



Regional Consultative Meeting of Partner- South region

13-14 May 2016

Bangalore

Report



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Background and Objective:

Regional Consultative Meeting of partners is one of the key events of PTCC. The Key objectives of this consultation meeting is to develop a common understanding and agreement among the key stakeholders for involving partners in TB care and control at state and regional level. Regional meetings have created a visibility of partners and provided a platform of brainstorming among all stakeholders in finding collaborative solutions to various challenges in the field and chalking out action plans state wise on enhancing the effort for TB care and control in India.

Objective of the meeting:

Provide a platform for brainstorming among all stakeholders in finding collaborative solutions to various challenges in the field.

Outcomes:

- Issues related to civil society engagement identified and solutions to challenges explored with action that civil society can take
- Develop a work plan for increased participation of civil societies and communities in RNTCP at the state and district level
- Planning on engaging affected community and discussion on developing a patient network forum.

New partners joining the Partnership increased

- Increasing communication between partners and the Secretariat.

Organization:

Total attendances of 35 participants were present for the two day deliberations with participants from southern states of Andhra Pradesh, Karnataka, Kerala and Tamil Nadu.

Proceedings: The agenda for the meeting was as follows:

- Inauguration
- Introduction
- Recent development in TB care and control and Air borne infection control
- Role of TB Forum in TB care and control
- Presentation and experience sharing by partners
- Urban Slum communities' engagement in TB control and engaging private sector
- What is media advocacy, Role of media advocacy in TB care and control
- Group Work

- Role in the State CSO/Community Challenges and Solution preparing list of recommendations from each state
- State wise presentations
- Importance of engaging community and patient group in TB care and control
- Advocacy through partnership
- Closing session

Inaugural Session:

The Regional Consultation meeting began with the inaugural address by Mr. Mohanadoss, Secretary, PTCC. Welcoming all the partners he explained about The Partnership for TB Care and Control (PTCC) which is committed to support and strengthen India's national TB control efforts. This was followed by a round of self introduction of the participants.

PTCC Background, activities and action plan for the region:

Mr. Mohanadoss welcomes all the participants and give an introduction of the Partnership, structure, governance, objectives, its progress and future plans. He also explained various accomplishments of activities for the year and discussion on action plan for the southern region. He urged the partners to discuss on various State level challenges and prepare plan during these two days consultation.

Recent Development in TB and Airborne infection control: Dr. Satish Kaipilyawar

Dr. Satish from Share India welcomes all the participants and proceed the session on recent development in TB and air borne infection control.

He explained about various points:

- Global and India TB situation
- Status of RNTCP implementation
- National strategic plan for TB control 2012-2017 with an objective to early and improved dignosised
- Program has wide laboratory network available in three tire level. From sub district level (DMC one for one lakh population) to IRL and National Reference laboratories. The program started with passive case finding strategy, then intensified efforts and now moving towards to more aggressive case finding strategies.
- He shared Program has initiated use of various ICT (information Communication Technology) enabled treatment adherence mechanism including 99DOTS which is based on missed call, mobile based Active compliance including Video DOT, and smart pill box. He also explained about 99DOTS to the participants.

99 DOTS:

99DOTS is a low-cost approach for monitoring and improving TB medication adherence. It can be utilized either as a supplement to existing DOTS programs, or to enable remote observation of doses administered by patients or their family members. Using 99DOTS, each anti-TB blister pack is wrapped in a custom envelope, which includes hidden phone numbers that are visible only when doses are dispensed. After taking daily medication, patients make a free call to the hidden phone number, yielding high confidence that the dose was "in-hand" and has been taken.

It is important to note that 99DOTS requires only a small number of phone numbers. The numbers called by a patient may repeat over time; however, on each blister pack, the numbers are arranged in an unpredictable sequence. As treatment progresses, the sequence of numbers called is checked against the blister designs, thereby verifying that the patient is taking medication as intended.

