

### India

### Community, Rights and Gender Country Profile

Working Document





## Table of Contents



**Quick Facts** 



**UNHLM Targets** 



National Strategic Plan and Funding Opportunities



**TB Situation** 



**Community Engagement and Representation** 



**CRG Interventions** 



**CFCS Round 10 Partners** 



**CFCS Round 11 Partners** 





### **Quick Facts**



1407 million people (2021)

#### WORKING DOCUMENT



High TB, TB/HIV and MDR/RR-TB Burden Country

THE GLOBAL FUND

**High Impact Asia** 





### **UNHLM Targets**



#### **Resource Needs (2022)**

1503.07 million (USD)

#### **Available TB Funding 2020 (USD)**

Domestic: 313.3 million

International (Excluding Global Fund):19.0 million

Global Fund: 57.9 million

Funding Needs: 496.7 million



#### **Diagnosis and Treatment Targets (2020)**

TB Target: 2,404,900 % Target Achieved: 75



#### **Prevention Therapy (2022)**

Total PT Targets: 2,252,910



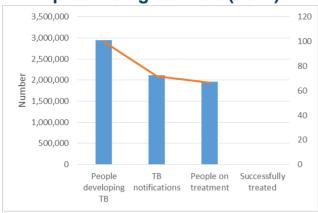


# National Strategic Plan and Funding Representation

- Next National Strategic Plan Development: 2025
- Next Global Fund funding request proposal development: 2023

### **TB Situation**

#### Epidemiological Data (2021)<sup>1</sup>



- 984,556 Missing people with TB (241,419 were children)
- 506,000 people died because of TB
- 47,902Laboratory confirmed people with MDR/RR-TB (WHO data, 2021)

#### Community, Rights and Gender Data

Between 2017/2018 various assessment were conducted in India which identified several key issues related to community, rights, and gender in the context of tuberculosis (TB).

Accessibility Barriers: includes the high cost of MDR-TB drugs, out-of-pocket expenses for first-line drugs in the private sector, and the limited availability of rapid molecular testing machines. Accessibility to sufficient nutrition for the poor was also a concern.

**Availability Barriers**: includes a lack of TB counseling services and inadequate availability of MDR-TB drugs due to slow regulatory approval. Additionally, there were drug stock-outs of first-line drugs and the BCG vaccine, as well as a slow roll-out of rapid molecular testing machines.

**Acceptability issues**: were evident in the form of discrimination faced by people with TB in healthcare settings. Lack of informed consent for TB testing, inadequate protection of privacy and confidentiality for people with TB in law and policy, and the absence of women healthcare workers and women-friendly services in TB centers were also highlighted.

**Quality issues:** such as the lack of enforcement of bans on serological tests and over-the-counter sales of TB drugs. The absence of regulation in the private health sector led to misdiagnosis and inappropriate treatment of TB.

**Discrimination issues:** against individuals with TB was widespread across various settings, including workplaces, schools, colleges, and healthcare facilities. People affected by TB experienced family abandonment, and the law did not provide workers with TB reasonable accommodation and compassionate allowance. Although some courts addressed TB discrimination in employment, there was no legal prohibition of TB discrimination.

**Freedoms**: Concerns were raised regarding freedoms and individual rights, such as the lack of rules and guidance for isolation by the National TB Program (NTP) and the broad powers granted to the government under old colonial laws for quarantine and isolation of infectious diseases. Informed consent for TB tests was not required, and there were insufficient protections for privacy, autonomy, and bodily integrity, as TB is a notifiable disease, and test results had to be shared with government authorities.

**Gender disparities** played a significant role in TB, with socio-economic inequities, patriarchal structures, poverty, caste, and class making women particularly vulnerable to TB. There was a need for disaggregated sex and age case notification data from the private sector to better understand the overall epidemic profile. Women faced unique socio-cultural barriers to diagnosis and experienced delays or no diagnosis at all. Factors such as household duties, low health literacy, TB stigma, fear of divorce or difficulties marrying, financial concerns, and patriarchal family norms further affected women's experiences. Women's infection and treatment compliance risk factors included malnutrition, diabetes, HIV, indoor air pollution, household duties, and TB stigma. Men, on the other hand, faced infection and treatment compliance risks associated with smoking, drug and alcohol use, labor migration, and work. Better integration of transgender individuals and sex workers into the health system was also needed, alongside addressing the lack of women healthcare workers and women-friendly services in TB centers.

**Key and Vulnerable Populations:** The report also highlighted various issues faced by key and vulnerable populations. Occupational health and safety laws did not cover healthcare workers (HCWs), which endangered them and fueled stigma and discrimination against people with TB. Prisons lacked adequate diagnosis, treatment, and screening for TB, and there were challenges related to mobile populations, such as lack of identity documents hindering access to services and migration leading to loss of follow-up.

