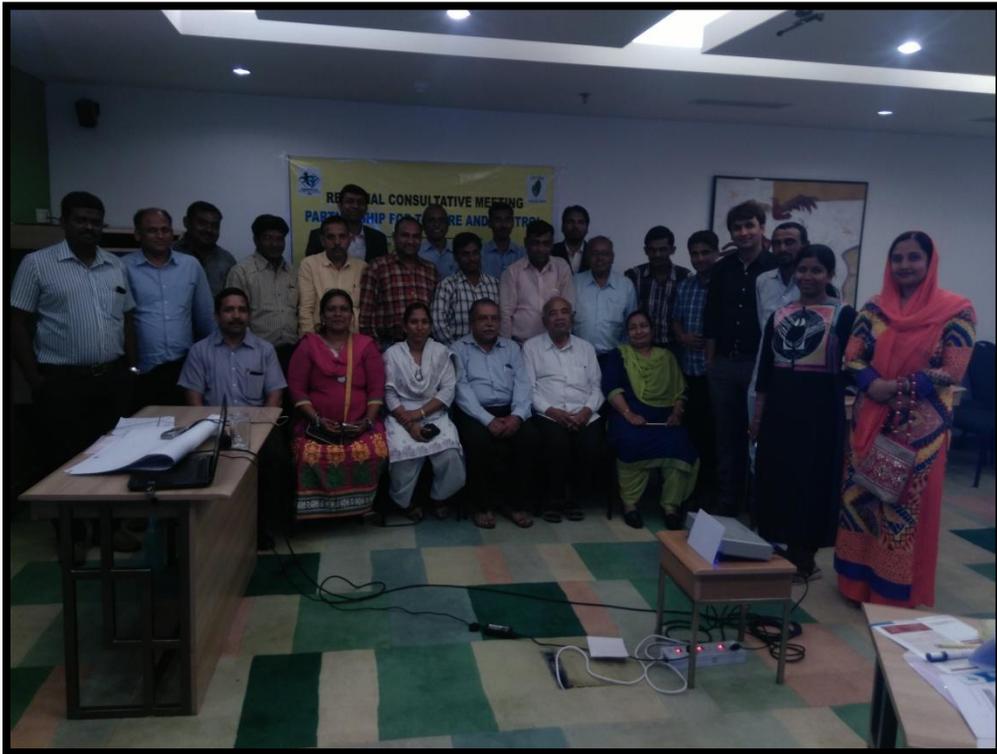




Regional Consultative Meeting Of partner
12-13 March 2016
Ahmedabad
Report



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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.

Organisation:

Total attendances of 30 participants were present for the two day deliberations with participants from western states of Gujarat, Madhya Pradesh, Maharashtra, Rajasthan and Goa.

Proceedings: The agenda for the meeting was as follows:

- Introduction
- Welcome Address
- Setting up meeting objectives
- Experience sharing by partners
- Discussion on key action points that can go in for regional call to action for western region
- Discussion on patient network and preparation of action plan
- Nutrition support for TB patients
- Setting up partnership quarterly action plan for each State and entrusting responsibility.

Inaugural Session:

The Regional Consultation meeting began with the inaugural address by Dr. R. K. Jhariya, Governing board member. 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:

Ms.Sanchita Raut, Project Coordinator PTCC welcomes all the participants and took them through a few ground rules for the 2 days consultation and explained about the folder being handed to participants containing the agenda, local travel claim, newsletter editions and the feedback forms. She then proceeded to give an introduction to the Partnership, structure, governance, objectives, its progress and future plans. She also explained various accomplishments of activities for the year and discussion on action plan for the western region. She urged the partners to discuss on various State level challenges and prepare an action plan during these two days consultation.

TB basics: Diagnosis, Treatment and Prevention: Dr. Abhijeet Sangma

Dr. Abhijeet Sangma, Treasurer PTCC welcomes all the participants. He briefed various activities about PTCC and explained the participants about the basic of Tuberculosis.

