-TB?	.... months

**Questions 11 and 12 apply to PATIENTS IN GROUPS A AND C ONLY. FOR OTHER PATIENTS, GO TO QUESTION 13.**

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

<sup>6</sup> DOT= directly observed treatment, short course

<sup>7</sup> Those originating from the provinces of Papua, Papua Barat, Maluku, Maluku Utara, Nusa Tenggara Timur



Respondent ID  -  -

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

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

	<b>Provider<sup>8</sup></b>	<b>Total Time spent per visit</b> (in minutes, includes travel time)	<b>Administrative costs</b> (consultative, registration)	<b>Test costs</b> (for sputum or other, except X-ray)	<b>Xray costs</b> (includes sending X-rays to radiologist, travel & fees)	<b>Drug costs</b> (all kinds total)	<b>Travel Costs</b> (return total; includes travel to laboratory, X-ray unit, etc.)	<b>Food costs</b> (total)	<b>Accommodation costs</b> (total)
<b>Visit 1</b>									
<b>Visit 2</b>									
<b>Visit 3</b>									
<b>Visit 4</b>									
<b>Visit 5</b>									
<b>Visit 6</b>									
<b>Visit 7</b>									
<b>Visit 8</b>									
<b>TOTAL</b>	-----								

<sup>8</sup> Types of providers: general physician, *Puskesmas* (district health center), private provider, or hospital. Does not include traditional healers, self medication, and pharmacy.

Respondent  
ID

-  -

	Loss of income experienced by the patient	Insurance Reimbursement <i>If yes: amount and for what, if no n/a</i>	Accompanied by someone else <i>(circle correct answer)</i>	Travel costs of accompanying person <i>(return total)</i>	Accommodation costs of accompanying person <i>(total)</i>	Loss of accompaniment
Visit 1			Yes / No			
Visit 2			Yes / No			
Visit 3			Yes / No			
Visit 4			Yes / No			
Visit 5			Yes / No			
Visit 6			Yes / No			
Visit 7			Yes / No			
Visit 8			Yes / No			
Visit 9			Yes / No			
TOTAL			Yes / No			

Total Direct Prediagnostic & Diagnostic costs (sum subtotals) minus costs covered by insurance = .....Rupiah



Respondent ID

	-		-		
--	---	--	---	--	--

**Treatment Costs (when not on treatment currently (group C), go to Q28)**  
 If the patient does not know costs, write "don't know" instead of leaving answers to cost questions empty

Costs related to DOT (for patients taking TB drugs under supervision of health care workers in health facilities)

**13. Where do you currently take your TB drugs?**  
 If the patient has visited two different DOT places, tick the current place and report costs only for that place.  
 If DOT at home, go to Q 18.

1. Health facility / hospital      2. Home (go to Q18)      3. Community      4. Workplace      5. Dispensary

**b) How many times per week do you go there to take your drugs?** ..... times

<b>14. How long does it take you to get there?</b> (one way)	.... minutes walking	..... minutes with transport	other: .....
<b>15. How long does one of these visits take on average, including time on the road and waiting time</b> (total turnaround time)?	..... minutes		
<b>16. From your home to the DOT place, how much does transportation cost you to visit DOT facility?</b> (both ways)	.....		
<b>17. How much money do you spend on average per facility visit?</b>			
<i>cost for food while waiting at the DOT place</i>	.....		
<i>other costs</i>	.....		

Costs related to picking up the TB drugs – where drugs are currently picked up  
 (if patient picks up drugs in a health care facility and takes these at home)

<b>18. How often do you travel to the health facility / hospital for picking up your TB drugs?</b> If interviewee never has to pick up TB drugs, fill out 'zero' and go to Q25	..... Times / month
<b>19. How long does it take you to get there</b> (one way)	.... minutes walking      .... minutes with own transport .... minutes with public transport
<b>20. How long does one of these visits take on average, including time on the road and waiting time</b> (total turnaround time) ?	..... minutes
<b>21. From your home to the facility, how much does transportation cost you?</b> (both ways)	.....
<b>22. If you go to a facility to pick up your drugs, how much do you spend on food on that day?</b> (on the road, while waiting, etc.)	.....
<b>23. a) Do you have to pay administration fees when picking up your TB drugs?</b> If No, go to Q24.	1. Yes    2. No
<b>b) If YES: how much?</b>	.....
<b>24. a) Do you have any accommodation costs when picking up your TB drugs?</b> If No, go to Q 25	1. Yes    2. No
<b>b) If YES: how much?</b>	.....