99DOTS patients receive a series of daily reminders (via SMS and automated calls). Missed doses trigger SMS notifications to care providers, who follow up with personal, phone-based counseling. Real-time adherence reports are also available on the web.

Compared to the current standard of care, 99DOTS offers three key benefits. First, it reduces patients' burden: instead of traveling to a center for every dose, patients can provide evidence of dosing from the comfort of their home. Second, it improves the efficiency of care providers: instead of waiting weeks or months for adherence records to be digitized, supervisors can view real-time adherence data for every patient and ensure prompt response to every missed dose. Finally, 99DOTS enables differentiated care: instead of mandating that all patients receive frequent counseling, adherent patients can proceed with less supervision, while limited program resources are focused on cases that need the most attention. He also clarifies if patient does not have mobile then he can call from neighbors or village Mukhia's number.

- Roll out of daily regimen in 104 districts of 5 States of Himachal Pradesh, Sikkim, Bihar, Maharashtra and Kerala with total population coverage of 2690 lakhs.
- Though prevention of drug resistant TB by implementation of quality DOTS remains the key strategy, the programme also has plans to expand the DOTS-Plus services across the country. Accordingly the RNTCP DOTS Plus vision is to ensure that by 2010 DOTS-Plus services available in all states by 2012, universal access under RNTCP to laboratory based quality assured MDR-TB diagnosis for all retreatment TB cases and new cases who have failed treatment by 2012, free and quality assured treatment to all MDR-TB cases diagnosed under RNTCP by 2015, universal access to MDR diagnosis and treatment for all smear positive TB cases under RNTCP
- Program is introducing BDQ under RNTCP through Conditional Access Program starting with 6 sites.
- RNTCP has a well defined strategy, to ensure participation of the NGOs and PPs in TB control activities under RNTCP. Well defined PPM schemes have been outlined. These schemes, provides scope for the participation of the NGOs and PPs in all major activities.
- Also informed about the missed call campaign, lunch of Call to action for a TB free India along with various key policies.
- After that he discusses on air borne infection control its effect and its prevention.

After that the session started on presentation and experience sharing by Partners from different States:

Partners presented their presentation and shared experience on their work on TB care and control.

Role of TB Forum in TB care and control: Mr. Ganesh, REACH:

Mr. Ganesh stated Participation of the community and patient is an essential component to increase political will for better health care delivery. TB forum aims to act as bridge between community, TB patient, health system and civil society along with advocacy activities to influence policy changes for accessible, affordable, supportive TB-services to entire population with special focus on poor and vulnerable groups.

Objective of the TB Forum:

- To carry out activities to ensure the rights & dignity of the TB patients.
- To educate the health service providers to ensure justice, rights and dignified treatment behaviour to the people with TB illness.
- To create awareness and advocate on various government schemes, provisions, facilities available for TB patients.
- To organize debates on policies and programs of the government on health in general and for the TB patients in particular.
- To supplement and complement government initiatives to enforce TB patient- friendly law, policy and programs.

He provided the list of TB Forum's established by REACH and list of forum's got registered.

Activities by TB Forum:

- The State level TB forum initiated along with CHAI on March 2013. Field level challenges and needs were discussed & memorandum was prepared by the members to address the vacancies in RNTCP, it was submitted to the state officials and ministers. Key points in the memorandum are:
- Scale up the financial support (pension) to all the needy TB patients, supply of nutritional supplements, filling up the vacancies in health system, ensuring better coordination with DPH, DMS and DME for better service delivery.
- Advocacy to CM cell to demand Gene X Pert machine.
- Advocacy to get "Amma canteen" in all government hospitals. Vellore TB forum submitted a memorandum to claim "Amma Canteen" Subsidised rate food canteen inside to all Govt. Hospitals. This was aimed to get benefit for the poor patients who are getting health services at free of cost in the Govt. Hospitals, Now in Tamil Nadu, all Govt. Hospitals provided with the Canteen, the result may also included the efforts of TB forum.

