Initiatives for Tuberculosis Prevention and Control

Patient-centric and collaborative responses to End TB by 2025
Tuberculosis (TB) is an infectious disease caused by the bacterium *Mycobacterium tuberculosis*. Tuberculosis most commonly affects the lungs, but can also affect other parts of the body. The classic symptoms of active TB are a chronic cough, sometimes accompanied by bloody sputum, fever, night sweats, loss of appetite and weight loss. A person may be infected by the TB bacteria and not develop symptoms. This is known as latent TB and this form of TB cannot spread to others. About 10% of latent TB infections progress to active TB, which spreads through the air when people cough, spit, speak or sneeze. If untreated, TB can be fatal.

Individuals living or working in overcrowded, badly ventilated spaces are vulnerable to developing TB, especially if they are in proximity to an infected person. TB also affects people with conditions that lower immunity, including diabetes, HIV/AIDS, undernutrition, and smoking. The very young and elderly are also more susceptible to TB infections.

The Burden of TB in India

One fourth of the global TB burden lies in India. According to the Global TB Report 2017, India had an estimated 2.79 million cases in 2016. A large proportion of these cases have not been reported to Nikshay, the national registry for monitoring TB patients. These ‘missing’ cases may be undiagnosed or receiving non-standardized treatment. Patients receiving non-standardized treatment or individuals who discontinue treatment run the risk of developing Drug Resistant TB (DRTB). This is a major obstacle to effective TB care and prevention, as DRTB is harder and more expensive to treat, and takes longer to cure.

In India, DRTB prevalence is 2-3% among newly diagnosed TB patients.1 The rate of treatment success of notified patients with DRTB in India was 46 percent in 2015, when compared to a 75 percent success rate of notified patients with drug-sensitive TB.2 Only 54 percent of Multi-Drug Resistant TB patients* and 30 percent of extensively drug-resistant TB are currently successfully treated worldwide.3
The Government of India’s National Strategic Plan for Tuberculosis Elimination (2017-2025) lays out a framework and set of strategies which involve the participation and collaboration of multiple stakeholders including the national and state governments, research institutions, civil society organizations and the private sector, with the goal of eliminating TB in India by 2025.

KHPT is working with TB partners across three states towards the vision of the Revised National Tuberculosis Control Programme (RNTCP), of a TB-free India with zero deaths, disease and poverty due to TB. KHPT and its partners are engaging with TB patients and caregivers, communities and community structures, as well as health system workers and health officials in order to effect TB control in urban areas through a set of initiatives intended to be sustainable and scaled-up.

KHPT implements two key projects apart from other smaller initiatives in the states of Karnataka, Andhra Pradesh and Telangana, to strategically contribute to the Government’s efforts towards TB elimination in India.

### Challenges to TB Prevention and Control

There is a lack of standardised and structured patient-centric treatment, care and support services and this can impact treatment outcomes and the overall effectiveness of TB control programs.

A large number of TB patients are ‘missing’; they have not been notified to the national registry and may either be undiagnosed or receiving poor-quality or non-standardized care.

Delayed and improper diagnosis, rampant and irrational use of antibiotics and inadequate follow-up support for people with TB result in increased cost, sickness, death and risk of drug resistance.

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**Andhra Pradesh**

- 110,887 TB patients
- 74,373 notified cases
- 33% cases missing

**Karnataka**

- 141,484 TB patients
- 68,462 notified cases
- 52% cases missing

**Bangalore**

- 22,134 TB patients
- 13,862 notified cases
- 37% cases missing

**Visakhapatnam**

- 9,636 TB patients

**Telangana**

- 79,025 TB patients
- 45,003 notified cases in 2016
- 43% cases missing

**Hyderabad**

- 9,006 TB patients
- 6,747 notified cases in 2016
- 21% cases missing

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2. The National Strategic Plan for Tuberculosis Elimination 2017-2025
3. WHO fact sheet on Tuberculosis http://www.who.int/news-room/fact-sheets/detail/tuberculosis
4. Calculated based on national Case Detection Rate of 217 per lakh population
5. The India TB Report 2017
* Multi-Drug Resistant TB patients refer to those who do not respond to the two most powerful TB drugs (Isoniazid and Rifampicin)
* Extensively drug-resistant TB patients refer to those who do not respond to the four core anti-TB drugs
The key objectives are:

