Regional Consultative Meeting- East

9-10 March 2017

Hotel Lee Lac, Ranchi

Background and objective:

The regional consultative meeting of eastern region held on 9-10 March 2017 at Hotel Lee Lac, Ranchi, Jharkhand. The main objective of the meeting is to provide all regional partners to unite and brainstorm to find collaborative solutions to challenges, review the past initiative and to expand the partnership in east region. Total participants participated from the States of Bihar, Chhattisgarh, Jharkhand, Odisha and West Bengal.

Outcome:

- Issues related to civil society engagement identified and solutions to challenges explored with action that civil society can take
- Strengthening of the relationship among all partners and building new connections
- Building capacity of the partners on key issues surrounding TB treatment access, timely diagnosis and quality care by expanding the base of support, organizing media outreach, community monitoring and advocacy.
- Gaining ownership of the partners of the Partnership.

Day 1: 9 March 2017

The Regional Consultation meeting began with the welcome address by Ms. Sanchita Rout, Project Coordinator, PTCC. Welcoming all the partners she explained about PTCC. The Partnership for TB Care and Control (PTCC) is one of the national coalition comprising of technical agencies, non-government organizations (NGO'), community based organizations (CBO's), affected community groups, corporate sector, professional bodies and academia committed to support and strengthen India's national TB control efforts. She stated Regional Consultative Meeting of partners is one of the key events of PTCC where all member civil society organizations of region 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. She highlighted the growth of PTCC to 223 partners. This was followed by a round of self introduction of the participants. After the inauguration session Mr. Subrat Mohanty, Project Coordinator, The Union welcomes all participants and discussed about role of CSOs in TB care and control. He also discussed about importance of community process in improving health outcomes. He shared why community need in TB. Because of

Patient in desperate need

Patient require point of care

Patient look for socio economic support

Patient treatment adherence

Patient rights/human rights

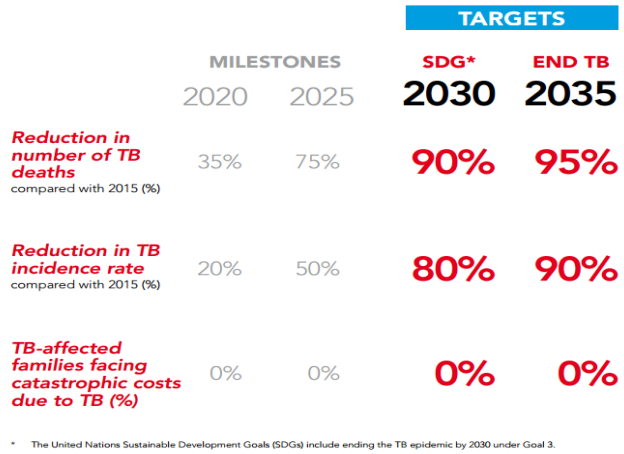
He told about social factor which affect tuberculosis intervention as proper nutrition, batter access, crowded urban inhabitation and clinical vulnerability.

Three C's, community awareness, community preparedness, community support.

Then he shared about the end TB strategy.

End TB Strategy target:

Mr. Subrat shared about the End TB strategy target among participants.



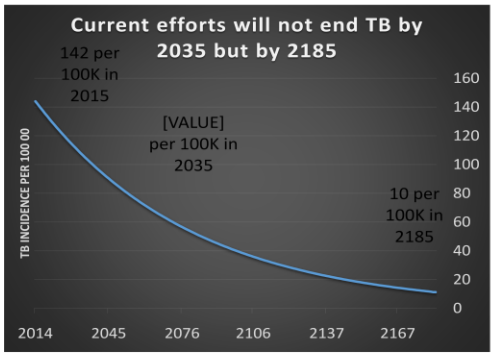
	MILESTONES		TARGETS	
			SDG*	END TB
	2020	2025	2030	2035
Reduction in number of TB deaths compared with 2015 (%)	35%	75%	90%	95%
Reduction in TB incidence rate compared with 2015 (%)	20%	50%	80%	90%
TB-affected families facing catastrophic costs due to TB (%)	0%	0%	0%	0%

* The United Nations Sustainable Development Goals (SDGs) include ending the TB epidemic by 2030 under Goal 3.

He stated there is a pivotal role of CSOs for achieving the target.

