Consolidated guidance on tuberculosis data generation and use: Module 4

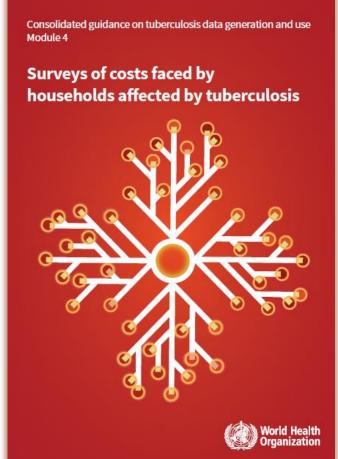
Surveys of costs faced by households affected by tuberculosis

(June 2025)

Overview and progress update

Last updated: September 2025



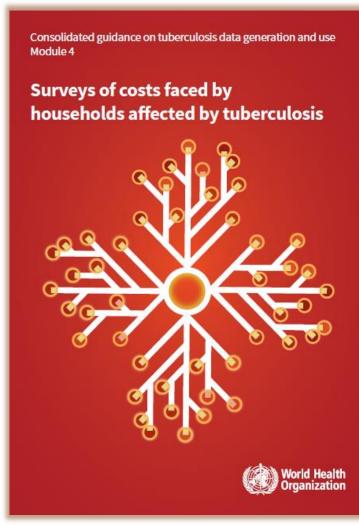


https://www.who.int/publications/i/item/9789240104570

Outline

- 1. Contents of updated WHO guidance
- What's new?
- 3. Rationale
- 4. Development process
- 5. Survey objectives, methods, average budget and timelines
- 6. Update on national surveys to date and examples of key outcomes
- 7. Further information and available support

Contents





- 1. Introduction
- 2. Situation assessment
- 3. Survey design overview and limitations
- 4. Survey population and sampling
- 5. Data collection procedures
- 6. Analysis
- 7. Ethical considerations
- 8. Organization of the survey team and training
- 9. Budgeting
- 10. Dissemination of survey findings, and policy and practice implications
- 11. Additional research



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June 2025

What's new?

- Comprehensive and expanded guidance* based on lessons learned from national surveys implemented between 2015 and 2024. Examples include:
 - 1. Revised terminology to reflect the importance of language and word choice with reference to people with TB; for example, "TB patients" has been replaced by "person/people treated for TB";
 - 2. A new third objective focused on access to social protection and the formulation of policy recommendations based on survey results;
 - 3. Expanded guidance on survey planning and budgeting;
 - 4. Enhanced guidance on survey sampling, data collection (including quality control), analysis and interpretation of results;
 - 5. Expanded guidance on the dissemination of results and their use in policy dialogue to inform multisectoral action to reduce costs faced by people with TB and to enhance social protection measures;
 - 6. Practical examples and experiences from 35 countries.
- Updated version of supporting materials including a generic questionnaire for data collection and a generic version of code that can be used for data analysis (available on the publication webpage).

^{*}The updated guidance replaces the first, 2017 edition titled "Tuberculosis patient cost surveys: a handbook"

Rationale – End TB strategy



Vision:

A world free of TB

Zero TB deaths, Zero TB disease, and Zero TB suffering

Goal:

End the Global TB epidemic

			TARGETS	
	MILESTONES		SDG*	END TB
	2020	2025	2030	2035
Reduction in number of TB deaths compared with 2015 (%)	35%	75%	90%	95%
Reduction in TB incidence rate compared with 2015 (%)	20%	50%	80%	90%
TB-affected families facing catastrophic cost due to TB (%)	0%	0%	0%	0%



Why focusing on financial burden?

TB-affected households suffer from a heavy financial burden

- Barrier to early diagnosis
- Cause treatment interruption and loss-tofollow-up
- Further impoverish TBaffected households

