



**THE REPUBLIC OF UGANDA  
MINISTRY OF HEALTH**

**Direct and Indirect costs due to Tuberculosis  
and proportion of Tuberculosis-affected  
households experiencing catastrophic costs  
due to TB in Uganda**

**FEBRUARY 2019**

---

**Funding:** *Funding for the Uganda tuberculosis patients' cost survey was made possible by USAID through the World Health Organization. Doctors with Africa CUAMM also supported the survey both financially and technically.*

**Citation:** *Ministry of Health (Uganda). Direct and Indirect costs due to Tuberculosis and proportion of Tuberculosis-affected households experiencing catastrophic costs due to TB in Uganda. Ministry of Health Uganda, 2019.*



THE REPUBLIC OF UGANDA  
MINISTRY OF HEALTH

**Direct and Indirect costs due to  
Tuberculosis and proportion of  
Tuberculosis-affected households  
experiencing catastrophic costs due to TB  
in Uganda**

**February 2019**

---

## Acknowledgements

Many people and institutions have contributed to the conceptualisation, proposal development, field work, data analysis, report writing, and final editing of this TB catastrophic costs report. Our thanks go to the World Health Organisation (WHO) who came up with the generic protocol and provided the technical assistance; Centres for Disease Control (CDC), Doctors with Africa CUAMM and United States Agency for International Development (USAID) for funding this survey; the Ministry of Health which provided the oversight; Makerere University Lung Institute (MLI) which provided the overall management; the implementation team (both from MLI, and Ministry of Health-National Tuberculosis and Leprosy Programme (NTLP) and those recruited as field data collectors; the District Health Officers in the survey districts, the regional and district TB focal persons, health workers at the survey sites and the respondents.

We are very grateful to all of them. We acknowledge the tremendous support from Dr. Frank Mugabe and Dr. Claudio Marra from Ministry of Health- NTLP; and the Technical Working Group members under NTLP. We convey our gratitude to WHO-Head Quarters - Ines Garcia Baena; WHO country office –Dr. Abel Nkolo, Dr. Kaggwa Mugaga; USAID – Dr. Estella Birabwa, Dr. Seyoum Dejene; CUAMM – Dr. Peter Lochoro, Dr. Ambrose Katungi for their dedication and advice.

The survey would not have materialized had it not been for the support of Makerere University Lung Institute (MLI) that oversaw its implementation. We acknowledge the support of the administration and finance management units at Makerere University College of Health Sciences and Makerere University Lung Institute. In a special way, we acknowledge the tremendous contribution of the investigation team led by the Principal Investigator Dr. Bruce J. Kirenga; Dr. Frank Mugabe, Dr. Abel Nkolo, Dr. Achilles Katamba, and Dr. Simon Kasasa.

Special thanks also go to the Survey Coordinators – Dr. Winters Muttamba and Ms. Racheal Tumwebaze; the data analysts – Dr. Charles Batte and Mr. Levi Mugenyi; and the data manager, Mr. Rogers Sekibira. Also appreciated are Dr. Joan Nalunjoji, Dr. Esther Buregyeya and Ms. Nalubega Fatuma for their contribution to the data analysis process. Special recognition also goes to Mr. Peter Nguhiu for the statistical analysis support.

A special thanks also goes to the following for their input in reviewing and finalizing the report as well as developing the monitoring and evaluation framework and intervention matrix: Dr Bruce Kirenga, Dr Winters Muttamba (MLI), Dr Stavia Turyahabwe, Dr Raymond Byaruhanga, Dr Majwala Robert, Dr Andrew Ocerro, Dr Matilda Kweyamba, Dr Andrew Kazibwe, Dr Simon Muchuro, Dr Moorine Sekadde, Linda Ruvwa, Godfrey Ekuka, Ebony Quinto, Dr Kaggwa Mugagga and Dr Imoko Joseph.

To all those not mentioned by name, especially to all the survey data collectors and the survey participants, you are greatly acknowledged, and your contribution will bear fruit in the use of this report.

---

## Foreword


I am delighted to present this report on the findings of the first-ever national tuberculosis (TB) patient catastrophic costs survey in Uganda. This report gives us an important beginning point if we are to combat TB care related catastrophic costs as a country. The TB burden has continued to cause an enormous health challenge to the people of Uganda and is a big public health challenge to the health care system in Uganda. TB presents an economic challenge and impacts negatively on the livelihood of our people. The WHO recommends that no individual or household should experience catastrophic costs. This, therefore, means that understanding the true burden is critical to devising policies and strategies to help ensure fulfilment of this goal.

My government is committed to conducting locally relevant research to respond effectively to the health needs of the citizens. National TB patient cost surveys, such as this one, are one way of improving the understanding of the costs and devise strategies to protect the patients from such costs.

This survey was conducted throughout the country in both rural and urban areas. All regions of the country were included. This survey was coordinated by our own Makerere University Lung Institute in close collaboration with the National TB and Leprosy Programme. I wish to express my sincere gratitude to the team of local experts. I want to sincerely applaud the support we received from our development partners especially WHO, CDC, USAID and Doctors with Africa (CUAMM) for the funding and overall technical assistance we received. The survey followed best international procedures in accordance with the WHO recommendations on conducting national TB patient cost surveys.

This report highlights the economic burden of TB and identifies gaps for ensuring TB patients are protected from overt costs in the process of seeking for a diagnosis as well as during and after treatment. It is my sincere hope that the developed interventions to combat catastrophic costs will be meaningfully implemented so that by the time a follow-up survey is conducted, the proportion of patients/households experiencing catastrophic costs will have reduced significantly. I urge all stakeholders to work with the government through the National TB and Leprosy Control Programme to ensure the findings in this report are used to devise appropriate interventions which will help the country to meet the End TB target. I am also hopeful that through the planned stakeholders meeting, the results of this survey will tremendously contribute in generating an action plan that will improve the lives of our TB patients.

Finally, I congratulate the Government of Uganda, the Ministry of Health and the team of investigators for this landmark achievement in the history of our country.



Dr. Henry Mwebesa

**Ag. DIRECTOR GENERAL HEALTH SERVICES**

---

## Contents

<b>Acknowledgements</b> .....	<b>2</b>
<b>Foreword</b> .....	<b>3</b>
<b>Contents</b> .....	<b>4</b>
<b>List of figures</b> .....	<b>6</b>
<b>List of Tables</b> .....	<b>6</b>
<b>List of Equations</b> .....	<b>6</b>
<b>List of abbreviations</b> .....	<b>7</b>
<b>Operational Definitions</b> .....	<b>8</b>
<b>Executive summary</b> .....	<b>9</b>
<b>INTRODUCTION</b> .....	<b>10</b>
Geography and demography .....	10
The organisation of TB services .....	10
Rationale.....	11
Summary of previous relevant surveys and social protection mechanisms.....	13
Survey Objectives.....	14
Primary objectives.....	14
Secondary Objective .....	15
<b>SURVEY ORGANISATION</b> .....	<b>15</b>
Organogram.....	15
Steering Committee function.....	15
Principal Investigator and Survey Coordinator .....	15
Research Assistants .....	16
Budget and funding sources .....	16
<b>METHODS</b> .....	<b>17</b>
Survey design overview and survey population (inclusion and exclusion criteria).....	17
Sampling strategy .....	17
Study population .....	17
Sampling strategy.....	17
Steps for cluster sampling .....	18
Sample size computation.....	18
Definitions .....	19
Data collection process (including piloting) and tools .....	20
Data management .....	20
Data analysis.....	20
Ethical considerations.....	22
Patient information.....	22
Compensation.....	22

<b>SURVEY RESULTS</b> .....	<b>23</b>
Survey participants' characteristics .....	23
Socio-demographic, clinical and economic characteristics .....	23
Models of care.....	26
Hours lost in accessing care and loss of income during TB treatment.....	27
Estimated total costs (USD†) borne by TB patients households .....	27
.....	30
Dissaving mechanisms and social consequences .....	30
Households facing catastrophic costs .....	32
Rates of Catastrophic costs .....	32
.....	34
Risk factors for experiencing catastrophic costs .....	35
<b>DISCUSSION</b> .....	<b>39</b>
<b>POLICY IMPLICATIONS AND RECOMMENDATIONS FROM THE FINDINGS OF THE STUDY</b> .....	<b>40</b>
Policy implications .....	40
Recommendations .....	41
<b>Annexes</b> .....	<b>44</b>
Annex 1: Survey team .....	44
Annex 2: Survey Pictures .....	45
Annex 3: Selected Survey DTUs and the corresponding districts/regions .....	47
Annex 4: Monitoring and Evaluation Frame work .....	49
<b>REFERENCES</b> .....	<b>51</b>

---

## List of figures

Figure 1: Survey Organogram .....	15
Figure 2: Average costs per TB episode .....	30
Figure 3: Proportion experiencing Catastrophic costs at 20% threshold based on Income Quintiles...	34
Figure 4: Impact of changing threshold to define catastrophic costs with catastrophic cost proportion amongst households affected by TB or MDR-TB .....	34
Figure 5: Impoverishment headcount due to TB care.....	38

## List of Tables

<b>Table 1: Summary of included DTUs and Districts in each Region.....</b>	<b>18</b>
<b>Table 2: Table of sample size computation.....</b>	<b>19</b>
Table 3: Socio-demographic and Clinical characteristics of the respondents.....	24
<b>Table 4: <i>Descriptive statistics and economic characteristics of survey sample</i>.....</b>	<b>25</b>
<b>Table 5: Model of care for Survey sample.....</b>	<b>26</b>
<b>Table 6: Hours lost seeking or accessing care and reported individual income by the patient ...</b>	<b>28</b>
<b>Table 7: Estimated total costs (USD†) borne by patients' households affected by TB, MDR-TB or all, median breakdown.....</b>	<b>29</b>
<b>Table 8: Reported dissaving mechanisms and social consequences .....</b>	<b>31</b>
<b>Table 9: Households classified as facing catastrophic costs under various thresholds .....</b>	<b>33</b>
Table 10: Proportion of respondents experiencing catastrophic costs by variables.....	35
<b>Table 11: Odds of experiencing catastrophic costs .....</b>	<b>35</b>
<b>Table 12: Monthly costs in USD by HIV status, sex, age, region and income.....</b>	<b>37</b>

## List of Equations

Equation 1: Sample size computation .....	18
<b>Equation 2: Table of sample size computation.....</b>	<b>21</b>



---

## List of abbreviations

AIDS	Acquired Immune Deficiency Syndrome
CDC	Centers for Disease Control
DEFF	Design Effect
DHO	District Health Officer
DOT	Directly observed therapy
DS-TB	Drug Sensitive Tuberculosis
DTU	Diagnostic and Treatment Unit
GTB	Global TB Programme
HIV	Human Immunodeficiency Syndrome
IQR	Inter-Quartile Range
MDR-TB	Multi-drug resistance Tuberculosis
MoH	Ministry of Health
NTLP	National Tuberculosis and Leprosy Programme
OOP	Out-of-pocket
RPMT	Regional performance Monitoring Team
TB	Tuberculosis
UHC	Universal Health Coverage
USAID	United States Agency for International Development
USD	United States Dollars
WHO	World Health Organization
PPP	Public private partnerships
US\$	United States Dollars

---

## Operational Definitions

Human capital approach:	This is an approach used to calculate indirect costs where by reported time use while seeking and receiving care during the TB episode (in hours) is multiplied by an individual hourly income
Output approach:	This is the approach that uses self-reported household income at three points in time (prior to the onset of TB symptoms, at the time of diagnosis and during the “current” treatment phase) to estimate income change before and during the TB episode
Catastrophic costs:	Total costs (indirect and direct combined) exceeding 20% of the household’s annual income Dissaving: These are coping measures used by the TB patients to help them defray TB related costs.
Direct costs:	Refers to out-of-pocket payments both medical costs for TB care and non-medical costs (transportation, accommodation, food, nutritional supplements)
Indirect costs:	These refer to productivity and economic costs a patient or household incur as a result of TB health care seeking and hospitalization, during the TB episode
Medical costs:	These refer to Out-pocket payments for TB care (e.g. consultation fee, drugs, diagnosis, hospitalization, etc.)
Non-medical costs:	These refer to Out of pocket payments made by a patient or guardian related to the use of TB health services such as payments for transportation, accommodation, food, etc.
Income:	This was money received, especially on a regular basis, for work or through investments. This was calculated both at the individual level and household level
Treatment delay:	In this survey this was defined as the period between onset of TB symptoms and initiation of TB treatment
Social protection:	An integrated set of policies and programmes (including social assistance, labour market programmes and social insurance) providing minimum income security in the event of illness or other external and unforeseen event, which aims for poverty reduction, and sustainable and inclusive economic growth
NTLP network:	Health facilities treating and notifying TB in line with NTLP guidelines, which may also include private and NGO facilities collaborating with NTP.

---

## Executive summary

Uganda faces a high burden of tuberculosis (TB), which is further complicated by the high costs incurred by TB patients. Until this survey, the proportion of TB affected households incurring catastrophic costs in the country was unknown. A national survey was therefore conducted in 2017 to primarily determine direct and indirect costs borne by TB patients and their households and to estimate the proportion of TB-affected households experiencing catastrophic total costs due to TB. This survey established a baseline that will be used as a benchmark for subsequent surveys, allowing monitoring of the WHO End TB indicator of zero affected households facing catastrophic expenditure due to TB. This survey was facility-based. A total of 1,178 TB patients attending 67 health facilities across the country who had been on TB treatment for at least two weeks were interviewed about TB healthcare-related costs, time loss, coping measures and asset ownership.

Of the 1,178 participants interviewed, 62.7% (739) were male, median age was 35 (IQR: 26- 44) years, 3.7% (44) had multidrug-resistant TB (MDR-TB) and 96.2% (1,134) had drug-susceptible (DS) TB. Nearly a third of the participants, 30.8% (362) were aged 25-34 years and, 52.5% (618) interviewed patients were in the continuation phase of treatment. In terms of treatment experience, 93.4% (1,060) of the DS-TB patients were new treatment TB cases while among those with MDR-TB, 64.0% (28) were retreatment cases. Overall, 55.5% (654) respondents were co-infected with HIV; 57.3% (25) and 42.9% (487) among MDR and DS-TB patients respectively.

The survey established that DS-TB patients spent on average 369 United States dollars (USD) on TB related care per episode while MDR-TB patients spend on average 3722 USD. In the pre-diagnosis period, major cost drivers for both types of TB were medical and travel costs with both costs being higher for MDR-TB than DS-TB. In post diagnosis period, the major cost drivers for MDR-TB were nutritional supplements, travel and food while for DS-TB patients in the same period the main cost drivers were nutritional supplements.

