



## National Consultative Meeting of Partners

11-12 September 2015

Report



## **National Consultative Meeting of Partner**

**11-12 September 2015, New Delhi**

### **Introduction:**

National Consultative Meeting of partners is one of the key yearly events of PTCC where all member civil society organizations of India are participating. Key objectives of this consultation are to review all past initiatives, efforts, evaluate level of achievements and plan for future course of action to enhance/improve TB care and control efforts at all levels. The consultation also provides an opportunity to all partners get together at one platform to discuss and debate on how to structure strategic vision of PTCC that envisage greater success to all initiatives in TB control at national/state/district level as the only National level civil society coalition.

### **Welcome Address:**

Dr. Abhijeet Sangma PTCC welcomed all the participants and provided an update on the Partnership for TB Care and Control. The main highlights were growth of partnership and updates on activities for the year. The welcome address followed by self introduction of partners.

### **Day 1**

#### **Group work**

After the welcome address partners were briefed on various advocacy efforts by the TB Advocates. Hence it was decided both the partners and TB Advocates together can contribute towards TB care and control. The partners will guide and can give technical support to TB Advocates and District level TB Forums/patient network forums. The participants were divided in to State wise groups and discussed on what are the issues and challenges in doing advocacy, what can be included as activities and what will be the support they require from PTCC and government.

#### **Group 1**

##### **State- Tamil Nadu Group Leader- Mr. Franklin, IDF, Bangalore**

The group has presented some activities on advocacy for TB Advocates that are advocacy with the State level LAB owners association for banning of serological tests, ensuring the provision of pension to the patients from government, it has been suggested a brief and effective awareness session for MLAs would be very helpful. While ensuring the provision of pension to the patients from government may take time as there are so much formalities. And a major issue is bribery. The group also chalked out the support that should be come from PTCC and government i.e representation at the State and central level to simplify the procedures, providing necessary data base and documentary evidence to represent the proposals in an effective manner, orientation and training in CSR

fund raising, channeling the service delivery to NGOs and TB forums and partners can come together on a regular basis to monitor and plan collaborative programmes.

#### Group 2: Karnataka, Andhra Pradesh, Telengana

Issues/gaps identified by group:

- Notification of TB cases, streamlining other providers of medicine
- Sensitization on NGO PPP schemes
- Building champions to address stigma and discrimination at community level.
- Lack of counseling and treatment support to patient
- TB forum

Activities by partners:

- Advocacy at National/State level to enhance notification
- Awareness among NGO/CBO about schemes, building of Champions at community level
- Enhancing communication skills of Health care providers by providing various soft skill training programme

Participants were chalked out what support they need from PTCC. That are engaging point person at State and National level to put this issue at appropriate forum, PTCC can organize local level training programs for NGOs

#### Group 3: Uttar Pradesh, Haryana, Jharkhand, Bihar, New Delhi and Himachal Pradesh

Advocacy efforts/Activities:

- Political advocacy for timely fund release in the RNTCP program
- Sensitization on food security
- Livelihood support for TB patients
- Organizing various campaigns, voice against stigma and discrimination
- Advocacy on establishing new diagnostic tools
- Media Advocacy

There may be certain challenges can occur while implementing the activities that are vacancies of various posts in RNTCP, lack of financial resources and planning, dysfunctioning of govt. structures and programmes and TB is not mentioned in PIPs. The group urged PTCC can support as a financial resource, providing capacity building training programs at local level and strengthen the networks.

Expectation from government:

- Recognition required by government, incorporating with government projects for financial support

#### Group 4: Odisha, West Bengal, Punjab

Activities can be incorporated:

Activities at Community level: patients support forum, engaging religious preachers/influential leaders, media as change agent, engaging PRIs to support TB programme

Challenges at field level:

Non cooperation of problem service providers/bureaucrats, adamant nature of policy makers and identity crisis of TB Advocates

What support PTCC can provide:

PTCC can influence at central level to involve NGOs in RNTCP programme, financial, technical and collaborative action.

Group 5: Madhya Pradesh, Rajasthan & Chhattisgarh:

Participants were chalked out various activities which can be implement by partners and TB Advocates i.e. linkages with social Organization and gram panchyat, working with SHGs and local level key persons(Line Workers & Prerak), nutrition support to TB patients, optimum utilization of government support. While implementing these activities participants also visualize various challenges. The challenges are poor linkages between communities.