He also shared various achievements of TB Forum as nutrition supplements to TB patients, vocational training programs, private lab technicians trained by TB forum members, DTC campus renovation, contribution in flood relief programs, livelihood support to MDR TB patient, education support to MDR TB patient, installation of water purifier system at DOTS center, engaging private practitioners in TB control program and mobilizing funding for helping TB patients.

Urban Slum community’s engagement in TB control and engaging private sector” an experience of KHPT, Dr. Aditi Krishnamurthy:

Dr. Aditi Krishnamurthy from KHPT shared about the slum community engagement and engaging private sector in TB care and control.

Under the USAID Strengthening Health Outcomes through Private Sector (SHOPS-TB) initiative, Karnataka Health Promotion Trust (KHPT) with technical support of Abt associates implemented a TB prevention and care model in Karnataka State, South India. KHPT is the interface agency between the public and private sectors, and providers and the target community facilitating early TB case detection and enhancing treatment compliance through private health care providers (pHCP) engagement in RNTCP. The project coverage is 1.1 million urban poor from 663 slums in 12 districts of Karnataka. A third of TB patients in India reside in urban slums. Under SHOPS, KHPT actively engages with communities through key opinion leaders and community structures. Interpersonal communication, by Outreach workers through house-to-house visits and at aggregation points, is the primary method used for communication about TB and its management and to increase demand for sputum examination and DOTS. pHCP are mapped, trained and mentored by KHPT. ORWs also provide patient and family counseling on TB treatment, side effects and adherence, screen close contacts of index patients especially children under 6 years of age and screen co-morbidities including HIV, diabetes and malnutrition and risk factors including alcoholism, tobacco use, occupational hazards making appropriate accompanied or documented referrals.

Then she explained about the Telephone careline. That is a low cost call center that provides information, counseling, adherence, monitoring and adherence support. It reaches TB patients who seek support through scheduled out bound calls. The objective is to promote treatment adherence, monitor adherence and reduce spread of TB.

What is media advocacy, Role of Media Advocacy in TB care and control: Ms. Bharathi Ghanashyam

Ms. Bharathi’s session included in-depth discussion about what’s role the media play in TB care and control, how to engage with media and what is the standard process for that. The session included how working with the media is a great way to draw attention to priority issues and events in TB care and control at any level. The session also included details of using social media along with correct approach of making best use of it in favor of TB care and control challenges at all levels. She conducted an open discussion group session on how media act as in order to reach the people in order to TB care and control. After the discussion participants stated one line that “Media to remove fear, educate the people on TB and create a sense of responsibility in the society”.

Presentation and experience sharing by partners:

Partner’s were presented and shared their experience about their work in TB care and control and how their organization contributed towards TB control. They have also shared various innovation and success stories and how they overcome various challenges in their respective areas.

Partners shared their experiences are:

1. Arogyavaram- Dr. Richard Boman
2. TB Alert- Mr. Bala Subramanyam

3. BWDA- Mr. Samuel
4. GLRA- Mr. Shibu George

Group work:

State wise groups were formed and the session to deliberate on challenges in implementation of RNTCP in the state, and possible solutions that can be done through collaborative action with Partnership was done. The groups were given 1 hour to deliberate on challenges and solutions after which each states were requested for presentation of group discussion on day two.

Day 2: 14th May 2016

Day two started with the recap by Mr. Shibu George.

State wise presentation on State level challenges and solutions:

Tamil Nadu:

Individual level:

Issue	Possible Solutions
<ul style="list-style-type: none"> ▶ Lack of awareness on continuous & regular treatment ▶ Un affordability of nutritious food ▶ Self Stigma ▶ Self isolation ▶ Sense of hopelessness ▶ Lack of health seeking behaviour ▶ Myths & Misconceptions Self medication ▶ School dropout ▶ Lack of personal responsibility ▶ Personal pain and struggle 	<ul style="list-style-type: none"> ▶ Counselling ▶ Awareness on treatment education and adherence ▶ Developing scoping skills ▶ Life skill education ▶ Regular follow up ▶ Linking with social welfare supports ▶ Promoting social support and networking.