<i>Costs related to check-ups and follow-up test during treatments</i>	
25. a) Did you ever have to go to the health facility for follow up tests since the beginning of treatment? <i>If No, go to Q 26.</i>	1. Yes      2. No
b) If yes, how many times?	..... Times
c) If yes, did you have to pay any additional costs for follow-up tests during the entire period?	1. Yes      2. No
d) If so, what kind of costs and how much?	
Fees: .....      Sputum /lab tests: .....      X-ray: .....	Total: .....
TB Drugs .....      Other Drugs: .....      Other (transport, etc): .....	

<b>Guardian Costs related to DOT, picking up drugs, and follow-up tests during treatment</b> <i>If the patient does not know costs, write "don't know" instead of leaving answers to cost questions empty</i>	
26. a) Did someone accompany you on visits related to DOT, picking up drugs, and follow-up test visits or go instead of you to collect your TB drugs? <i>If No, go to Q27.</i>	1. Yes      2. No
b) If YES, on how many visits were you accompanied or has someone gone instead of you?	..... times
c) Did this accompanying person lose income due to going with you?	1. Yes      2. No If yes, how much in total .....

<b>Hospitalization</b> <i>If the patient does not know costs, write "don't know" instead of leaving answers to cost questions empty</i>	
<i>Note to interviewer: if the patient is still hospitalized, ask about situation up to and including time of interview</i>	
27. Have you been hospitalized at any time before (but due to TB) or during your TB treatment? <i>If No, go to Q33.</i>	1. Yes      2. No
28. If YES: how many days in total did you stay at the hospital?	..... days
29. How much did you pay in the hospital during your entire stay?	
Hospital administration fees: .....      Sheets/Linen: .....	
Food (not provided by hospital): .....      Transport (return): .....	Total: .....
Drugs: .....      Tests:.....      Other fees: .....	
30. Did any family/friend stay with you while in hospital? <i>If No, go to Q33.</i>	1. Yes      2. No
31. If YES: How many days did he/she/they stay with you (sleep there)?	..... Days
32. Were there any extra costs for your relative(s)/friend(s) for staying at the hospital?	1. Yes      2. No
Accommodation (hospital or other): .....      Food: .....	
Transport: .....      Loss of income: .....	Total Costs: .....
Other: .....	



<b>Relocation costs</b>	
<i>If the patient does not know costs, write "don't know" instead of leaving answers to cost questions empty</i>	
<b>33. Did you have to move to be able to receive (MDR) TB treatment?</b>	1. Yes      2. No
a) If YES: how much did you pay for relocation?	.....

<b>Other Costs</b>	
<i>If the patient does not know costs, write "don't know" instead of leaving answers to cost questions empty</i>	
<b>34. a) Do you buy any supplements for your diet because of the TB illness, for example vitamins, meat, energy drinks, soft drinks, fruits or medicines? If No, go to Q35.</b>	1. Yes      2. No
<b>b) If YES: What kind of items? (specify)</b>	
1. Fruits      2. Drinks      3. Vitamins/Herbs      4. Meat      5. Other (specify):	
<b>c) How much did you spend on these items in the last 30 days approximately?</b>	.....
<b>35. a) Did you experience any adverse events during the 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) If No, go to Q36</b>	1. Yes      2. No
<b>b) If YES: Was treatment required of these events? This includes changes in TB drug regimen!</b>	1. Yes      2. No
<b>c) IF YES, How much did you spend on treatment of adverse events and/or changes in the TB drug regimen approximately?</b>	
Drugs: .....      Fees: .....	Total: .....
Transport: .....      Accommodation: .....	
Costs made by guardian: .....      Other: .....	

<b>Insurance, reimbursements and vouchers</b>	
<i>If the patient does not know costs, write "don't know" instead of leaving answers to cost questions empty</i>	
<b>36. a) Do you have any kind of private or government health/medical insurance scheme? If No, go to Q 37</b>	1. Yes      2. No
<b>b) If YES: What type?</b>	1. Reimbursement system      2. Monthly health allowance      3. (Private) donor 4. Family/community funds      5. Other (specify)
<b>c) Have you received reimbursement for any costs related to the TB illness? Cross-check with question 12 (table on prediagnostic &amp; diagnostic costs) If No, go to Q 38</b>	1. Yes      2. No
<b>d) If yes, how much have you received as reimbursement?</b>	
For diagnosis: ..... For treatment: ..... For transport costs:..... Other: .....	Total: .....
<b>37. Did the government or other organisations provide you with any of the below items?</b>	1. Yes      2. No
<b>1. Transport vouchers</b> number: ..... value in money: .....	Total value: .....
<b>2. Food vouchers</b> number:      number Value in money: .....	
<b>3. Other (specify):</b> .....      value in money: .....	