<sup>&</sup>lt;sup>1</sup> Source: Stop TB Partnership Interactive Map Dashboard





#### Community, Rights and Gender Data Con't

Overcrowded living conditions in slums promoted TB transmission, and there were specific challenges related to tribal populations, migrants, and miners. Mobile populations are at high risk of TB due to lack of identity documents which hinder access to services. Migration also causes loss to follow-up. Tribal issues including no disaggregation of case notification data for tribal population despite NTP/NGO service being available, NTP lacks access to some tribal villages, language barriers to TB information and awareness. Difficulties in Key population size estimates, poor information and ability to track migrants on treatment, fear of stigma prevent engaging public health officials, low knowledge of about health facilities; allopathic & healers first contact point. Also there was no data on population of TB/diabetes co-morbidity, Recently there was a NTP/NCD programme integration but there is still insufficient cross-references and services. Fear of TB stigma among people with diabetes delays diagnosis and treatment. Miners issues include no district level population estimates, poor coordination between industry and NTP.

The reports proposed several **remedies and accountability** measures. Workers with TB should be provided with reasonable accommodation and compassionate allowance, and legal aid should be available to resolve cases of TB discrimination. Mechanisms should be established for people with TB to address breaches of privacy and confidentiality and obtain court orders for protection. Laws should focus on training and incentives rather than criminalizing failure to notify diseases. Litigation should be pursued for the lack of access to MDR-TB drugs as a violation of fundamental rights, and accountability should be held for custodial TB deaths, neglect of prisoners with TB, and lack of infection control in prisons.





### Community Engagement and Representation

Active National Stop TB Partnership

Yes

National Network of People Affected by TB

- Touched by TB, Survivors against TB, TB Muki Vahini TB Network/Community represented on CCM
  - Yes

National High-Level Engagement with Parliamentarians

Yes

Celebrities Engagement in TB response

Yes

Challenge Facility for Civil Society Round 10 Regional Level Partners

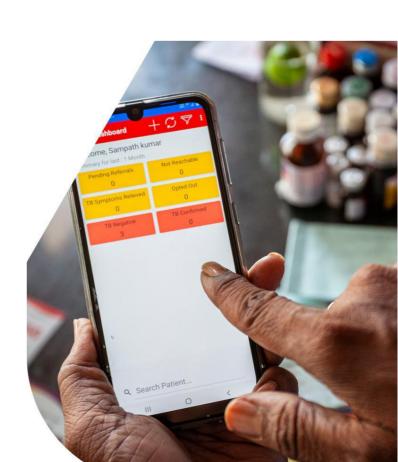
APCASO

CFCS Round 10 Regional Level Partners

APCASO

**Global Network:** 

· Lean on Me Foundation







## Community, Rights and Gender



CRG Assessment Complete



- Costed CRG Action Plan Available
  - No



- TB Stigma Assessment Conducted
  - Yes



- TB Stigma Elimination Plan Available
  - o Yes



- Community-led Monitoring Mechanism in place
  - In progress



 Legal and Human Rights Scorecard Assessment



。No

## **CFCS Round 10 Grantees**

#### **Blossom Trust**

**Project Location:** Virudhunagar, Madurai and Ramanathapuram Districts in the state of Tamil Nadu, India.

Timeline: December 2021 - December 2022

- To develop a guiding policy recommendation document based on multi-level discussions held by stakeholders from the district, state and national levels.
- To mitigate the effects of COVID-19 on the National TB response through increased treatment adherence and advocacy within the community.
- To mobilise TB Advocates promoting a transformative approach through community-led monitoring and advocacy to overcome barriers to services and stigma.



## **CFCS Round 10 Grantees**

#### Gramin Samaj Vikas Kendra

Project Location: Block-Rajpura, District-Meerut, Statrê-

**Uttar Pradesh** 

Timeline: December 2021 - December 2022

- To build understanding on geographic context, resource availability, populations at risk for Tuberculosis and COVID-19 in Rapura block.
- Vulnerable population groups including girls and women have increased knowledge, and information of their health rights and entitlements, and TB risk, symptoms, care and treatment management in 50 villages.
- To improve the access to TB and COVID-19 services among vulnerable population groups in 50 villages.
- To increase effective project management, engagement and coordination.





## **CFCS Round 10 Grantees**

#### Karnataka Health Promotion Trust

#### Global Fund NFM3 Sub Recipient

Project Location: Bellary, Belgaum and Bagalkote

Districts of Karnataka, India

Timeline: December 2021 - December 2022

- To strengthen the TB response with rights-based, people-centred approaches, through community led monitoring forums, among PLHIVs, Mining population and Urban poor.
- To sensitize and engage the elected representatives of local self-governments (PRI) in TB awareness, stigma reduction and better linkages of service, schemes and supports.
- To conduct the rapid CRG assessment in the project geographies among the focused vulnerable communities to elicit information on the barriers and inequalities in the community and develop community lead monitoring forums.
- To participate and engage in various TB advocacy and accountability initiatives at national, regional and global levels.





