

# Adaptation of the Tool to Estimate Patient Costs Questionnaire into Indonesian Context for Tuberculosis-affected Households

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## ABSTRAK

**Latar belakang:** Indonesia adalah negara dengan prevalensi tuberkulosis (TB) tertinggi kedua di dunia. Karena itu, sangat membutuhkan perbaikan dan inovasi atas strategi yang diterapkan di seluruh wilayah. Satu langkah mendasar dalam memantau penerapan ini adalah menyiapkan alat yang divalidasi untuk mengukur total biaya pasien dan total biaya bencana. Organisasi Kesehatan Dunia (WHO) merekomendasikan menggunakan versi kuesioner generik yang telah disesuaikan dengan konteks budaya lokal untuk menafsirkan temuan dengan benar. Tujuan penelitian ini adalah mengadaptasi kuesioner “the Tool to Estimate Patient Costs” untuk menghitung biaya total dan biaya total katastrofik pada rumah tangga terdampak tuberkulosis (TB) di Indonesia. **Metode:** Perangkat tersebut diadaptasi sesuai panduan terstruktur. Berdasarkan uji coba yang dilakukan pada studi sebelumnya (dinamakan sebagai ‘Studi Fase I’). Kami mengembangkan proses adaptasi dengan membandingkannya dengan kuesioner generik yang dikeluarkan oleh WHO serta mengevaluasinya dalam pertemuan komite pakar. Kami melakukan uji coba pada 30 pasien TB, menerima umpan balik kemudian melengkapinya dengan lembar penjelasan sebelum finalisasi kuesioner. **Hasil:** tujuh puluh dua perubahan mayor dilakukan selama proses adaptasi, termasuk mengubah pilihan jawaban agar sesuai dengan konteks Indonesia, memperbaiki alur pertanyaan, menghapus pertanyaan, mengubah susunan kata dan mengembalikan pertanyaan asli yang diubah sebelumnya di Studi Fase I. Partisipan menyatakan bahwa pertanyaan jelas dan mudah dipahami. Untuk mengatasi kesulitan partisipan mengingat data yang ditanyakan, kami melakukan beberapa perubahan untuk mendapatkan data yang mungkin tidak terisi, misalnya dengan merujuk data pada rekam medis, membuat proxy biaya, dan memandu pewawancara untuk menanyakan harga tertentu jika partisipan tidak yakin harga perkiraan pasar dari barang yang mereka jual. **Kesimpulan:** ‘The Tool to Estimate Patient Costs’ yang diadaptasi dalam Bahasa Indonesia dinilai komprehensif, siap dipakai untuk studi lain tentang biaya katastrofik terkait TB dan untuk memonitor pencapaian target the End TB Strategy.

**Kata kunci:** tuberkulosis, biaya pasien, biaya katastrofik, adaptasi, Indonesia.

## ABSTRACT

**Background:** Indonesia is the second-highest country for tuberculosis (TB) incidence worldwide. Hence, it urgently requires improvements and innovations beyond the strategies that are currently being implemented throughout the country. One fundamental step in monitoring its progress is by preparing a validated tool to measure total patient costs and catastrophic total costs. The World Health Organization (WHO) recommends

using a version of the generic questionnaire that has been adapted to the local cultural context in order to interpret findings correctly. This study is aimed to adapt the Tool to Estimate Patient Costs questionnaire into the Indonesian context, which measures total costs and catastrophic total costs for tuberculosis-affected households. **Methods:** the tool was adapted using best-practice guidelines. On the basis of a pre-test performed in a previous study (referred to as Phase I Study), we refined the adaptation process by comparing it with the generic tool introduced by the WHO. We also held an expert committee review and performed pre-testing by interviewing 30 TB patients. After pre-testing, the tool was provided with complete explanation sheets for finalization. **Results:** seventy-two major changes were made during the adaptation process including changing the answer choices to match the Indonesian context, refining the flow of questions, deleting questions, changing some words and restoring original questions that had been changed in Phase I Study. Participants indicated that most questions were clear and easy to understand. To address recall difficulties by the participants, we made some adaptations to obtain data that might be missing, such as tracking data to medical records, developing a proxy of costs and guiding interviewers to ask for a specific value when participants were uncertain about the estimated market value of property they had sold. **Conclusion:** the adapted Tool to Estimate Patient Costs in Bahasa Indonesia is comprehensive and ready for use in future studies on TB-related catastrophic costs and is suitable for monitoring progress to achieve the target of the End TB Strategy.