Close to half (48.5%) of the TB patients in the survey reported to have undertaken at least one coping mechanism to defray TB costs; 26.5% reported to have sold their assets, 26.3% took loans, and 11.2% used personal savings (dissaving). TB also had other social consequences on patients; 49.7% reported food insecurity, 8% divorced, 40.5% lost a job, 11.8% had their children drop out of school and 53.7% experienced social exclusion (Stigma). Only a marginal number of participants (3.9%), reported having received any form of social protection to deal with these problems.

Catastrophic expenditure, defined as spending at least 20% of household income on TB care, was experienced by up to **53.1%** of the households of TB patients. The proportion of TB patients in the poorest income quintile experiencing catastrophic costs is way higher than that of patients in the better income quintiles.

The extremes of age (less than 15 and over 65) incur more costs than others. Also, being HIV positive and female was associated with incurring bigger direct medical, direct non-medical and indirect costs.

In conclusion, this survey has established that more than half of the TB patients in Uganda face catastrophic TB care costs. The main cost drivers are non-medical expenditure such as travel, nutritional supplements and food. These costs result in coping behaviors such as selling property, taking up loans and using up savings. The patients at extremes of age (less than 15 years and over 65 years), HIV positive patients, and females incur higher costs.

---

## INTRODUCTION

### Geography and demography

Uganda is a landlocked country located in East Africa covering a surface area of 241,038 sq. km. It is bordered by South Sudan to the North, Kenya to the East, the United Republic of Tanzania and Rwanda to the South, and the Democratic Republic of Congo to the West. The capital city is Kampala and English is the official language. Uganda's climate is typically tropical, with two rainy and two dry seasons a year.

The 2014 national census estimated the population of Uganda to be 39 million people, with 51.4% of the population under 18 years of age. About 82% of the population lives in the rural areas, while the rest, 18% lives in urban areas. The proportion of males to females is 1:1 and life expectancy is 56 years for males and 59 years for females.

### The organisation of TB services

Tuberculosis (TB) management in the country is under the National Tuberculosis and Leprosy Programme (NTLP) which is a disease control programme under the department of the National Disease Control of the Ministry of Health (MoH). The NTLP operates on three levels, namely the national level (also referred to as the central unit), the regional level, and the district level.

The NTLP is charged with performing the national core function of TB and leprosy control through 1) the establishment of country-wide quality diagnosis and treatment of TB and leprosy; 2) coordination and supervision of the implementation of TB and leprosy prevention and care services, and 3) prevention and management of leprosy-related disabilities.

The central unit of NTLP is headed by a Programme Manager who is supported by several officers who coordinate the following units: Prevention and Health Promotion; Monitoring and Evaluation; Care and Treatment Services; Laboratory Services and Policy; and Regional TB and Leprosy services. These units each employ focal officers for specific programme functions.

At the regional level, management and supervision of TB and leprosy services are performed by the Regional TB and Leprosy Focal Persons (RTLFP). There are currently 12 regions which are aligned to the 12 MoH Regional performance monitoring teams (RPMT) structure. At the district level, the District Health Officer (DHO) is responsible for the management of health service delivery, including TB and leprosy prevention and care services. The DHO assigns a district health team member the responsibility of overseeing TB and leprosy care and prevention services in the district. The assigned person is referred to as the District TB and Leprosy Supervisor (DTLS). At the Health Sub-district (HSD) level, a medical officer or other administrator is responsible for the management of health service delivery, including TB and leprosy care and prevention services. A health worker, referred to as the HSD Focal Person, is assigned the responsibility of overseeing TB and leprosy care and prevention services at the HSD level. At the district, HSD and health facility level, TB and leprosy care and prevention services are integrated into the general health services.

---

## Rationale

Patients with TB often incur large costs related to illness and disability, as well as seeking and receiving health care. Such costs can create access and adherence barriers which can affect health outcomes and increase the risk of disease transmission. These costs also contribute to the economic burden on households. In low- and middle-income countries, patients with TB face costs that, on average, amount to half their annual income. TB affects the poorest segment of society disproportionately and the poverty-aggravating effects of TB are therefore gravest for those who are already vulnerable.

While direct payments for health care (sometimes called out-of-pocket medical expenditures) are important, lost income is often the dominant contributor to economic hardship for people with TB. Direct non-medical costs, such as for travel, food and nutritional supplements during care, are also significant given an often-protracted health-seeking period, and treatment lasting six-months to two-years. To overcome access and adherence barriers, and to minimise the economic burden for TB patients (and their households), it is, therefore, essential to address direct medical, direct non-medical, and indirect costs. Interventions are needed to address high medical costs, as well as the cost of food, nutritional supplements and transport, as well as lost earnings. Health financing and patient-centered delivery models, as well as social protection mechanisms (such as job protection, paid sick leave, social assistance, or other transfers in cash or kind), need to be considered.

Uganda faces a high burden of TB with a prevalence of 253 per 100,000 population [1] and the incidence rate of 201 per 100,000 population. The incidence rate in the HIV positive population is 85 per 100,000 population [2]. The proportion of MDR TB among the new TB cases and previously treated TB cases is 1.6% and 12% respectively [2]. Most of the TB cases are in the age category of 30-44 years [1], a sign of high transmission but also affecting the most economically productive sector of the population. The disease can, therefore, cause enormous economic and social disruption by reducing both labour supply and productivity. Studies have reported that costs faced by TB patients and their households reveal a high economic and financial burden due to the disease. To reduce these financial risks, the World Health Organisation (WHO) has asked countries to put in place innovative health financing systems to ensure Universal Health Coverage (UHC) [3]. The Global TB Programme (WHO) promotes several measures including increasing insurance coverage, reimbursements, regulating and eliminating user fees, social protection schemes among others to lower the financial and economic burden of TB amongst households [4]. In addition, WHO aims to annually report on results from national surveys of costs faced by TB patients and their households. These surveys have two primary objectives: to document the magnitude and main drivers of different types of costs incurred by TB patients (and their households) in order to guide policies to reduce financial and economic barriers to accessing care as well as minimize the adverse socioeconomic impact of TB. Additionally, to determine the baseline and periodically measure the percentage of TB patients (and their households) treated in the National TB Programme (NTP) network, who incur catastrophic total costs due to TB. This information is needed to monitor progress towards attainment of the target of one of the three high-level indicators of the End TB Strategy. That is; no TB patients and their households should face catastrophic total costs due to TB by 2020. Tuberculosis patients often incur large costs related to illness, as well as to seeking and receiving healthcare. Such costs can create access and adherence barriers which can affect health outcomes and increase the risk of transmission of disease. These costs can also contribute to the economic burden of households. In low- and middle-income countries, TB patients face costs that on average amount to half their annual income. In all settings, the poorest segment of society is affected

---

the most by TB. The poverty-aggravating effects of TB are, therefore, gravest for those that are already most vulnerable.

While out-of-pocket medical expenditures are important, lost income is often the dominant contributor to economic hardships. Direct non-medical costs, such as costs for travel and food during health-seeking, are also significant given the often-long health-seeking period and the six months to two years period of treatment.

To overcome access and adherence barriers, as well as to minimise the economic burden for TB patients (and their households) it is, therefore, essential to address both direct and indirect costs. Interventions are needed to address high medical costs, as well as costs of food and transport, as well as lost earnings. Therefore, health financing and delivery models, as well as social protection mechanisms (such as job protection, paid sick leave, social welfare payments, or other transfers in cash or kind) need to be considered.

One of the three targets of the End TB Strategy is that no TB patient or their household should face "catastrophic total costs" due to TB, with this target achieved by 2020 (1). This is in line with policy efforts to move health systems closer to UHC since the TB epidemic cannot be ended unless general health care access barriers are addressed. The End TB target is also in line with policy efforts to move health systems closer to UHC because TB cannot be eliminated without addressing the barriers to uptake and completion of the needed treatment, an important aspect of service coverage. The share of the population incurring "catastrophic expenditures" (expenditures beyond a defined threshold of a household's capacity to pay) is one measure of financial protection that is commonly used as an indicator of progress towards UHC. The TB-specific indicator of "catastrophic total costs" is different from the population-based indicator of "catastrophic expenditures" because it incorporates, both direct medical payments for treatment, direct non-medical payments (such as transportation, lodging charges) and indirect costs, such as income losses. The TB-specific indicator is also restricted to a particular population: diagnosed TB patients treated in NTLN networks. Furthermore, the objective of the TB-specific measure is to identify and reduce barriers to treatment adherence and not, strictly speaking, to measure financial protection for households.

Measuring financial protection for households at the level of an individual disease would make little sense as it would suggest a policy concern with impoverishment from one disease as compared to other diseases. Hence, due to the differences in both the concept and the approach to measurement, the indicator of catastrophic TB cost is not comparable to the population-based indicator of catastrophic expenditures, and should not be used in relation to any other measure, apart from "TB catastrophic total costs" over time in the same country. It should be noted that the TB-specific indicator of "catastrophic total costs" does not capture all TB-related costs for patients and households. It does not explicitly measure income loss due to disability per se, or other factors (e.g. stigma and discrimination) leading to loss of employment or earnings unless such income loss is closely related to, or impossible to distinguish from lost earnings due to health-seeking, healthcare visits and hospitalization. That is, the indicator measures indirect costs related to TB care, but not strictly speaking to the illness itself. This is part of the rationale for measuring the indicators only among people who are diagnosed and treated for TB. Moreover, indirect costs of TB for the patient and the household can extend well beyond the treatment period, also for people who are declared cured of TB. People may be left with short- or long-term (even life-long) consequences of the disease. Effects of coping mechanisms, such as selling household assets or taking children

---

out of school can impair household economy for years. For the documentation of long-term need of social and economic support for TB-affected households, measures of costs need to have a longer-term time-window than the present indicator.

However, the relevance and importance of this work is clear: reducing the direct and indirect costs related to TB care will contribute to improvements in treatment adherence and in financial protection. Thus, surveys to assess the magnitude of patient costs and identify the main cost drivers, can be used to monitor financial barriers to adherence and inform related health and social policy changes to improve TB control. This perspective is essential because given the nature of the TB treatment protocol, reforms to the health financing systems alone are unlikely to be sufficient to enable the diagnosed TB patients to overcome fully the barrier to completing treatment successfully. Action on the demand-side is essential, such as the extension of certain social protection mechanisms to ensure successful treatment for people in the informal sector and the vulnerable population groups that comprise most of the TB-affected population. Reforms to the service delivery strategies are also needed in many settings to reduce direct and indirect costs associated with care-seeking. Another potential benefit of implementing this type of survey is that it can also inform the development of more in-depth operational research to investigate the identified problems and to evaluate the proposed solutions.

It is recommended that countries assess the composition and magnitude of these direct and indirect costs through periodic health facility-based surveys. This is complementary to other needed assessments of local and national TB epidemiology; health-seeking; healthcare and social service coverage; and bottlenecks for TB patients. Such assessments are a fundamental part of the End TB Strategy, which stresses the need for national adaptation based on the local epidemiological and the health system's situation.

This survey was designed to assess the economic burden (i.e. direct and indirect costs) incurred by TB patients (and their households) and to identify cost drivers in order to guide policies on cost mitigation and delivery model improvements. The survey measured the proportion of TB patients (and their households) that experienced catastrophic total cost in the year 2017. This data will be used as a baseline against which progress towards the End TB Strategy target on catastrophic costs will be measured.

## **Summary of previous relevant surveys and social protection mechanisms**

Previous work done in Uganda on costs of TB treatment shows the amount needed to successfully treat a new smear-positive TB patient using the hospital-based approach would be 911 USD while when a community-based care approach is used, 391 USD is needed [5]. A study done in rural Uganda found the mean cost over the treatment period to be 294 USD [6]. Similar studies done in Sierra Leone, Tanzania and Zambia put the cost of TB treatment at 47 USD, 662 USD and 25 USD respectively [7-10]. In Nigeria, the mean annual income was 1,123 USD and of this, mean direct household payments for TB accounted for 14%, with 45% of this spent during the pretreatment period and 25% spent during the treatment period [11].

Catastrophic costs in most surveys have been set at 20% of the household's annual income as this threshold was mostly associated with adverse TB outcomes [12]. This is also the cutoff point proposed by the End TB Strategy. A Peru study found up to 39% of the households

---

experiencing catastrophic costs and the likelihood of experiencing catastrophic costs was more associated with Multidrug Resistance (MDR) TB status [12].

Data from previous studies have highlighted the contribution of food and transportation to the nearest TB care service on indirect costs; putting the figures at 50% and 37% respectively [13]. The same study highlights that as much as the costs are incurred before, during, and after treatment, the costs incurred tend to peak at diagnosis and treatment initiation. Importantly this study found out that minimizing costs during treatment does not guarantee financial risk protection, as a big portion of the costs is often incurred before treatment is initiated [13]. Alleviating costs during the period before treatment initiation through affordable health services and social protection schemes is one way of reducing the patient costs [13].

In most of the countries, health services are paid for through out-of-pocket payments to the providers and in a survey done in 89 countries, about 150 million people experience catastrophic costs due to out-of-pocket payment for health services [14]. Prepayment mechanisms have been found to protect people against catastrophic health expenditure [14].

Various social protection strategies have been suggested including TB-specific social protection schemes (cash transfers, food support, travel support, housing support and vocational training for the TB patients); general social protection schemes that TB patients may be eligible for (social assistance e.g. through cash transfers, social insurance e.g. health insurance); labor market interventions (e.g. vocational training programs); and legislations (e.g. right to employment) [15].

Cash transfers can be used to defray TB costs in households with a confirmed TB diagnosis (TB-specific approach), or to increase the income of households at high risk of TB, to make them economically resilient (TB-sensitive approach) [16]. A comparison of the two cash transfer approaches found out that as much as the TB-sensitive approach could have broad benefits through reduction of poverty, it was unlikely to be as effective and affordable as the TB-specific approach, in reducing the catastrophic costs [16].

## Survey Objectives

### Primary objectives

1. To document the magnitude and main drivers of patient costs in order to guide policies on cost mitigation for the purpose of reducing financial barriers to access and adherence.
2. To determine baseline percentage of diagnosed TB patients treated in the NTLN network (and their households) in Uganda, who incur direct and indirect costs beyond a defined threshold of their annual income.
3. To determine the correlation between facing costs above different thresholds of annual household income and the borrowing or selling assets to finance health care expenditure (or dissaving), in order to assess if the measure of dissaving is a sufficient metric of catastrophic total costs (for field testing period to inform selection of proxy for final protocol).
4. To help design a standardized approach for periodic measurements of financial barriers to adherence based on baseline experience and to enable reporting on the



2020 End TB Strategy target that no family affected by TB will incur total (direct and indirect) catastrophic costs as specifically defined in the context of this work.