Families and Communities:

Issues	Possible Solutions
<ul style="list-style-type: none"> ▶ Social Stigma ▶ Economic burden ▶ Family disintegration ▶ Lack of support from Family & Community 	<ul style="list-style-type: none"> ▶ Mass Awareness program ▶ Sensitization program ▶ Family counselling ▶ Linking with income generation program ▶ Advocacy with local key members.

System:

Issues	Possible Solution
<ul style="list-style-type: none"> ▶ Lack of knowledge on available schemes ▶ Lack of confidentiality from Health care providers ▶ Fear of NGOs contribution ▶ Lack of coordination from DTOs and health care providers ▶ Non implementation of serological tests banned by GOI. ▶ Scale up of Gene x pert machine ▶ Lack of transference in selection of NGOs and Grand in AID ▶ Insufficient cleanliness in the hospital ▶ Lack of staffing mainly counsellors ▶ Lack of NGOs participation in state level planning ▶ Interruption of drug supply ▶ Lack of monitoring 	<ul style="list-style-type: none"> ▶ Implementation of modern mechanism in all districts ▶ Providing supportive therapy ▶ Addressing the existing gaps like staffing , testing and drug supply, ▶ RNTCP should establish proper monitoring system ▶ Providing adequate facilities and sensitizing the public on cleanliness ▶ Transparency in NGOs selection ▶ Proper and regular training to Health care providers

NGOs:

Issues	Possible Solutions
<ul style="list-style-type: none"> ▶ Lack of NGOs involvement in all the district ▶ NGOs contribution not recognized ▶ Lack of transparency between NGOs 	<ul style="list-style-type: none"> ▶ Effective involvement of NGOs in all district ▶ Recognize the NGOs contribution ▶ Strengthening the state level NGOs network ▶ Develop transparency between the NGOs

Karnataka:

Challenges	Solutions
<p>Community Challenges</p> <ul style="list-style-type: none"> • Entry into community is a challenge. Multiple Language is a problem 	<ul style="list-style-type: none"> • Calling people thru anganwadi/ ASHA workers • Anganwadi sensitization on HIV/ TB – benefits etc (once in 3-6 months as part of their routine training) • HIV Support group meetings are a key affected

<ul style="list-style-type: none"> • Stigma • People don't tell symptoms easily • Bringing people together is a problem for community meeting • No correct info for HIV infected • Going to anganwadi for HIV benefits is a problem • Poverty, no food to eat • Going to a center for tablets is a problem • Late diagnosis – local medicines/ chemist SHOPS • HIV testing a challenge while doing SC&T. unable to take time off for late diagnosis • Families of HIV/TB persons resistant for TB testing • Genexpert not • Private Sector – STCI, Dx, Rx, <p>NGO Challenges</p> <ul style="list-style-type: none"> • RNTCP • LT • Counseling • Treatment literacy • Fast tracking proved innovations • Research funding to be increased • AICC not having community members • Private sector medicines 	<p>population</p> <ul style="list-style-type: none"> • Government benefits • Nutritional support needed • Children's groups and awareness programs • Door to door campaign • SC &T and report • Advocacy with DTO for TB +ve SC& T to go for HIV testing • Accountability mechanism to be worked out <p>Need a dedicated cadre of dedicated counselors</p>
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Kerala:

Key Challenges: Affected groups, within system, self

Challenges	Solutions
<p>Affected groups:</p> <ul style="list-style-type: none"> • Stigma – Self/ Family/Social • Exclusion – Self/ Family(Among marginalized) • Wandering / migrants • Acceptance (higher & lower) <p>System:</p> <ul style="list-style-type: none"> • Deficient infrastructure & HR 	<ul style="list-style-type: none"> • TB & communicable diseases to be added in high school syllabus • System to be implemented to monitor migrants • Conviction situation to be adopted that TB is no more scare • Mapping TB resources, identification & utility • Constant monitoring mechanism with an assessment tool lead by DTO • Participatory yearly action plan including CSOs • Nutritious food supply in line with Mid-day meal • Advocacy to follow NRHM & RNTCP guideline