## CFCS Round 10 Grantees

#### Prakruthi Social Service Society

Project Location: Rampachodavaram ITDA area of East

Godavari district of Andhra Pradesh, India **Timeline:** January 2022 - January 2023

- To identify TB CRG members in the project area
- To sensitize all consented Traditional healers, Pharmacist and RMPs from seven sub districts in Rampachodavaram ITDA area of East Godavari district of Andhra Pradesh, India
- To ensure referrals, treatment initiation and adherence of all TB confirmed to avert drug resistance cases from seven sub districts in Rampachodavaram ITDA area of East Godavari district of Andhra
- To increase Media Advocacy
- To participate advocacy with district level TB officials





### **CFCS Round 10 Grantees**

Resource Group for Education and Advocacy for Community Health (REACH)

Global Fund Sub Recipient

Project Location: India

Timeline: January 2022 - January 2023

- To empower affected communities to adopt a "Data for Action" approach, thereby equipping them to advance the agenda of quality assured person-centered care.
- To support TB healthcare services and communities to develop greater genderresponsiveness by providing training and tools that help integrate these concepts at every step of the care cascade.





## **CFCS Round 11 Grantees**

#### **Blossom Trust**

Project Location: Tamil Nadu, India.

Timeline: May 2023 – April 2024

. Aim:

 To expand and promote access to inclusive, gendertransformative, stigma-free health and social services for women with TB at all levels through a community-owned TB response and policy changes at the national level

- To establish a strengthened and self-sufficient TB Survivors Forum (Rainbow TB Forum) with TB Advocates supporting and advocating for vulnerable women with TB, particularly those affected by comorbidities, In line with the Deadly Divide
- To Identify Community Rights and Gender (CRG) barriers to TB detection, Treatment Adherence, and Social Stigma at the grassroots and district levels and accomplish a community originated and owned response to support the movement to find and assist the "Missing Million" TB patients
- To mobilizing stakeholders at the community and district levels to advocate for community-centered and gendertransformative state and national TB policies and TB control programmes in line with UNHLM targets and commitments supported by community level data
- To Increase accessibility to social services for TB patients, particularly legal aid, to strengthen the ability of TB survivors and patients to assert their rights and protect themselves from mistreatment and discrimination
- To participate and engage in TB advocacy and accountability initiatives at national, regional, and global levels.





### **CFCS Round 11** Grantees

#### Karnataka Health Promotion Trust

Project Location: Bagalkot, Bangalore, Bellary, Belgaum and Koppal Districts of Karnataka state of Indi and Dibrugarh District

in Assam State of India

**Timeline:** May 2023 – May 2024

#### Aim:

o To empower vulnerable communities, in terms of awareness, demand generation, mitigation of stigma for TB and a community lead monitoring of TB services, eventually for all health-related services in the selected districts of Assam and Karnataka states of India, with special focus on the communities such as PLHIV, urban vulnerable, Transgender, Hijra, Jogappa and other LGBTIQ communities, garment factory workers, migrants, female sex workers and tea garden temporary workers

- o To strengthen the TB response with rights-based, peoplecentred approaches, through community led monitoring forums, among PLHIVs, LGBTQ/TG, Female Sex workers, Urban vulnerable, garment workers and tea garden workers.
- o To sensitize and engage the elected representatives for stigma reduction and better linkages of service, schemes and supports.
- o To conduct the Rapid CRG assessment among the tea garden communities to elicit information on the barriers and inequalities in the community and develop community led monitoring forums.
- o To participate and engage in various TB advocacy and accountability initiatives at national, regional and global levels.



### **CFCS Round 11 Grantees**

#### Humana People to People India

Project location: Shahdara, East Delhi, New-East Delhi Districts

Timeline:

#### **Overall Aim:**

To sustain essential TB activities in the homeless communities of Delhi by a planned and coordinated task-shifting, where the homeless people can be capacitated, engaged and mobilized to take care of their health and TB-problems, and protect their rights by themselves.

#### **Proposal Objectives:**

- To select and train 50 TB Survivors of homeless communities of 3 targeted districts by using TASA manual, and mobilize 30 of them as TASAs to serve their community-members
- To engage TASAs to educate and screen at least 10,000 homeless people in 3 targeted districts for TB, detect at least 100 TB cases from them, and put at least 90 of them on treatment at local chestclinics
- To enhance and strengthen community voices by engaging TASAs to report human right violation, stigma and discrimination faced by homeless TB patients in 72 advocacy meetings with health-staff and TB-managers, and demand equity and rights for homeless people in 21 rallies
- To engage TASAs in strengthening linkages with local key community stakeholders by organizing 150 advocacy and coordination meetings with them to ensure their regular support and services



## **CFCS Round 11 Grantees**

#### Pi Consulting/Survivors Against TB

Project location: New Delhi

**Timeline:** 

#### **Overall Aim:**

To create a survivor-led and defined rights-based model of high quality TB care that will be used for community-led advocacy, monitoring and accountability to build political will to ensure equitable, accessible, affordable, high quality TB care in India.

#### **Proposal Objectives:**

- To engage Communities to create a survivor-led and defined and rights-based model of high quality TB care for community led advocacy, monitoring and accountability
- To build survivor and community capacity and expand survivor-led advocacy and community-led monitoring and accountability at the national level on issues of high quality care
- To engage and advocate with key experts for advocacy to build political will and focus for achieving high quality TB care
- To create a mainstream media led narrative on issues of rights-based survivor and community defined paradigms of TB.

# Questions? Contact us.

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