Coping Costs	
If the patient does not know costs, write "don't know" instead of leaving answers to cost questions empty	
<b>38. To what extent has the TB illness affected the family financially*?</b> (circle)	1 = little 2 3 4 5=very seriously
<b>39. Where did the money come from to pay for these expenses?</b> (circle, multiple responses allowed)  <i>If no money borrowed or property sold, go to Q 42</i>	1. Health insurance 2. Employer 3. Cutting down on other expenses 4. Using savings 5. Borrowing 6. Selling assets 7. Asking for donations from friends and relatives 8. Others, specify
<b>40. a) If you borrowed money, how much did you borrow?</b>  <b>b) From whom did you borrow (most)? Circle most appropriate</b> 1. Family    2. Neighbors/friends    3. Private bank    4. Cooperation 5. Other (specify): .....	Amount of money borrowed: .....
<b>c) What is the interest rate on the loan? (%)</b>	1. .... % 2. I don't pay any interest 3. I am not expected to pay back the money
<b>41. a) Have you sold any of your property to finance the cost of the TB illness?</b> <i>If No, go to Q 42.</i>	1. Yes    2. No
<b>b) If YES: What did you sell? Circle most appropriate</b> 1. Land    2. Livestock    3. Transport/vehicle    4. Household asset    5. Farm produce 6. Other (specify): .....	
<b>c) What is the estimated market value of the property you sold?</b>	A. Less than 1 million rupiah B. More than 1 million but less than 10 million rupiah C. More than 10 million rupiah but less than 50 million rupiah D. More than 50 million rupiah
<b>d) How much did you earn from the sale of your property?</b>	A. Less than 1 million rupiah B. More than 1 million but less than 10 million rupiah C. More than 10 million rupiah but less than 50 million rupiah D. More than 50 million rupiah

Socioeconomic Information Individual Situation and Income	
If the patient does not know costs, write "don't know" instead of leaving answers to cost questions empty	
<b>42. Who is the primary income earner in the household? Circle most appropriate</b> 1. Patient    2. Other (specify): .....	
<b>43. Are you currently working (includes non-formal work such as housework)?</b> <i>If No, go to Q51.</i>	1. Yes    2. No
<b>44. How are you usually paid (before TB disease, if this has changed)?</b>  1. cash    2. in kind    3. cash and in kind    4. not paid    5. bank transferred salary    6. Other	
<b>45. Did you have to change jobs when you became ill with TB?</b>	1. Yes    2. No





Socioeconomic Indicators		
If the patient does not know costs, write "don't know" instead of leaving answers to cost questions empty		
57. Does any member of the household currently own any of the following assets which are in working condition?	Fill in: 1. Yes 2. No	Attempt to mention the estimated value of the current property. If you can not mention the value, specify the type, amount or size
1. Car		
2. Motor bike		
3. Truck		
4. Tractor		
5. Freezer/refrigerator		
6. AC		
7. Gold or jewelry		
8. Land line		
9. Internet access at home		
10. House/apartment		
11. Land for farming		
12. Other land		
13. Account with financial institution		
14. Company shares		
15. Livestock		
16. Non-farm bussiness		
17. Electrical power at home (Watt)		450 / 900 / 1300 / 2200 / > 2200
<b>58. If the government could provide you with some service to ease the financial burden of TB on you and your household, what would you prefer to have? <i>Don't give options unless patient does not bring up answer him/herself. Only choose one.</i></b> <b>1. Transport vouchers      2. food vouchers      3. More efficient service      4. Other (specify): .....</b>		

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

.....  
 .....

**Comments by Interviewer:**

.....  
 .....

**Date and Signature of Interviewer**

dd/mm/yy

.....



## **Annex 3. Details of the national workshop on costs faced by (MDR) TB patients during diagnosis and treatment**

Kerangka Acuan Lokakarya

### **Dampak TB dan MDR-TB terhadap Pola Pengeluaran Rumah Tangga Pasien**

*Impact of TB and MDR-TB on patient's household expenditure patterns*

#### **Pendahuluan**

Infeksi TB banyak menyerang populasi dengan tingkat ekonomi yang lemah. Kelompok ini juga mempunyai risiko perburukan penyakit lebih tinggi. Beban keuangan yang dihadapi pasien TB tidak hanya berkaitan dengan pelayanan kesehatan yang dibutuhkannya, melainkan juga biaya sampingan yang cukup tinggi seperti transportasi, akomodasi, nutrisi, dan kehilangan penghasilan karena tidak bisa bekerja.

