TB patient cost surveys to improve TB care delivery and social protection
An overview of progress

WHO Global TB Programme
Contents

• The End TB Strategy target
• WHO’s generic protocol and handbook
• Global progress and WHO’s roles
• Policy implications
• Technical updates and the next steps
**Vision:**

A world free of TB

*Zero TB deaths,*

*Zero TB disease,* and

*Zero TB suffering*

**Goal:**

End the Global TB epidemic

<table>
<thead>
<tr>
<th>MILESTONES</th>
<th>SDG*</th>
<th>END TB</th>
</tr>
</thead>
<tbody>
<tr>
<td>2020</td>
<td>35%</td>
<td>90%</td>
</tr>
<tr>
<td>2025</td>
<td>75%</td>
<td>95%</td>
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</table>

*Reduction in number of TB deaths*

compared with 2015 (%)

<table>
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<tr>
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<tbody>
<tr>
<td>2020</td>
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<td>80%</td>
</tr>
<tr>
<td>2025</td>
<td>50%</td>
<td>90%</td>
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*Reduction in TB incidence rate*

compared with 2015 (%)

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<th>END TB</th>
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<tbody>
<tr>
<td>2020</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>2025</td>
<td>0%</td>
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</tr>
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</table>

*TB-affected families facing catastrophic costs due to TB (%)*

<table>
<thead>
<tr>
<th>MILESTONES</th>
<th>SDG*</th>
<th>END TB</th>
</tr>
</thead>
<tbody>
<tr>
<td>2020</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>2025</td>
<td>0%</td>
<td>0%</td>
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</tbody>
</table>
Financial hardship of TB patients and families

- TB patients on average, face expense equivalent to a half of their annual income.
- A half of the costs are incurred before TB treatment
- Patients often have to resort to coping mechanisms:
  - up to 75% of TB patients take out a loan
  - up to 50% sell household items
- Requires interventions in:
  - Universal health coverage
  - Social protection

Breakdown of cost incurred by TB patients

TB patient cost survey

• In 2015, WHO convened a taskforce to develop a generic protocol and instrument for TB patient cost surveys.
• Several pathfinding countries implemented their national surveys by 2017, which provided valuable feedback to revise the protocol.
• In 2017, the protocol was published as *TB Patient Cost Survey: a handbook*.
Survey objectives

1. 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 access barriers and minimize the adverse socioeconomic impact of TB.

2. To determine the baseline and periodically measure the percentage of TB patients (and their households) treated in the NTP network who incur catastrophic total costs due to TB.
Basic design

- **Facility-based** patient survey: national sample of patients on treatment - all consecutive patients on TB treatment in sampled facilities

- **National sample**: 500-1000 patients (min. 20 clusters)

- **Cost** ranges: $30,000 - $150,000

- **Survey frequency**: once every 5 years

- **Cross sectional** study with retrospective data collection and projections

- Estimated survey **implementation time**:
  - data collection: 2-3 months
  - all survey: 5-6 months

- **Questionnaire** (130 questions - 40-60 mins long): 28 questions directly from treatment card, rest to complete depending on treatment type or phase

- **Extrapolations** based on data collected from other patients

- Adaptation of WHO methodology involves **not deleting any questions**
End TB Strategy indicator –
Percentage of TB-affected households with catastrophic costs due to TB

% households who incur in costs equivalent to 20% or more of household’s annual income relative to those on treatment

Costs are defined as catastrophic if:

\[
\frac{Direct + Indirect costs}{Household \ capacity \ to \ pay \ for \ health} > 20\% 
\]

Where household capacity to pay = (permanent) income
"Catastrophic health expenditure” vs “Catastrophic total costs due to TB"

<table>
<thead>
<tr>
<th>What are measured</th>
<th>Catastrophic health expenditure (SDG 3.8.2)</th>
<th>Catastrophic total costs due to TB</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Out-of-pocket payments for health care (for all conditions)</td>
<td>• Direct medical expenditure associated with TB</td>
<td>• Direct medical expenditure associated with TB</td>
</tr>
<tr>
<td></td>
<td>• Direct non-medical expenditure (nutritional supplements, food, transportation, etc)</td>
<td>• Direct non-medical expenditure (nutritional supplements, food, transportation, etc)</td>
</tr>
<tr>
<td></td>
<td>• Indirect cost (lost income)</td>
<td>• Indirect cost (lost income)</td>
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<tr>
<td>Criteria of ‘catastrophic’ / large</td>
<td>• Exceed 10% (or 25%) of the household income or total consumption</td>
<td>• Exceed 20% of the household income / total expenditure / consumption</td>
</tr>
<tr>
<td>Method</td>
<td>• Household survey</td>
<td>• Facility-based survey</td>
</tr>
<tr>
<td>Sampling unit / frame</td>
<td>• Household / General population</td>
<td>• TB patients / All registered TB patients</td>
</tr>
<tr>
<td>Implications</td>
<td>• Level of medical expenditure in general population (households)</td>
<td>• Economic burden faced by TB-affected household</td>
</tr>
<tr>
<td></td>
<td>• General progress in UHC</td>
<td>• Financial protection among TB patients</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Social protection among TB patients</td>
</tr>
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</table>
Implementing TB patient cost surveys

- A baseline survey (the first national survey) should be implemented by 2020 at the latest
- Repeat surveys every 5 years will allow monitoring of progress
- The survey is also useful to monitor the impact of major transitions/reforms on TB patient care (e.g. health financing reforms, the withdrawal of donors, etc)

Steps to implement the survey
1. Initial discussion and identification of funding
2. Situation assessment
3. Protocol development
4. Training
5. Data collection
6. Analysis
7. Dissemination, policy dialogue and action planning
8. Publish final report
WHO’s roles

1. **Guidance**—Provides guidance for national TB patient cost surveys and their application to improve TB care and prevention. Advice from Task Force members will be incorporated in guidance provided by WHO.

