Introduction

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The Tool to Estimate Patients' Costs has been developed by KNCV Tuberculosis Foundation, the World Health Organization and the Japan Anti-Tuberculosis Association from 1. October 2007 until 30.September 2008, coordinated by KNCV. Its development was funded by the Tuberculosis Control Assistance Program TB CAP www.tbcta.org. We aim to continuously improve the tool and will be therefore grateful for any suggestion or comment. In this case, please write to Verena Mauch mauchv@kncvtbc.nl.

1. Acknowledgements

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2. Background and Context

Tuberculosis is a disease that disproportionately affects the poor. TB programs therefore need to ensure that the economically and socially disadvantaged groups do not face barriers that keep them from seeking treatment. In addition, TB programs need to ensure that TB doesn't stand at the beginning of a spiral into (deeper) poverty.

By addressing barriers and reasons for delay to timely diagnosis and treatment by the NTP, costs to TB patients, particularly among the poor, can be effectively reduced. The Poverty Sub-Working Group of the Stop TB Partnership has therefore decided to develop a tool which can assist TB programs to estimate the costs of TB patients before and during diagnosis and during treatment by the NTP.

The aims of the tool are to:

1. To make economic constraints to individuals and households more apparent.
2. To Provide means to assess the impoverishing impact of TB on patients and their families.
3. To establish an evidence-base upon which subsequent interventions can contribute to poverty reduction, increased equity in access to diagnosis and treatment, increased case detection, better treatment adherence

As a first step in developing the Tool, a literature review on studies dealing with patients' costs and methodologies employed was conducted. The objective of the review was to provide a detailed account of research findings at which stage what kinds of costs are incurred. The findings of the review formed the basis and context upon which the tool has been developed. The Tool to Estimate Patients' Costs integrates findings of the review with respect to types of costs, magnitude of costs, specific cost items and indicators to be measured.

3. The Tool and its parts – The tool consists of:

1. **Introduction** (this document)
2. **Detailed literature review on patient cost studies**

The literature review provides a comprehensive overview of past research on patient costs, conceptual frameworks, definitions of different types of costs, approaches to measure the costs of illness, income data and income indicator usage, knowledge gaps and methodological problems. We developed the tool according to findings of the literature review. It is recommended to first read the review in order to understand the tool, and the choice of questions in the questionnaire.

3. **Brief review of socioeconomic indicators**

This short review of was prepared to identify the most important se indicators to ask for in the questionnaire. With the help of these indicators, it will be easier to understand the se background of patients, their vulnerability and their ability to cover the costs they incur due to TB. The review also lists useful literature on se indicators and their usage.

4. **List of indicators to be measured**

This list basically shows what we will know after analysing the results obtained from patient interviews with the questionnaire. It therefore gives you a quick overview what kind of information will be generated through application of the questionnaire.

5. **Generic questionnaire to be adapted to local circumstances**

The questionnaire is the heart of the tool. It is designed to interview patients about their costs due to TB. It has been successfully tested in Kenya in 2008. It is a generic version which needs to be adapted to the respective country and setting. Please refer to the guidelines on adaptation and methods when adapting the questionnaire.

6. Guidelines on adaptation to local circumstances

These guidelines give advice on translating the questionnaire and pretesting it, and it lists and explains all questions that need to be adapted to the local setting.

7. Guidelines on methods, sampling and training of interviewers

These guidelines provide a step by step overview of the methodology that needs to be adhered to in order to produce replicable results. They highlight important points to be considered when the sample, sample size, the target group and in- and exclusion criteria are chosen, data is analyzed and the training of interviewers is planned; in addition, they provide examples of other patient cost survey methods and the coding of questions. It is recommended to refer to a qualitative and quantitative research methods book in addition to these guidelines; respective literature is listed and a quick guide and explanation to the Epi Info data entry template can be found here as well.

8. Guidelines on interpretation of results generated by the questionnaire

These guidelines will help you to interpret your findings - what the results actually mean. The guidelines address each type of costs and related issues such as gender, socioeconomic questions, affordability, productivity etc that were measured by the questionnaire; in each section, the respective indicator and the questions that were used to measure the costs are listed - to guide you through each topic on a step-by-step basis. In addition, the guidelines provide an overview of income indicator usage and income data with links to databases and websites, so that you can compare your income data results with those of other sources.