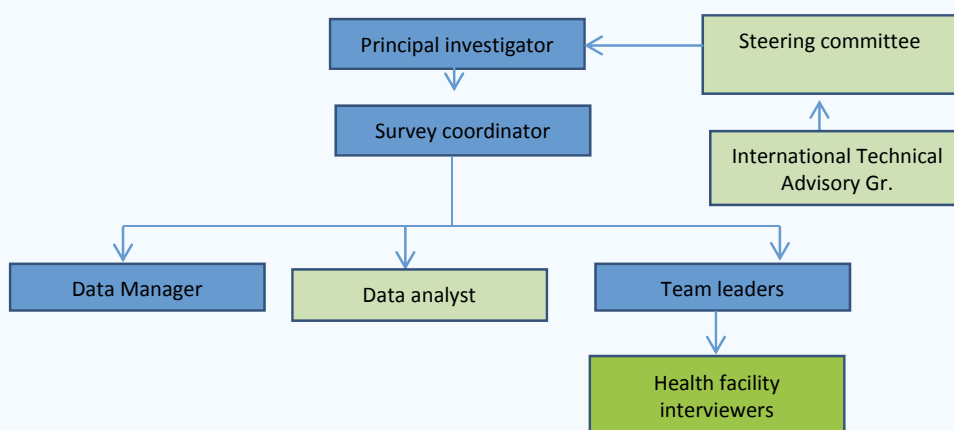
## Secondary Objective

1. To assess costs for specific subgroups, for example, disaggregated by type of TB (MDR vs. drug-susceptible TB, urban vs. rural), age, sex, and income.

## SURVEY ORGANISATION

### Organogram

For the purposes of managing and coordinating the survey, the organization of the survey was arranged as represented diagrammatically in the organogram, in **Figure 2** below.



*Figure 1: Survey Organogram*

### Steering Committee function

The steering committee was tasked with advising the Principal Investigator and Survey coordinator on all technical aspects of the survey and also on issues such as the survey approval and acceptance process. It provided technical input (statistical, epidemiology, health economics) for the activities of the Principal Investigator and consisted of experts in these fields. Collaboration with the group was intense during the design and adaptation of the protocol, but ad-hoc advice during actual data collection was also available. Members performed these activities on a part-time basis.

The terms of reference of the steering committee included advising on the survey protocol, advising on the design, pre-testing and production of survey materials, providing technical assistance in training and pilot-testing, providing ad-hoc advice during survey implementation and providing feedback on the interpretation of results.

### Principal Investigator and Survey Coordinator

There were two Principal Investigators- the technical Principal Investigator and the programme Principal Investigator—Dr. Bruce Kirenga and Dr. Frank Mugabe, respectively, who were responsible for the overall supervision of the survey. The Survey Coordinator

oversaw all field activities and logistics. He was responsible for the overall planning and implementation of the field activities to ensure the smooth-running of operations.

### **Research Assistants**

The Survey Coordinator was directly in charge of the research assistants. Sixteen research assistants were recruited to collect data in the 67 sampled health facilities. They only went to the health facilities after introducing themselves to the responsible authorities in the districts they went to. This was either at the district health office if the facility was a Health Centre IV, or at the hospital director's office if the facility was a Regional Referral Hospital. Each research assistant was allocated a minimum of three facilities and allocated more after completing the allocated facilities. The research assistant was to conduct all the interviews at the health facility as patients came back for either drug refill or follow-up. The research assistants also responded to data queries generated by the data manager. They reported any problems in implementing the survey protocol in the field.

For the average facility size and TB patients notified, it was estimated that the field-work would last at least two weeks per facility thus field data collection was anticipated to take three months.

### **Budget and funding sources**

The total budget required for this survey was USD 89,645.

<b>Budget line</b>	<b>Total in USD</b>
Human resources	58,400
Subtotal Technical assistance	4,800
Subtotal ICT	6,100
Subtotal Patient incentives	6,261
IRB, Protocol translation	1,389
Total (without % overhead)	76,950
Overhead (10%)	7,695
Total (with % overhead)	84,645
Technical support	5,000
Grand Total	<b>89,645</b>

Funding for this survey was obtained from WHO through CDC, CUAMM and USAID. This tremendous financial contribution enabled the successful completion of the survey.

---

## METHODS

### Survey design overview and survey population (inclusion and exclusion criteria)

This survey employed a cross-sectional survey design with retrospective data collection and projections. All consecutive Drug Sensitive Tuberculosis (DS-TB) and MDR-TB patients registered for treatment who were attending a sampled facility for a follow-up visit (after a minimum of two weeks into the present intensive or continuation treatment phase) were invited to the survey.

Each patient was interviewed only once and reported on expenditures, time loss and coping mechanisms (as well as socioeconomic status) retrospectively. Some of the patients were interviewed in the intensive treatment phase while others were interviewed in the continuation treatment phase, with expenditure and time loss data collected for that particular phase only. Patients in each of these two phases were interviewed at different time points during their treatment. Data collection for patients in different treatment phases allowed for the imputation of data and model projections of future and past costs during the entire illness episode.

All consenting patients on treatment for DS-TB or MDR-TB in an NTLP linked health facility were eligible for inclusion in the survey as long as they had completed a minimum of 2 weeks on a treatment phase. Conversely, patients who were treated in facilities that are not linked to NTLP (i.e. private facilities that are not formally part of a public private partnership initiative) were excluded, as were those in NTLP linked health facilities who had not been put on TB treatment.

### Sampling strategy

#### Study population

The study population included all patients (including children) who are on DS-TB or MDR-TB treatment (in the continuation or intensive phase) within the NTLP network (public and private facilities). The patients included were patients accessing TB treatment in health facilities belonging to the NTLP network. These findings can therefore only be extrapolated to the subset of TB patients who receive care under NTLP network and their household, and conclusions cannot be drawn about all people with TB in the country.

#### Sampling strategy

This survey employed a cluster sampling strategy where health facilities were sampling unit. All TB patients found in the facility TB-register, and attending the sampled facilities during the study period, were eligible for inclusion in the study. All included patients attending one sampled facility became a cluster.

Random cluster sampling approach ensured national representativeness. In random cluster sampling, facilities (TB Diagnostic and treatment Units) were randomly selected from a sampling frame of health facilities in the NTLP network. In order to improve the efficiency of random cluster sampling, we stratified by NTLP regions (formerly zones) as represented in **Table 1** below. The clusters were allocated depending on TB notification for the year 2015.

*Table 1: Summary of included DTUs and Districts in each Region*

Region	DISTRICTS	DTU'S
Central	8	11
Kampala	1	10
Eastern	7	7
North	5	6
North Eastern	5	5
North Western	4	5
South Eastern	7	7
South Western	10	11
Western	5	5
TOTAL	52	67

## Steps for cluster sampling

### *Sampling of clusters*

Following calculation of the sample size and determining the total number of clusters, we obtained the list of diagnostic and treatment units (DTU) for each region (formerly zones) from a list of facilities obtained from the NTLF. It would have been desirable to select from urban/rural strata however this was not done because Kampala is a region within NTLF management therefore patients from Kampala represented urban. Within each region, the clusters were allocated between primary and hospital DTU again according to notification numbers. There are few MDR-TB DTUs in the country, i.e., a total of 13. We allocated 4 DTUs to MDR to be sampled depending on numbers from the list of 13.

### *Sampling of TB patients*

Within sampled facilities, consecutive patients on TB treatment visiting the facility were eligible for inclusion. Inclusion of consecutive patients attending the facility can be considered equivalent to random sampling since no additional inclusion criteria was introduced (e.g. attending at certain times of the day only). The TB register of the facility (hospital or ambulatory care) was used as an entry-point for the sampling of patients at the facility level.

## Sample size computation

Sample computation was based on the cluster sampling formula below which is already programmed on the WHO Global TB software (<http://samplesize.herokuapp.com>)

$$N = N_{SRS} * DEFF \rightarrow N = \left[ 1.96^2 \frac{(1 - \pi_g)}{d^2 \pi_g} \right] \times \left[ 1 + (m - 1) \frac{k^2 \pi_g}{(1 - \pi_g)} \right]$$

*Equation 1: Sample size computation*

Where:

$N$	Number of people included in the patient survey
NSRS	Simple Random Sampling size
$\pi_g$	“Prior guess” of the true proportion of families experiencing catastrophic total costs due to TB illness (expressed as a proportion), taken as 27%
$d$	Relative precision (expressed as a proportion).
$m$	Cluster size (=number of targeted individuals), assumed to be constant across clusters.
$k$	Coefficient of between-cluster variation.

Taking the current total of 46,171 [17], the estimated TB patients in Uganda for the year 2014 (N), a design effect (DEFF) of 2.0 (as found Uganda AIDS Indicator  $\pi_g$  Survey 2011), a catastrophic rate of 30% which is slightly higher than the 27% that was estimated by Sethe P. B et al 2015, and precision level (d) of 4%, a minimum sample size was generated as shown in **Table 2** below from the WHO software:

*Table 2: Table of sample size computation*

Anticipated guess	Absolute precision d=4.0 %			
	Cluster size - 10 clusters -	Cluster size - 15 clusters -	Cluster size - 20 clusters -	Sample size
20.0%	77	51	39	762
30.0%	100	67	50	998
35.0%	108	72	54	1080

Assuming an average cluster size of 15 patients and a total number of 67 clusters (m) countrywide, translated to 998 patients needed to be included in the survey. However, after adjusting for a non-response rate of 15% (based on Kampala TB epidemiology 2013 and TB prevalence survey-2015 experience), translated to an estimated minimum sample size of **1,174** patients.

In this survey, a DTU was considered as a cluster. In situations, where the number of patients was less than 15 (cluster size), nearby DTUs were annexed accordingly.

## Definitions

**Patient costs.** In this survey, patient costs were categorized into direct and indirect costs;

- 1. Direct costs:** Refers to out-of-pocket payments both medical costs for TB care and non-medical costs (transportation, accommodation, food, nutritional supplements).
- 2. Indirect costs:** Refers to productivity and economic costs a patient or household incurred as a result of TB health care seeking and hospitalisation, during the TB episode. These were estimated using two alternative methods: a) self-reported household income loss net of welfare payments (net effect of income change pre as compared to during the TB episode) and b) total period of absence (in hours) multiplied by the hourly wage rate of the absent worker.

- 
- a. **Medical costs:** Refers to Out-of-pocket payments for TB care (e.g. consultation fee, drugs, diagnosis, hospitalisation, etc.)
  - b. **Non-medical costs:** Refers to Out of pocket payments made by patient or guardian related to the use of TB health services such as payments for transportation, accommodation, food, etc.

**Income:** This was money received, especially on a regular basis, for work or through investments. This was calculated both at the individual level and household level.

**Catastrophic costs:** Total costs (indirect and direct combined) exceeding 20% of the household's annual income [15]. The total indirect and direct costs of TB are defined as the sum of the following: a) Out-of-pocket payments for TB diagnosis and treatment made by TB patient's households, net of any reimbursements; b) Payments related to the use of TB health services, such as payments for transportation, accommodation or food net of any reimbursements to the individual who made the payments (i.e. guardian or patient); c) Income losses incurred by both the TB patient and any accompanying household member, net of any welfare payment

**Coping measures:** These were measures used by the TB patients to help them defray TB related costs. These included taking a loan or selling assets or using up personal savings and were thought to be significant enough to be remembered by the patient and hence collected for all patients regardless of which phase of the TB episode they were interviewed in. Reported interest rates and foregone income due to selling income-generating assets were summed for the whole illness episode.

## **Data collection process (including piloting) and tools**

This survey was a facility-based survey conducted at 67 health facilities across the country. Piloting of the data collection tool was done in February 2017 and necessary adjustments made to the survey instrument. Data were collected by trained research assistants using tablets and uploaded onto the online ONA database. A centralized 5-day training was conducted before field data collection by the investigation team with input from WHO and NTLF. The training covered key TB concepts and the protocol. Part of the data was collected from the unit TB registers while the rest was collected by interviewing eligible patients.

## **Data management**

All the data uploaded through tablets onto the ONA database was accessed online and in real time. The data manager did all the necessary checks and gave feedback to the research assistants in the field. Queries generated were sent to the research assistants and resolved. Regular uploads for this data were done daily to ensure the safety of the data.

## **Data analysis**

The primary objective of this survey was to estimate medical and non-medical out-of-pocket payments and indirect costs exceeding a given fraction of household's income. This is expressed in the equation:

$$I_{NTP}^{TB} = \frac{1}{n_{NTP}^{TB}} \sum_{i=1}^{n_{NTP}^{TB}} 1 \left( \frac{\sum_{j=1}^{n_i} (OOPM_j^{TB,h} + OOPNM_j^{TB,h} + IN_j^{TB,h})}{y_i^h} > \tau^{TB} \right)$$

*Equation 2: Table of sample size computation*

Where  $i$  denotes the household of patient  $j$ . If more than one household member is registered for treatment, costs for all patients within a household will be collected (if possible logistically) or estimated.  $n_{NTP}^{TB}$ , the total sample size across all NTLP networks engaged in this survey.  $1()$  is the indicator function which equal to 1 if the condition is satisfied and 0 otherwise.

$I_{NTP}^{TB}$  proportion of TB-affected households that are experiencing catastrophic total costs. The nationally-representative sample estimate uses patients as the unit of analysis. However economic consequences in the context of the household of the patient will be analysed. The analysis will bear in mind, the number of patients sampled that belong to the same household. Some form of adjustment will consider clustering at the household level whenever needed.

$OOPM_j^{TB,h}$  out-of-pocket payments for TB diagnosis and treatment made by TB patient's household members net of reimbursements ( $j$ ). These are direct net medical payment for TB treatment.

$OOPNM_j^{TB,h}$  out-of-pocket payments related to the use of TB health services, such as payments for transportation, accommodation or food net of any reimbursements to the individual (patient or guardian) who made the payments  
Multiple patients per household will result in direct and indirect costs added.

$IN_j^{TB,h}$  time loss valuation or reported income loss incurred by both the TB patient and any household guardian net of any welfare payment

$y_i^h$  reported amount of money received by the household in the year before the TB episode started, in exchange for labor or services, from the sale of goods or property, or as a profit from financial investments and welfare payments. Alternatively, household income will be estimated based on asset ownership.

$1()$  is the indicator function which is equal to 1 when the condition is satisfied and zero otherwise

$n_{NTP}^{TB}$ , the total sample size across all NTLP networks engaged in this survey

$\tau^{TB}$  threshold (20% tentatively selected)

In the light of the operational definition and formula,  $I_{NTP}^{TB}$  can be interpreted as the proportion of TB-affected households' patients (treated within the NTLP network) with total costs exceeding a given threshold of household's income.

