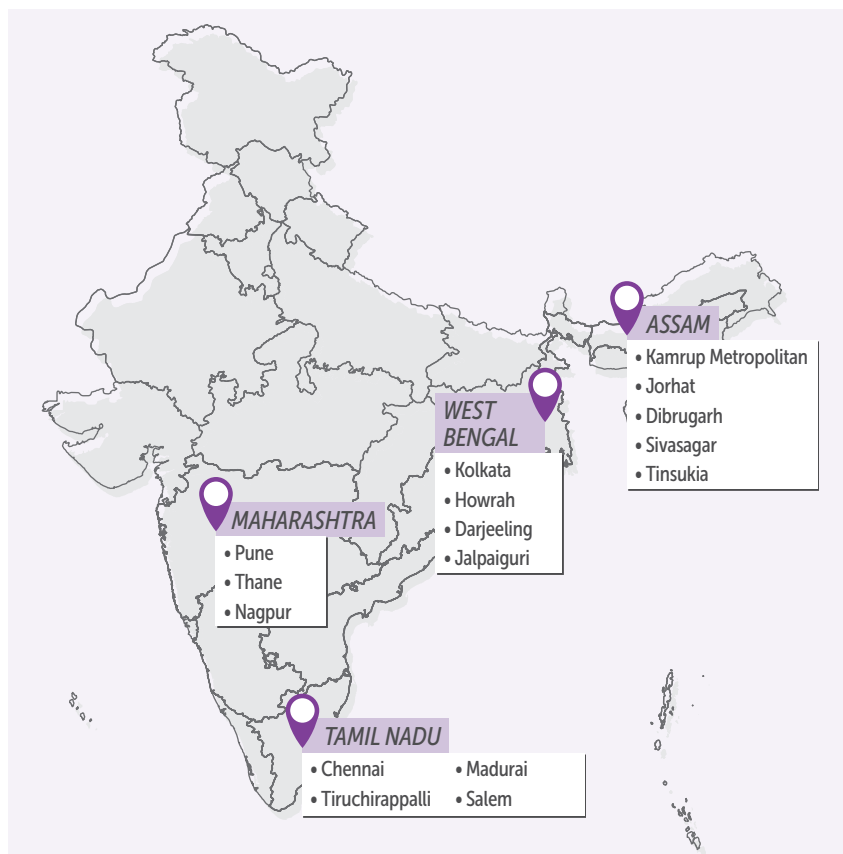


India has the highest tuberculosis (TB) burden in the world, with more than 24 lakh cases in the year 2022. Several advancements have been made in India for better management of TB over the years. The policy of the Government of India has been to provide "free" diagnosis and treatment to all registered TB cases, which include basic diagnostic tests such as sputum smear microscopy, chest x-ray, rapid molecular tests, and anti-TB medications.

Despite free diagnostic and treatment services being offered under the National TB Elimination Programme, households with members suffering from TB are exposed to high cost associated with TB treatment, resulting in catastrophic cost.<sup>1</sup> This could be because the patients may need to pay for other diagnostic tests such as CT scans, MRI scans, biopsy, consultation fees, travel expenses in pre-treatment period (i.e., from symptom onset to treatment initiation) and travel expenses for picking up TB drugs, additional food/nutritional supplements, and management of side effects during treatment period which are not covered under the programme. As a signatory to the "End TB strategy"<sup>2</sup>, the Government of India set a target of achieving zero catastrophic cost (defined as total TB treatment cost  $\geq$ 20% pre-TB annual household income) for TB affected households by 2025. It is, therefore, important to understand what proportion of TB patients in India are currently facing catastrophic cost.

This study, following up a representative cohort of 1482 drug-susceptible (DS) TB patients from three diverse groups of population: general population (n= 529), urban slum dwellers (n=526) and tea garden residents (n=427) examined the complete economic burden faced by the tuberculosis patients. Study participants were selected from four states (Assam, Maharashtra, Tamil Nadu, and West Bengal), 16 districts, 118 TB units and 182 tea gardens. They were interviewed three times: at the beginning of treatment, towards the end of treatment, average 7 months post-treatment during February 2019 till April 2023.



## OBJECTIVES OF THE STUDY

- To estimate total cost associated with TB treatment in India.
- To understand proportion of TB patients faced catastrophic cost.
- To examine economic consequences of TB disease in post-treatment period.