He explained about various points:

- How long has been TB infecting humans
- What is TB, How TB is transmitted, TB infection and disease, transmission of TB.
- TB definitions, What is the risk of Latent TB Infection progressing to active disease
- What happens during active TB disease
- Multi-Drug Resistant TB, Drug Resistant TB, Extensively drug resistant TB - XDR TB
- Prevention of Tuberculosis, TB Infection control in HIV care
- Infection Control and Isoniazid Preventive Therapy

RNTCP NGO Scheme:

Mr.Hiren Patel, RNTCP Consultant, Gujarat participated in the two day consultation meeting. He presented a brief on NGO RNTCP scheme.

State wise consultation: Setting up action points for Regional Call to action:

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 1 hour on solutions after which each state made a presentation of their deliberations.

Madhya Pradesh & Rajasthan: Presented by Dr. Jhariya and Mr.Ajay Lavre

Sl No	Challenges identified	Suggested Solutions	Recommendation for PTCC
1	Lack of Awareness at all levels	Sensitization is needed for; - Local health care providers (medicine shop keeper, baidya) - traditional /opinion leaders - community based organizations - SHGs, GKS, Youth clubs, etc - PRI members	Advocacy with Government on nutrition supply for TB patients
2	Lack of Nutrition support	Supply nutrition support to TB patients at regional/district level Providing education on Nutritious food.	Advocacy on preparing diet chart for patients. Providing training on resource mobilization.
3	Delay on early diagnosis and proper treatment	Strengthening the monitoring at all levels	
4	Social stigma and unnecessary diagnosis expenses. Stigma towards women	Involvement of more regional level TB experts/champions.	
5	Lacuna in machinery equipments	Advocacy with Government departments	

Maharashtra & Goa: Presented by Mr. Anand and Mr. Shahid

Sl No	Challenges Identified	Suggested Solutions
1	Defaulter patients: <ul style="list-style-type: none"> ➤ Lack of nutrition ➤ No proper counseling ➤ Addiction of Alchol and drugs ➤ Lack of transportation ➤ Illiterate DOTS providers ➤ Lack of family support ➤ No knowledge of side effects of treatment 	1. Provision of TB counselor at District Level, Frequent Patient provider Meeting at grass root level. 2. Soft Skill training for ANM and ASHA, RNTCP Staffs 3. Linkage with social welfare scheme of Govt. and NGO run projects (c) ANMs to be trained for possible ADRs and supply of required medicines at sub centre level/PHI 4. Flexi DOTs by more involvement of Community 5. Monthly checkup by the attending Physician and prompt address of any Co-Morbid condition detected. 5. health education- awareness camp on lung 6. Training on silicosis and TB 7. IEC material on local languages.
2	Testing: <ul style="list-style-type: none"> ➤ Timing of health staff ➤ Availability of LTs ➤ Scarcity of Lab ➤ Lack of knowledge of diagnostic tests ➤ Poor infrastructure; general and health 	
	Case holding: <ul style="list-style-type: none"> Lack of Counseling Livelihood (Social Securities) Adverse drug reaction not attended of DOTs due to Distance (e) Co-Morbidity 	
3	Lack of private practioners involvement	
4	Lack of information in IEC materials	

Proposals and recommendation for Call to Action:

- Advocacy with district level/ State level officials on recommended issues.
- Identifying CSR opportunities.
- Identifying and utilizing local resources.
- Soft skill trainings
- Nutritional support for TB patients

Additional remarks and observations:

- Under VHND (village and health nutrition day) ensure TB is included through advocacy efforts
- Monitoring of the program can be done by NGOs who can give objective feedback to the government on the program. Generating evidence is important for advocacy to government for change so as to convince them of the need.

Discussion on Patient Network/ Preparation of action plan:

Ms. Sanchita explained that one of the major gaps in TB care and Control is the lack of community engagement especially in terms of advocates for TB services who can highlight the gaps and lacunae at the community and district level and bring this to the attention of the RNTCP. Hence involvement of the patient group has a major role in TB control efforts. An effective patient involvement yields positive results, such as improved case-finding and treatment outcomes, raised awareness concerning the nature of the disease and the availability of effective treatment. She informed the partners that for the enhancement of the engagement of patients group Partnership for TB care and control (PTCC) is in the process of establishing a country –wide patient network for bringing forward any issues regarding TB services in the field and also promoting volunteers among them to become TB advocates. The objectives is to bring the patients together where they can discuss their needs, problems, suggest solutions and identify opportunities towards greater engagement of patient community in RNTCP.