<ul style="list-style-type: none"> • Participatory monitoring • Shortage of funds • CSO – less recognition • Lack of conducive atmosphere <p><u>NGOs:</u></p> <ul style="list-style-type: none"> ▪ Dependency on external financial resources on project execution ▪ Adequate trained staff 	<p>to involve CSOs</p> <ul style="list-style-type: none"> • CSO need to take up innovative TB projects • Consortium approach to implement multi centre projects with qualified & adequate staff
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Andhra Pradesh:

Partners presented the challenges at field level as confidentiality, issues of stigma, lack of nutrition, regular habits of people, overcrowding, social economic status of people emerges as the challenges in TB control.

The discussion points on issue and challenges taken in to note for further discussion and recommendation.

The Importance of community and patient engagement for TB Care and control: Ms. Mercy Annapoorni

Her session included importance of engagement, formation of TB forum, Rainbow TB forum successes, and obstacles, case studies- engage TB, TB Action group, final thoughts and group discussion.

Importance of engagement:

- ⦿ The World Health Organization (WHO) says engagement:
 - “is critical to improve the reach and sustainability of [TB] interventions, helping save lives from this top infectious killer”¹
- ⦿ Sustainability:
 - Community engagement encourages the sustainability and consistency of programs
- ⦿ Impact is enhanced when the patients do the work

Rainbow TB Forum:

- ⦿ A forum for affected members of the community
- ⦿ Composed of past and present TB patients
- ⦿ Utilize various strategies to create awareness to the public about the effects and spreading nature of TB
- ⦿ Bridge the gap between patients and RTNCP
- ⦿ Work publicly against the disease by spreading awareness about it
 - Helps community to understand how to deal with TB and treat those affected

Successes:

- ⦿ Since 2009, we have mobilized over 600 members to join us in our fight against the stigma attached to TB
- ⦿ Between 2009 and 2011
 - 4033 TB patients identified

- 2986 TB patients cured
- ⊙ These numbers are constantly increasing
- ⊙ But we still have a long way to go

Obstacles:

- ⊙ Stigma associated with TB
- ⊙ Government support
 - Need an appropriate team who can support the RNTCP
- ⊙ Importance of the program and how to help it run properly
- ⊙ Ideally we can all work together with PTCC to help organize the forum so there is one unified forum for the whole country
 - Promotes continuity and sustainability

Case Study- Engage TB: Case study

- ⊙ Piloted by WHO in 5 African countries
- ⊙ Collaborated with NGOs/CSOs that were unengaged in community-based TB activities
 - Helps nationwide scale-up of community-based TB activities
- ⊙ DRC, Ethiopia, Kenya, South Africa, Tanzania
 - Integrating TB into a community through active finding and contact tracing among urban poor
 - within remote, nomadic communities.
 - Strengthening reporting of community-based activities in routine TB monitoring systems
 - Using mobile technology to raise awareness, screen and refer communities for TB diagnosis.

Case Study- TB Action group

- ⊙ Patient support group
- ⊙ Only network of people affected by TB in UK
- ⊙ Members give patient support:
 - During and after treatment
 - Through phone calls, e-mails and one-on-one or group meetings
- ⊙ So successful it's on its way to becoming an independent organization
- ⊙ TB policy-makers contact them when looking for the patient's perspective
- ⊙ Has been at the forefront of the development of the civil society response to TB in the UK
- ⊙ No country can effectively respond to TB without engaging affected individuals

Thoughts:

- ⊙ India still have a long way to go
- ⊙ If these two countries on opposite economic spectrums are able to make this work, how can India, the country with the highest rate of TB in the world (23% of global total¹), come together to do the same?

Open Discussions:

- ⊙ Break up into groups and discuss:
 - Your experiences with patient led groups
 - What steps need to be taken in India for these to become successful?
 - What can be taken from existing models to support this in India?
 - What to do next?
 - How to move forward?