Pasien dengan *Multidrug Resistant Tuberculosis* (MDR TB) harus menanggung biaya 5-20 kali lebih besar daripada pasien TB biasa, karena proses diagnosis dan terapi yang jauh lebih lama dan kompleks. Prevalensi MDR TB juga lebih tinggi di populasi yang tingkat ekonominya lemah seperti mereka yang tinggal di lingkungan kumuh, atau tuna wisma. Dengan permasalahan ekonomi tersebut, mempengaruhi ketaatan pasien dalam menyelesaikan proses diagnosis maupun berobat.

Kementerian Kesehatan atau Program Nasional Pengendalian TB membutuhkan data sebagai *evidence-based policy* yang menjelaskan kesulitan keuangan terbesar yang dialami pasien TB yang akan mempengaruhi akses dan kelanjutan pengobatan TB.

Penelitian terkait beban biaya pasien TB dan MDR-TB telah dilaksanakan di 3 negara, yakni Indonesia, Ethiopia, dan Kazakhstan. Penelitian tersebut memiliki 2 tujuan utama: 1) untuk berkontribusi pada pembuatan perangkat untuk mengevaluasi komponen biaya yang dikeluarkan pasien untuk diagnosis dan terapi TB dan MDR TB, termasuk kehilangan penghasilan; 2) Memperkirakan biaya yang dikeluarkan pasien untuk diagnosis dan terapi TB dan MDR TB.

Sebagai tindak lanjut dari penelitian tersebut, perlu diadakan lokakarya untuk sosialisasi hasil penelitian dan pembuatan rekomendasi kebijakan.

#### **Tujuan Lokakarya**

1. Sosialisasi dan review hasil penelitian beban biaya rumah tangga pasien TB dan MDR-TB.
2. Konsensus rekomendasi untuk pengembangan kebijakan atau rencana aksi untuk menurunkan beban ekonomi dari pasien TB dan MDR TB



## Pelaksanaan

Pelaksanaan lokakarya dibagi menjadi 2 bagian utama lokakarya:

1. Internal: Diseminasi dan diskusi hasil sementara kepada Subdit TB, dan pihak lain yang terkait langsung dalam proses penelitian.

Pelaksanaan pada:

Hari / tanggal: 13 November 2013

Pukul : 08.30 - 16.00 WIB

Tempat : Akmani Hotel

Pihak-pihak yang diundang:

- Kementerian Kesehatan
  - Subdit TB
  - Litbangkes
  - Biro Perencanaan Kemenkes
- USAID
- TORG (dr. Bacht Alisjahbana, Sp.PD. PhD., Dr. Pandu Riono, MPH, Ph.D, Dr Muhammad Noor Farid, S.Si, Ph.D., dr. Ari Probandari, MPH, PhD,)
- TB-CARE (KCNV, MSH, WHO)
- Rumah Sakit (RS Persahabatan and RSUD Dr Moewardi)

Agenda: hari 1.

TIME	TOPIC	PRESENTER
08:00-08:30	Pendaftaran	
	<b>OPENING</b>	
08:30-09:00	Pembukaan : Selamat datang, Tujuan dan pentingnya workshop	Kepala subdit TB
	<b>SESSION 1: Overview / Tinjauan</b>	
09:00-09.15	Pengenalan, Tujuan workshop dan Hasil Penelitian	KNCV (Edine Tiemersma)
09:15-10:00	Overview study biaya pasien Beban Ekonomi TB (menggunakan estimasi local / data Indonesia) dan biaya pasien (MDR) TB di Ethiopia	MSH (David Collins)
10:00-10:15	Coffee break	
	<b>Session 2 : Hasil Diskusi dan Konsensus</b>	
10:15-11:30	Hasil Presentasi dan Diskusi, termasuk Laporan	KNCV (Edine Tiemersma)
11:30-12:30	Diskusi dan prioritas daftar pilihan untuk mitigasi beban keuangan perawatan (MDR) pasien TB	KNCV (Edine Tiemersma)
12:30-12:45	Pengantar untuk hari ke 2 dan umpan balik	KNCV (Edine Tiemersma)
12:45-13:00	Penutupan	Kepala subdit



TIME	TOPIC	PRESENTER
		TB
13:00-14:00	Istirahat makan siang	
14:00-16:00	Diskusi lanjutan untuk perbaikan hasil	UGM Team-Edine