Support required from PTCC:

- Meetings at district and State level.

The presentations were followed by an open discussion.

An experience from project Axshya: Mr. Subrat Mohanty

Mr. Subrat Mohanty (Project Coordinator, The Union) shared the experience of project Axshya in community engagement. At first he introduced on what are the social determinants. And they are

- Poverty
- Literacy/Education
- Living conditions in slums and peri-urban areas
- Hard to reach/unreached population in difficult geographical settings
- Seasonal migration and forced migration
- Working environment
- Addressing Gender

And the challenges are:

- Inefficient services and poor funding
- Demotivated health care staff
- Poor drug use practices (providers and patients)
- Lack of effective educational strategies
- Stigma and discrimination

- Weak or struggling civil society – TB patients have few advocates
- Inclusion
- Stigma
- TB as a disease
- Social support
- Capacity
- Resource

Support Inclusion:

- Creation of an enabling environment that empowers patients and affected communities
- Support for nurturing of TB and TB/HIV patients organization and networks
- Training programme for patients to become community TB educator, monitor and advocate
- Capacity building of NTP staff at all levels in involving patients in TB Programming
- Development and advocacy of behavioral change strategies targeted at health workers to reduce stigma
- Operational research to document good and innovative approaches that involve and empower patients and affected communities
- Active support strategies to enable patients/those most affected to participate effectively in programme design, implementation and monitoring

Then he discussed on various opportunities for the CSOs for engaging community. They are:

- Formation of District Level Networks of TB patients
- Support Group
- Inclusion in the National TB Programme working groups
- Involve in the District TB Planning exercise
- Advocacy for services- Nutrition, travel support, etc
- India CCM
- STOP TB Board
- Global Fund Community Board

He stated Axshya is a resource, a collaboration to support our common objective of reaching out and benefitting

thousands of TB patients who continue to suffer because of ignorance and lack of access. During the session he discussed on social determinants, challenges, support inclusion, opportunities, key activities of Project Axshya, geographical coverage and SRs, outcomes, linkages and national strategic plan, grant rating and how Project Axshya supporting RNTCP towards achieving goal.

**Project Axshya supporting the RNTCP in achieving the following:**

- Reducing the proportion of undiagnosed and mistreated cases
- Ensuring that patients present themselves to the health facilities early in the course of the disease
- Accessing of programme services to vulnerable and marginalised populations
- Preventing Multi-Drug Resistant TB (MDR-TB) by ensuring that patients successfully complete the first line anti-TB treatment

**Key changes in phase II:**

Then he explained about changed activities of Axshya which includes as Maas media campaign discontinued, strategy changed from training to engagement, sensitization of GKS and community groups, strengthening the District TB Forums, linking TB patients with social welfare schemes. Axshya has also intervene various new activities

**Intensified outreach activity- Axshya SAMVAD**

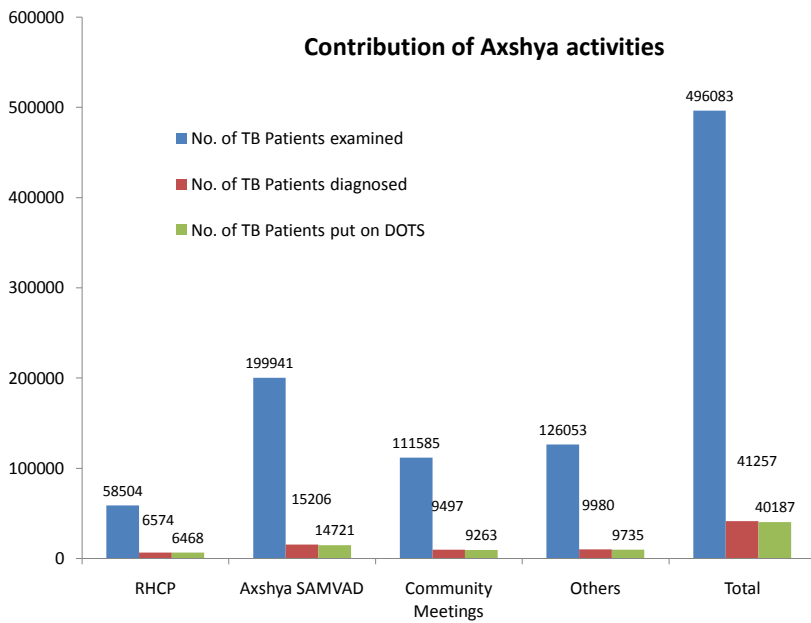
- 1000 households per district/month (Prisons/Homeless shelters etc.)
- Enhance awareness and identify and link symptomatic to TB services
- Sensitizing and engaging private labs on 'ban on TB serology' and notification of TB
  - 3000 private labs across 60 districts will be sensitized
- State TB hiplines – (6 states- KA, MH, HR, RJ, PB, BI)
  - Information on diagnostic and treatment services and TB
- Counseling of MDR-TB patients – (Piloted in 30 districts)
  - 50 MDR patients per district; 1 session per month per patient.