Then he stated the reason for slow decline of incidence.

Reasons for slow decline of incidence



1. Existing tools not reaching all in need
   - especially the poor, vulnerable and marginalized

2. Research for new tools is under funded and slow progress

The slow decline of incidence occurs because of existing tools are not reaching all in need. Especially the poor, vulnerable and marginalized are still unreached. Again research for new tools is underfunded and slow in progress.

Globally over 4 million TB patients missing each year is a major concern. The missing people with TB are more likely to be migrants and other vulnerable group. He discussed about the pillars, bold policies and supportive system for TB eradication.

Pillar 1:

a. Early diagnosis of TB including universal drug susceptibility testing, and systematic screening of contacts and high-risk groups.
b. Treatment of all people with TB including drug-resistance TB, and patient support.
c. Collaborative TB/HIV activities and management of co morbidities.
d. Preventive treatment of persons at high risks, and vaccination against TB.

Pillar 2:

Bold policies and supportive system:

a. Political commitment with adequate resources for TB care and prevention.
b. Engagement of communities, civil society organisation and all public and private care providers.
c. Universal health coverage policy and regulatory frameworks for case notification, vital registration quality and rational use of medicines and infection control.
d. Social protection, poverty alleviation and actions on other determinants of TB.

he urged the participants to help in achieving the targets, identify challenges and suggest recommendation for the implementation of programmes.

After this session Dr. Rajeev pathak, WHO consultant, Jharkhand welcomed the participants and share and discuss about the national updates in TB care and control. At first he discussed about the basic of TB. Tuberculosis (TB) is one of the oldest diseases of humans. It is a major cause of death worldwide; it competes with HIV/AIDS as the greatest killer globally due to a single infectious agent. TB is also one of the top killers of women worldwide, 0.45 million women died from TB in 2015 which is caused by the bacterium *Mycobacterium tuberculosis*. Tuberculosis usually affects the lungs, although other organs are involved in 15-30% of cases If properly treated, TB caused by drug-susceptible strains is curable in virtually all cases If untreated, TB may be fatal within 5 years in 2/3 of cases. One third of world has latent TB infection.

He shared about the TB scenario of global and India:

	Global	**India**	
Indicators	**Number**	**Number**	**Rate (per lakh pop)**
Incidence TB	10.4 M	28.4 lakh	217/lakh
Mortality of TB (excludes HIV TB)	1.4 M	4.8 lakh	36/lakh
Incidence HIV TB only	1.2 M	1.13 lakh	8.6/ lakh
Mortality of HIV-TB only	0.4 M	37000	2.8/ lakh
MDR-TB	4,80,000	79000 (2.5% among New & 16% among RT cases)	

TB/HIV co infection a double burden:

- ✓ TB leading cause of death in PLHIV
- ✓ ¼ of PLHIV worldwide die due to TB.
- ✓ PLHIV infected with TB 20-40 times more likely to develop active TB.
- ✓ Untreated, TB in PLHIV leads to death in weeks
- ✓ 80% of all TB/HIV cases are in Africa

Drug Resistance TB: A major Challenge:

- Multi-drug resistant TB (MDR-TB)
    - Second-line drugs, toxic, costly, lengthy
- Extensively drug resistant TB (XDR-TB)
    - Almost incurable, fatal
- Drug resistant TB results from inadequate TB care and irrational use of drugs
- at least Rifampicin and Isoniazid
- Treat with second-line drugs
- Treating MDR TB takes 3-4 times longer and costs 100 times more
- Extensively drug resistant TB (XDR-TB) is resistant to any fluoroquinolone, and at least one of three injectable second-line drugs (capreomycin, kanamycin, and amikacin), in addition to MDR-TB
- Difficult to diagnose
- Time for culture
- Special laboratories
- About 10% of MDR TB is XDR
- High fatality rate in people living with HIV
- Drug resistant TB results from inadequate TB control and irrational use of drugs
- No new TB drugs for more than 40 years
- MDR resistance to at least the 2 most potent TB drugs
- MDR is a man-made problem that arises from inadequate TB control – poor adherence with standard 6 month treatment course on the part of the patient or clinician, poor treatment literacy, poverty, other illnesses….lack of adequate investment in and political commitment to TB control
- Treatment takes longer; more side effects, higher default rates and outcomes are not nearly as good.
- TB that is resistant to any fluoroquinolone, and at least one of three injectable second-line drugs (capreomycin, kanamycin, and amikacin), in addition to MDR-TB
- Difficult to diagnose