2. Eksternal: Diseminasi dan diskusi hasil penelitian ini kepada stakeholder terkait yang berada di dalam dan di luar lingkungan Kementerian Kesehatan

Pelaksanaan pada:

Hari / tanggal: 14 November 2013

Pukul : 08.30 - 16.00

Tempat : Akmani Hotel

Pihak-pihak yang diundang:

- Kementerian Kesehatan (MOH)
  - Direktur Jenderal PP&PL
  - Direktur PP&ML
  - Bina upaya kesehatan (BUK) – rujukan, dasar, BPPM (Bina penunjang pelayanan medis)
  - Subdit TB
  - Litbangkes
  - Puskomlik
  - Promkes Kemenkes
  - Biro perencanaan Kemenkes
  - Biro hukum kemenkes
- USAID
- TB-CARE
- CCM
- Global Fund
- TORG (dr. Bacht Alisjahbana, Sp.PD. PhD., Dr. Pandu Riono, MPH, Ph.D, Dr Muhammad Noor Farid, S.Si, Ph.D., dr. Ari Probandari, MPH, PhD,)
- Kementerian Keuangan. –Perimbangan dana pusat dan daerah.
- Kemendagri, Otoda.
- Kementerian Koordinator Bidang Kesejahteraan Rakyat
- Kemeterian Sosial, Bansos, Pekerja sosial.
- BAPPENAS
- Sekretariat MDGs



- TNP2K
- Akademisi (UGM, dr. Riris Andono Ahmad, MPH., Ph.D)
- Dinas kesehatan provinsi (Jawa Tengah dan Jakarta)
- Rumah Sakit (RS Persahabatan and RSUD Dr Moewardi)
- Pokja BPJS
- PT. Askes
- Direktur FETP: Dr. I Nyoman Kandun MPH
- Community NGO, Pamali, Japeti, Peer group, Aisyiyah
- Asosiasi profesi: IDI, PAPDI, IDAI, PDPI

Agenda: Hari 2

TIME	TOPIC	PRESENTER	FACILITATOR
08:00-08:30	Pembukaan		
	<b>OPENING</b>		
08:30-08:45	Pembukaan : Selamat datang, Tujuan dan pentingnya workshop	Dirjen PP&PL	
8:45-9:00	Pengenalan, Tujuan workshop dan Sesi	Direktur PP&ML	
	<b>SESSION 1: Tinjauan Umum dan Presentasi Hasil</b>		Dr. dr. Erlina Burhan, MSc, Sp.P (K)
09:00-09:45	Tinjauan study biaya pasien. Beban ekonomi TB (menggunakan estimasi lokal / data Indonesia) dan biaya pasien (MDR) TB di Ethiopia	MSH (David Collins)	
09:45-10:30	Analisis Biaya Pasien : temuan kunci, anekdot dari yang di wawancarai	KNCV (Edine Tiemersma)	
10:30-10:45	Diskusi		
<b>10:45-11:00</b>	<b>Coffee break</b>		
	<b>SESSION 2: Workshop Pilihan Kebijakan (I)</b>		KNCV (Edine Tiemersma)
11:00-11:15	Pengenalan workshop Hasil singkat dan daftar pilihan untuk mengurangi biaya pasien (MDR) pengobatan TB (dari Hari 1)	TB-CARE	
11:15-12:00	Diskusi Grup (7-8): Tantangan, Pilihan dan rekomendasi Catatan: Di setiap kelompok ada perwakilan dari pasien/komunitas.		
12:00-12:45	Presentasi dan Diskusi (@ 7 menit)		



TIME	TOPIC	PRESENTER	FACILITATOR
12:45-13:45	Istirahat Makan Siang		
	<b>SESSION 3: Workshop Pilihan Kebijakan (II)</b>		<i>Dr. I Nyoman Kandun MPH</i>
13:45-15.00	Ringkasan hasil sesi, prioritas dan diskusi sesi pagi		
15:00-15:15	Coffee break		
15:15 – 15:45	Rangkuman, pilihan kebijakan dan rekomendasi serta rencana		
15:45-16:00	Penutupan	Kepala subdit TB	

### Fasilitas

- Ruang pertemuan dengan proyektor untuk presentasi
- Konsumsi snack pagi dan makan siang.
- Kit pertemuan termasuk bahan presentasi dalam bentuk hardcopy.

### Pembiayaan

Seluruh kegiatan dibiayai dari TB-CARE I

