

Consolidated guidance on tuberculosis data generation and use: Module 4

# Surveys of costs faced by households affected by tuberculosis

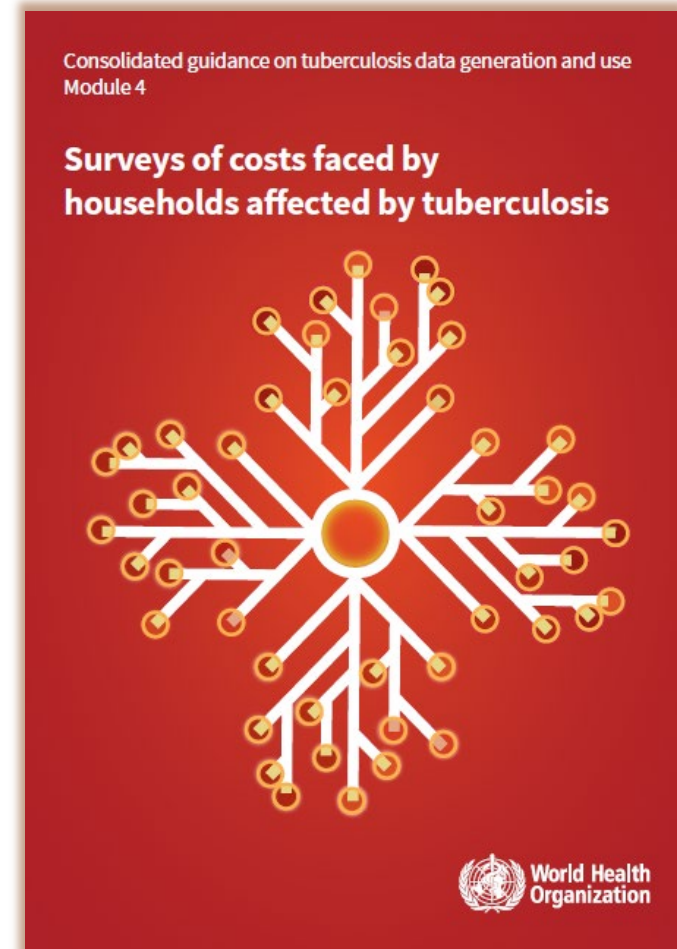
(June 2025)

## Overview and progress update

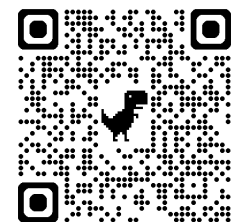
Last updated: **August 2025**



Department of HIV, Tuberculosis, Hepatitis, and Sexually Transmitted Infections



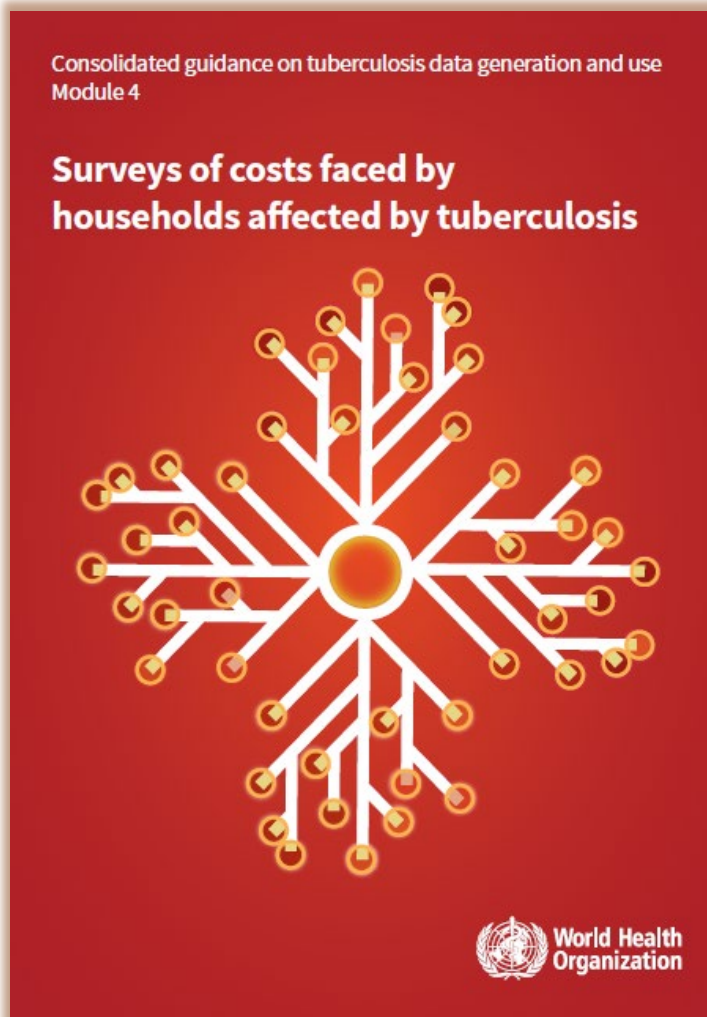
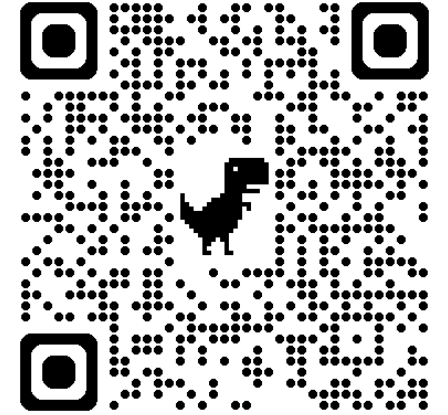
<https://www.who.int/publications/i/item/9789240104570>