After the group discussion the session started on advocacy the role of civil society through advocacy in TB care and control.

Mr. Mohanadoss discussed on the role of advocacy in TB care and control. Advocacy is the only one approach that has a potential to influence TB prevention care, community mobilization, awareness and education, public health measures, good medical services and community support. He urged the participants to prepare State wise recommendation for advocacy on different issue which can be taken up by Partnership for further advocacy. He also showed an interesting video on advocacy.

The participants divided in to State wise groups and discussed on recommendation.

Recommendation from the partners:

Andhra Pradesh:

- A local NGO is piloting active case finding in collaboration with DTOs. This is done as a part of general survey they are doing in Chittoor district
- NGO PP scheme need to be strengthen
- NGOs are not paid for the schemes they implemented
- Mechanism need to be strengthen to enroll more NGOs in scheme
- Coordination between STO, DTO needs to be strengthen

Kerala:

- TB and communicable diseases to be added in the high school curriculum. PTCC may do advocacy in ministry of HRD.
- Migration health check up centers should be established at district level e health card. Advocacy through labor and employment ministry.
- Insist health monitoring at PHC level through the support of local NGOs by advocacy with state health departments
- Initiate state level advocacy with RNTCP for appropriate planning and funding
- Advocacy with RNTCP and NRHM to create a conducive atmosphere for CSOs
- Develop a state level TB resource mapping
- Ensure nutritious food supply to all TB patients in next budget

Tamil Nadu:

- Advocacy with DTOs on availing RNTCP programmes through NGOs.
- Advocacy with Central TB division to avail all possible social welfare schemes to TB patients
- To provide Gene-x-pert machine to all districts
- To provide DOTs providers remuneration on regular basis.
- To appoint adequate counselors
- To form proper mechanism for diagnostic in private sector especially serological test banned.

Karnataka:

1. Scale up GenXpert for testing all patients

2. Daily regimen for all
3. Community level DOTS
4. Nutritional support for TB patients and their families
5. District Wise TB Forum to be converged to State level forums needing state level recognition
6. Recognize TB Champions from community
7. Private Health care provider needs to provide better care for TB patients in the private sector
8. Better HIV TB Convergence to be fast tracked
9. Social Protection and Welfare mechanism for patients/families with TB
10. Counseling training for TB in RNTCP.

Mr. Mohanadoss thanked all the participants for the State wise recommendation for advocacy issues. Those were taken in to note for further details and planning.

Closing session:

At the end of the session participants shared their feedback of the two days consultation. They shared it was a good opportunity to interact with different Organizations of different States and they get to know about their way of intervention and various success stories which can be implement in their own States. The group discussion on various issues provided a platform of brainstorming among all stakeholders in finding collaborative solutions to various challenges in the field and chalking out action plans.

Expressing his gratitude on behalf of PTCC Mr. Mohanadoss thanked all participants for their active and informative participation. He also thanked Tulip Inn for their great hospitality.

Annex 1: Feedback Form analysis

- ❖ Did the venue of the meeting meet to your satisfaction?

Yes

- ❖ Do you feel that meeting is well coordinated/facilitated? What would you recommend to change/add?

Well coordinated and facilitated.

Add scientific sessions

More time slot for partners to present Organization activity.

- ❖ Is the agenda relevant to the objectives of the meeting? Which topic do you feel strongly about and need to be addressed further:

Yes

Recent development in TB care and control

Funding opportunities and detail information on government schemes.

More meetings and training on media advocacy

Detail on project management, RNTCP, CCM, Global fund

State level issues & challenges and recommendation from each State

- ❖ Any suggestions of new topics that need to be addressed in a wider scope in subsequent meetings?

Organize State as well as district level consultations.

Research in tuberculosis

Need special attention on NGO PP scheme and project proposals

Private sector engagement

Media Advocacy in TB care and control

NGO RNTCP scheme