2. **Capacity building**—Develops capacity in all aspects of surveys, from design to dissemination at global, regional and national levels (e.g. consultant training, maintenance of the consultant roster)

3. **Technical support**—Provides coordinated technical support to countries for all aspects of surveys, from design and implementation, to policy translation and dissemination, including direct support to priority countries.

4. **Synthesis**—WHO synthesizes the results and lessons learned from the surveys through cross-country analyses and annual tracking of progress towards the End TB Strategy target.
Global progress (as of April 2018)
# Implementation status by country

<table>
<thead>
<tr>
<th>Country</th>
<th>TA partners</th>
<th>Funding for survey activities</th>
<th>Funding for TA missions</th>
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<td>Dominican Republic</td>
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<td>Fiji</td>
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Results of selected national surveys (preliminary)

- % households facing catastrophic cost: **35% to 83%**
- Cost drivers vary—different policy implications
- DR-TB incur much higher cost in general
- Additional values
  - Impoverishment
  - Impact of current social support interventions
Patient costs components along the patient pathway

Before TB diagnosis
- Medical expenditure
- Other direct cost (food, transportation, etc)

After TB diagnosis
- Medical expenditure
- Other direct cost (food, transportation, etc)
- Lost income
Patient costs components along the patient pathway

**Before TB diagnosis**
- UHC for general medical coverage
- Streamline patient pathways (service decentralization, engaging all providers, innovative technologies for early diagnosis)
- Systematic TB screening including contact investigation

**After TB diagnosis**
- Enhancing TB care financing within UHC policies (including free TB care policies)
- Service/benefit package design
- Adopting innovative approaches
- TB specific support for non-medical cost
- Social assistance schemes
- Service decentralization

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**Patient costs components**

- **Risk group Screening**
  - Contact screening
  - Infection
  - Sick

- **Patient**
  - Medical expenditure
  - Other direct cost (food, transportation, etc.)
  - Lost income

- **Community Health posts**
  - Social support

- **Social assistance schemes**
  - Income compensation (e.g. sickness insurance)
  - Social assistance schemes (e.g. disability grant)
  - Address stigma and discrimination / legal protection

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**GLOBAL TB PROGRAMME**

[World Health Organization Logo]
Social protection mapping

- Social protection mapping is a qualitative assessment to map the social protection landscape in the country.
- Should be part of the situation assessment before designing the survey.
- Ministries and agencies whose mandates cover any of these schemes should be identified as a key stakeholder and engaged as early as possible.

**TB-specific social protection schemes**
- Cash transfers for TB patients (conditional or unconditional)
- Food / travel / housing and other support for TB patients (in-kind, vouchers, cash allowance)
- Vocational training, micro-credit or enterprise support for TB patients

**General social protection schemes**
- Social assistance
- Social insurance
- Labor Market interventions

**Rights-based country legislation**
- Right to employment
- Right to social protection, and or services
- Right to life
- Rights for those living with disabilities
Policy dialogue and action planning based on the survey findings in Viet Nam

• A stakeholders’ meeting was held to review the survey results, and agree on priority actions to address the catastrophic patient cost
  – Partners: Ministry of Labour and Social Affairs (MOLISA), relevant departments in the Ministry of Health, the Farmer Union, the Women Union, WHO, VICTORY (national TB research network), TB patient representatives

• The roadmap with priority actions:
  – Costing a package of ambulatory TB services for inclusion in the national health insurance scheme,
  – Advocating for donor support for TB-specific patient support
  – Establish a charity fund for TB patients
  – Strengthen the collaboration between MOH and MOLISA (e.g. to enhance the use of existing social protection schemes, improve coordination between health and social workers, monitoring and evaluation, etc)
  – Collaboration with the labor sector
Preparation for dissemination and policy dialogues in other countries

Kenya
• TB Social Protection TWG established before the survey
• WHO, NTP and the TWG members are preparing for a dissemination meeting in June/July
• Aiming at a high-level participation from relevant stakeholders
• Willing to have other NTP representatives as observers

Ghana
• Preparation started and WHO supports sensitization/preparation through in-country mission

Uganda, Nigeria, China, Mongolia
Technical updates

Technical annex of the handbook to be issued

• Three areas for improvement identified in terms of guidance on survey design and analysis
  – Methods for calculating confidence intervals for key survey indicators, adjusted for the sampling design.
  – Detailed Methods for sampling and stratification.
  – Recommendations on the design of a household expenditure/consumption questionnaire (to derive a household capacity to pay for health measure based on consumption/expenditure)

Adaptation to high-income settings

• Discussions are underway regarding the design of TB patient cost surveys in low incidence and/or high-income settings (e.g. Japan, Republic of Korea, UK). Areas for further methodological development in these settings have been identified during preliminary discussions.

Adaptation of materials into Spanish, French and Russian
Next steps

• Guidance:
  – Development of standard ToR for TA
  – Development of guidance on how to conduct an assessment of social protection and access barriers

• Capacity building:
  – Post-graduate course during the UNION Conference
  – Preparation workshop held with WARN-TB
  – Multi-country training workshops are being planned in Q4/2018 or 2019

• Technical support:
  – Global coordination of technical and funding support for surveys
  – Maintenance and periodic updating of a consultant roster
Group discussion tomorrow

Morning:
- Implementation challenges:
  How to accelerate the implementation of surveys
  Recommendations for countries, WHO and partners

Afternoon 1:
- Dissemination and policy translation:
  Experience sharing and discuss facilitating factors for policy translation

Afternoon 2:
- Other issues identified
- e.g. high income adaptation?