**What does THALI do?**

THALI’s **overarching goal** is to increase TB case finding and improve TB treatment outcomes using a patient-centred approach to care and treatment support.

**The key objectives are:**

- To demonstrate community-centred and community-driven interventions to improve health seeking behaviour and service delivery to increase TB case finding and treatment outcomes among vulnerable people diagnosed and initiated on treatment for TB.

- To support and develop capacity of the Revised National Tuberculosis Control Programme (RNTCP), and leverage public resources to improve access to acceptable and quality TB services from public and private care providers, thereby increasing case finding and improving treatment outcomes. (capacity building of RNTCP staff using the funds available with medical colleges with the help of state and zonal task forces).

- To develop and demonstrate models and innovations for patient care and support which may be scaled up and replicated. These new models and innovations are designed to fill in gaps, or address challenges, in the health system and aid community health workers (CHWs) and RNTCP staff in providing TB treatment, care and support.
THALI’s Reach

- 10.2 million in 13 other districts of KARNATAKA
- 8.3 million in five other districts of TELANGANA
- 4.2 million in two other districts of ANDHRA PRADESH
- 1.7 million

THALI focuses on education for the general population, linkages to treatment for people living with TB and, patient care and support services.
THALI’s Guiding Principles

THALI’s approach is based on five principles of TB care:

- **Appropriate health-seeking behaviour of people with TB symptoms**
  People recognize early symptoms and signs of TB, know where to seek care, and access microbiological testing for TB diagnosis and quality services.

- **Evidence-based diagnosis**
  All persons with symptoms of TB are prescribed the best available and affordable microbiological tests to establish definitive diagnosis. These tests are done at certified, quality-assured laboratories.

- **Standard, evidence-based treatment**
  Standard anti-TB regimens are used to treat new TB patients presumed to be drug sensitive. Previously treated TB patients, and those exposed to drug-resistant TB, are initiated on tailored treatment regimens after drug sensitivity testing.

- **TB notification**
  All TB patients diagnosed and initiated on treatment by clinical providers, and all patients tested microbiologically positive for TB at laboratories, are notified to public health authorities.

- **Treatment follow through**
  All TB patients initiated on TB treatment are counselled, monitored and supported for treatment adherence, completion and prevention of spread of the disease.

THALI’s Strategic Approach

THALI’s approach to eliminate TB is through **multi-sectoral collaboration, integration with the RNTCP, establishing patient-centred systems for care and support and demonstration of evidence-based models and innovations** that address the needs and service gaps identified in the continuum of TB care.

**The Continuum of Care**

- **Symptoms perceived**
- **Health seeking**
- **Screening by 1st provider**
- **Diagnostic test(s)**
- **Diagnosis**
- **Treatment prescribed**
- **Treatment initiated**
- **Patient notified**
- **Patient counselled**
- **Treatment monitored**
- **Care and support for treatment adherence, contact screening & TB prevention**
- **Treatment outcome**
- **Continued evaluation**
- **Public Health Action**
- **Service Delivery**
- **Demand**
THALI’s approach to Prevention, Care and Support (PCS)

THALI’s patient-centred treatment support system promotes treatment adherence to medication beyond a simple monitoring mechanism. THALI’s approach to PCS includes psychosocial, financial, nutritional, medical and infection prevention components.

