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

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1. Introduction

Patients with TB often incur large costs related to illness and disability. These include medical and transport costs associated with seeking and receiving health care, and costs related to loss of income. Such costs can create access and adherence barriers, which in turn affect health outcomes and increase the risk of disease transmission. They also place an economic burden on households, worsening existing levels of income and wealth; some may fall below the poverty line as a consequence, or be pushed further below that line than before they became ill with TB.

One of the three targets of the End TB Strategy is that no TB patients or their households should face “catastrophic total costs” due to TB, with the target date set for 2020. This is in line with policy efforts related to progress towards achieving universal health coverage (UHC), which is Target 3.8 of the Sustainable Development Goals (SDGs). The targets and milestones of the End TB Strategy for reductions in TB cases and TB deaths cannot be achieved unless UHC is in place. For example, the 2025 milestones require that the case fatality ratio falls to around 6% by that year, which can only be achieved if all those with TB access quality diagnosis and treatment.

In 2015, WHO established a standardized protocol for conducting a national survey to assess the direct and indirect costs incurred by TB patients and their households. Based on experience in pathfinding countries who piloted the protocol, in 2017 this was refined and also expanded into the Tuberculosis Patient Cost Surveys: A Handbook. To date, nationally-representative surveys have been conducted in more than 14 countries, using the guidance in the protocol and the handbook.

This document is complementary to the quarterly update (Background document C). It covers four major topics, which are: WHO’s role in supporting national surveys of costs faced by TB patients and their households; an overview of progress to date, including a summary of key results and how these are informing policy and action at country level; technical updates to guidance on methods; and next steps in terms of guidance development, capacity building and technical support.

2. WHO’s role

WHO encourages all high-TB burden countries to conduct a national survey of costs faced by TB patients and their households, to establish a baseline for this high-level indicator of the End TB Strategy and to allow assessment of progress when repeat surveys are done. WHO’s role includes guidance, capacity building, technical support and synthesis of findings (Figure 1).

**Figure 1: WHO’s role in supporting surveys of costs faced by TB patients and their households**

- **Guidance:** WHO 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.
- **Capacity building:** WHO and collaborating centres develop capacity in all aspects of surveys, from design to dissemination at the global, regional and national level.
- **Technical support:** WHO 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.
- **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.
3. Global progress – an overview

Survey implementation

Figure 2 provides an overview of progress in implementation of surveys.

Since 2016, ten countries have completed national surveys according to methods set out in the WHO standardized protocol and subsequently, the WHO handbook: China, Ghana, Kenya, Moldova, Mongolia, Myanmar, Nigeria, Philippines, Timor Leste, and Viet Nam. Final reports have been published or are being finalized.

Seven additional countries are preparing a survey in 2018 or a survey is ongoing: Fiji, India, Papua New Guinea, Sudan, Uganda, UR Tanzania and Zimbabwe. A further ten countries are planning a survey in 2019: Burkina Faso, Colombia, Dominican Republic, DR Congo, Guatemala, Indonesia, Liberia, Mozambique, Solomon Islands, and Thailand.

Figure 2: Overview of global progress in high TB burden countries implementing national surveys of costs faced by TB patients and their households (shown by year of data collection start)

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1 A subnational survey is also planned in Sao Paolo, Brazil.
Results from selected surveys (provisional)

Provisional results from selected surveys are shown in Table 1 and Figure 3.

Table 1: Provisional results for the proportion of TB patients and their households that faced catastrophic costs in 8 national surveys, for drug-susceptible (DS) and multidrug-resistant (MDR) TB separately

<table>
<thead>
<tr>
<th>Country</th>
<th>Sample size</th>
<th>Households facing catastrophic costs (%)</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>DS-TB</td>
<td>DR-TB</td>
<td>DS-TB</td>
<td>DR-TB</td>
<td>Overall</td>
</tr>
<tr>
<td>Fiji*</td>
<td>222</td>
<td>2</td>
<td>40</td>
<td>100</td>
<td>*</td>
<td>40</td>
</tr>
<tr>
<td>Ghana</td>
<td>625</td>
<td>66</td>
<td>63</td>
<td>77</td>
<td>64</td>
<td></td>
</tr>
<tr>
<td>Mongolia</td>
<td>547</td>
<td>193</td>
<td>65</td>
<td>85</td>
<td>68</td>
<td></td>
</tr>
<tr>
<td>Myanmar</td>
<td>901</td>
<td>66</td>
<td>57</td>
<td>100</td>
<td>60</td>
<td></td>
</tr>
<tr>
<td>Nigeria</td>
<td>1095</td>
<td>95</td>
<td>69</td>
<td>89</td>
<td>71</td>
<td></td>
</tr>
<tr>
<td>Philippines</td>
<td>1492</td>
<td>301</td>
<td>31</td>
<td>67</td>
<td>35</td>
<td></td>
</tr>
<tr>
<td>Timor Leste*</td>
<td>457</td>
<td>0</td>
<td>83</td>
<td>-</td>
<td>83</td>
<td></td>
</tr>
<tr>
<td>Viet Nam</td>
<td>677</td>
<td>58</td>
<td>60</td>
<td>98</td>
<td>63</td>
<td></td>
</tr>
</tbody>
</table>