9. Guidelines on possible interventions

This table will help to think of measures to address the issues found through the analysis of the data generated by the patient interviews. It lists problems and related possible action points and therefore works in the sense of: if you found this, you could think of doing that. The conceivable action points and recommendations are based on the WHO guideline *Addressing Poverty in TB Control.*

10. Epi Info template for data entry

In order to alleviate data entry after patient interviews, we have developed a template which is aligned with the generic questionnaire. The software Epi Info can be downloaded for free on the CDC website. The template needs to be still adapted in line with the adaptations made to the questionnaire according to the local setting.

11. MS Excel template to summarize results

This Excel template lists all types of costs measured by the questionnaire. You can enter results and it will give you a nice overview of all costs incurred and it calculates for you aggregated costs and summaries. This will make it easier for you to report on the costs found by your study. It is recommended to look at this template in the preparation stage of your study to get an idea what the end result should look like.

4. Types of costs

The three main types of costs are:

1. charges for health services,
2. transport, accommodation and subsistence and
3. lost income, productivity and time.[1]

Individuals suffering from TB are often ill in their most economically-productive age, which poses a significant economic burden on the household. Poor people have longer pathways to care and costs of accessing care are generally higher before than after diagnosis.[2] Relative costs for poor people as a percentage of their income is much higher than for non-poor patients, although aggregate real costs may be smaller.[3] Out-of-pocket costs for public and private healthcare services may stand at the beginning of a spiral into poverty for many families and exacerbate the poverty of the already-poor. This situation has been termed the "the medical poverty trap"[4].

Stratification of patients along several indicators (gender, geography, socioeconomic status) is therefore necessary to obtain an accurate picture of the economic situation facing TB patients.

Direct costs:

- ☐ Travel, food, accommodation during visits to care givers for seeking help in private and public sector including pharmacies, traditional healers etc. before diagnosis by the program
- ☐ Expenditures on medicines, special foods, tests before diagnosis by the program
- ☐ Travel forth and back for tests and receiving test results
- ☐ Food and “special foods”
- ☐ Guardian costs
- ☐ Diagnostic tests (if not provided for free)
- ☐ Additional informal payments
- ☐ Charges for drugs
- ☐ ‘Under the table’ fees
- ☐ Costs due to hospitalization
- ☐ Travel, food, accommodation for follow up tests
- ☐ Travel, food for DOT visits (if applicable)
- ☐ Travel, food for medicine collection visits (if applicable)
- ☐ Consultation / user fees (if applicable)
- ☐ Guardian costs (person accompanying the patient to health center)
- ☐ Informal payments (if applicable): additional diagnostic tests, drugs
- ☐ Additional costs due to (parallel) treatment sought by other providers
- ☐ Additional costs for TB-HIV co-infected patients
- ☐ health insurance up front payments to be reimbursed later (if applicable)

[1] WHO 2005
[2] Nhlema et al 2003, Kamolratanakul 1999, Rajeswari et al 1999
[3] Nhlema et al 2003, Kemp et al 2007
[4] Dahlgren & Whithead 2006

Indirect costs:

- ☐ Income reduction due to missed work days/hours, lost job, loss of time to seek job, uptake of less paid labor due to illness
- ☐ Reduced household activities (or cost of other household member replacing household work)
- ☐ Missed work for guardian/DOT supporter
- ☐ Decreased productivity
- ☐ Coping costs: use of savings, reduction of food intake, assets are sold, extra job, kids drop out of school to work, debt / loans

5. Limitations of the tool

The tool can only reach those who, in the end, reached a health facility which provides DOTS. It does not reach those who have not sought help or begun treatment or defaulted due to high costs. Unless specifically defaulters are targeted and interviewed, the tool is biased towards those who have somehow been able to afford treatment and all that is related. Depending on the place of the interview, automatically a certain group of patients is excluded. The results of the tool will be heavily dependent on the districts and facilities where patients are interviewed; If the sampling strategy was purposive, the results will not be representative for all TB patients, but only for those considered poor or who live in the chosen districts; this needs to be taken into consideration when interpreting the results and designing interventions based on the results.

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TBCTA The Tuberculosis Coalition for Technical Assistance

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