# Outline

1. Contents of updated WHO guidance
2. 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



## Chapters

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

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

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to reflect the importance of language and word choice with reference to people with TB; for example, “TB patients” has been replaced by “person/people treated for TB”;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   |
| <i>Reduction in number of TB deaths</i><br>compared with 2015 (%)   |      | 90%     | 95%    |
| <i>Reduction in TB incidence rate</i><br>compared with 2015 (%)     |      | 80%     | 90%    |
| <i>TB-affected families facing catastrophic costs due to TB (%)</i> |      | 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-to-follow-up
- Further impoverish TB-affected households

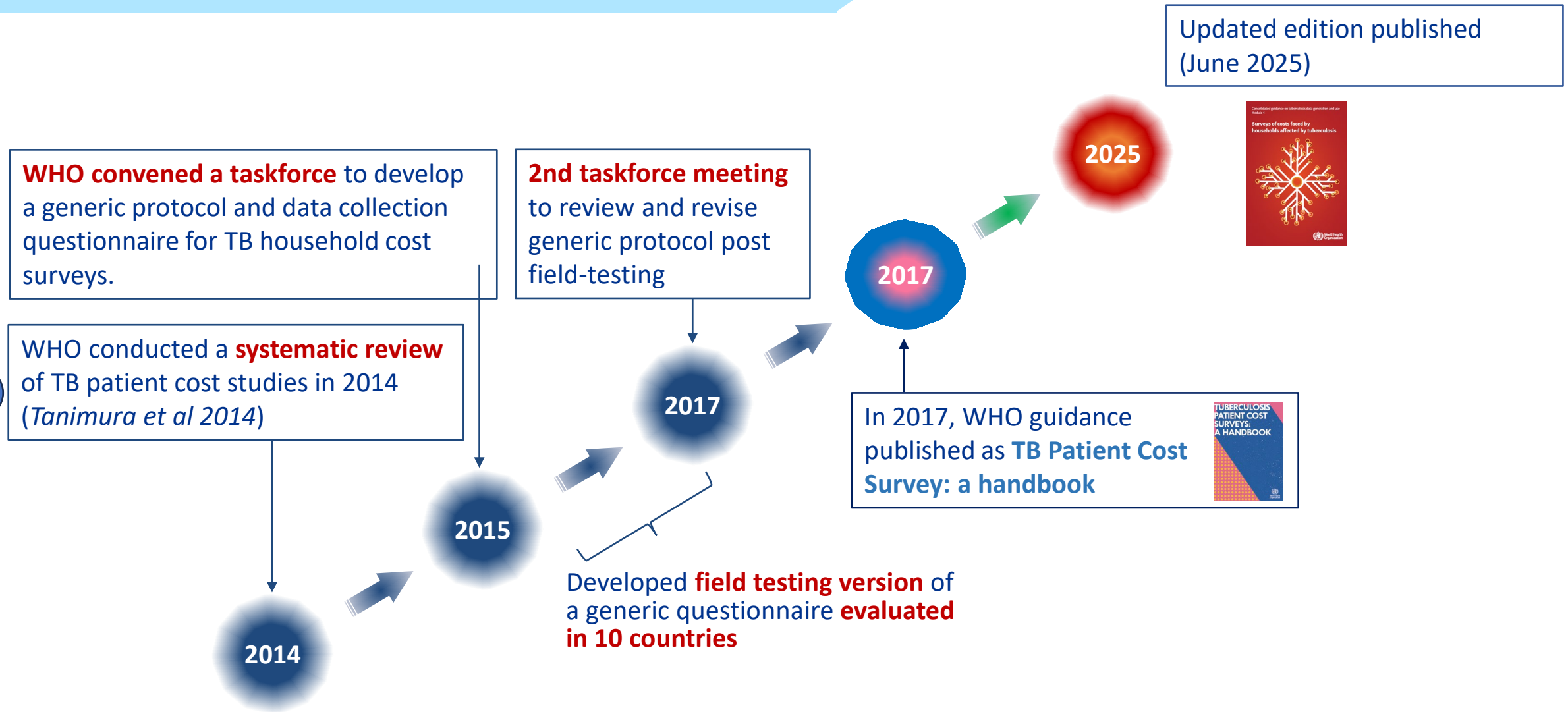
Increase

- further disease transmission
- drug-resistance

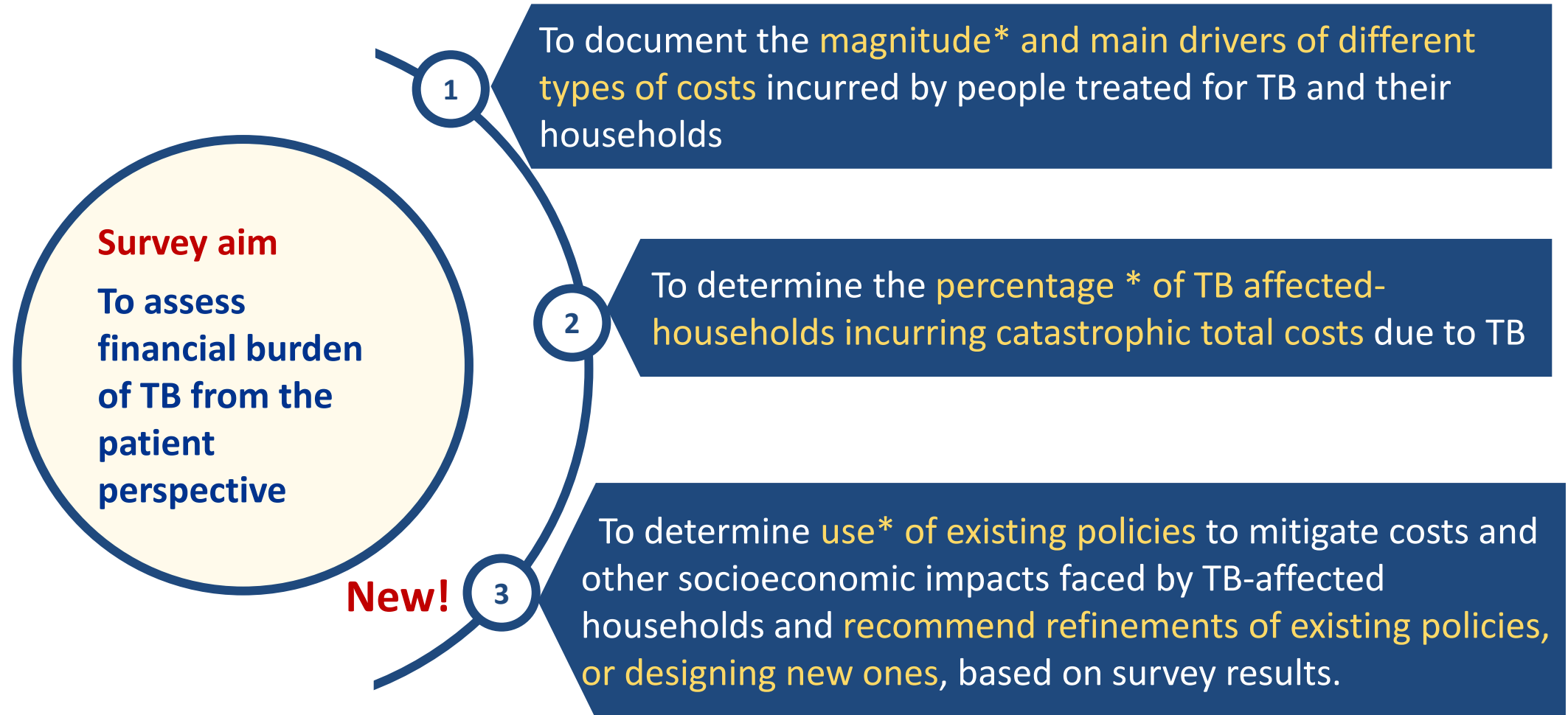
- Consequences are **beyond individual level**
- TB household cost survey can provide information to **improve the delivery of TB services** and to **enhance relevant social protection mechanisms**