**Keywords:** tuberculosis, patient costs, catastrophic costs, adaptation, Indonesia.

## INTRODUCTION

Indonesia is achieving slow progress in its struggle to eliminate tuberculosis (TB). With the world's second-highest TB incidence worldwide,<sup>1</sup> it urgently requires improvements and innovations beyond the strategies that are currently being implemented throughout the country. While training of healthcare workers is essential, it is also important to note that access to healthcare often brings financial hardship to TB patients. The most vulnerable are poor families, who must deal not only with medical costs, but also with non-medical costs, such as travel and supplementation costs, which can drain up to half of their annual income.<sup>2,3</sup> All these costs are compounded by potential income loss.<sup>4</sup>

Challenges in eliminating TB therefore go beyond clinical management and are often related to socioeconomic problems. These problems can increase delay in TB diagnosis and treatment and plunge patients into a more severe state of TB illness and a higher risk of treatment failure and MDR-TB development.<sup>2-4</sup> This, in turn, will lead to more complicated cases with substantial implications for clinical management. Clinicians should therefore consider the financial problems faced by TB patients and their affected families during consultations.

Many patients, because of embarrassment,

prefer firstly to seek care from private providers rather than public health facilities, regardless of their financial capacity. Assessing patients' financial capability will help clinicians to decide whether they can prescribe additional diagnostic tests such as X-ray and branded drugs that may be unaffordable for patients. Otherwise, they should refer patients to public health facilities linked to the National Tuberculosis Program (NTP) that provides free laboratory examinations and TB treatment. During TB treatment, clinicians should also assess whether patients can afford transportation costs before deciding the number of visits per month. Assessing all of these issues is important to increase patients' adherence to the TB diagnostic procedures and treatment, as well as TB treatment success.

Understanding the complexity of TB burden, the End TB Strategy acknowledges the importance of these socioeconomic determinants in its target that by 2020, no TB-affected family should face catastrophic spending due to TB.<sup>5-7</sup> In some countries including Indonesia, it is very important that progress towards this target is monitored properly. One fundamental step in monitoring progress is preparing a validated tool for measuring total patient costs and catastrophic total costs. The World Health Organization (WHO) recommends using a version of the

generic questionnaire “The Tool to Estimate Patient Costs”<sup>7,8</sup> (henceforth referred to as the Generic Tool) that has been adapted to the local cultural context in order to interpret findings correctly.<sup>9,10</sup> Before Indonesia implemented Universal Health Coverage (UHC) in 2014, Van den Hof et al. had adapted the Generic Tool to be used in Indonesia and it was pretested in 2013 study. For the sake of convenience, we refer to the study as the Phase 1 Study.<sup>11,12</sup> However, the tool is no longer suitable with recent situation partly due to implementation of UHC and various answer categories in the Phase 1 tool including categories on health insurance and healthcare facilities. Also, since the pretesting in the Phase 1 Study involved only five multi-drug-resistant (MDR) TB patients, a larger sample size was needed to perfect the adaptation.

To monitor progress towards the target of eliminating catastrophic spending on TB in Indonesia, the present study aimed to pursue further adaptation of the questionnaire that had been developed in the Phase 1 Study.