## SUMMARY RESULTS

### 1. Treatment pathway

- On an average, there was a delay of 9 weeks from the onset of TB symptoms to initiation of treatment. Additionally, between 72% and 75% of study participants chose a private healthcare provider as their first choice for seeking care after experiencing symptoms. This preference for private providers may be due to factors such as a perceived better quality of care and lack of awareness of the free TB diagnosis and treatment provided at government facilities.
- During the period leading up to their TB diagnosis, they made an average of 8-11 visits to different healthcare providers. Some individuals even made more than 20 visits (with the maximum of 52 visits) before their diagnosis highlighting the need for further training on TB diagnosis to health care providers.

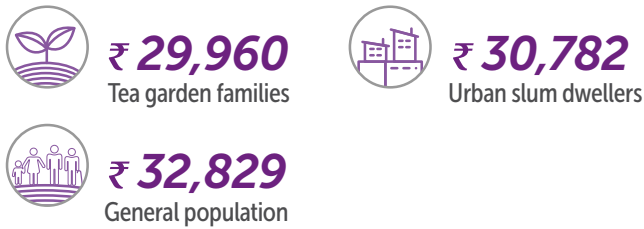
1 Yadav, J., John, D., & Menon, G. (2019). Out of pocket expenditure on tuberculosis in India: Do households face hardship financing?. *The Indian journal of tuberculosis*, 66(4), 448-460. [www.doi.org/10.1016/j.ijtb.2019.02.016](http://www.doi.org/10.1016/j.ijtb.2019.02.016)

2 Global Tuberculosis Programme (who.int)

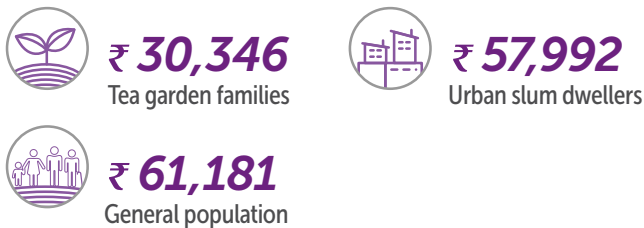
## 2. Treatment cost and catastrophe

- The total cost of TB treatment, including both direct<sup>3</sup> and indirect<sup>4</sup> costs was found to be significantly higher using output approach<sup>5</sup>, as compared to human capital approach<sup>6</sup>, of indirect cost calculation<sup>7</sup> implying massive household income loss associated with TB treatment. The lower cost for tea garden residents using output approach was because of their extremely low wage rates resulting in lower income loss.

### Total treatment cost using HCA method of indirect cost calculation (INR):



### Total treatment cost using OA method of indirect cost calculation (INR):



- Using HCA method, actual money spent contributed more than time loss in total treatment cost and majority of total treatment cost was incurred even before starting the treatment as there was huge delay from symptom onset to treatment initiation and during that period, patients made several visits to different providers.
- Percentage of total treatment cost that was direct cost (i.e., actual money spent)



- Percentage of cost incurred during pre-treatment phase (i.e., from symptom onset to treatment initiation)



- Because of high TB treatment cost, a large proportion of study participants faced catastrophic cost, i.e., their total TB treatment cost was more than 20% of their pre-TB annual household income.

Using HCA method	Using OA method
<b>30%</b>	<b>61%</b>

## 3. Direct Benefit Transfer (DBT)

- The Indian government introduced “Nikshay Poshan Yojana” scheme in 2018 to provide nutritional support for all registered TB patients. Financial incentive of INR 500 per month was proposed to be transferred directly to the registered beneficiaries’ validated bank accounts – Direct Benefit Transfer (DBT).
- The uptake of this benefit during treatment period was modest among our study participants with study participants from tea garden areas received the lowest. This could be because of their remote locations, dormant bank accounts.
- Percentage of study participants who received DBT benefit and full amount of benefit till the end of treatment.

DBT benefit amount received	Full amount of benefit (INR 3000) received
<b>31% to 54%</b>	<b>5% to 11%</b>

### 5% to 27%

Percentage of study participants who received the benefit after treatment completion.

### Usage of DBT benefit

The study participants mostly used DBT benefit amount for food, i.e., for the purpose it was given (Figure 1). However, the benefit was also used for other purposes such as travel expenses, medicines and tests. A proportion of study participants did not know whether they have received the benefit, and a proportion did not withdraw the money from their bank accounts.