**Contribution of Axshya:**

Mr.Mohanty explained about contribution of Axshya. The contributions through sputum collection & transportation, referral of TB symptomatic, sputum positive cases detected, and sputum positive cases initiated on treatment. He emphasized on the activity Axshya Samvad which was an innovative intervention which contribute towards Sensitization and Advocacy in Marginalized and Vulnerable areas of District, slums, tribals, migrants, difficult to reach areas etc. the session concluded with a question answers and discussions on Reducing the proportion of undiagnosed and mistreated cases ,Ensuring that patients present themselves to the health facilities early in the course of the disease ,Accessing of programme services to vulnerable and marginalised populations.

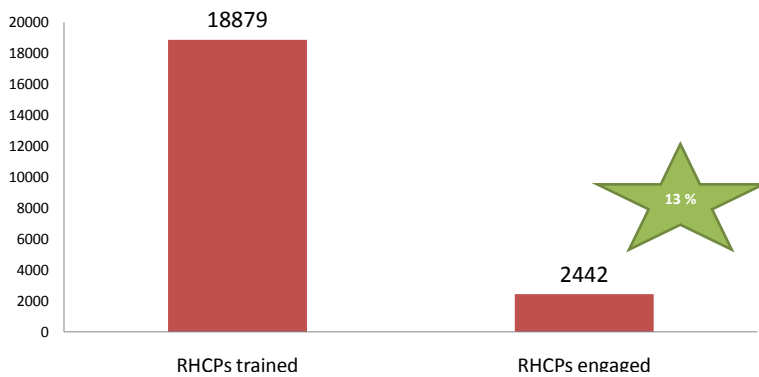
He sensitized the representatives from civil societies about various NGO schemes in RNTCP.

Highlights of Project Axshya:



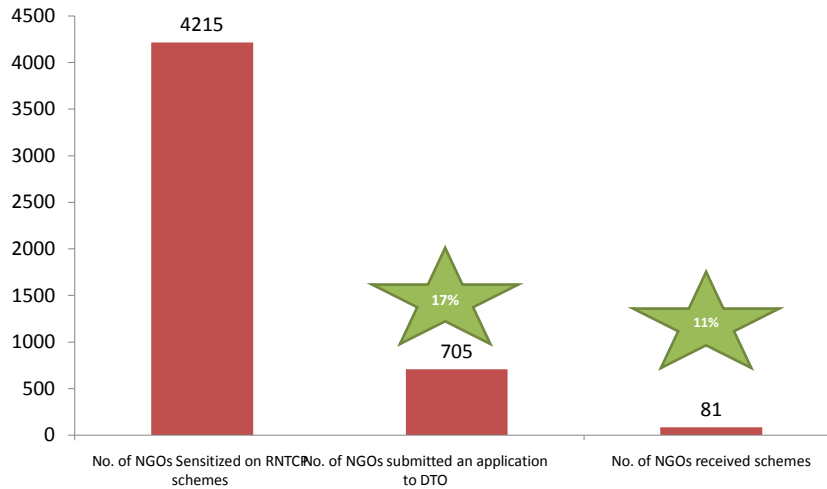
### RHCPs – Training and engagement

Apr 2013 - Dec 2014



- Engaged-
  - Referral of at least 3 TB symptomatic per quarter
  - At least 1 sputum collected and transported per month
  - DOT Provision- at least 1 patient per quarter

## NGO Engagement (Apr 13-Dec 2014)



He sensitized the partners to apply for various RNTCP NGO schemes.