---

The unit of analysis is the patient, but we considered the economic consequences in the context of the household of the patient in the analysis. The analysis accounted for the number of patients sampled that belonged to the same household and made adjustments. Costs were calculated from the patient perspective and ignored costs to the provider (e.g. staff time) and other societal costs with the exception of caregiver time.

Costs were analyzed using local currency units as the patients were directly reporting them. All local currency amounts were converted into 2015 US\$ as well as PPP\$ using conversion rates and deflators for the year in question provided by the World Bank.

## **Ethics considerations**

### **Patient information**

Each potential survey participant was adequately informed of the survey in a format (verbal, written) and language acceptable to her/him. The purpose and procedures of the survey were explained, possible discomforts and the available social welfare options to the TB or MDR patients were also provided. Patients were informed of the right to abstain from participation in the survey or to withdraw consent to participate at any time without reprisal. Also discussed with the patient was a description of how anonymity and/or confidentiality would be protected and the extent to which results would be made available to the participant and/or the community.

To ascertain whether the individual really understood the implications of consent, the survey allowed individuals to ask questions for clarification. After ensuring that the subject had understood the information, informed consent from the patient was obtained. All consent was obtained in writing.

### **Compensation**

Patients were compensated in cash (transport voucher amounting to 3.0 USD) for the time, travel and inconvenience allocated during the interview.

Ethical approval was obtained from the Mulago Hospital Research and Ethics committee and the Uganda National Council for Science and Technology.



---

## SURVEY RESULTS

### Survey participants' characteristics

#### Socio-demographic, clinical and economic characteristics

The survey included 1,178 patients. The socio-demographic, clinical and economic characteristics of the survey participants are presented in **Tables 3** and **4** below. Out of the 1,178 TB respondents interviewed, 62.7% (739) were male. This is in agreement with literature that shows males are more affected by TB than females. At 30.8% (362) the age group more affected was that of 25-34 years. This was the same trend across all types of TB. Just over half, 52.5% (618) of the respondents were interviewed while they were in the continuation phase of treatment. This was the same across the TB types (i.e. 58.1% and 52.3% for MDR-TB and DS-TB respectively).

In this survey, 43.4% (512) of the respondents were HIV positive, 55.5% (654) were HIV negative, while up to 1% (12) of the respondents didn't have a documented HIV result. In this survey, majority of the respondents 91.3% (1,075) were new TB cases. When broken down by TB type, among MDR-TB, more cases were in the retreatment group than new i.e. 64% (28) Vs 36% (16) respectively. The scenario was different for the DS-TB where majority were the new cases i.e. 93.4% (1060).

In terms of occupation, the commonest occupation among participants were service or sales workers 287 (24.4%), elementary occupations 229 (19.4%), peasant farmers 161 (13.7%) and 17.4% (206) of the patients were not employed at all.

Of the surveyed participants, overall 56.2% (661) were the family's main income earner. The proportion of survey participants that were the family's main income earner among MDR TB and DS TB patients was 64.8% (28) and 55.8% (633) respectively.

Income was measured through three parallel measures: by self-report, income imputed based on assets owned, and income estimated based on consumption data collected. The median annual income was 1,001 USD (500-1668). Based on asset ownership the median income was 1,437 USD (928-2429) while household income pre-TB based on consumption was 1,253 USD (702-2158).

Table 3: Socio-demographic and Clinical characteristics of the respondents

	DR-TB	DS-TB	Overall
	Sample (weighted)	Sample (weighted)	Sample (weighted)
N	44	1134	1178
<b>Socio-demographic characteristics of survey sample</b>			
Sex, N (%)			
Male	30 (67.9%)	709 (62.5%)	739 (62.7%)
Female	14 (32.1%)	425 (37.5%)	439 (37.3%)
Age (%)			
0-14	2 (5.1%)	54 (4.8%)	57 (4.8%)
15-24	5 (11.3%)	159 (14%)	164 (13.9%)
25-34	14 (31.3%)	349 (30.7%)	362 (30.8%)
35-44	11 (24.4%)	294 (25.9%)	304 (25.8%)
45-54	9 (21.5%)	159 (14.1%)	169 (14.3%)
55-64	0 (0%)	74 (6.5%)	74 (6.3%)
65+	3 (6.6%)	45 (4%)	48 (4.1%)
Province			
Kampala	1 (1.5%)	237 (20.9%)	238 (20.2%)
Central1	2 (5.6%)	127 (11.2%)	129 (11%)
Central2	5 (10.5%)	54 (4.8%)	59 (5%)
East Central	0 (0%)	68 (6%)	68 (5.8%)
Mid-Eastern	8 (17.9%)	99 (8.8%)	107 (9.1%)
Mid Northern	2 (3.9%)	144 (12.7%)	146 (12.4%)
Mid-Western	8 (18.8%)	111 (9.8%)	119 (10.1%)
North East	5 (12.4%)	86 (7.6%)	91 (7.8%)
South Western	12 (27.2%)	137 (12.1%)	149 (12.7%)
West Nile	1 (2.2%)	70 (6.1%)	70 (6%)
<b>Clinical Characteristics</b>			
Phase, N (%)			
Intensive	18 (41.9%)	541 (47.7%)	560 (47.5%)
Continuation	25 (58.1%)	593 (52.3%)	618 (52.5%)
Recorded HIV Status, N (%)			
Positive	25 (57.3%)	487 (42.9%)	654 (55.5%)
Negative	19 (42.7%)	636 (56%)	512 (43.4%)
Unknown	0 (0%)	12 (1.1%)	12 (1%)
Retreatment status, N (%)			
New	16 (36%)	1060 (93.4%)	1075 (91.3%)
Retreatment/Relapse	28 (64%)	75 (6.6%)	103 (8.7%)

**Table 4: Descriptive statistics and economic characteristics of survey sample**

	DR-TB		DS-TB	Overall
	Weighted			
N	44		1134	1178
<b>Household income pre-TB</b>				
Reported (annual, USD) Mean (95% CI)	1,268.32 (775.38 - 1,761.24)	-	1,742.79 (1,371.54 - 2,114.03)	1,725.23 (1,360.58 - 2,089.88)
median (IQR)	1,000.5 (366.85 - 1,667.5)	-	1000.5 (500.25 - 1,667.5)	1,000.5 (500.25 - 1,667.5)
Estimated based on assets owned (annual, USD) Mean (95% CI)	1,607.28 (1,213.76 - 2,000.80)	-	1,657.47 (1,318.84 - 1,996.10)	1,655.61 (1,326.20 - 1,985.02)
median (IQR)	1,457.18 (1,013.09 - 1,891.91)	-	1,436.52 (927.87 - 2,440.71)	1,436.52 (927.87 - 2,429.05)
Reported consumption (annual, USD) Mean (95% CI)	1830.40 (1194.82 - 2465.98)	-	2268.24 (1221.150 - 3314.99)	2252.04 (1239.15 - 3264.94)
Median (IQR)	1451.83 (869.32 - 1989.88)	-	1244.51 (692.62 - 2166.63)	1252.57 (702.02 - 2158.30)
<b>Socio-demographic characteristics of survey participants</b>				
Patient's (guardian's) education status %				
Not yet started school	8 (18.8%)		151 (13.3%)	159 (13.5%)
Primary school	23 (53%)		546 (48.2%)	570 (48.3%)
Secondary school	12 (26.5%)		315 (27.8%)	327 (27.7%)
Tech/Tertiary School	0 (0%)		75 (6.6%)	75 (6.4%)
University and higher	1 (1.7%)		46 (4.1%)	47 (4%)
<b>Occupation pre-disease</b>				
Managers	0 (0%)		4 (0.4%)	4 (0.4%)
Professionals	2 (5.3%)		70 (6.2%)	72 (6.1%)
Technicians and associate professionals	0 (0%)		33 (2.9%)	33 (2.8%)
Clerical support workers	1 (2.8%)		7 (0.6%)	8 (0.7%)
Service and sales workers	15 (34.2%)		272 (24%)	287 (24.4%)
Skilled agricultural, forestry and fishery workers	0 (0%)		21 (1.8%)	21 (1.8%)
Craft and related trades workers	2 (4.3%)		56 (4.9%)	58 (4.9%)
Plant and machine operators, and assemblers	0 (0%)		6 (0.6%)	6 (0.5%)
Elementary occupations	4 (10.3%)		225 (19.8%)	229 (19.4%)
Armed forces	2 (3.6%)		14 (1.2%)	15 (1.3%)
Peasant farmer	8 (18.9%)		153 (13.5%)	161 (13.7%)
Other	2 (3.9%)		76 (6.7%)	78 (6.6%)
Not applicable (not employed before TB)	7 (16.9%)		198 (17.5%)	206 (17.4%)
Patient was main income earner prior to disease, %	28 (64.8%)		633 (55.8%)	661 (56.2%)

## Models of care

A total of 44 MDR TB patients were recorded in this survey, and of these 41.9% (18) were hospitalized by the time of the interview, as shown in **Table 5** below. Of the DS-TB respondents, 6.5% (74) were hospitalized. The median number of days of hospitalization for the MDR-TB patients in either phase was longer than that of DS-TB patients. This is the common practice in Uganda where the treatment for MDR is longer with a period of injectable treatment that initially requires hospitalization and culture conversion. The average number of Directly Observed Treatment (DOT) visits by the MDR-TB and the DS-TB patients throughout the whole treatment episode is 1,093 and 51 respectively. Up to 47.2% of the MDR TB patients had their treatment delayed while 46% of the DS TB patients had their treatment delayed (i.e. >4 weeks between symptom onset and treatment initiation). Up to 27% of the DS-TB patients and 5% of the DR-TB patients were diagnosed by the private or NGO facility. Over a quarter (28.8%) and a third of MDR-TB and DS-TB (32.8%) patients first consulted private health facilities for their symptoms. Regarding level of health facility initially consulted, 39% (189) and 84.2% (5) of the DS-TB and MDR-TB respondents respectively initially consulted at primary health level facilities.

*Table 5: Model of care for Survey sample*

<b>3 Model of care for survey sample</b>		
	<b>MDR-TB</b>	<b>DS-TB</b>
	44	1134
	<b>Mean (95% CI)</b>	<b>Mean (95% CI)</b>
<b>Hospitalization</b>		
Hospitalized at time of interview, N (%)	18 (41.9%)	74 (6.53%)
Previously hospitalized during current phase, N (%)	7 (16.7%)	125 (11.0%)
Times hospitalized during current phase, Mean (95% CI)	1.64 (0.83 - 2.45)	1.14 (1.04 - 1.23)
Mean duration (days) hospitalized during current phase (95% CI)	91.4 (0 - 199.2)	12.9 (10.1 - 15.8)
Median duration (days) hospitalized during current phase (IQR)	30 (26 - 102)	7 (5 - 14)
<b>Ambulatory care</b>		
Number of visits per episode: total (95% CI)	1093.4 (917 - 1269.8)	51.2 (42.1 - 60.3)
Number of visits: DOT (95% CI)	614.5 (555.6 - 673.5)	167.6 (157.7 - 177.5)
Number of visits: follow-up (95% CI)	10.9 (0 - 22.5)	3.7 (3.1 - 4.3)
Number of visits: drug pick-up (95% CI)	569.1 (529.9 - 608.3)	9.1 (7.7 - 10.5)
Number of visits pre-diagnosis (95% CI)	1.6 (0.9 - 2.2)	0.9 (0.8 - 1.1)
Proportion of first visits to primary health facilities	5 (84.2%)	189 (39%)
Proportion of first visits from private facilities	2 (28.8%)	159 (32.8%)
Proportion of TB diagnoses made at private or NGO facility	2 (5%)	300 (26.5%)
<b>Treatment duration</b>		
Treatment duration: intensive phase, weeks Mean (95% CI)	7 (6.1 - 7.9)	2 (2 - 2.1)
Treatment duration: continuation phase, weeks Mean (95% CI)	14.8 (12.8 - 16.8)	4.1 (4.1 - 4.1)
<b>Treatment delay (among new patients in intensive phase)</b>		
Weeks of treatment delay Mean (95% CI)	9.5 (3.4 - 15.7)	9.9 (8.1 - 11.8)
Proportion of patients with delay > 28 days (%)	3 (47.2%)	223 (45.9%)

---

### **Hours lost in accessing care and loss of income during TB treatment**

**Table 6** below shows the hours lost by the patients while accessing care during the pre-treatment phase as well as the treatment phase. As noted in the table, more time is lost by the MDR-TB patients than the DS-TB patients, with an average loss of up to 6,097 hours for MDR TB patients and 262 hours for the DS TB patients. For both categories of TB patients, more time was lost during continuation than intensive phase. This could be explained by the fact that this phase is generally longer than the intensive phase. MDR-TB patients lost more time than their DS-TB counterparts (6,097 vs 262 hours). Also noted in table 6 below, is that the individual monthly income had dropped for MDR-TB and DS-TB patients by the time of the interview with current income as proportion of pre-TB income being bigger for DS-TB patients than DR-TB patients i.e. 42% vs 11% respectively.

### **Estimated total costs (USD†) borne by TB patients households**

**Table 7** below shows the estimated costs borne by the TB patients households. Higher costs were experienced in the post diagnosis period on each of the cost drivers than the pre-diagnosis period. In the pre-diagnosis phase, travel and medical constituted the main cost drivers for both MDR-TB and DS-TB. In the post diagnosis period, nutritional supplements and travel were the main cost drivers for MDR-TB patients. Similarly, nutritional supplements and travel were the main cost drivers for DS-TB in the post diagnosis period. Food was the third biggest cost driver for both MDR-TB and DS-TB in the post diagnostic period. More hours were lost by the caregivers and patients in the post diagnostic period with more losses for the MDR-TB patients and caregivers than the DS-TB patients and caregivers. More indirect costs were incurred by the MDR-TB patients (USD 1,219.6) than the DS-TB patients (USD 116.5).