## METHODS

The adaptation of The Tool to Estimate Patient Costs questionnaire consisted of two phases. The first phase was performed separately by van den Hof et al as a preliminary Indonesian study (the Phase 1 Study) in 2013.<sup>12</sup> Our study, which was referred to henceforth as the Phase 2 study, comprised the second phase of adapting the Generic Tool. Our study had a cross-sectional design and was conducted in 2016. In line with existing guidelines,<sup>13,14</sup> the whole process of adaptation consisted of seven steps. While the Phase 1 Study went through all the steps from I to VII, our Phase 2 Study re-ran steps V to VII, i.e. production of the definitive Indonesian Language version of the Tool. (Figure 1)

### Study Population

We interviewed 30 TB patients who had undergone at least one month of TB treatment in two sub-district Primary Health Centres (PHCs, *Puskesmas*), East Jakarta, which were Puskesmas Cakung and Puskesmas Jatinegara.

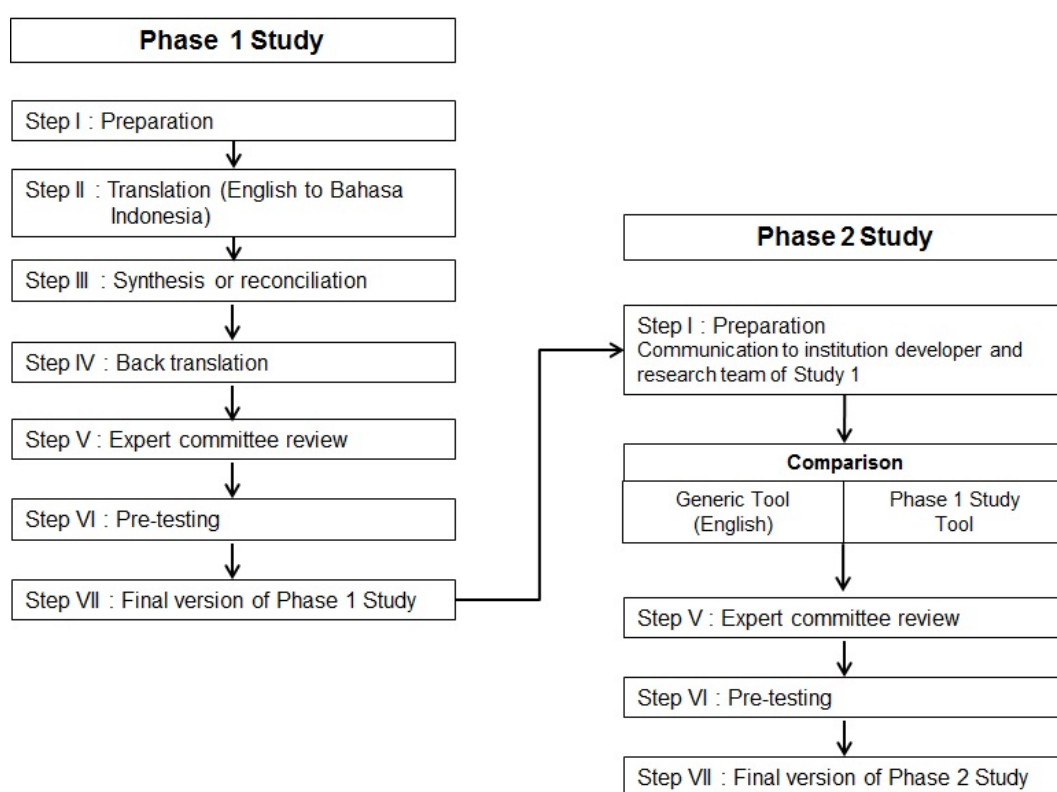


Figure 1. Study design: adaptation of the Tool

We tracked patients registered on the TB patient list and chose patients who met the inclusion criteria consecutively from the most recent date of treatment initiation. In PHC Cakung, we invited TB and MDR-TB patients to come to PHC and interviewed patients who were coming to the PHC consecutively. On three consecutive days, we interviewed 18 patients. In PHC Jatinegara, we made calls to the patients to make an appointment and visited them at home for an interview until 12 TB and MDR-TB patients had participated. If patient could not be interviewed because they were unable to communicate or not available at the time of interview, we asked their caregiver (termed “drug observer”) to participate in the study. The procedure brought the total number of interviewees to 30.