* Surveys are not designed to calculate disaggregated estimates for DS and DR-TB.

Figure 3: Provisional results for the distribution of costs faced by TB patients and their households and (centre of each circle) the percentage of households facing catastrophic costs.
**Dissemination of survey findings and policy translation**

Results from surveys have the potential to significantly inform policy discussion in two major ways. First, costs can be mitigated by changing approaches to health financing and service delivery, including revisions to health financing policy, insurance schemes, fee structures, and models of care that are more decentralized, and outpatient or community-based. All of these changes should be consistent with the country’s progress towards UHC. Second, any costs that remain after optimization of approaches to health financing and delivery can be mitigated by improved social protection measures, in collaboration with stakeholders across the social sector.

Results from surveys should be used to facilitate policy discussion in both areas and stimulate the engagement of multisectoral partners (Annex 2 provides examples of concrete options for intervention).

A multi-stakeholder consultation can be the most effective approach to dissemination of results. This can be used to engage key stakeholders, secure political commitment and advocate for strong social support for TB patients and their households. For example, in Viet Nam a multisectoral meeting was used to disseminate findings; this resulted in a joint action plan with the Ministry of Labour and Social Affairs aimed at mitigating costs. Similar dissemination and stakeholder consultations are scheduled in Kenya and Ghana during the second quarter of 2018.

4. **Technical updates**

**a) Technical annex of the handbook**

Based on experience and lessons learned from surveys to date, three areas for improvement in terms of available guidance related to survey design and analysis of results have been identified and are being addressed. These are:

- Methods for calculating confidence intervals for key survey indicators, adjusted for the sampling design.
- Methods for sampling and stratification.
- Recommendations on the design of a household expenditure questionnaire (to derive a household income measure based on expenditure).

Updates to guidance on these topics will be published as web annexes to the TB patient cost survey handbook.

**b) 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, including: adaptation of the survey instrument for a longitudinal study design (and associated definition of the optimal timing for multiple interviews of patients); methods to capture metrics related to living standards, for example using health insurance claim systems to capture direct medical costs; and how to ensure compliance with laws and regulations related to confidentiality, which are often more strict in high-income countries.

**c) Adaptation of materials into Spanish, French and Russian**

*Tuberculosis Patient Cost Surveys: A Handbook* will be translated into French in the second quarter of 2018 and into Spanish shortly thereafter. The generic survey instrument is already available in French. There are no plans to translate materials into other languages at this time.
5. Next steps

Priority areas of future work planned by WHO are listed below.

**Guidance:**
1) Development of standard Terms of reference (ToR) for partners/consultants providing technical assistance to countries implementing TB patient cost surveys.
2) Development of guidance on how to conduct an assessment of social protection and access barriers as part of national TB programme reviews.

**Capacity building:**
1) A post-graduate course ("An introduction to national tuberculosis patient cost surveys") is planned for the 49th World Union Conference on Lung Health and Tuberculosis in October 2018 in The Hague, The Netherlands.
2) A training workshop will be organized in 2019 with two objectives: (i) to harmonise global practices for providing technical assistance to countries implementing patient cost surveys, and (ii) to train a group of consultants (epidemiologists and health economists) based on standard ToRs on methods for the design, implementation, analysis and reporting of TB patient cost surveys.

**Technical support:**
1) Global coordination of technical and funding support for surveys, based on regular communication with technical and funding agencies.
2) Maintenance and periodic updating of a consultant roster.
Annex 1. Steps to implement TB patient cost surveys and related activities and roles of WHO and partners.