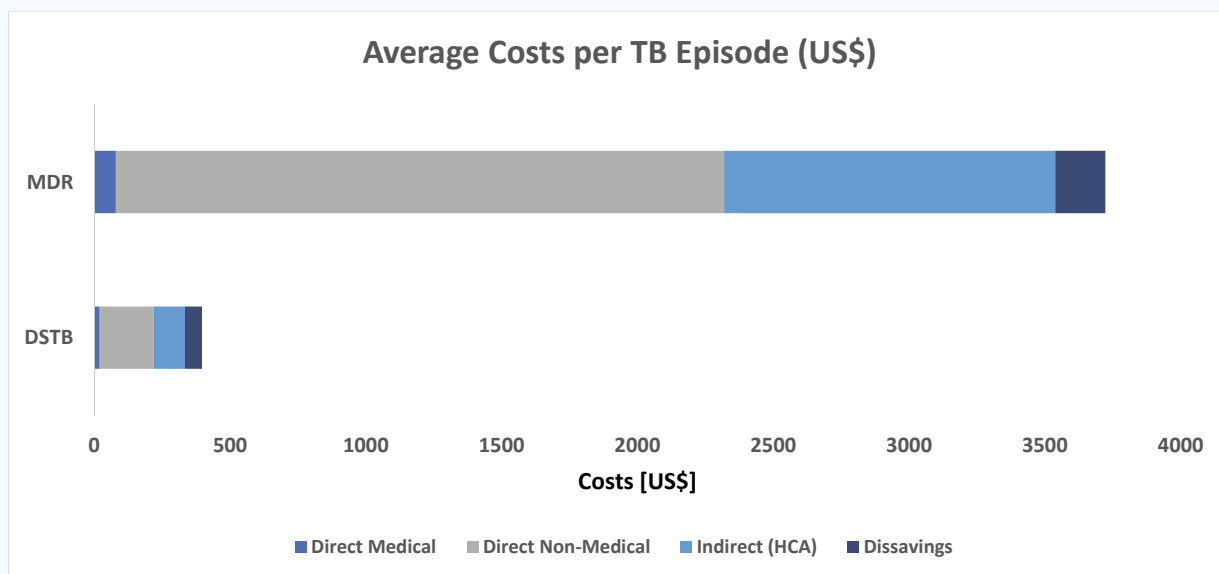
In terms of overall costs, on average an MDR-TB patient spent about USD 3,722 whereas a DS-TB patient spent on average up to USD 369.

*Table 6: Hours lost seeking or accessing care and reported individual income by the patient*

	MDR-TB				DS-TB			
	Mean	(95% C.I.)	Median	(IQR)	Mean	(95% C.I.)	Median	(IQR)
<b>Hours lost by patient and guardian, overall</b>	<b>6096.8</b>	<b>(4777.1 - 7416.5)</b>	<b>5193.4</b>	<b>(3341.7 - 7098.5)</b>	<b>261.7</b>	<b>(235.6 - 287.8)</b>	<b>169.3</b>	<b>(155.7 - 246.6)</b>
Hours lost by patient, pre-diagnosis	6.6	(3.7 - 9.5)	3.5	(2 - 5.5)	4.5	(2.8 - 6.2)	2	(1.5 - 3.5)
Hours lost by patient, intensive phase	894.2	(709.8 - 1078.5)	977.4	(401.5 - 1170.7)	97	(89.4 - 104.6)	140.7	(15.5 - 141.7)
Hours lost by patient, continuation phase	2477.8	(2176.9 - 2778.7)	2904.3	(1539.8 - 2951.2)	99	(89 - 108.9)	135.3	(22.1 - 135.3)
Hours lost by caregiver, intensive phase	692.7	(78.3 - 1307)	1200	(62.57 - 1260.8)	97.6	(68 - 127.3)	30.6	(16 - 114.22)
Hours lost by caregiver, continuation phase	1968	(216.5 - 3719.6)	1800	(0 - 4440.4)	137.8	(99.6 - 175.9)	52.9	(29.33 - 154.5)
Individual income reported by patient								
Pre-diagnosis (USD)	53.10	(37.5 - 68.7)	41.69	(8.3 - 83.4)	79.50	(59.3 - 99.7)	41.7	(13.9 - 83.4)
At diagnosis (USD)	83.90	(48.7 - 119.2)	55.58	(4.17 - 118.1)	112.10	(84.8 - 139.4)	55.6	(23.6 - 111.2)
At time of interview (USD)	5.70	(0 - 12.3)	0.00	(0 - 0)	33.60	(17.8 - 49.5)	0.0	(0 - 27.8)
Current income as proportion of pre-TB income	10.7%				42.3%			

*Table 7: Estimated total costs (USD†) borne by patients' households affected by TB, MDR-TB or all, median breakdown*

	Medical costs drivers				MDR-TB			DS-TB			Overall		
	Mean	(CI)	Median	[IQR]	Mean	(CI)	Median	[IQR]	Mean	(CI)	Median	[IQR]	
Pre-diagnosis	(A) Medical	4.11	(0.27-7.94)	1.95	(0 - 9.45)	8.55	(2.8 - 14.31)	1.39	(0 - 5.56)	8.5	(2.79 - 14.2)	1.39	(0 - 5.56)
	(B) Travel	6.48	(3.84 - 9.13)	5.56	(4.17 - 5.56)	2.1	(1.39 - 2.81)	1.39	(0.56 - 1.97)	2.15	(1.45 - 2.86)	1.39	(0.56 - 2.22)
	(C) Accommodation	0	(0 - 0)	0	(0 - 0)	0.34	(0.1 - 0.58)	0	(0 - 0)	0.34	(0.1 - 0.57)	0	(0 - 0)
	(D) Food	0.69	(0.41 - 0.97)	0	(0 - 0.97)	1.1	(0.33 - 1.87)	0	(0 - 0.28)	1.09	(0.33 - 1.85)	0	(0 - 0.28)
	(E) Nutritional supplements	0.44	(0.15 - 0.73)	0	(0 - 0.28)	1.08	(0.32 - 1.84)	0	(0 - 0)	0.8	(0.2 - 1.41)	0	(0 - 0)
	(F) Hours lost by patient and guardian x Hourly wage	1.52	(0.97 - 2.08)	0.56	(0.53 - 1.95)	1.7	(0.67 - 2.72)	0.55	(0.25 - 1.2)	1.69	(0.67 - 2.71)	0.55	(0.25 - 1.2)
Post-diagnosis	(G) Medical	78.72	(12.49 - 144.96)	8.69	(0 - 17.38)	16.21	(9.18 - 23.23)	0	(0 - 4.84)	18.52	(11.17 - 25.87)	0	(0 - 6.05)
	(H) Travel	1019.4	(895.73 - 1143.02)	833.75	(804.57 - 1143.66)	43.85	(33.99 - 53.71)	12.69	(9.95 - 20.66)	79.94	(51.04 - 108.84)	13.13	(10 - 22.91)
	(I) Accommodation	0.42	(0 - 1.12)	0	(0 - 0)	1.43	(0 - 3.38)	0	(0 - 0)	1.39	(0 - 3.29)	0	(0 - 0)
	(J) Food	497.82	(353.39 - 642.25)	416.87	(291.81 - 494.69)	30.63	(15.79 - 45.48)	5.56	(3.89 - 5.56)	47.92	(25.75 - 70.08)	5.56	(3.89 - 5.56)
	(K) Nutritional supplements	1262.6	(928.09 - 1597.02)	869.48	(724.57 - 1738.96)	189	(151.25 - 226.84)	130.42	(57.97 - 239.11)	224.8	(172.66 - 276.93)	137.67	(60.86 - 253.6)
	(L) Caregiver (guardian) costs Hours lost by patient and guardian x Hourly wage	115.09	(0 - 248.26)	45.63	(4.53 - 130.27)	25.2	(14.66 - 35.74)	3.08	(0.43 - 11.83)	27.91	(17.33 - 38.5)	3.24	(0.46 - 12.71)
Medical costs	79.31	(12.74 - 145.88)	10.64	(0 - 18.14)	19.97	(11.72 - 28.23)	0	(0 - 11.12)	22.17	(13.95 - 30.39)	0	(0 - 12.36)	
Non-medical costs	2239.5	(1741.72 - 2737.31)	1814.8	(1257.43 - 2820.85)	197.9	(161.92 - 233.85)	94.43	(22.05 - 227.97)	273.1	(199.53 - 346.62)	101.18	(22.94 - 255.06)	
Indirect costs	1219.9	(538.26 - 1901.43)	723.41	(464.31 - 1250.09)	116.5	(96.63 - 136.38)	67.92	(44.67 - 106.49)	157.3	(117.3 - 197.35)	69.63	(45.53 - 113.56)	
Dissaving/ Coping Costs	183.69	(19.03 - 348.35)	44.47	(16.67 - 166.75)	62.14	(48.82 - 75.47)	0	(0 - 41.69)	66.64	(50.31 - 82.97)	0	(0 - 44.47)	
Total	3722.3	(3070.56 - 4374.03)	3213.7	(2436.69 - 4261.46)	396.1	(336.62 - 455.67)	230.42	(116.25 - 443.45)	519.2	(406.67 - 631.75)	243	(118.43 - 483.48)	



**Figure 2: Average costs per TB episode**

### Dissaving mechanisms and social consequences

The dissaving mechanisms and social consequences among the survey respondents are presented in **Table 8** below. Overall, nearly a half of the patients in the survey; 571 (48.5%) reported having used at least one coping mechanism to defray TB costs. This was higher among MDR-TB respondents 81.2% (35) than DS-TB respondents 47.2% (536). Overall, 26.5% (312) reported to have sold assets, 26.3% (309) reported to have taken loans and 11.2% (131) used their own savings. As expected, respondents in the lowest income quintiles (poorest and less poor) took loans commonly and sold assets than using their own savings since they may not have any savings.

In regard to social consequences, 49.7% (585) of the survey participants reported having experienced some form of food insecurity, 8% (94) reported having experienced divorce or separated from a spouse/partner. Four hundred and seventy-seven (40.5%) reported that they had lost a job due to TB and 11.8% (140) reported that their children had school interrupted. Stigma or social exclusion was commonly reported with 53.7% (633) of the respondents reporting that they had experienced some form of social exclusion due to TB. Food insecurity, divorce and loss of job were more common among MDR-TB patients than DS-TB patients.

Only 3.9% (MDR-TB: 56.4%, DS-TB: 1.8%) of the respondents reported having received some form of social protection after being diagnosed with tuberculosis.

In terms of self-reported impact due to TB, MDR-TB patients experienced the very serious impact compared to DS-TB (48.7% Vs. 29.3%). Bigger impact (serious and very serious impact) was mainly experienced by respondents in the poorest and less poor income quintiles.



Table 8: Reported dissaving mechanisms and social consequences

	Income Quintiles					Treatment Group		
	Poorest (N=226)	Less Poor (N=235)	Average (N=221)	Less Wealthy (N=278)	Wealthiest (N=218)	Overall (N=1178)	DS (N=1134)	MDR (N=44)
<b>Dissaving Strategies</b>								
Loan	70 (30.8%)	63 (26.9%)	67 (30.3%)	74 (26.8%)	35 (16.1%)	309 (26.3%)	294 (25.9%)	15 (35.5%)
Use of savings	15 (6.7%)	22 (9.3%)	20 (9%)	45 (16.2%)	29 (13.5%)	131 (11.2%)	114 (10%)	17 (39.9%)
Sale of assets	83 (36.5%)	61 (25.8%)	61 (27.4%)	69 (24.7%)	40 (18.3%)	312 (26.5%)	288 (25.4%)	24 (54.4%)
<b>Any of the three above</b>	<b>121 (53.3%)</b>	<b>110 (46.7%)</b>	<b>111 (50.2%)</b>	<b>143 (51.6%)</b>	<b>86 (39.6%)</b>	<b>571 (48.5%)</b>	<b>536 (47.2%)</b>	<b>35 (81.2%)</b>
Food insecurity	144 (63.6%)	131 (55.7%)	114 (51.5%)	125 (45.1%)	71 (32.6%)	585 (49.7%)	559 (49.3%)	26 (59.7%)
Divorce or separated from spouse/partner	21 (9.2%)	22 (9.3%)	17 (7.7%)	19 (6.8%)	15 (7.1%)	94 (8%)	89 (7.8%)	5 (10.6%)
Loss of Job	104 (46%)	104 (44.3%)	91 (41.1%)	101 (36.5%)	77 (35.3%)	477 (40.5%)	453 (39.9%)	24 (56%)
Child interrupted schooling	29 (12.6%)	26 (11.2%)	23 (10.3%)	37 (13.3%)	25 (11.5%)	140 (11.8%)	135 (11.9%)	5 (11.5%)
Social exclusion	121 (53.4%)	141 (59.8%)	127 (57.6%)	140 (50.3%)	104 (47.9%)	633 (53.7%)	613 (54%)	20 (46.1%)
Any days of work lost	35 (15.4%)	17 (7.2%)	14 (6.2%)	13 (4.5%)	7 (3.1%)	85 (7.2%)	83 (4.4%)	2 (2.6%)
<b>Self-reported impact: how big of a financial impact did TB have on your household?</b>								
No impact	5 (2.1%)	3 (1.2%)	3 (1.2%)	2 (0.8%)	7 (3.4%)	20 (1.7%)	16 (1.4%)	4 (9.5%)
Little impact	13 (5.6%)	14 (5.9%)	24 (10.9%)	19 (6.8%)	45 (20.4%)	114 (9.7%)	113 (9.9%)	1 (3.3%)
Moderate impact	27 (12.1%)	41 (17.2%)	50 (22.5%)	78 (28%)	53 (24.3%)	249 (21.1%)	244 (21.5%)	4 (10.1%)
Serious impact	92 (40.5%)	107 (45.7%)	74 (33.4%)	114 (41%)	55 (25.4%)	442 (37.5%)	430 (37.9%)	12 (28.3%)
Very serious impact	90 (39.7%)	71 (30%)	71 (32%)	65 (23.3%)	58 (26.4%)	353 (30%)	332 (29.3%)	21 (48.7%)
<b>Household received social protection after TB diagnosis</b>								
	11 (4.8%)	3 (1.2%)	6 (2.9%)	13 (4.6%)	12 (5.6%)	46 (3.9%)	21 (1.8%)	25 (56.4%)

---

## Households facing catastrophic costs

### Rates of Catastrophic costs

**Table 9** below presents the proportion of households experiencing catastrophic costs for different households using the human capital approach. In this survey, 20% was taken as the threshold for catastrophic costs. At a 20% threshold, **53.1%** (614) of the survey participants experience catastrophic costs. The proportion experiencing catastrophic costs increased with lower thresholds at 15% and 10% i.e. 62.4% and 75.2% respectively. The proportion of respondents experiencing catastrophic costs decreased with increased thresholds; 25% and 30% i.e. 45.2% and 38.9% respectively.

Regarding direct costs (direct medical and direct non-medical), 33.1% (383) of the respondents spent up to 20% of their annual household income and the same trend as for catastrophic costs was followed with changing thresholds.