**Components - Prevention, Care & Support**

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<thead>
<tr>
<th>Psychosocial</th>
<th>Nutritional</th>
<th>Infection prevention</th>
<th>Financial</th>
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<td>- Reassurance</td>
<td>- Nutritional advice</td>
<td>- Cough hygiene</td>
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<td>- Counseling</td>
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<td>- Disclosure</td>
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<td>- Co-morbidity</td>
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<td>- Contact screening</td>
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<td>- Lifestyle/habits</td>
<td>- Non-Government Organizations, Civil Society Organizations</td>
<td>- INH Prophylaxis Therapy</td>
<td>- Panchayati Raj Institutions</td>
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<td>- Family support</td>
<td>- Panchayati Raj Institutions</td>
<td>Isoniazid Prophylaxis Therapy</td>
<td>- Social security linkage</td>
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<td>- Stigma reduction</td>
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<td>- Support groups</td>
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<td>- Livelihood linkage, loan access</td>
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**Medical**

- Post diagnosis support
- Adherence support & monitoring
- Patient status evaluation
- Side effects/symptom management
- Tertiary care linkage*

*Within healthcare settings

- Referral for follow-up sputum microscopy cultures
- Treatment rupture intervention (when patient not traceable)
- Post treatment follow up

- Diagnosis, Treatment, Adverse Drug Reaction Management
- Comorbidity management, deaddiction
- Medical emergencies, complications
- Ancillary drugs
- Palliative care, physiotherapy

The Differentiated Care Model

THALI’s approach to patient-centred care is implemented through a Differentiated Care Model for PCS. This model prioritizes care for vulnerable populations who are at a higher risk of poor treatment outcomes because of their physical condition, comorbidities, or difficulty completing their course of treatment. It is estimated that these ‘difficult’ cases constitute 25-28 percent of TB patients requiring PCS services. It will identify these patients through a process of risk and needs assessment carried out for each patient and to subsequently provide a package of care and support services in synergy with RNTCP field staff.

**THALI targets seven categories of patients through its differentiated care model.**

- Elderly patients over 60 years of age
- Patients who are living alone
- Patients who were treated previously, and had taken medication irregularly
- DRTB Patients
- Patients consuming alcohol
- Patients co-infected with HIV
- Patients with diabetes

It aims to push positive treatment outcomes over the 90 percent mark by addressing the needs of these patients through prioritized outreach, intensified monitoring and follow-up, counselling and linkages to services.
THALI’s engagement is positioned at two levels in addition to a few cross cutting activities:

I. Community Engagement
THALI works to improve health seeking behaviour and promote patient and family-focused care among key affected populations which are vulnerable to TB because of their socio-economic status, where they work or because of biological factors. These vulnerable population may not seek timely treatment or may visit numerous practitioners- qualified or unqualified, before being tested and diagnosed. These include population groups such as:
- The urban poor who are concentrated in densely populated areas like slums
- High-risk occupation groups such as construction workers, miners and garment industry labourers
- Persons with co-morbid conditions, including HIV/AIDS, under-nutrition and diabetes
- Tribal populations, especially people of indigenous tribes with poor access to quality health services
- Vulnerable subpopulations, including women, children and the elderly, who tend to be additionally marginalized, neglected and are prone to inequitable access to health care.

THALI uses robust micro planning and outreach processes that help identify new and ‘missing’ TB cases. It uses a monthly tracking system that helps find Loss to Follow Up (LFU) TB patients, re-initiate their treatment regimen and place them back into the continuum to care.

II. Government Engagement
THALI engages with state and district RNTCP officials, as well as state government representatives to implement the strategies laid out by the RNTCP’s National Strategic Plan (NSP) to eliminate TB by 2025. THALI orients and sensitizes relevant government departments on TB, increases visibility and demand generation for RNTCP’s TB services, enhances governments’ capacity to improve TB case finding and case holding through improved service delivery of health services, and streamlines patient care and support and financial benefits.

