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**TB CARE I**

## Summary report

# Costs faced by (multidrug resistant) tuberculosis patients during diagnosis and treatment: report from a pilot study in Ethiopia, Indonesia and Kazakhstan

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## Background

Although tuberculosis (TB) diagnosis and treatment are free in most high TB-burden countries, TB patients face costs due to charges for health services, costs for transport, accommodation, nutrition and suffer lost income due to inability to work. These costs are expected to be higher for patients with multidrug resistant (MDR) TB than for other TB patients. In most countries, MDR-TB is more prevalent in more-vulnerable social groups, for which the economic impact of the disease may be even bigger. At the same time, a high financial burden may cause patients to not get diagnosis, to not start treatment, or to default from treatment. There is then a higher risk of transmitting the disease to others and also of developing MDR-TB.

One of the main goals of the post-2015 global TB strategy is that no families affected by TB face catastrophic costs. Relieving the economic burden related with TB requires expansion of social protection measures. Policy makers such as Ministries of Health and National Tuberculosis Control Programs need to understand patient costs in their country to identify and mitigate potential bottlenecks in 1). access to (MDR)TB diagnosis, 2). adherence to (MDR)TB treatment 3). the impact on the economic status of patients and their families. With this in mind, TB CARE I developed a tool for estimating MDR-TB patient costs. We built on the existing TBCAP Tool and simplified and adjusted it to also cover costs of MDR-TB patients. The new tool was piloted in Ethiopia, Kazakhstan and Indonesia. Separate reports have been produced with detailed results in the respective countries (submitted separately with this summary report), which have been used in national workshops to develop policy options to decrease the economic burden of (MDR) TB.

This report summarizes the main findings on (MDR) TB patient costs in the three pilot countries, and recommendations from respective policy workshops. Based on the experiences obtained in the three countries, the patient cost tool itself has been further improved as well.

Through structured interviews with (MDR) TB patients in different stages of treatment, 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. Direct costs included costs for hospitalization, follow-up tests, transport costs for health care visits, and food supplements. Calculation of indirect costs was based on time needed for diagnosis and treatment. Costs were extrapolated over the patient's total treatment phase. Medians, interquartile ranges (IQR), means and ranges were calculated for all cost components.

In total 406 MDR-TB patients and 197 other TB patients participated in the pilot: 169 MDR-TB patients and 25 other TB patients in Ethiopia; 143 MDR-TB patients and 118 TB patients in Indonesia; and 94 MDR-TB patients and 54 other TB patients in Kazakhstan.

## Financial impact of TB illness

Table 1 shows the main indicators of the socio-economic impact of TB disease in the three countries.

Table 1. The main indicators of financial impact of TB illness experienced by the (MDR) TB patients in the three countries.

	Ethiopia		Indonesia		Kazakhstan	
	TB	MDR-TB	TB	MDR-TB	TB	MDR-TB
<b>Patients who lost their job</b>	76%	72%	26%	53%	31%	41%
<b>Patients hospitalized for TB</b>	36%	82%	33%	62%	98%	100%
median duration of hospitalization (days)*	40	80	7.5	10	90	195
<b>% of patients reporting income loss due to TB</b>	92%	79%	38%	70%	67%	56%
<b>% reduction in median income (for those reporting an income change)</b>	100%	100%	25%	100%	100%	100%
<b>Patients who received assistance from government or other organizations</b>	24%	73%	22%	34%	17%	27%
<b>Coping costs</b>						
patients who sold property	24%	38%	3%	21%	0%	1%
patients who took out loans	56%	41%	9%	27%	0%	4%
patients who received donations from family/friends	N.A.	N.A.	32%	43%	57%	66%

## Main cost components related to (MDR)TB diagnosis and treatment

The median costs (with interquartile ranges) for patients in the three countries are shown in Table 2. Since patients were asked about the current phase of (pre) treatment, the costs are separated for diagnostic and treatment costs. Also, we show direct (out of pocket) and indirect (loss of income) costs separately. The main cost components related to (MDR) TB diagnosis and treatment in the countries were:

Ethiopia: The largest cost share for (MDR) TB diagnosis was food, while the main cost component for treatment of TB and and MDR TB was food supplements.