3 Direct cost: actual money spent on consultations, drugs, tests, travel expenses, additional food, nutritional supplements.

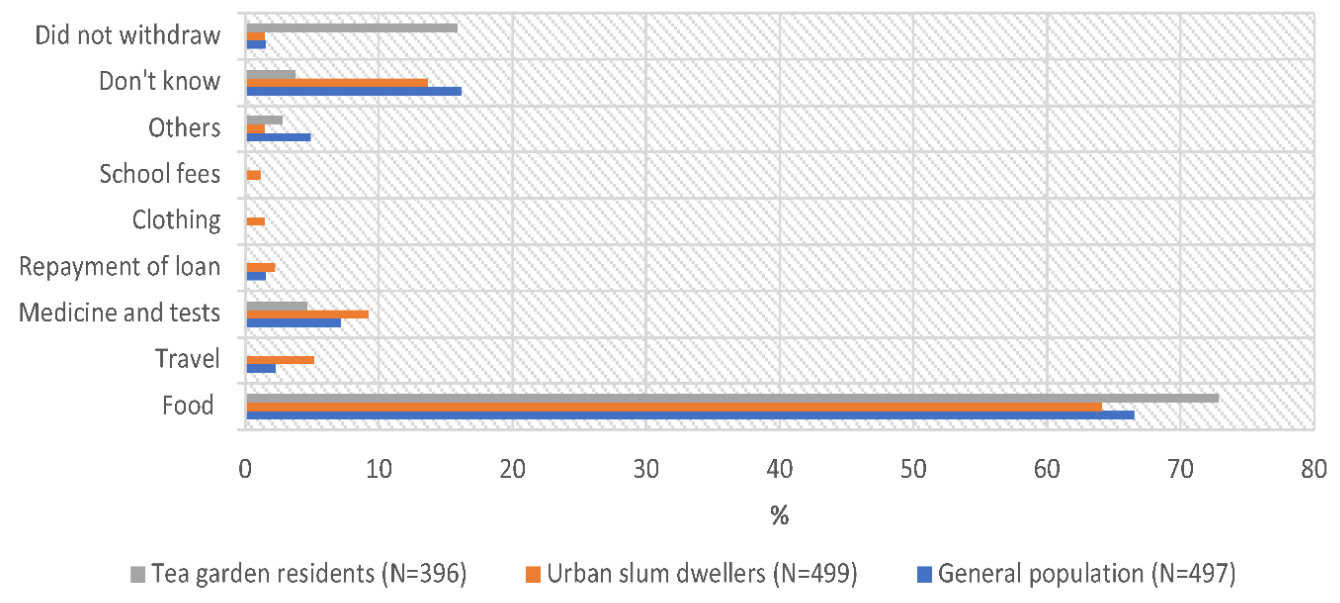
4 Indirect cost: time loss of patient and guardians related to TB treatment and income loss.

5 Output Approach (OA): household income loss from the onset of TB symptom till end of treatment.

6 Human Capital Approach (HCA) method: hours spent for various TB treatment related activities by the patients and guardians multiplied by hourly minimum wage rate of study states.

7 Indirect cost calculation methods include Human Capital Approach and Output Approach

Figure 1: Usage of DBT benefit by study participants reported at end of treatment interviews