She urged the partners to share their view and feedback on patient network forum e.g. how we can form the forum, who can be the potential stakeholders, objective and activity.

Partners suggested that we can form forum from the ground level as block/district and State level. One representative from the State level will be representing at National level forum. The forum must have advisory body of different stakeholders from all sectors.

Suggested stakeholders for patient network forum:

1. Quacks
2. Chemist
3. Pathological lab
4. Radiological Centre
5. Media person
6. Teachers
7. Advocates
8. PRIs
9. Social Activist
10. Students
11. CSR representative

12. Transport union
13. Labor union
14. Manufacturing/pharma units
15. IMAI
16. Experts
17. Industries

Suggested activity for patient network:

1. Contact tracing
2. Experience sharing
3. Advocacy on funding opportunities
4. Advocacy for livelihood support
5. Advocacy for employment opportunities
6. Advocacy on linking TB patients in various govt.Schemes
7. Advocacy for nutritional support

The partners urged PTCC to organize a capacity building training program for the patient that will help them for functioning of network and for advocacy activities.

Experience sharing by partners:

The experience sharing session began with Mr. Ajay Lavre, Madhya Pradesh who introduce his organization and its work, implementing activities for Project Axshya in Madhya Pradesh and its achievements in increasing referrals, increased number of sputum samples transported for examination and creating awareness in the community through mid media activities.

Mr. Joes presented about his experience working in Goa. He has represented the Organisation IDF. IDF is enlisting student's participation in spreading awareness on Tuberculosis. They are conducting school program in order to create awareness through school children.

Mr.Mahitosh from HEDCON, Rajasthan shared about his experience on working in the field of silicosis. He stated In Indian situation silicosis should be regarded as a major cause of tuberculosis since under nourished and overworked workers who often have to stay at the place of work which may be a quarry or mine have much higher chance of getting tuberculosis.

Organisation representatives from Maharashtra shared their experience working in the field of TB under project Axshya. They focused on involvement of RHCP in the TB care and control program. They also emphasized the role of patient network for TB control program.

Mr. Ajay Nigam, Jyoti Mahila Mandal and Mr. Ritesh Salunke from Chatrapati Shivaji Samiti, Madhya Pradesh shared their experience on mobilizing resources for providing nutritional support to TB patients. Mr. Ritesh shared how they mobilize resource from CSR opportunities. They have approached the Dabur Company to give some nutritional support for TB patients and the company provided various products for the affected community. In this way they are mobilizing some resources for helping TB patients.

Nutrition support for TB Patient:

Nutrition support for TB Patient is a major point during group discussion. Partners emphasized on advocacy for nutrition supply. It has been demonstrated that under nutrition is a risk factor for progression from tuberculosis infection to active tuberculosis disease Treatment for TB is long – at least six months – and often difficult. Patients have to take many tablets every day, and often suffer from unpleasant side effects. They may also feel isolated or that no-one understands what they are going through. From travel

to regular hospital appointments to eating the nutritious diet that is essential to support recovery. Hence advocacy for nutrition supply and other cost is highly necessary. Partners said there should be policy level intervention needed.

Action plan for each State and entrusting responsibilities:

In the final session partners discussed on the action plan for each States. It was decided partners will prepare a State level action plan for each State and share it with PTCC Secretariat and also they will share their feedback time to time. A Google group will constitute and partners will share their advocacy level intervention through this group also they can suggest, give feedback, new ideas of intervention through this group. They can use social media for dissemination of information. Every month they will share their report of activities to the secretariat. And also will share any issue of their region which needed to be address or advocate at national level. Ms.Sanchita also requested the participants to share various case studies, success stories for the partnership newsletter.

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 Organisations 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.

Ms.Sanchita requested all participants to share their experiences what they have learnt from the two days consultation. Expressing her gratitude on behalf of PTCC she thanked all participants for their active and informative participation.