### **Phase 1 Study**

The principal investigator of the Phase 1 Study was a researcher from the KNCV Tuberculosis Foundation in the Netherlands, where the Generic Tool was originally developed. The study was prepared in Indonesia together with local researchers, one of whom was appointed to prepare for the forward translation into Bahasa Indonesia. Various questions, such as insurance types, types of healthcare facility and reimbursement schemes, were adapted to the local context. To check for interpretation errors, the questionnaire was back-translated and then pre-tested on five MDR-TB patients at Persahabatan Hospital, in Jakarta.<sup>11</sup> Its clarity for patients and interviewers was tested. After the pre-testing, further adaptations were made culminating in the final version of the Phase 1 Study Tool. We obtained the final version and compared it with the English version of the Generic Tool.

### **Phase 2 Study**

In our Phase 2 Study, we further refined the adapted version of the Tool to current Indonesian context. Rather than going through all of the steps again, we used the Phase 1 Study Tool as a starting point for adaptation and began the process at step V (i.e. expert committee review). Before doing so, we contacted the researchers of the Phase 1 Study by telephone and email and asked their permission to use their version for further adaptation.

### **Expert Committee Review**

The objective of the expert committee review (step V) was to check the content of the Tool once again. For the purpose, we held a meeting and invited key persons to discuss the Phase 1 Tool. Besides local researchers, the meeting included the following external experts: a pulmonologist specialized in infectious disease, a staff member from the Sub-Directorate for Tuberculosis at the Ministry of Health Republic of Indonesia and a psychometrics expert.

Before the meeting, the principal investigator, an Indonesian citizen, made a brief report in which he commented on questions and choices in the Generic Tool that remained uncertain or could be misinterpreted. The committee then compared the Generic Tool and the Phase 1 Study Tool, focusing on various sections in the WHO protocol that would need to be adapted to the local context. The adaptations included provider type, the TB care-delivery model, socio-demographic variables, net revenue from labour-related activities, health insurance and social protection and household assets. In addition to revising these sections, the committee also checked the entire Generic Tool and suggested some changes to the Phase 1 Study Tool. This stage resulted in a penultimate Indonesian translation version of the tool.

### **Pre-testing**

In a one-day training session before the pre-testing, we trained six medical students to interview 30 TB and MDR-TB patients or their caregiver (if the patient were unable or unavailable for interview) in two sub-district PHCs of East Jakarta. After each respondent had been interviewed, interviewers reported any difficulties they had encountered with regard to completing the tool or to the respondents' understanding of the questions. The researchers also discussed the findings, made changes and formulated the final version of the Tool in Indonesian Language.

### **Final Version**

After pretesting and refinement, we developed the final version of the Tool. We also provided comprehensive explanation sheets to guide the interview.

## Ethics

Pre-testing the Tool was part of our main study, which assessed catastrophic total costs among TB-affected households. We had obtained ethical approval from the Ethical Committee of the Faculty of Medicine, Universitas Indonesia and Cipto Mangunkusumo Hospital (No. 416/UN2.F1/ETIK/VI/2016) before commencing the study. Before the interview, we provided oral and written explanation to respondents and required them to sign informed consent forms. We ensured the confidentiality of all information collected from the interview.

## RESULTS

In total, 72 major changes were made during the adaptation process from the Generic Tool to the final version of Phase 2 Study (see Annex). The adaptations consisted of the following: reformulating questions and choices to reflect the current Indonesian context; re-structuring the ordering of several questions; deleting certain questions from the Generic Tool; and later restoring questions which had previously been deleted in the Phase 1 Study.

Phase 1 Study involved 60 changes relative to the Generic Tool. As well as the addition of two question sets under new sub-topics (moving costs and adverse effect costs), these changes included changing question sets into table form, adding seven questions and one sub-question, altering five answer choices and two wordings, and deleting three question sets (sub-topics) and 33 questions.