<table>
<thead>
<tr>
<th>Activities and roles of WHO and partners</th>
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<tbody>
<tr>
<td>- WHO supports National TB Programmes (NTPs) to initiate discussion with key stakeholders for scoping and conceptualizing the survey.</td>
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<td>- Funds to be identified from domestic and external resources.</td>
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<td>Situation assessment includes reviewing recent epidemiological assessment and existing health and economic surveys, stakeholder identification and social protection mapping.</td>
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<td>WHO and international partners can support protocol development in close collaboration with NTPs and designated principal investigators of the survey.</td>
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<td>WHO and partners will provide training for data collectors and field supervisors in close collaboration with NTPs and designated principal investigators.</td>
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<td>Data collection is preferably done by an independent entity who is not engaged in care delivery. WHO and international partners can support field monitoring and data quality assurance.</td>
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<td>WHO has developed standard codes for data analysis and provides assistance to perform analyses.</td>
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<td>Dissemination and policy dialogues are the most critical steps to make the best use of the survey. The findings of the survey can help NTPs to identify strategies to eliminate catastrophic costs due to TB in line with the End TB Strategy target. They also serve as a great tool to advocate for enhanced social protection that benefits TB patients.</td>
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<tr>
<td>Multi-sector dialogues should lead to a concrete action plan with clear roles of responsibilities and accountabilities.</td>
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<td>WHO developed a guiding template for the survey report. Countries can also consider journal publication of the survey to contribute to the national and global body of evidence.</td>
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Annex 2. Examples of main cost categories and possible interventions that might be considered to eliminate costs or mitigate their impact (from TB patient cost survey handbook)

<table>
<thead>
<tr>
<th>Cost category</th>
<th>Possible change in service delivery</th>
<th>TB patient social support and social protection schemes</th>
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</table>
| **Direct medical: before TB diagnosis** | • Streamline the TB patient pathway  
  - Understand and adapt to treatment-seeking behaviours  
  - Update and promote the national standard of TB diagnosis and eliminate irrational testing  
  - Extend access to rapid molecular diagnostics  
  - Effectively use chest radiography  
  - Improve links with private sector providers using consistent policies (e.g. quality of care, free of charge)  
  • Intensify targeted case finding, including systematic screening for priority risk groups | • Reduce/subsidise/eliminate out-of-pocket (OOP) payment  
  - Increase insurance coverage (general)  
  - Reimburse OOP made by TB patients  
  - Regulate and eliminate informal fees  
  • Engage relevant actors in or outside TB to identify opportunities that can enable better access |
| **Direct medical: after TB diagnosis** | • Expand free-of-charge or highly subsidised TB service package including all TB medicines, ancillary drugs, procedure to monitor adverse events and preventive treatment.  
  • Promote integrated management of comorbidities and risk factors (HIV coinfection, diabetes, other lung diseases, tobacco smoking, harmful use of alcohol).  
  • Improve the quality of TB care  
  - Update and promote the national standard of TB care with an emphasis on people-centred care  
  - Eliminate irrational treatment, hospitalization and testing. | • Reduce/subsidize/eliminate OOP  
  - Increase insurance coverage for TB-related services  
  - Increase insurance coverage for relevant comorbidities and risk factors  
  - Regulate and eliminate informal fees  
  • Improve provider payment mechanism to avoid over-provision of services  
  • Explore social protection available for specific vulnerable groups and people with medical conditions |
| **Direct non-medical** | • Advocate local health-seeking and for care models bringing services close to patients, including community- and workplace-based care.  
  • Improve the quality of nutritional advice and regulate irrational nutritional recommendations by health care providers (e.g. supplements) | • Provide assistance via TB programme  
  - Cash transfer  
  - Specific allowances (e.g. food, transportation, etc.) by cash, voucher, or in-kind  
  • Expand the use of general social assistance schemes  
  • Engage NGOs, civil society organizations (CSOs) and patient groups to ensure patient support suitable for the locality |
| **Indirect costs (income loss)** | • Range of interventions to enable earlier diagnosis and patient-centred care delivery that minimize time spent seeking and receiving care (decentralization, shorter waiting times, fewer health care visits, avoid unnecessary hospitalization, etc.)  
  • Improve access to social services  
  - Improve health workers’ knowledge on social protection schemes  
  - Seamless link between health and social offices (one-stop site)  
  - Engage civil society and community organizations and volunteers in non-health sectors (social work, charity, legal services and volunteers) | • Facilitate enrollment of eligible patients/households in existing social protection schemes  
  - Social assistance for poor and vulnerable families  
  - Sickness/disability grant  
  - Cash or in-kind transfer programme  
  • Advocate review and/or improvement of social insurance as income replacement during illness.  
  • Legislate and/or enforce provisions related to social, economic and labour rights to protect individuals during TB illness and care |