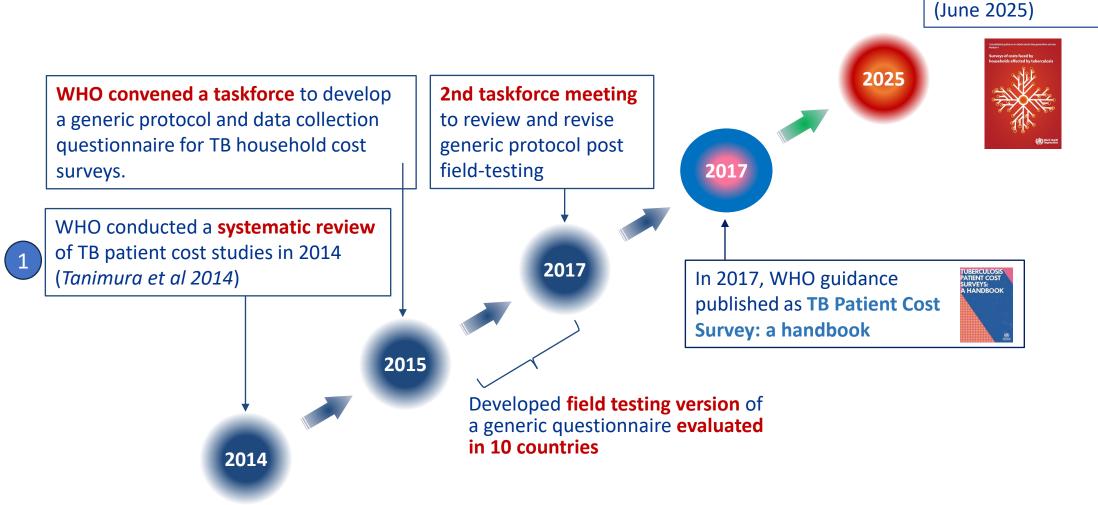
Increase

- further disease transmission
- drugresistance

- Consequences are beyond individual level
- TB household cost survey can provide information to improve the delivery of TB services and to enhance relevant social protection mechanisms



Development of survey methods





Updated edition published

Generic survey objectives

To document the magnitude* and main drivers of different types of costs incurred by people treated for TB and their households **Survey aim** To determine the percentage* of TB affected-To assess households incurring catastrophic total costs due to TB financial burden of TB from the patient perspective To determine use* of existing policies to mitigate costs and other socioeconomic impacts faced by TB-affected New! households and recommend refinements of existing policies, or designing new ones, based on survey results.

^{*}At baseline and measuring change over time in repeat surveys.

Methods – survey design

Design

- Facility-based survey: national sample of people on TB treatment
- Cross sectional study with retrospective data collection and projections

Budget Timeline

- **Budget range**: average US\$ 100,000 (US\$ 70,000-150,000)
 - (excl. WHO TA; 30 days \$11,000-15,000)
- Survey period: average 1.5 years (including data collection: 2-3 months)

Sample size

- Nationally representative sample: 600-1300 people on TB treatment
- With minimum 20 clusters (basic management unit of TB)

Data Collection*

- Questionnaire: 70-146 questions interview average 70 mins, depending on responses
- Android tablet-based questionnaire: using ODK, Ona, KoboToolbox etc



Methods – assessing catastrophic total costs due to TB

- Survey measures three main cost categories:
 - Direct medical (diagnostic tests, drugs, consultation, treatment)
 - Direct non-medical (transportation, food, accommodation, nutritional supplements)
 - Indirect
 (income loss and time loss through sensitivity analysis)

Costs are defined as **catastrophic** if:



> 20%

Annual household income before onset of TB





Methods – other key indicators

TB household cost surveys assess other key indicators:

- Coping mechanisms
 - Taking loans
 - Selling household assets
- Social consequences
 - Divorce or separation
 - Food insecurity
 - Interrupted schooling
 - Job loss
 - Social exclusion

Access to social protection mechanisms

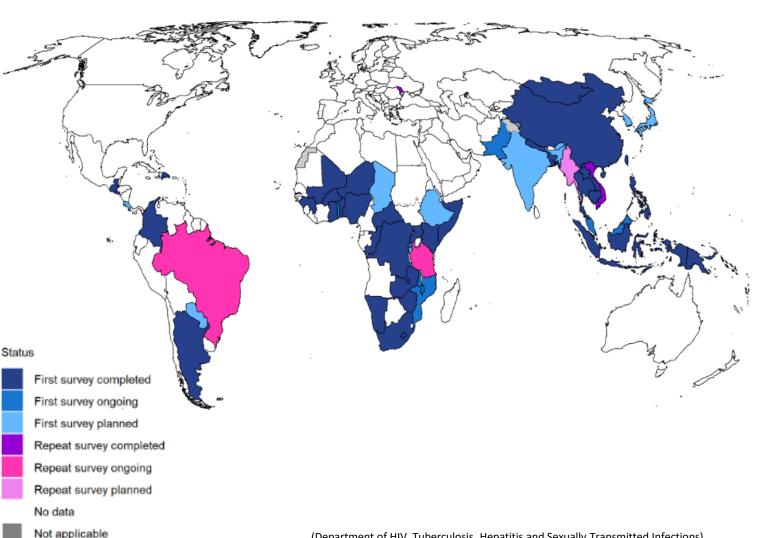
- Job protection
- Salary compensation
- Sickness benefit
- Food/transportation support

Changes* in:

- Household income
- Poverty level
- * Comparing data at 3 time points:
- before having TB symptoms
- at TB diagnosis
- during TB treatment



Progress to date: 42 countries



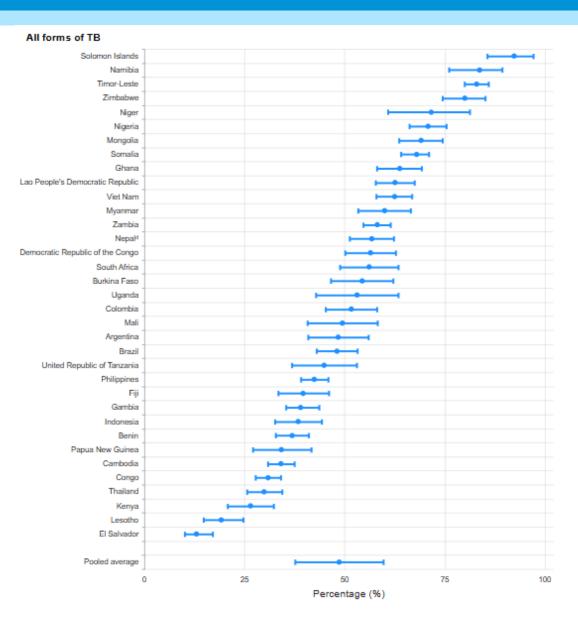
First survey

- By August 2025, 42 countries completed the first survey
- 6 first surveys are ongoing:
 - 4: data analysis/reporting Malawi, Mozambique, Rwanda, Togo.
 - 2: data collection Malaysia, Pakistan.
- 8 are planned