After all discussion on community level engagement, issues, challenges & solutions for TB care and control. A session held on discussion on **Regional level Network forums/ civil society** and what are the role of these forums.

Ms.T.Mercy Annapoorni conducted a session on regional level patient/TB network forum and discussed on how the TB forum can act, who will be the members, various examples of forums and what will be the role of these regional level forum.

### Definition

#### Patients Network:

A well-established practice in addressing issues on diseases where in affected people forms a support group.

#### Civil Society:

Wide array of non-governmental and non-profit organizations that have a presence in public life, expressing the interests and values of their members or others

Benefits of State network Forum:

- Keeps members of the community up to date.
- Provides a readymade audience for advocacy issue
- Can pool resources from multiple sources and people for a common goal.



Local example of Network forum:

**The Rainbow TB forum** is unique among India's TB activist networks in that it is comprised of past and present TB patients. With over 600 members, the RTBF leverages the distinct knowledge that comes with fighting TB to foster conversation and further societal acceptance of those afflicted with TB.

White Chamomile:

The Russian Red Cross Society in the Republic of Khakassia, Siberia, has established a social club called "White Chamomile" for TB patients. Patients can share their struggles and support each other. Those who fully recover are invited to share their experience, thereby boosting morale among those who are still recovering. The support is shown to bring positive attitude and reduce default among current patients.

GCTA global coalition of TB activists:

An advocacy platform for TB affected communities seeking to influence global TB control agenda

Areas of work: advocacy, community engagement, networking, communication of TB issues

There are two models of patient network forum:

Peer participatory

Professional expert

Build a peer support system:

- Organize and promote network events
- Meet, welcome and support new and current patients
- Liaise with medical service providers for improvement
- Share success stories and generate a discussion

Mobilize for Action:

Advocacy issues will depend upon local political realities

Bring together partners and share ownership of common goals

Bring together resources and create a self-sustaining environment for TB/HIV activities

After the discussion Ms.Mercy urged the house for an open discussion on network forum, how it can contribute towards TB control, how civil society and network can supplement each other and also on issues and challenges of establishing network forum.

Various issues and suggestions come out from the floor. Participants suggested network forum and civil society can work together as the ultimate goal is to eradicate TB hence both can supplement each other. NGOs/CSOs should encourage the patient network forum and can give technical support to them. Some of participants also shared their experiences working with network forums how it put an impact on advocacy issues. HIV network forum is an example

for us so the same kind of determination needs in Tuberculosis. As a CSO we have to play a major role. Ms. Mercy urged the participants to give PTCC some ideas how to form a patient network forum at the national level. The participants were divided in to State wise groups and discussed on formation of National level patient network forum. It was decided they will present the same in day two.

Day one completed with the concluding remarks by Ms. T. Mercy Annapoorni.

### **Day 2:**

Day two started with a brief recap by the participant.

After the recap session participants presented their ideas on how to form a National level network forum. Each groups presented on it.

### **Group 1:**

What should be done for forming National level Patient forum:

- Empowering and educating the TB patients.
- Training of cured TB patients counselors/ building champions
- Continuous activities on reducing stigma and discrimination
- Cured TB patients to be trained as DOTS providers
- Starts from Panchyat level/district level
- Motivation and nutrition/financial support to the patient

### **Group 2:**

- Listing out the persons who had critical experience with TB and share the idea of network.
- Identify drug resistant TB patients who have got a passion and social inclination and who is able to communicate in English or Hindi or in both.
- Shortlist a few names from the existing TB Forums of the Axshya project and Rainbow TB Forum
- Find out potential candidates from the HIV/TB co-infected
- Seek suitable references from existing patient network members ex:- teachers, professors, lawyers

### **Group 3:**

Planning:

- Compilation and listing of willing institutions/individuals
- Listing of cured TB patients, geographical list, activity list
- Regular interaction and linking with other programmes

Execution:

- Sensitization program for identification of volunteers
- Listing and due diligence of volunteers(volunteers per population)
- Capacity building and review on quarterly basis as

- Drug stock out group
- Service delivery group
- TB/HIV group
- Nutrition/livelihood group
- Childhood TB group

#### Group 4:

Formation of Network National level

District level TB Forum (2 NGOS from each district 10 to 12 people in the forum)

State Level TB Forum (representation from each district maximum 15 to 20 people)

National level TB Forum (representation from each State)

#### Group 5:

Role of Network:

- Provide training to TB patients on role and responsibilities of network, self care and patient charter
- Providing nutritional support
- Providing knowledge on various govt. schemes
- Providing insurance facility for TB patients

After the tea break session Ms. Urvashi Prasad (GB member PTCC) presented on MDR-TB in India: challenges and priorities:

#### Challenges in MDR-TB:

Diagnosis:

- Shortage of laboratories
- Patient detected positive for first time not considered as suspect for MDR-TB
- treatment following a positive GeneXpert result is a matter of concern for several physicians; believe that further drug susceptibility tests are necessary
- Not enough GeneXpert machines available for testing all patients suspected of having MDR-TB
- High cost of GeneXpert cartridges results in only those who fail to respond to first 2 months of DOTS getting tested

#### Challenges in Treatment:

- Long & complex treatment regimen (24-27 months of medicines & injections) often results in poor adherence
- Severe side effects of cocktail of medicines
- Difficulty of ensuring treatment adherence for inaccessible/hard to reach populations
- Bedaquiline treatment is not without concerns including those around survival chances & toxicity

### Other challenges:

- Weak nutritional status
- Need for compassionate counselling of patients & families, regular hospital visits
- Need for providing chemoprophylaxis for children of MDR-TB patients
- Follow-up & ensuring patients get tested every month
- Lack of awareness in communities
- Protection of health care personnel interfacing with MDR-TB patients e.g. availability of quality masks for community workers

### Priorities in MDR TB:

There are certain priorities in MDR TB which need to be address.

- Widespread availability of rapid, quality drug sensitivity testing
- Strengthening human resources including training for healthcare cadres
- Enabling management of drug resistance at primary care level to reduce overloading of hospitals
- Improved infection control at TB hospitals (e.g. air extractors) & in other settings
- Research including operations research in the areas of laboratory testing, treatment strategies, programmatic aspects & management of contacts of drug-resistant TB patients
- Population-based surveys & repeat surveys to estimate prevalence of drug resistance
- Tracking & minimising misuse of Bedaquiline (when approved for routine use)

She shared that she has attended a national consultation on providing nutritional support for TB patients organized by the ministry of health and WHO. Some interesting discussions and experiences shared by various state governments. CTD announced that they will be developing some guidelines with respect to TB and nutrition. It could be a good opportunity for CSOs to also make a contribution on this subject in the form of a brief policy note.

She has shared the email ids of officials from RNTCP with the partners.

### Thematic group Meeting:

Four thematic group meetings were held during the NCM. Partners were divided in to four groups as per their thematic area Advocacy, service delivery, Women and childhood TB and TB/HIV group. The overall objective of this meeting was to engage all partners who are having these topics as one of the priority area within their organizational work plan to: Get together and discuss and come up with: a set of recommendation that can feed into the process of development of state level action plans to address key priority issues within advocacy thematic area. An action towards building a strong and proactive network that covers national/ state/district/sub-district levels this core group of partners with common thematic area is mandated to influence TB care and control efforts at all levels. Partners were asked to get together in groups based on their thematic areas and brain storm for about 60 minutes to identify key issues and challenges along with suggested solution that can have maximum impact focusing improvement of TB care and control efforts through their thematic area and related activities. The group was also requested to prepare a presentation and present it to the larger group for critical analysis of issues and also to get some valuable inputs

After the patient network forum discussions and thematic group meetings the Secretary and Treasurer updates the partners on various PTCC-Axshya activities reports and financial reports.

## Summarizing the Discussions and valedictory session

The meeting ended with concluding remarks from Dr. Langkham (Vice Chair) who thanked the Partners for their active and informative participation and urged all partners to continue to network in their States as well as with other Partners.

### Annexure 1: List of Participants

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