In terms of direct medical costs, 3 % (35) households used up to 20% of their annual income for these costs. Again, a similar trend of proportions was followed with adjusted thresholds as for catastrophic costs (i.e. proportions increasing/decreasing) with decreasing/increasing thresholds.

**Figure 3** below shows the proportion experiencing catastrophic costs at 20% threshold based on the income quintiles of the respondents. As can be seen, respondents in the lowest quintile (poorest) experience more catastrophic costs than anyone else. **Figure 4** below further demonstrates the effect of changing the threshold levels. As can be see, with decreasing threshold levels, the percentage experiencing catastrophic costs rises while at increasing thresholds, the percentage experiencing catastrophic costs decreases.

**Table 10** below shows the distribution of the respondents facing catastrophic costs by different variables. As can be seen, majority of the respondents experiencing catastrophic costs were at the extremes of age (i.e. below 15 years and more than 65 years). Up to 61.8% of the households that had a patient who delayed by more than 4 weeks from symptom onset to treatment initiation had catastrophic costs. Households of all the MDR-TB patients had catastrophic costs. Households of patients in the lowest income quintiles (88.7%) experienced catastrophic costs while 63.4% of households of patients that sought care from a government hospital for their diagnosis experienced catastrophic costs.

Table 9: Households classified as facing catastrophic costs under various thresholds

		Expenditure quintiles *					Overall
		Poorest (N=219)	Less Poor (N= 229)	Average (N= 218)	Less Wealthy (N= 274)	Wealthiest (N= 215)	(N= 1155)
<b>Number of households experiencing total (direct and indirect) costs above (%) - Human capital Approach</b>							
10%		178 (81.4%)	162 (70.8%)	168 (77.2%)	214 (78.2%)	145 (67.5%)	868 (75.2%)
15%		157 (71.7%)	133 (58.4%)	141 (64.8%)	171 (62.4%)	118 (54.9%)	721 (62.4%)
20%		143 (65.4%)	106 (46.6%)	112 (51.3%)	152 (55.5%)	100 (46.4%)	613 (53.1%)
25%		119 (54.2%)	90 (39.4%)	98 (44.8%)	130 (47.4%)	86 (39.8%)	522 (45.2%)
30%		103 (47%)	76 (33.2%)	84 (38.7%)	117 (42.8%)	68 (31.7%)	449 (38.9%)
<b>Number of households experiencing direct medical and non-medical costs above (%) annual household income</b>							
10%		123 (56.1%)	106 (46.2%)	115 (52.9%)	140 (51.2%)	83 (38.6%)	567 (49.1%)
15%		107 (48.9%)	86 (37.5%)	95 (43.4%)	117 (42.6%)	61 (28.5%)	465 (40.3%)
20%		89 (40.7%)	69 (30.4%)	81 (37.2%)	95 (34.8%)	48 (22.2%)	383 (33.1%)
25%		82 (37.3%)	53 (23%)	72 (32.8%)	79 (28.9%)	40 (18.6%)	325 (28.1%)
30%		74 (33.9%)	46 (20.2%)	64 (29.4%)	67 (24.4%)	29 (13.3%)	280 (24.2%)
<b>Number of households experiencing direct medical costs above (%) annual household income</b>							
10%		18 (8%)	22 (9.6%)	14 (6.4%)	11 (4%)	7 (3.1%)	71 (6.1%)
15%		11 (5%)	12 (5.4%)	10 (4.3%)	9 (3.3%)	3 (1.4%)	45 (3.9%)
20%		9 (3.8%)	12 (5.4%)	6 (2.5%)	7 (2.6%)	1 (0.5%)	35 (3%)
25%		8 (3.4%)	11 (4.8%)	5 (2.3%)	6 (2.2%)	1 (0.5%)	30 (2.7%)
30%		8 (3.4%)	11 (4.8%)	5 (2.3%)	5 (1.7%)	1 (0.5%)	29 (2.5%)

\* 12 people excluded due to zero consumption data

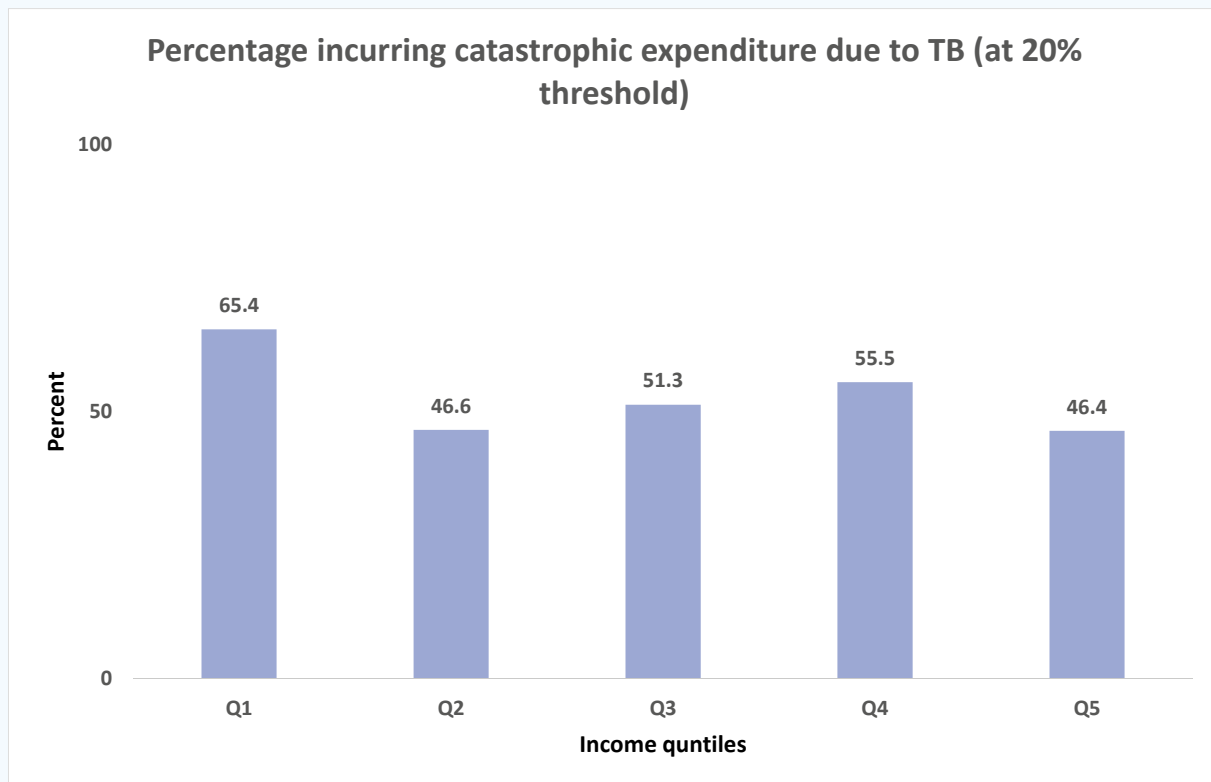


Figure 3: Proportion experiencing Catastrophic costs at 20% threshold based on Income Quintiles

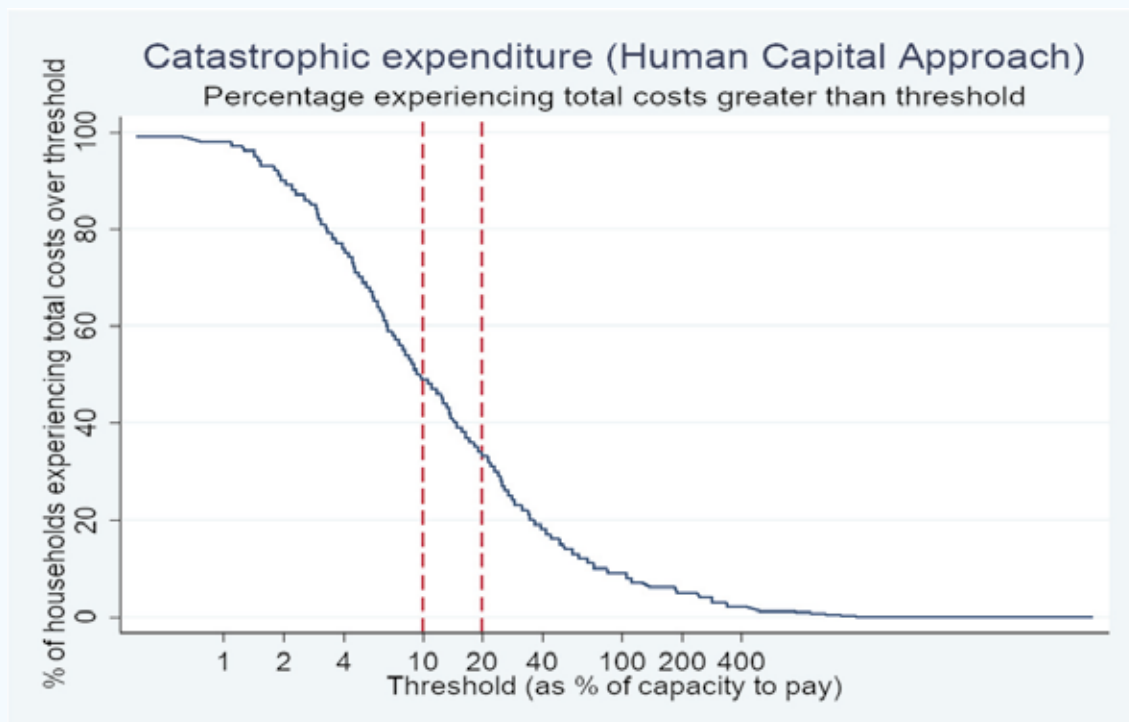


Figure 4: Impact of changing threshold to define catastrophic costs with catastrophic cost proportion amongst households affected by TB or MDR-TB

*Table 10: Proportion of respondents experiencing catastrophic costs by variables*

Variable		%age with catastrophic costs
Age	0-14	37 (64.9%)
	15-24	86 (54.1%)
	25-34	190 (55.3%)
	35-44	171 (53.3%)
	45-54	88 (53.3%)
	55-64	44 (62.0%)
	65+	35 (68.6%)
Sex	Male	419 (56.6%)
	Female	232 (56.0%)
HIV	Positive	269 (56.4%)
	Negative	371 (55.9%)
Income Quintile	Poorest	205 (88.7%)
	Less Poor	155 (67.1%)
	Average	132 (56.9%)
	Less Wealthy	101 (43.9%)
	Wealthiest (Reference)	58 (25.1%)
Facility category	1. Government Hospital	358 (63.4%)
	2. Government HCIII	30 (41.7%)
	3. Government HCIV	126 (49.4%)
	4. NGO/charitable health center or hospital	102 (53.7%)
	5. Private clinic or hospital	34 (47.9%)
DS-TB		615 (55.0%)
MDR-TB		36 (100%)
Long delay (> 4 weeks before diagnosis)		134 (61.8%)

### **Risk factors for experiencing catastrophic costs**

The risk factors for experiencing catastrophic costs are presented in **Table 11** below. Bivariate and multivariate analysis was done to ascertain factors associated with experiencing catastrophic costs. At both bivariate and multivariate analysis, being in the poorest expenditure quintile had higher odds of experiencing catastrophic costs i.e. Bivariate Analysis: OR (IQR): 23.5 (12.9-42.7) and Multivariate Analysis: 24 (13.2-43.8). At multivariate analysis level, the other factor associated with higher odds of experiencing catastrophic costs was long treatment delay (delay of more than 4 weeks before a diagnosis was made).

*Table 11: Odds of experiencing catastrophic costs*

*Table 11: Odds of experiencing catastrophic costs*

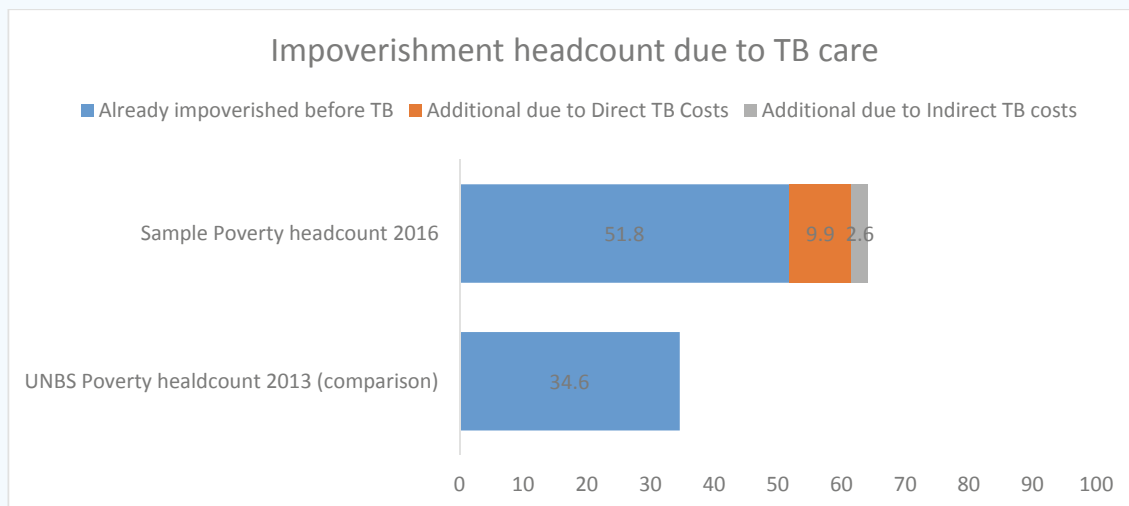
<b>5.8 Odds ratios of experiencing catastrophic costs</b>			
a. * < 0.05, ** <0.01, *** <0.001			
	Univariate Catastrophic incurred (N=1155)	cost	Multivariate Catastrophic incurred (N=1155)
			cost
<b>Age</b>			
0-14	Reference		Reference
15-24	0.6 (0.3 - 1.3)		0.4 (0.2 - 0.9)
25-34	0.7 (0.3 - 1.4)		0.5 (0.2 - 1)
35-44	0.7 (0.3 - 1.4)		0.5 (0.2 - 1)
45-54	0.6 (0.3 - 1.3)		0.4 (0.2 - 1)
55-64	0.9 (0.4 - 1.9)		0.5 (0.2 - 1.1)
65+	1.2 (0.5 - 2.8)		0.7 (0.3 - 1.8)
<b>Sex</b>			
Male	1 (0.8 - 1.4)		1 (0.7 - 1.3)
Female	Reference		Reference
Long delay (> 4 weeks before diagnosis)	1.3 (0.9 - 2)		<b>1.1 (0.7 - 1.8)</b>
<b>HIV</b>			
+	1 (0.7 - 1.4)		1 (0.7 - 1.3)
-	Reference		Reference
<b>Expenditure Quintile</b>			
Poorest	<b>23.5 (12.9 - 42.7)</b>		<b>24 (13.2 - 43.8)</b>
Less Poor	6.1 (3.9 - 9.6)		6.2 (4 - 9.8)
Average	3.9 (2.7 - 5.8)		4 (2.7 - 5.9)
Less Wealthy	2.3 (1.6 - 3.5)		2.3 (1.5 - 3.4)
Wealthiest (Reference)	Reference		Reference

**Table 12** below shows the estimated costs (medical, non-medical and indirect) incurred by the patients' households affected by TB stratified by HIV status, age groups, gender, region and income quintiles. Across all categories of costs, HIV positive respondents incurred more costs than their HIV negative counterparts., while respondents at the extremes of age (i.e. below 15 years and above 65 years) incurred higher costs across all cost areas (direct medical, direct non-medical, and indirect). Females experienced more costs than males for the direct medical, direct non-medical and indirect costs. More costs were incurred by respondents in Kampala than in any other region. This could mainly be due to the high costs of living in Kampala by virtue of its status as a capital. The wealthiest households/individuals experience higher non-medical costs and indirect costs than those in other quintiles.