Indonesia: The main cost components of MDR TB diagnosis were costs for travel and food, while TB patients spent most on laboratory tests and administration fees. The only major cost component of (MDR) TB treatment was travel costs.

Kazakhstan: The main cost component of TB diagnosis in KZ was related to transport. The main cost components of (MDR) TB treatment were indirect costs of hospitalization, and direct costs related to food supplements and DOT visits.

## **Cost mitigation options**

During national workshops, participants representing different Ministries, Universities, hospitals, non-governmental organizations (NGO's), civil society organizations (CSO's), and patients, policy options for mitigating patient costs due to (MDR) TB were listed. Table 3 summarizes all options considered per country. Options related to TB service improvements prioritized in all three countries were 1) to ensure that the policy of free care for all (MDR) TB services is fully implemented and 2) that services are brought closer to patients, followed by social service improvements related to 3) inclusion of including direct (transport, food support) costs in social support schemes provided through TB services, 4) inclusion of indirect (sick leave allowance) costs in social protection schemes, and 5) improvements of employment protection. Note that these recommendations are not mutually exclusive – it may be necessary to provide more than one at the same time.

## **Conclusion**

While the financial burden of MDR TB patients was (much) higher than that of TB patients in all three countries, all patients experienced substantial socioeconomic impact of TB disease, most importantly due to inability to work and job loss. If the patient is the breadwinner of the family the combination of lost income and extra costs are generally catastrophic. A too high financial burden may cause patients to not get diagnosis, to not start treatment, or to default from treatment. There is then a higher risk of transmitting the disease to others and they are likely to die. Therefore, it should be a priority of the government to relieve the financial burden especially for MDR TB patients.

The cost mitigation options in all three countries should 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.

Table 2. Summary table on median costs (in US dollars) for MDR-TB and other TB patients in the three countries

	TB			MDR-TB		
	Ethiopia	Indonesia	Kazakhstan	Ethiopia	Indonesia	Kazakhstan
<b>Subtotal direct pre(diagnosis) costs</b>	14 (4-109)	33 (9-64)	5 (1-13)	68 (35-191)	39 (12-63)	N.A.
<b>Subtotal indirect pre(diagnosis) costs</b>	0 (0-30)	4 (0-9)	3 (1-5)	0 (0-8)	3 (1-6)	N.A.
<b>Total pre(diagnosis) costs</b>	14 (6-129)	35 (16-69)	9 (4-19)	75 (40-191)	46 (16-82)	N.A.
<b>Subtotal direct treatment costs</b>						
intensive phase	104 (10-231)	41 (8-108)	0 (0-74)	639 (259-968)	596 (342-1,035)	165 (0-541)
continuation phase	80 (34-156)	59 (17-224)	179 (90-328)	634 (458-1,048)	976 (558-1,584)	754 (344-2,022)
<b>Subtotal indirect treatment costs</b>						
intensive phase	0 (0-34)	10 (0-40)	404 (303-674)	220 (89-374)	315 (153-848)	1,537 (0-2,696)
continuation phase	0 (0-4)	9 (0-57)	104 (70-159)	73 (1-375)	254 (0-504)	227 (0-300)
<b>Total treatment costs</b>						
intensive phase	119 (19-260)	52 (17-134)	607 (317-809)	831 (462-1,525)	1,079 (600-2,299)	1,914 (175-3,370)
continuation phase	128 (34-177)	82 (26-286)	319 (236-702)	931 (494-1,296)	1,227 (730-1,846)	1,202 (657-2,245)
<b>Total (pre)diagnosis and treatment costs*</b>	260	169	929	1,838	2,342	3,125

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

Table 3. Summary of policy options to mitigate (MDR)TB patients' costs considered per country