# Development of survey methods



# Generic survey objectives



\*At baseline and measuring change overtime 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)

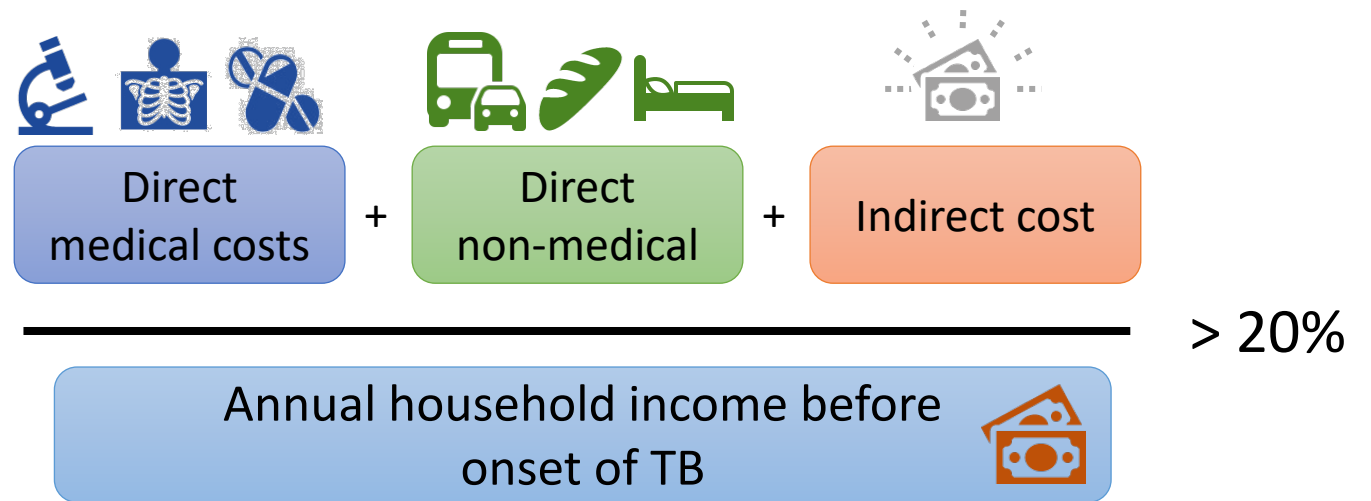
## Data Collection\*

- **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:



# Methods – other key indicators

TB household cost surveys assess other key indicators:

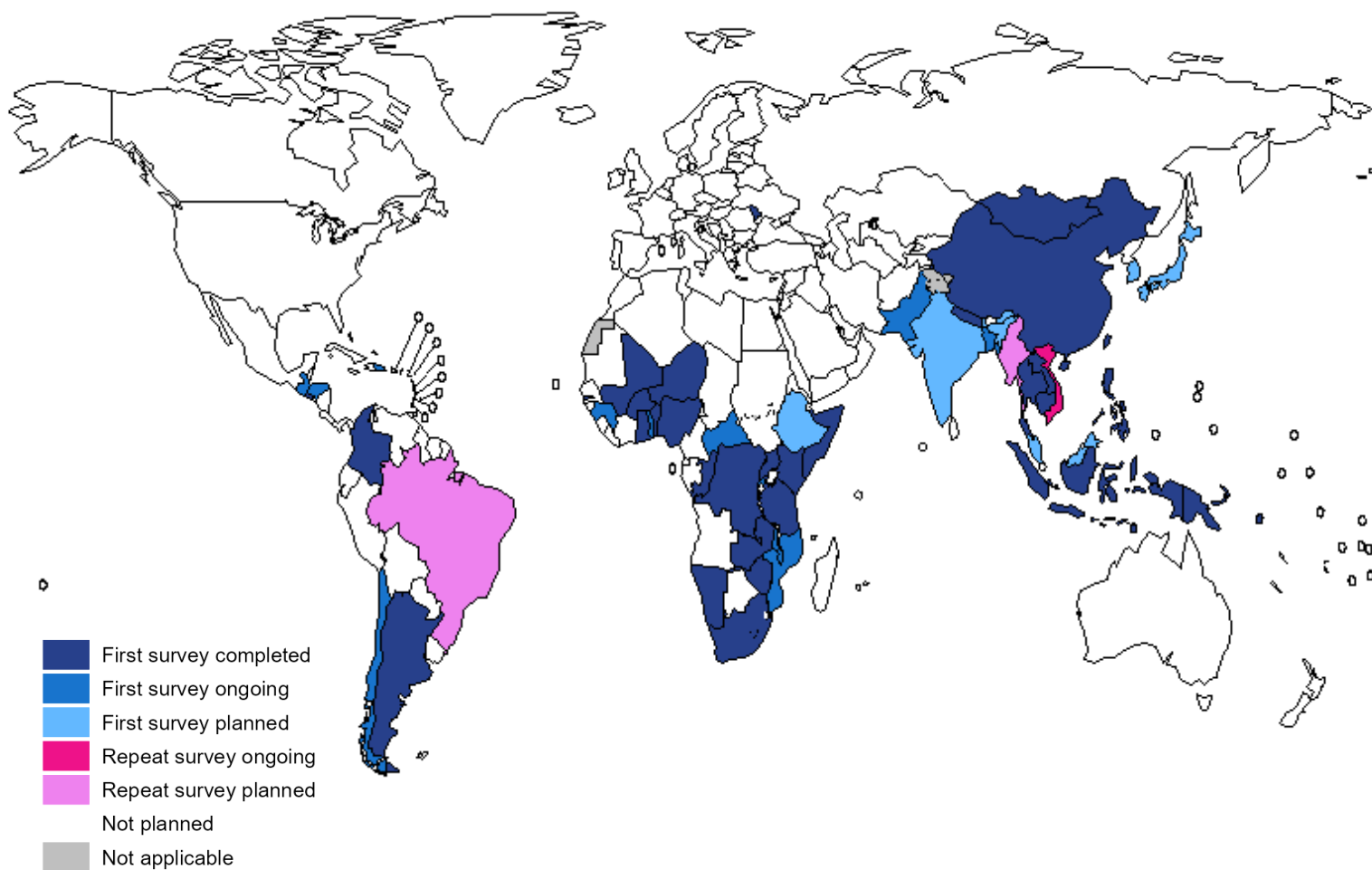
- **Coping mechanisms**
  - Taking loans
  - Selling household assets
- **Social consequences**
  - Divorce or separation
  - Food insecurity
  - Interrupted schooling
  - Job loss
  - Social exclusion
- **Access to social protection mechanisms**
  - Job protection
  - Salary compensation
  - Sickness 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: 37 countries



(Global Tuberculosis Report 2024)

## First survey

- By August 2024, **37** countries completed the first survey
- **13** first surveys are ongoing:
  - **5**: data analysis/reporting  
Guinea, Malawi, Mozambique, Rwanda, Togo
  - **5**: data collection  
Bangladesh, Central African Republic, Dominican Republic, Guatemala, Pakistan
  - **3**: protocol development and ethical clearance  
Chile, Honduras, Malaysia
- **7** are planned