*Table 12: Monthly costs in USD by HIV status, sex, age, region and income*

	Medical costs Median (IQR)	Non-medical costs Median (IQR)	Indirect costs Median (IQR)
<i>HIV status</i>			
HIV-	11.12 (2.78 - 29.31)	95.67 (22.84 - 270.52)	66.91 (44.42 - 108.29)
HIV+	13.9 (4.84 - 31.91)	113.6 (25.01 - 227.75)	74.78 (45.54 - 118.73)
<i>Age group (years)</i>			
0-14	13.99 (5.75 - 95.22)	260.52 (97.56 - 688.29)	94.63 (52.16 - 135.13)
15-24	9.66 (3.89 - 26.64)	84.11 (19.45 - 219.55)	66.63 (49.02 - 97.38)
25-34	11.12 (2.78 - 30.66)	118.11 (27.45 - 250.27)	66.91 (36.95 - 106.17)
35-44	12.44 (1.7 - 32.69)	98.06 (21.94 - 237.28)	73.11 (45.08 - 116.28)
45-54	16.66 (7.27 - 26.68)	115.53 (31.27 - 255.23)	65.29 (43.14 - 115.92)
55-64	9.73 (2.4 - 28.98)	42 (18.06 - 165.24)	68.91 (40.56 - 117.73)
65+	12.51 (8.44 - 32.93)	128.58 (25.01 - 456.47)	87.7 (54.74 - 118.34)
<i>Sex</i>			
Female	13.76 (4.38 - 34.8)	119.25 (24.97 - 294.69)	66.27 (41.21 - 104.03)
Male	11.55 (2.78 - 29.78)	97.53 (23.42 - 239.24)	70.79 (46.06 - 116.81)
<i>Region</i>			
Kampala	14.91 (2.78 - 53.22)	96.55 (18.06 - 241.66)	70.17 (46.01 - 112.63)
Central	7.52 (1.59 - 21.39)	92.51 (20.13 - 227.41)	76.52 (49.61 - 121.8)
Eastern	11.08 (3.81 - 25.61)	132.55 (61.28 - 278.66)	89.55 (56.66 - 158.34)
Northern	10.6 (1.39 - 36.75)	83.84 (18.52 - 276.51)	54.63 (32.45 - 82.76)
Western	17.38 (8.73 - 36.24)	141.61 (27.64 - 295.33)	79.48 (49.81 - 124.9)
<i>Income Quintile</i>			
Poorest	8.34 (3.45 - 20.46)	57.47 (19.45 - 185.31)	49.95 (22.55 - 71.62)
Less Poor	12.43 (4.92 - 35.22)	78.21 (21.7 - 203.54)	53.46 (28.8 - 73.33)
Average	11.12 (1.74 - 29.44)	128.56 (28.58 - 278.66)	66.29 (42.36 - 97.66)
Less wealthy	17.49 (5.56 - 42.49)	148.81 (32.01 - 305)	87.32 (62.67 - 120.41)
Wealthiest	10.5 (2.78 - 23.62)	122.79 (24.2 - 347.51)	148.88 (89.12 - 252.51)

**Figure 5** below shows the impoverishment due to TB care. Even before TB, 51.8% of the respondents were already below the poverty level. Direct costs pushed an additional 9.9% of the TB patients below the poverty level while the indirect costs pushed an additional 2.6% below the poverty level.



*Figure 5: Impoverishment headcount due to TB care*



---

## Discussion

This survey was the first national population-based TB catastrophic costs survey in Uganda. It provides unique findings on the costs that TB patients incur before and during the course of TB treatment. At a threshold of 20%, the proportion of households experiencing catastrophic costs was 53.1% using the human capital approach. The human capital approach computes costs lost by multiplying the reported time lost while seeking and receiving care during the TB episode (in hours) by the individual's hourly income. The proportion obtained in this survey is much higher than the 28.8% reported by Shete et al among patients in rural Uganda [18] but is lower than what was obtained in a similar survey in Vietnam where the proportion was found to be 63% [4], and another survey done in Myanmar where the proportion was found to be 65% [19]. The difference could be due to differences in sample size where the Vietnam survey had a small sample size of 677 patients. Other reasons could be the difference in the economic settings in both countries.

A lot of expenses for the patients were experienced in the continuation phase of TB treatment. This is expected given the length of the continuation phase which is longer than the intensive phase for both the MDR-TB and DS-TB. In Uganda, the continuation phase for DS-TB is up to 4 months whereas that for DR-TB can go up to 18 months. DS-TB patients spent up to USD 369.0 while MDR TB patients spent up to USD 3,722 before and during treatment. These figures, for both categories of patient are very high in a setting like Uganda where the minimum monthly wage is 36 dollars [20] and up to 19.7% of the population below the poverty level [21]. This survey established that even before TB care, up to 52% of the TB patients were already below the poverty level. A further 12.5% were pushed below the poverty level due to TB care. These costs thus incur a big burden on the financial resources for most of the TB affected patients and their households, and also are incurred by patients/households that are already compromised financially.

The main drivers of catastrophic costs after TB diagnosis were travel, nutritional supplements and food for both types of TB. Nutritional supplements were also found to be major drivers of catastrophic costs in similar surveys in Vietnam, Philippines and Myanmar [4, 19]. In the Philippines, it was discovered that paying attention to the nutrition costs could cut the catastrophic costs by 5%. In Uganda, MDR-TB patients are supposed to receive enablers in form of food and transport vouchers [24]. This survey, however, shows despite this, patients still incur high costs on nutrition and food. There is need to increase this support in the MDR-TB patients while also introducing similar support in the DS TB patients.

This survey found out that TB patients adopted various coping mechanisms to manage the economic burden they experienced, try to. Close to half (48.5%) of the patients had adopted at least one coping mechanism. Almost a similar proportion had either sold assets (26.5%) or taken up a loan (26.3%). For example, a Nigerian study found borrowing money was the commonest coping mechanism [25]. Similar studies have also found taking loans/borrowing as a widely used coping strategy for TB patients [26]. Respondents in the lowest income quintiles (poorest, less poor and average) more commonly take loans and sell assets as opposed to using up their own savings. This is hardly surprising as this group of patients do not normally have a stable income source compared to individuals in the high-income quintiles and thus hardly have any savings.

HIV positive respondents, respondents at the extremes of age, and female respondents spent more on direct medical, direct non-medical and indirect costs. HIV positive patients spent

more than their HIV negative counterparts. This could be mainly due to the duo expenses for both HIV and TB care. In instances where the facilities do not have the one stop model for HIV/TB care, this is likely to worsen the situation as patients have to make several trips to the facility to attend the HIV clinic and TB clinic. This would thus call for increased HIV/TB collaboration. HIV clinics could also empower the clients to start income generating activities like making mats, bags among others that could offer them a source of income. Previous studies done have also found higher costs in HIV/TB co-infected patients [11].

The proportion of HIV-positive respondents in this survey (43.4%) as evidenced by a documented result is similar that observed in routine surveillance data (43%) [2] but higher than findings from the national TB prevalence survey of 26.9% [27]. The difference could in part be due to the nature of the two studies where the TB prevalence survey was done in the community while this study and routine surveillance data was done at health facilities, thus the populations are completely different. The patients that seek care at health facilities are very different in characteristics from the patients in the community.

### **Limitations**

The survey had some limitations; it did not include a representative number of MDR-TB patients. Subsequent surveys should purposively involve more MDR-TB patients in the sample.

### **Conclusion**

In conclusion, this survey has established that almost a half of the TB affected households face catastrophic TB care expenditure. The main areas of expenditure are nutritional supplements, travel, and food. This expenditure results in adverse coping behaviors such as selling assets, taking loans and using savings at high rates among the patients. Patients at the extremes of age (less than 15 years and over 44 years), HIV negative patients, and female TB patients are at the greatest risk of catastrophic costs.

## **Policy implications and recommendations from the findings of the study**

### **Policy implications**

This survey unraveled many findings that have potential policy implications. These among others include:

#### **1. Operationalization of the national health/social insurance [NHI]**

As ascertained by the survey TB patients experience catastrophic costs before and during treatment. We envisage that once this scheme is operationalized, the patients will be financially cushioned by this scheme. There is thus a need to expedite the operationalization of this scheme.

#### **2. Strengthening and enforcement of legislation related to social protection**

As was ascertained in this survey, a substantial number of patients lost jobs as a result of TB disease. These need a form of protection which can only be possible once legislative policies to protect these patients are put in place and actively implemented.

#### **3. Intersectoral collaborations**

TB effects are cross cutting and span all sectors beyond the health sector. There is thus a need to actively engage all relevant sectors in a bid to protect the TB patients. Nutritional supplements and food were the biggest cost drivers and a substantial number of patients also experienced a form of food insecurity. Furthermore, children had their school programs due to TB. This in addition to patients that lose jobs due to TB. Several sectors thus need to be involved and these could include agriculture, education, gender and labour sectors.

---

## Recommendations

We put forward several recommendations and we are hopeful these have the potential to reduce the proportion of TB affected households experiencing catastrophic costs in the country. These include:

***Social protection:*** Tuberculosis affects the poorest and most vulnerable individuals. Considering that a lot of TB patients and their households are experiencing catastrophic costs, there is a need for social protection cover for these patients if their treatment outcomes are to be improved. Catastrophic costs have been previously found to negatively affect TB treatment outcomes. There is thus need to develop guidelines for social protection among TB patients and subsequent roll out of social protection policies and programmes to tuberculosis patients across the country. These are designed to reduce poverty and vulnerability in patients and could be in the form of cash transfers, microfinance schemes, as well psychosocial support. Evidence has shown such programmes to have a wide array of benefits including food security and better health outcomes.

***Roll out enablers and incentives to Drug sensitive patients.*** We are cognizant of the fact that food rations and financial hand-outs are currently being availed to the MDR-TB patients. We believe this is a step in the right direction. However, the DS-TB patients need such protection as well. The biggest drivers of costs among DS-TB patients as found in this survey are transport, food and nutritional supplements. Interventions that avail these patients with food and nutritional support as well as transport refund would go a long way in reducing the catastrophic costs these patients incur. Both categories of patients (MDR-TB and DS-TB) spend heavily on transport/travel. This occurs during the pre-diagnostic pathway as they seek a diagnosis, as well as during TB treatment.

***Development of community mobilization and engagement strategy for TB.*** Part of the strategy could be increasing awareness about TB in the community. This would help empower individuals in the community to recognize symptoms and seek care while still early. The strategy could also include bringing diagnostic services closer to the community, which could significantly reduce the costs patients incur on travel. This could be in form of outreaches that bring screening, diagnosis and treatment services closer to the people at community level. Specimen referral systems could also be incorporated in the community to ensure early diagnosis of the TB patients in the community. Community-based DOTS could also help reduce the travel costs as the patients would not need to travel long distances to access treatment. Furthermore, the strategy could advocate for the strengthening of the village health teams (VHTs). Much as this is existent, it needs to be strengthened. This could be one way of ensuring health services are brought closer to the people. The village health team members could be empowered to screen and refer patients in communities so that early and appropriate care is obtained for the presumptive TB cases. This would ultimately reduce the time and financial resources individuals take visiting several health facilities for care.

***Strengthen the sputum referral system.*** The country has experienced a national roll out of the Xpert MTB/RIF assay. However, given this technology is still expensive, it is impossible that all health facilities could get this technology. Sputum referral mechanisms are one way the facilities without this technology could benefit. The existing specimen transport systems could thus be expanded and improved, to ensure accessibility to better technologies that could ultimately lead to reduced out of pocket payments for patients.

***Adopt shorter treatment regimens.*** Shortening of the treatment duration especially for MDR-TB patients is another way of ensuring reduction of catastrophic costs among this group of patients. There is thus a need to roll out the shorter treatment regimens for MDR-TB treatment.

***Insurance schemes.*** Several insurance schemes could be introduced to offer TB patients a form of social protection. These would include community health insurance schemes and the national health insurance. There is thus a need to promote formation of community health insurance schemes subsequent linkage of TB affected households to these schemes. There is also a need to fast track the operationalization of the national insurance schemes.

***Advocate and link TB affected households to income generating projects.*** The TB affected households could be linked to several income generating projects that would help them generate additional funds to meet TB related costs.

***Advocate for prioritization of TB affected households in national financial empowerment schemes.*** The government has in the recent past launched several financial empowerment schemes including “Youth fund”, “Prosperity for All”. TB affected households and individuals could be helped to partake of these funds so they can be able to start up something to bring in capital that could help offset some of the TB related costs.

***Engagement of employer and employee associations.*** As was noted in the survey, a substantial number of patients lost jobs. To overcome this, the employers and employee associations could be engaged with a view to protecting employees when they get TB. Some of their actions could be related to misconceptions about TB. This could be overcome by engaging them and offering them all facts about TB. Engagement of these could be easy as many employees belong to different associations e.g. national trade unions.

***Development of a referral mechanism between health facilities and social protection services.*** As was found out in the survey, TB patients experience social exclusion due to TB. There is a need to identify the social protection services across the country and subsequently empower health facilities to refer the patients experiencing a form of social exclusion to these services for help. Furthermore, the community awareness about the social protection services at their disposal could be raised. This will empower the TB patients to seek their services should they experience any form of exclusion.

***Strengthening TB case finding interventions at health facility level.*** To ensure early diagnosis and prompt treatment initiation that would shorten the treatment delays, TB case finding at health facilities could be strengthened. This can be done through increasing health worker knowledge about TB, screening for TB at all entry points, prompt diagnosis and treatment initiation.