<b><i>TB service improvements</i></b>	<b>Indonesia</b>	<b>Ethiopia</b>	<b>Kazakhstan</b>
<b>Ensure that policy of free care for all (MDR) TB services is fully implemented.</b> Agreements need to be in place so that presumed TB patients can make use of the necessary diagnostic tools for free.	X	X	X
<b>Bring services closer to patients.</b> Further decentralization should reduce patient expenditures on transport and patient time and should reduce detection and treatment delays, especially for MDR-TB patients. For areas where there is no public transport, transport for patients or home visits should be arranged. This includes improving downward referral from national or provincial MDR TB treatment centers to local community health centers.	X	X	X
<b>Detect and treat MDR-TB cases earlier.</b> Especially detection of drug-resistant TB should reduce the time to appropriate treatment, and thus reduce direct and indirect treatment costs for patients, especially the amount of income lost due to inability to work during initial first-line drug treatment. Full implementation of new diagnostics such as Xpert MTB/RIF should reduce time to diagnosis and thus patient costs.	X	X	X
<b>Raise the awareness of health workers.</b> Provide education and training of primary level health workers to recognize suspects and ensure speedy diagnosis, and to follow up on cases and contact tracing.	X	X	X
<b>Involve local NGO's and civil society organizations</b> to support patients and hereby improve (MDR) TB treatment adherence.	X		X
<b>Reduce hospitalization.</b> Kazakhstan has moved in recent years from full in-patient treatment to partial outpatient treatment, usually in the continuation phase. The country plans to move towards full outpatient care. This has the potential to greatly reduce indirect patient costs.			X
<b>No unnecessary or substandard tests.</b> Sometimes, 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., IS6110 based PCR for detection of <i>Mycobacterium tuberculosis</i> ) and serological tests. Such tests are not only unnecessary, but also may importantly increase the costs of (MDR) TB diagnosis.	X		
<b>Obligatory treatment for MDR TB patients</b> 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.	X		
<b><i>Social protection improvements</i></b>			
<b>Include direct (transport, food support) costs in social support schemes provided through TB services.</b> Such incentives and enablers should reduce direct costs associated with TB treatment and improve treatment adherence.	X	X	X
<b>Include indirect (sick leave allowance) costs in social protection schemes.</b> 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.	X	X	X
<b>Improve employment protection.</b> Advocate for regulations and policies that mandate that both public and 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.	X	X	X

Table 3. Summary of policy options to mitigate (MDR)TB patients' costs considered per country, *continued*.

<b><i>TB service improvements</i></b>	<b>Indonesia</b>	<b>Ethiopia</b>	<b>Kazakhstan</b>
<b>Reduce stigma and acceptance of outpatient treatment.</b> 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.	X	X	X
<b>Increase re-socialization and employment possibilities.</b> Develop mechanisms to involve socially vulnerable patients in different re-socialization activities provided e.g. through temporary, assisted living facilities. Develop mechanisms to involve patients in income generating activities and advocate government to support this, for example through microfinance.	X	X	X
<b>Use social health insurance.</b> Advocate with government to incorporate TB services in the future social health insurance system to provide sustainable financing. Also advocate for social protection to be included in the benefits package on the grounds that this will reduce severity of illness and transmission and thus save on treatment costs.	X	X	
<b>Consistency across social assistance programs and over time.</b> The data collected on vouchers indicates that the amounts provided are very low compared with the patient costs and taking into account reductions in income. In addition there may be inconsistency in the amounts provided across facilities and over time. It is recommended that the government develops a standard.		X	
<b>Assure continuation of education.</b> When rendered non-infectious, children and students need to be able to continue their education.			X
<b>Involve local NGO's and civil society organizations</b> 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.	X		
<b>Provide convenient lodging</b> 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 housing will decrease with the roll out of the PMDT program.	X		
<b>Empower patient groups that can support MDR TB patients</b> 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. MDR TB patient support groups provide information 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.	X		