The most important change made in the Phase 1 Study was the overall flow of the Tool. In the Generic Tool, the questions are grouped on the basis of the types of cost. This required respondents to recall the costs they had incurred back and forth between the pre-diagnostic, diagnostic, and treatment phases. To facilitate the flow of interview, the Phase 1 Study had re-arranged the flow to match the time sequence. Other prominent changes involved redesigning some questions into table form, which made it easier for the interviewers to ask them and thereby to complete the Tool.

During the expert review meeting in Phase 2 Study, we changed the answer choices

relating to provider type from “Health Post (Pos Kesehatan)”, “PHC (Puskesmas), and “district hospital (RSUD)” to “PHC (Puskesmas)”, “private clinic”, “public hospital”, “private hospital”, and “other”. With reference to the TB delivery model, we changed the term “DOT” (Directly Observed Treatment), which respondents may not know, to “visit to take TB drugs” to make it easier for participants to understand the questions. In the section with socio-demographic questions, we changed categories relating to income payments (paid regularly, uncertain, paid in kind, not paid, and others). We also changed a question from “currently formally employed” to “formally employed before being diagnosed”, and followed with the question “Did you have to change or quit your employment after being diagnosed with TB?”. We restored a question “how many people regularly sleep in your household”, and modified it to “how many family members live in your household?”.

As UHC had been implemented in Indonesia since the Phase 1 study, the insurance system had changed. Using the abbreviation BPJS to indicate the national health insurance agency (*Badan Penyelenggara Jaminan Sosial*, BPJS), we adapted the types of insurance to government-paid BPJS, self-paid BPJS, and private insurance. No changes were made to questions in the revenue section. However, we made changes in the costs section, including the type of supplement taken (“drinks” to “milk”); the frequency of taking supplementation (from “per month” to “per week”); and the coping section (by changing the order of the questions on the amount of money gained from selling property). We also changed some wordings to make it easier for participants to understand questions, for example changing the term “smear” to “*Basil Tahan Asam* (BTA)” or the Acid-Fast Bacilli (AFB) testing, and “*pengembalian asuransi*” to “*reimbursement asuransi*”.

We retained 38 questions that were the result of adaptations made in the Phase 1 Study. We also restored 12 original questions from the Generic Tool that had been changed, and five original questions that had been deleted in the Phase 1 Tool. The restored questions included “date of

first diagnostic examination”, “date of starting treatment”, “where did you seek treatment?”, “what symptoms did you experience?”, and “why didn’t you go to a public facility?”. We also deleted three questions and three answer choices that had been added in the Phase 1 Study.

### Pre-testing

Seventy-four percent of the participants received the Category I therapy regimen; only 7% took MDR therapy. The majority (63%) underwent TB treatment in the continuation phase. (Table 1)

**Table 1.** Subject’s characteristics

Variables	n (%)
Participant	
- TB patients	27 (90.0)
- Drug observers	3 (10.0)
Sex	
- Male	15 (50.0)
- Female	15 (50.0)
Age category, years	
- 18-30	5 (17.0)
- 31-40	6 (20.0)
- 41-50	5 (17.0)
- >50	14 (46.0)
Educational level	
- Low	10 (33.0)
- Intermediate	20 (67.0)
Type of TB	
- Pulmonary, smear +	22 (73.0)
- Pulmonary, smear -	7 (23.0)
- Pulmonary, smear unknown	1 (4.0)
Therapy regimen	
- Cat I	22 (73.0)
- Cat II	6 (20.0)
- MDR	2 (7.0)
Therapy phase	
- Intensive phase	11 (37.0)
- Continuation phase	19 (63.0)

The respondents indicated that the majority of questions were clear and easy to understand. However, they had problems answering some others. Most respondents forgot the date of their first TB examination (63%) and the date they started treatment (57%). Neither did they know their HIV status (53%). We therefore

added explanatory notes for interviewers in the interview guidance. Instead of asking these data to participants, interviewers should track the data in the patients’ medical records. Respondents had difficulty to estimate transportation costs if they used their own vehicle. To deal with that, we guided interviewers to ask transportation-related costs such as parking or toll fees, but not fuel costs.