### DBT and catastrophe

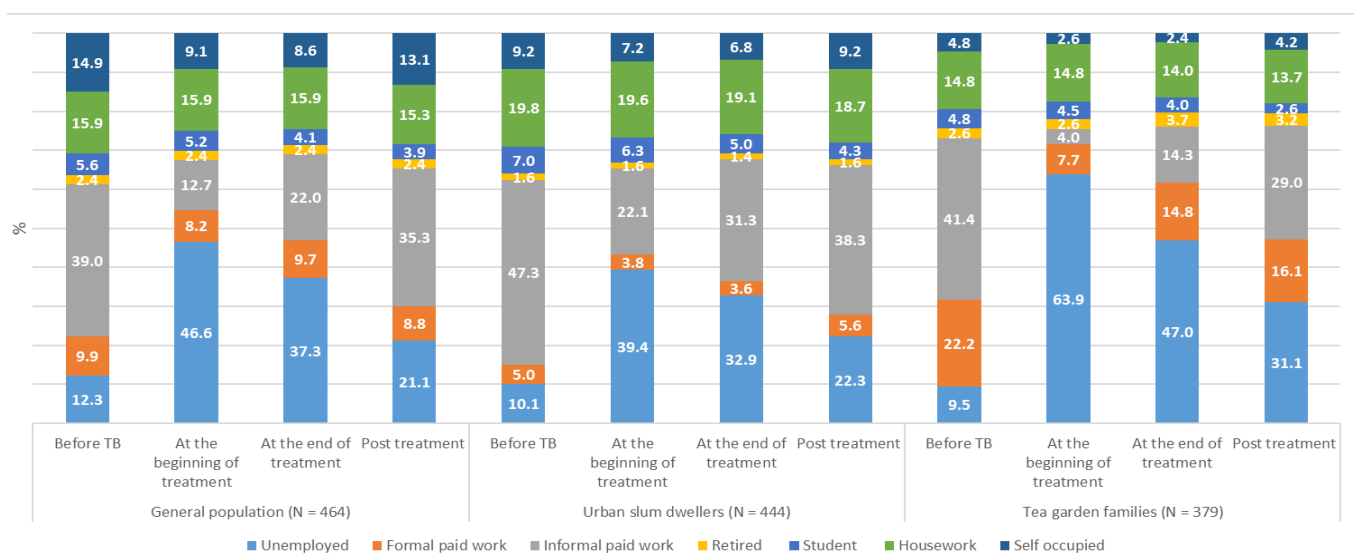
- It was found that the DBT benefit amount helped only 2% study participants to remain below catastrophic cost threshold.
- It was estimated that a uniform benefit amount of INR 10,000 for the whole duration of treatment (i.e., 6 months) will be able to push back about 43% DS-TB patients who faced catastrophic cost below 20% threshold.

however, at the beginning of treatment, the percentage of unemployment increased to 39% among slum dwellers, 47% for patients in general population, 64% among participants in tea garden areas implying that TB had serious impact on participants' employment (Figure 2). During the end of treatment, the situation improved, and unemployment rate ranged from 33%-47%. About seven months post-treatment, however, all study participants could not return to their pre-TB condition. Unemployment rate in post-TB period ranged from 21%-31% as compared to 10%-12% in the pre-TB condition.

### 4. Employment status of study participants at different phases

Before TB, approximately 10% patients among urban slum dwellers and tea garden areas and 12% among general population were unemployed,

Figure 2: Employment status of study participants at different phases



## 5. TB knowledge at post-treatment phase



The study participants had poor knowledge around TB even after completion of treatment.

**73%** of participants did not know ways of prevention after treatment completion.

**55%** of study participants were not aware of the mode of transmission of TB after completion of TB treatment.

**71%** of participants did not know who could be infected with TB.

## CONCLUSION

- A significant proportion of TB patients in India are still facing catastrophic cost. One of the major contributors of catastrophic cost was the delay from onset of symptoms till treatment initiation and during this period majority of cost was incurred because the patients made several visits to different providers before they were diagnosed with TB.
- Unemployment and Income loss associated with TB treatment was massive among study participants.
- Uptake of DBT benefit was modest and it helped only 2% study participants to remain below catastrophic cost. The uptake was the lowest among the participants from tea garden areas.
- Our estimate shows a uniform benefit amount of INR 10,000 for the whole duration of treatment (i.e., 6 months) will be able to push back about 43% DS-TB patients who faced catastrophic cost below 20% threshold.

## POLICY RECOMMENDATIONS

1. Strengthen policies to reduce delay in diagnosis to reduce cost of TB treatment and eventually reduce catastrophic cost. Empowering community around TB knowledge and available free services will help along with other government initiatives such as private sector engagement, active case finding.
2. Notify policies to protect TB patients from unemployment and income loss because of treatment.
3. Revision of Direct Benefit Transfer amount.
4. Notify policies to reimburse expenses incurred in the pre-treatment phase through revised Direct Benefit Transfer amount. At least 50% of the revised benefit amount can be transferred at the time of treatment registration.
5. Targeted approach may be considered for revised amounts in Direct Benefit Transfer. TB patients from tea garden areas could be the targeted group as the study showed they had very low income, significant proportion of them were in poorest quintiles, more patients faced catastrophic cost and death rate among them was higher as compared to other two groups. Further, their poor nutritional status was reported in the literature. This group also received the minimum amount of Direct Benefit Transfers among all study groups. Therefore, supporting them with the increased benefit amount could be the first step towards targeted approach.



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