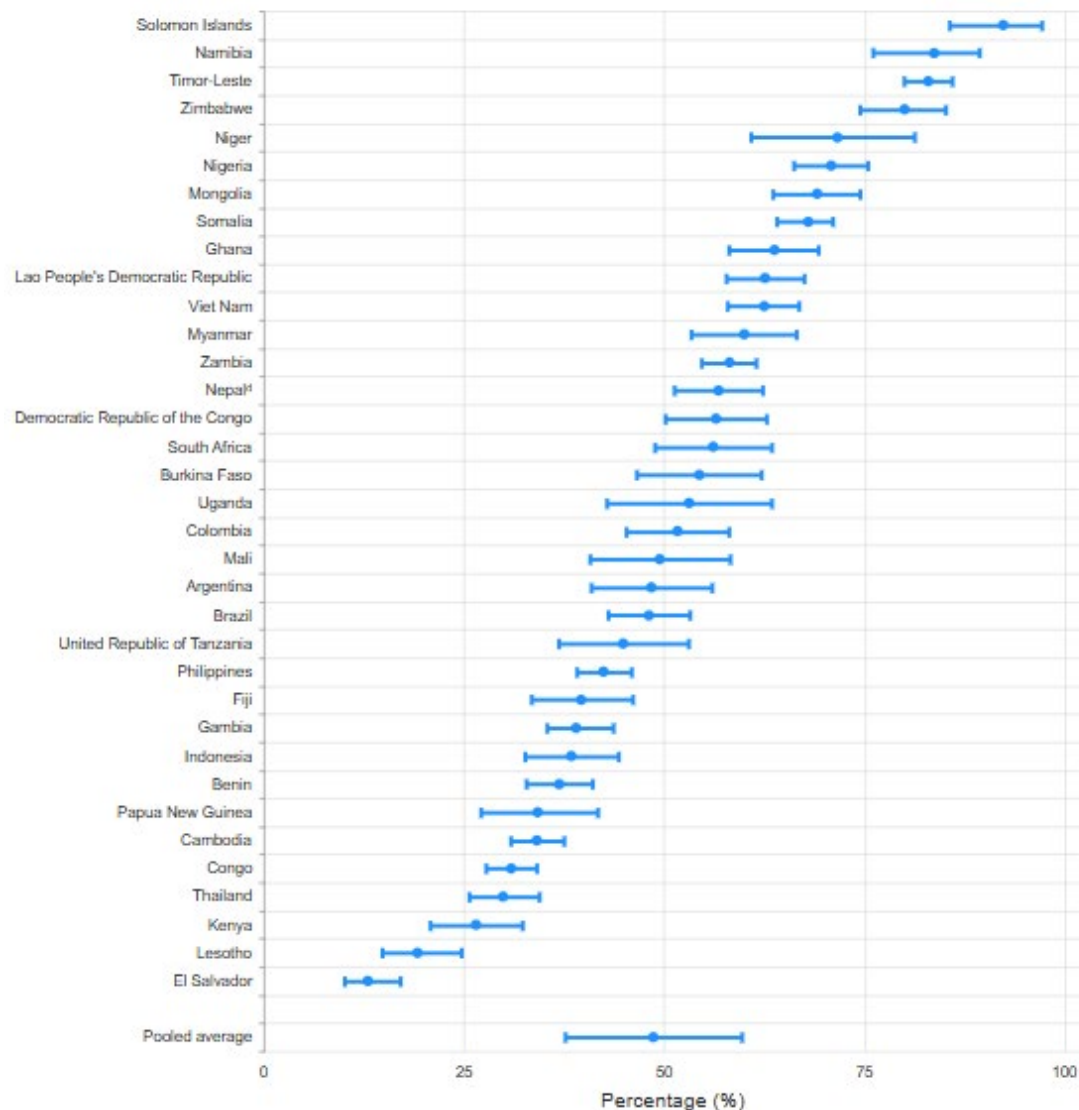
## Repeat survey

- Viet Nam: data analysis
- Brazil, Myanmar: planning



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

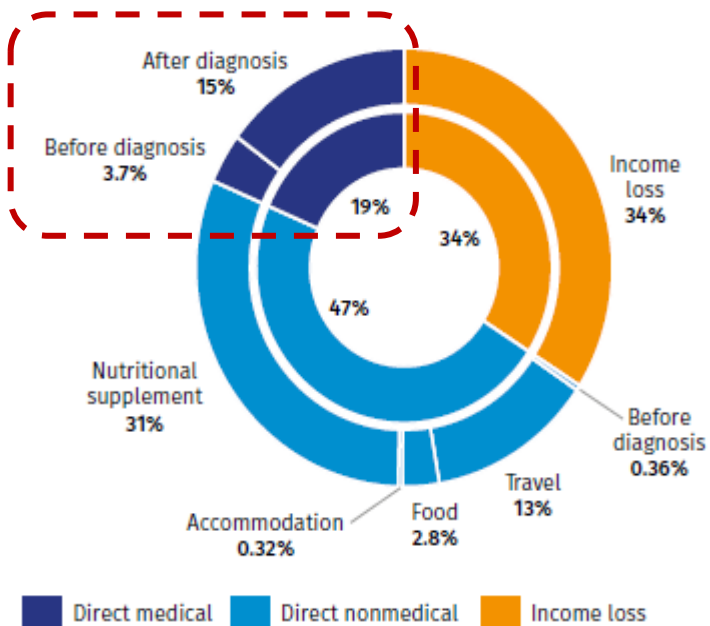
All forms of TB



- % 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%**

\*Pooled average for 34 countries for which results have been reported, weighted for each country's number of notified cases.

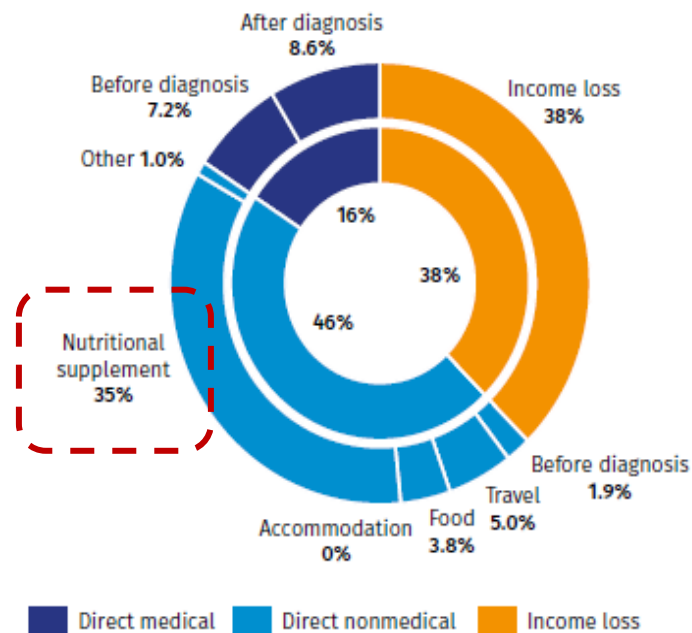
# Policy implications – direct medical costs



## 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 [intervention study](#) 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.

\*BMI of TB patients is available only for MDR-TB patients in Lao PDR, in paper record.





# Policy implications – indirect costs



IT'S TIME FOR TB-1402



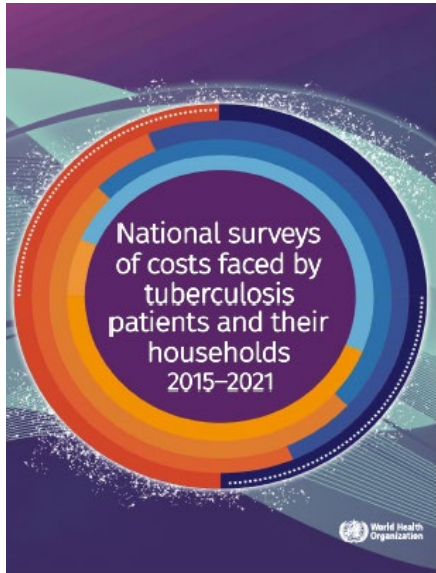
9:00-11:00 24/4/2019

## 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: **P**atient **S**upport Foundation to End **T**uberculosis (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).
- ▼
- In 2023, PASTB supported more than **USD 425,000 to approx. 9,000 people with TB.**



# 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: [Portnoy, Yamanaka, Nguhiu et al., Lancet Global Health, 2023.](#)
- **Renewed WHO consultant roster** for TB household cost surveys: 12 health economists available for country support



# For more information

Taghreed Adam  
[adamt@who.int](mailto:adamt@who.int)

Inés Garcia Baena  
[garciabaenai@who.int](mailto:garciabaenai@who.int)

## Related publications and webpages

- [Surveys of costs faced by households affected by tuberculosis](#)
- [Tuberculosis 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 low-income and middle-income countries: a meta-regression analysis](#)