III. Cross Cutting Activities
THALI implements cross-cutting activities such as monitoring, evaluation, research and learning, partnerships and communication, and technology-based innovation to support the first two activity streams.
The THALI model

Strategic Framework- Patient Care and Support

**TB ELIMINATION**

Case Finding (Active Case Finding Campaign, Contact Screening, Access to Services)

RNTCP → THALI, JEET

Public Sector (Detect-Diagnose-Treat) → THALI, RNTCP, JEET

Private Sector (Detect-Diagnose-Treat) → THALI, JEET

Community Structures → THALI

Continuum of Care

**Patient Centred & Family Focused**

- Patient Support Groups
- Patient Advocates
- HICs, Volunteers, Care givers
- Key Opinion Leaders

- In-person care
- Careline, 99 Dots
- Build Community Support
- Direct Benefit Transfer and Social entitlements

**INNOVATION**

**RESOURCE**

**EVIDENCE**

THALI partnerships

The KHPT -led THALI consortium collaborates with the RNTCP at the central, state and district levels. The project is aligned closely with the vision and strategy laid out by the NSP to support the government in its endeavour to eliminate TB by 2025.

The consortium includes TB Alert India (TBAI), the implementing partner for Telangana and Andhra Pradesh, and St John’s Medical College and Research Institute, a technical support partner to steer the engagement with health care providers and medical colleges, and develop capacity building tools.

FLWs- Frontline Workers, HICs- Health Information Centres, JEET- Joint Effort for Elimination of Tuberculosis, RNTCP- Revised National Tuberculosis Control Programme
JEET: Private sector engagement towards TB control

The RNTCP’s National Strategic Plan recognizes that the private sector is an ever-expanding component of the health system and provides care for over half of the TB patients in India. However, it also realizes that many patients in the private sector are not notified to the national registry, affecting TB control - especially in urban areas - due to diagnostic delays, variable treatment quality and absence of drug quality controls.

The Joint Effort For Elimination of Tuberculosis (JEET) aims to set up effective and sustainable structures to strengthen existing systems and seamlessly extend quality TB care to patients seeking care in the private sector. JEET is supported by the Global Fund to Fight AIDS, Tuberculosis and Malaria in the districts of Bengaluru Urban, BBMP and Bengaluru Rural, and works in collaboration with the RNTCP. THALI provides wraparound support to JEET in these geographies.

The key objectives of JEET are:

1. To develop an insight into private sector by conducting mapping & prioritization of private sector healthcare providers

2. To facilitate access to RNTCP-approved affordable TB diagnostics for patients seeking care in the private sector through public and private lab network for increased notifications and quality diagnosis

3. To facilitate access to early, appropriate and free treatment initiation, public health actions and adherence support systems for patients seeking care in the private sector.

These services will be provided through the establishment of a Patient Provider Support Agency (PPSA), which will:
- Map private health care providers and identify champion providers
- Continuously follow up and engage private providers through visits and continuing medical education (CME)
- Facilitate private sector notifications on the Nikshay national registry portal
- Establish linkages to quality-assured free diagnostics and treatment (FDCs) services under RNTCP through SCT
- Support treatment adherence through Treatment Coordinators
KHPT also engages with Indegene Lifesystems Pvt. Ltd, which partly supports the TB Careline, a phone-based patient care and support service providing information on TB, treatment monitoring and counselling to TB patients and caregivers free of cost, with the intent of improving treatment outcomes through the systematic counselling of patients on treatment.

The Careline goes beyond asking whether people have taken their medicine, to finding out why a person is missing medicines and then addressing the underlying factors. It is a patient-centric system, which provides information and clarifies everyday misconceptions that a patient and caregiver may have, as well as providing emotional support to patients. The TB Careline also has the potential to vastly increase the coverage of treatment adherence monitoring in a cost-effective manner. If integrated into the RNTCP’s current system of patient follow-up, the counselling component of the Careline will be a particularly significant value addition to ensure that patients do not deviate from the continuum of care.