Many participants received bills from healthcare facilities that stated total amount of cost without any itemization. They had difficulty to distinguish between administration, laboratory, X-ray and drug costs. In such cases, we allowed interviewers to enter the total amount under administration costs. We deleted sub-questions under hospitalization costs and left only one question on total hospitalization costs since participants could not explain the detail of hospital item costs. If a TB patient had sold property and did not know the estimated market value, we added a question “Did the price conform to the estimated market value?” and trained interviewers to ask the specific price when participants were uncertain about the market value of property they had sold.

Annex 2 (available on [www.actamedindones.org](http://www.actamedindones.org)) contains the final version of the questionnaire resulting from our Phase 2 study, along with the explanatory notes.

## DISCUSSION

The Tool was successfully adapted to the current Indonesian context. It is now ready for use in similar studies on TB cost measurement and for monitoring progress to achieve the End TB Strategy target. Under the terms of the strategy, the government should monitor the target until 2035. Monitoring TB-related costs can help identify determinants of TB treatment outcomes and reduce the risk of treatment failure, severe adverse outcome, and further spread of TB, MDR-TB, or even XDR-TB because of socioeconomic problems.<sup>2,4,15-17</sup>

In our view, the adapted Tool is suitable for the purpose as it is more comprehensive than previous versions and is fully consistent with the situation in Indonesia since the implementation of UHC. The Tool can measure not only total

costs, but – as recommended by the WHO – also catastrophic total costs.<sup>7</sup>

Besides the refinements made to the Phase 1 version of the Tool, the strengths of this study include the relatively large number of respondents recruited, their wide age-range, and the balance between the sexes. The limitation is the fact that we only interviewed participants who were undergoing TB and MDR-TB treatment in PHCs. Thereby we excluded those who underwent TB treatment in other types of health facility or who dropped out of TB treatment. However, this limitation has been acknowledged in the WHO protocol, which excludes TB patients treated in facilities that are not linked to the national tuberculosis program. It means that the adapted Tool is now the most appropriate questionnaire for measuring catastrophic total costs.

The translation version that has been followed from the Phase 1 Study is acceptable and easily understood and there was no need for re-translation from English into Bahasa Indonesia. However, difficulties were encountered when we were seeking appropriate translations for terms such “DOT”, “dispensary”, and “mission hospital” that have no specific equivalent in Indonesian language, which may cause misunderstanding. Another potential source of misunderstanding was how participants define “primary income earner” or “*pencari nafkah*”, which may lead to confusion between “*pencari nafkah*” (primary income earner/breadwinner) and “*kepala keluarga*” (head of family). We therefore inserted an explanation of “primary income earner” as the highest earners who actually spent their earnings on financing the household.

In rural or remote areas of Indonesia where the Indonesian language is not being used in daily life, future studies should further adapt the Tool to the cultural context and local languages. It is imperative that all question items are explained clearly in the local languages.

The adaptation of the tool also provides useful insights for clinical practice. Instead of merely focusing on clinical complaints of TB patients, clinicians should also take socioeconomic problems into account, including the availability of health insurance, traveling costs to visit the health facility, and potential income or job loss

faced by the patient and their families. Assessing patients’ financial capacity will help clinicians to decide on appropriate prescription, including any additional supplements needed. Clinicians may also refer patients to existing social protection programs, e.g., national health insurance or national employee insurance, if patients are uninsured, or refer them to primary health centers that provide TB diagnostic and treatment freely.

## CONCLUSION

Our adapted version of the Tool to Estimate Patient Costs had been proven to be acceptable for use in Indonesia. Together with its explanations, it is easily understood by interviewers and interviewees. It is also ready for use in future studies on tuberculosis-related cost estimation and catastrophic spending measurement.

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