Repeat survey

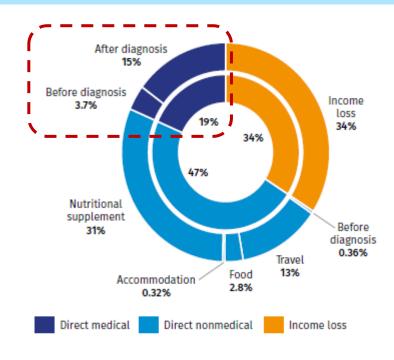
- **2** Completed: Republic of Moldova and Viet Nam
- 2 Ongoing: United Republic of Tanzania and Brazil
- 1 Planned: Myanmar

Global estimate based on empirical data - catastrophic total cost due to TB



- % of TB-affected households facing costs >20% of annual household income ranged 13% to 92%
- The global pooled average is 49%
- The percentage is much higher for people with drug-resistant TB: 82%

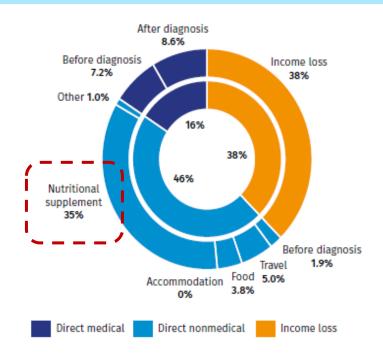
Policy implications – direct medical costs



Ghana TB household cost survey (2016)

- Direct medical costs accounted for 19% of total costs incurred by TB-affected households.
- NTP and National Health Insurance Authority (NHIA) identified low health insurance coverage among TB patients.
- 20% of people with TB were uninsured throughout TB treatment.
- In 2018, Ghana Health Service and NHIA agreed on the need for people with TB to be enrolled into the national health insurance once diagnosed as TB, without payment of insurance premiums.

Policy implications – direct nonmedical costs



Lao PDR TB household cost survey (2019)

- Nutritional supplement/additional food accounted for 35% of total costs incurred by TB-affected households.
- 60% of MDR-TB patients were with malnutrition*.
- "National Nutrition Strategy to 2025" has a strategic objective to prevent TB-related malnutrition. However, no actions were planned at the time of survey dissemination.
- NTP and National Nutrition Programme conducted an <u>intervention study</u> assessing malnutrition at TB diagnosis and impact of nutritional counselling and support on catastrophic costs and TB treatment outcomes.
- Intervention group had significantly lower nutritional supplement costs and less progressive catastrophic total costs than the observation group.

Policy implications – indirect costs





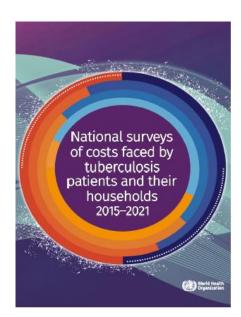
Viet Nam TB household cost survey (2017)

- Indirect cost (income loss) accounted for 44% of total costs incurred by TB-affected households.
- Ministry of Home Affairs established a new non-profit fund in 2018: Patient Support Foundation to End Tuberculosis (PASTB) to encourage people to support TB-affected households.
- People can text the message "TB" to 1402 to donate VNĐ 20,000 (=USD 0.8-0.9).





Other relevant publications and available support



https://www.who.int/publications/i/item/9789240065536

- In February 2023, WHO published a summary of 20 surveys conducted between 2015-2021 that used the WHO-recommended methods, including:
 - Comprehensive documentation of survey methods, results and policy translation
 - Country profiles of the survey with standardized data analysis and visualization
- In October 2023, using available survey data, modelling the estimated percentage of TB-affected households facing catastrophic costs for countries without survey data was published: <u>Portnoy, Yamanaka,</u> <u>Nguhiu et al., Lancet Global Health, 2023.</u>
- Renewed WHO consultant roster for TB household cost surveys:
 12 health economists available for country support



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Related publications and webpages

- Surveys of costs faced by households affected by tuberculosis
- <u>Tuberculosis</u> patient cost survey: a handbook
- National surveys of costs faced by tuberculosis patients and their households 2015-2021
- Global Tuberculosis Report 2024 (section 5.2)
- Global Task Force on TB Impact Measurement
- Good practices guidance handbook for national TB surveys
- Costs incurred by people receiving tuberculosis treatment in lowincome and middle-income countries: a meta-regression analysis



MEASUREMENT