***Strengthen Public private partnerships (PPP).*** A substantial number of TB patients first consult private health facilities for their symptoms. A vibrant PPP would be able to strengthen the private health facilities to diagnose and treat TB and thus ensuring early TB diagnosis. Such a partnership could also include government supporting these facilities through diagnostics and supplies which could ensure the patient don't have to pay for these. This would ultimately reduce the direct medical costs the patients incur.

***Strengthen TB preventive therapy for populations at increased risk of developing TB disease.*** Intermittent preventive therapy is proven way to prevent TB disease in at risk populations. This has the potential to reduce TB in the population and thus reduce any TB related costs incurred by individuals and households.

---

***Contact tracing and community education.*** There is a need to strengthen contact tracing activities in the community to ensure contacts are identified and investigated for TB. This would lead to early TB diagnosis and ultimately shorten the delays. Delay in this survey was associated with higher chance of experiencing catastrophic costs. The community education would include increasing awareness about TB symptoms, breaking the community myths about TB among others.

***Routine catastrophic cost measurement.*** The national TB program and country at large needs to incorporate catastrophic cost measurement in routine reporting. This could be through developing and implementation of a monitoring and evaluation frame work to report on the indicator. Routine data could then be generated from the health facilities and analyzed centrally to track progress. There are already some in country online DR TB Management information systems (MIS) which could be customized to collect such data regularly.

## Annexes

### Annex 1: Survey team

Investigation team	Steering Committee	Data Manager	Research Assistants
Dr. Frank Mugabe	Dr. Frank Mugabe	Mr. Rogers Sekibira	Ms. Nabule Esther Norah
Dr. Bruce J Kirenga	Dr. Bruce Kirenga	<b>Data Analysis team</b>	Mr. Sewankambwe Nicholas
Dr. Abel Nkolo	Dr. Achilles Katamba	Dr. Simon Kasasa	Mr. Buhangazi Lincoline
Dr. Achilles Katamba	Dr. Claudio Marra	Mr. Levi Mugenyi	Mr. Mubiru Dickson
Dr. Simon Kasasa	Dr. Nalunjoji Joan	Dr. Charles Batte	Mr. Bakabulindi Simon
Dr. Claudio Mara	Ms. Tumwebaze Rachel	Dr. Esther Buregyeya	Ms. Namuleme Rashidah
<b>Technical Support</b>	Mr. Sekibira Rogers	Mr. Rogers Sekibira	Mr. Sagala Steven
Ines Garcia Baena	Mr. Ndawula Gideon	Dr. Nalunjoji Joan	Ms. Acabo Judith
<b>Study Coordinator</b>	Dr. Simon Kasasa	Ms. Fatuma Nalubega	Mr. Buni Boniface
Dr. Winters Muttamba	Dr. Estella Birabwa		Mr. Kyaligonza Steven
	Dr. Peter Lochoro		Ms. Yasarira Anna
			Ms. Namubiru Joyce
			Mr. Akampurira Boaz
			Ms. Bitakwitse Lestine
			Mr. Busumba Charles

## Annex 2: Survey Pictures



*Dr. Abel Nkolo and Ines Garcia Baena on a monitoring trip to one of the survey sites*



*A Survey research assistant interviewing a TB patient at one of the survey facilities*



*Data analysis workshop of the collected survey data*



*Research assistants undergoing a survey training*



### Annex 3: Selected Survey DTUs and the corresponding districts/regions

DTU	District	Region
Mpigi HCIV	Mpigi	Central 1
Gombe Hospital	Butambala	Central 1
Gomba Kanoni HC III	Gomba	Central 1
Villa Maria Hospital	Kalungu	Central 1
Masaka RRH	Masaka	South Western
TASO Masaka Clinic	Masaka	South western
Kalisizo Hospital	Rakai	South Western
Mbarara RRH	Mbarara	South Western
Ibanda Hospital	Ibanda	South Western
Rwekubo HC IV	Isingiro	South Western
Itojo HOSPITAL	Ntungamo	South Western
Kisiizi NGO Hospital	Rukungiri	South Western
Kisoro Hospital	Kisoro	South Western
Mityana Hospital	Mityana	Central 2
Mubende RR Hospital	Mubende	Central 2
Kyenjojo Hospital	Kyenjojo	Mid-western
Fort Portal RRH	Kabarole	Mid-western
Rukunyu HC IV	Kamwenge	Mid-western
Kagando Hospital	Kasese	Mid-western
Nsambya Police Clinic	Kampala	Kampala
Kiboga Hospital	Kiboga	Central 2
Luwero HCIV	Luwero	Central 2
Hoima RRH	Hoima	Mid-western
Kagadi Hospital	Kagadi	Mid-western
Kawolo Hospital	Buikwe	Mid-eastern
Jinja RRH	Jinja	East central
Bugiri Hospital	Bugiri	East central
Buyinja HC IV	Namayingo	East central
Busia HC IV	Busia	Mid-eastern
Tororo Gen Hospital	Tororo	Mid-eastern
Buluba Hospital	Mayuge	East central
Mbale RRH	Mbale	Mid-eastern
Muyembe HC IV	Bulambuli	Mid-eastern
Kapchorwa Hospital	Kapchorwa	Mid-eastern
Magale HC IV	Manafwa	Mid-eastern
Soroti RRH	Soroti	North east
Amuria HC IV	Amuria	North east
Kaberamaido HC IV	Kaberamaido	North east
Tokora HC IV	Nakapiripirit	North east
Matany Hospital	Napak	North east
Moroto RRH	Moroto	North east
Kaabong Hospital	Kaabong	North east
Kotido HC IV	Kotido	North east
Gulu Regional Referral Hospital	Gulu	Mid northern
Aber Hospital	Oyam	Mid northern

Lira Regional Ref Hospital	Lira	Mid northern
Ober HC III	Lira	Mid northern
Kalongo Ambrosoli Mem HOSP	Agago	Mid northern
5 <sup>th</sup> Military Division Hospital	Pader	Mid northern
Arua RRH	Arua	West Nile
Adumi HC IV	Arua	West Nile
Koboko Hospital	Koboko	West Nile
Angal St. Luke HOSP	Nebbi	West Nile
Zeu HC III	Zombo	West Nile
Mildmay Uganda Hospital	Wakiso	Central 1
Entebbe Hospital	Wakiso	Central 1
Kasangati HC IV	Wakiso	Central 1
Kisubi Hospital	Wakiso	Central 1
Mulago National Hospital- MJAP TB HIV Clinic	Kampala	Kampala
Kawaala Health Centre HC III	Kampala	Kampala
Lubaga Hospital	Kampala	Kampala
Naguru Hospital - China Uganda Friendship	Kampala	Kampala
Kisenyi	Kampala	Kampala
Kisugu Health Centre	Kampala	Kampala
Mengo Hosp	Kampala	Kampala
Butabika	Kampala	Kampala
Nsambya Home Care	Kampala	Kampala

#### 4. Annex 4: Monitoring and Evaluation Framework

Output	Intervention	Indicators
Output 1.1 Increased access to health insurance for TB affected households	Advocate for operationalisation of the national health/ social insurance [NHI]	Proportion of advocacy meetings integrating TB
	Promote community health insurance schemes	
	Promote linkage of TB affected households to available health insurance schemes	Proportion of TB affected households covered by any form of health insurance
Output 1.2 Increase proportion of TB affected households linked to financial empowerment schemes	Advocate for prioritisation of TB affected households in income generating projects	Proportion of TB affected households benefiting from financial empowerment programs
	Advocate for prioritisation of TB affected households in national financial empowerment schemes	
	Promote active linkage of TB affected households to financial empowerment programs	
Output 1.3 Increased community awareness of cost implications for TB affected households	Development of community mobilisation and engagement strategy for TB	
	Development and dissemination of IEC materials and messages	
	Generation of policy briefs on TB related costs	
Output 2.1 Increased access to adherence [treatment] enablers	Advocate for provision of transport for patients with TB	Proportion of TB patients accessing any form of treatment enabler
	Advocate for policy review for inclusion of nutritional support for TB patients among others	
Output 2.2 Increased access to psychosocial support services for TB affected individuals and households	Develop/adopt a package of interventions for psychosocial support for TB patients and their households	Proportion of TB health care providers oriented on TB psychosocial support
	Strengthen community support structures for TB patients and their households	
	Strengthen capacity of health care workers to deliver psychosocial support	
Output 2.3 Reduced social exclusion of TB affected individuals and their households from 54% in 2018 to 27% by 2023	Advocate for strengthening enforcement of legislation related to social protection	Proportion of TB patients experiencing any form of social exclusion
	Engagement of employers and employer associations	Number of employer associations engaged
	TB stigma index study	
	Engagement of law enforcement agencies	
Output 2.4 Strengthened linkages between health facilities and social protection services	Development of a referral mechanism between health facilities and social protection services	Proportion of TB patients linked to social protection services
	Map available social protection services	
	Build community awareness for social protection	

Output	Intervention	Indicators
<b>Output 3.1</b> Eliminate treatment delays	Strengthening TB case finding interventions at health facility level	Proportion of TB patients initiating treatment within one week of diagnosis
	Scale up community systems for active case finding and community awareness	
	Strengthen PPP for TB	
<b>Output 3.2</b> Promoting TB prevention	Strengthen TB preventive therapy for populations at increased risk of developing TB disease	Proportion of populations at increased risk for TB disease accessing TB preventive therapy
	Infection control at health facilities and community	
	Contact tracing and community education	Proportion of PBCs whose contacts are screened for TB
Output 3.3 Strengthening TB/HIV integration	Strengthen sensitivity of TB screening in HIV infected individuals	
	Strengthen TB/HIV integration follow up at the facility and community level	Proportion of TB/HIV co-infected patients successfully treated

## REFERENCES

1. Uganda, M.o.H., The Uganda National Tuberculosis Prevalence Survey, 2014-2015 Survey Report. 2017.
2. Organisation, W.H., Global Tuberculosis Report 2017. 2017.
3. WHO, Health Systems Financing: The Path to Universal Coverage. 2010.
4. WHO, Tuberculosis Patient Cost Surveys: A handbook. 2017.
5. Okello, D., et al., Cost and cost-effectiveness of community-based care for tuberculosis patients in rural Uganda. *The International Journal of Tuberculosis and Lung Disease*, 2003. 7(9): p. S72-S79.
6. Saunderson, P.R., An economic evaluation of alternative programme designs for tuberculosis control in rural Uganda. *Social science & medicine*, 1995. 40(9): p. 1203-1212.
7. Gibson, N., F. Boillot, and H. Jalloh, The cost of tuberculosis to patients in Sierra Leone's war zone. *The International Journal of Tuberculosis and Lung Disease*, 1998. 2(9): p. 726-731.
8. Wyss, K., P. Kilima, and N. Lorenz, Costs of tuberculosis for households and health care providers in Dar es Salaam, Tanzania. *Tropical Medicine & International Health*, 2001. 6(1): p. 60-68.
9. Aspler, A., et al., Cost of tuberculosis diagnosis and treatment from the patient perspective in Lusaka, Zambia. *The international journal of tuberculosis and lung disease*, 2008. 12(8): p. 928-935.
10. Sitienei, J., J. Mutai, and E. Munui, The Socio- Economic Burden of Tuberculosis on Households of Machakos District, Kenya. *Am J Respir Crit Care Med*, 2009. 179: p. A1420.
11. Ukwaja, K.N., et al., Household catastrophic payments for tuberculosis care in Nigeria: incidence, determinants, and policy implications for universal health coverage. *Infectious diseases of poverty*, 2013. 2(1): p. 21.
12. Wingfield, T., et al., Defining catastrophic costs and comparing their importance for adverse tuberculosis outcome with multi-drug resistance: a prospective cohort study, Peru. *PLoS medicine*, 2014. 11(7): p. e1001675.
13. Sotgiu, G., et al., Evidence-based, agreed-upon health priorities to remedy the tuberculosis patient's economic disaster. 2014, *Eur Respiratory Soc*.
14. Xu, K., et al., Protecting households from catastrophic health spending. *Health affairs*, 2007. 26(4): p. 972-983.
15. Organization, W.H., Tuberculosis patient cost surveys: a handbook. 2017.
16. Rudgard, W.E., et al., Comparison of two cash transfer strategies to prevent catastrophic costs for poor tuberculosis-affected households in low-and middle-income countries: An economic modelling study. *PLoS medicine*, 2017. 14(11): p. e1002418.
17. WHO, Global Tuberculosis Report. 2015.
18. Shete, P., et al., Pathways and costs of care for patients with tuberculosis symptoms in rural Uganda. *The International Journal of Tuberculosis and Lung Disease*, 2015. 19(8): p. 912-917.
19. WHO, Global Tuberculosis Report. 2016.
20. Kiwuwa, M.S., K. Charles, and M.K. Harriet, Patient and health service delay in pulmonary tuberculosis patients attending a referral hospital: a cross-sectional study. *BMC Public Health*, 2005. 5(1): p. 122.
21. Oola, J., Factors influencing delayed Diagnosis of Tuberculosis in Mukono District, Uganda. 2001.
22. Dye, C., et al., Trends in tuberculosis incidence and their determinants in 134 countries. *Bulletin of the World Health Organization*, 2009. 87(9): p. 683-691.
23. Harris, B., et al., Inequities in access to health care in South Africa. *Journal of public health policy*, 2011. 32(1): p. S102-S123.

- 
24. MoH, NATIONAL TUBERCULOSIS AND LEPROSY CONTROL PROGRAMME: Revised National Strategic Plan 2015/16 - 2019/20. 2017.
  25. Ukwaja, K.N., I. Alobu, and P.C. Hopewell, The high cost of free tuberculosis services: patient and household costs associated with tuberculosis care in Ebonyi State, Nigeria. PLoS One, 2013. 8(8): p. e73134.
  26. Tanimura, T., et al., Financial burden for tuberculosis patients in low-and middle-income countries: a systematic review. European Respiratory Journal, 2014. 43(6): p. 1763-1775.
  27. Lawn, S., B. Afful, and J. Acheampong, Pulmonary tuberculosis: diagnostic delay in Ghanaian adults. The International Journal of Tuberculosis and Lung Disease, 1998. 2(8): p. 635-640.
  28. Organisation WH. The End TB Strategy [cited 2018 13th November 2018]. Available from: [http://www.who.int/tb/strategy/End\\_TB\\_Strategy.pdf?ua=1](http://www.who.int/tb/strategy/End_TB_Strategy.pdf?ua=1).





**Ministry of Health**  
P.O. Box 7272,  
Kampala Uganda  
[www.health.go.ug](http://www.health.go.ug)

THE REPUBLIC OF UGANDA