- Time for culture
- Special laboratories
- About 10% of MDR TB is XDR
- High fatality rate in people living with HIV
- Present in every region of the world
- Can be cured or treated in some cases
- Several countries with good TB control programmes have shown that cure is possible for up to 30% of affected people.
- Successful outcomes also depend greatly on the extent of the drug resistance, the severity of the disease and whether the patient's immune system is compromised.
- Effective treatment requires that all six classes of second-line drugs are available to clinicians who have special expertise in treating such cases

- He also discussed about the mission, vision, target and goal of end TB strategy. We have to now move towards new era of SDG and from STOP TB Strategy to END TB Strategy.

Everyone with TB should have access to the innovative tools and services they need for rapid diagnosis, treatment and care. This is a matter of social justice, fundamental to our goal of universal health coverage. Given the prevalence of drug-resistant tuberculosis, ensuring high quality and complete care will also benefit global health security.

The TB elimination strategy:

- An important step this year was the consultation on the vision inspiring the future post-2015 Strategy.
- The participants at this consultation convened by WHO and the Stop TB Partnership agreed that our future vision should be one of a world free of TB and that our ultimate aims should be to move towards no more TB deaths, TB cases and suffering from this disease. This is expressed by the ambitious word "zero".

There is now a paradigm shift in approach. Earlier, engagements were based on Referral of TB patients for any services (diagnosis, treatment, public health services) to RNTCP. Now – focus is on Quality of care, every patient should get quality acre as per STCI, wherever they service from, the programme role is facilitatory, focus on surveillance and necessary patient support. He also discussed about 3 pillars and 4 principles of end TB strategy.

Standard of TB care in India:

- It was felt that India should have its own standards that could be used as a benchmark by all providers managing TB patients within India
- A set of standards recognized as appropriate for the specific challenges of India will spur observance to these standards by all care providers of India when managing a TB patient.
- 26 Standards developed after a National Workshop

He also discussed about the new tools, CBNAAT, strengthening laboratory service, FCDs potential advantages. Daily regimen for TB/HIV. For new TB cases, the treatment in intensive phase (IP) will consist of eight weeks of Isoniazid, Rifampicin, Pyrazinamide and Ethambutol in daily dosages as per four weight band categories. There will be no need for extension of IP. Only Pyrazinamide will be stopped in the Continuation Phase (CP), while the other three drugs will be continued for another 16 weeks as daily dosages.

For previously treated cases of TB, the IP will be of 12 weeks, where injection Streptomycin will be stopped after 8-weeks and the remaining four drugs (INH, Rifampicin, Pyrazinamide and Ethambutol) in daily dosages as per weight bands will be continued for another 4-weeks. There will be no need for extension of IP. At the start of CP, Pyrazinamide will be stopped while the rest of the drugs – Rifampicin, INH and Ethambutol will be continued for another 20 weeks as daily dosages in the CP.

The CP in both new and previously treated cases may be extended by 12-24 weeks in certain forms of TB like CNS TB, Skeletal TB, Disseminated TB etc. based on clinical decision of the treating physician. Extension beyond 12 weeks should only be on recommendation of experts of the concerned field. Loose Drugs would be needed as substitutions in case of adverse drug reaction or with co-morbid conditions.

He also discussed on TB –Diabetes, TB surveillance system, 99 DOTS, private sector notification, PPM intervention, One most important aspect of TB notification is to ensure public health support for the patients notified by private sector this includes - Patient home visit as per convenience of patient,

Counselling of TB patient and family members,

Treatment adherence and follow up support ensure treatment completion,

Contact tracing, symptoms screening, evaluation of TB symptomatic and offering INH chemoprophylaxis to eligible contacts,

Offering HIV testing, Drug Susceptibility Testing (DST), if eligible.

This ensure value addition by public health system to patient care in private sector and if done properly, has a huge potential to develop trust which is a pre-requisite for partnership much required for TB control.

He also discussed about BDQ launch and active case finding.

Challenges to elimination:

1. Funding not secure; catastrophic expenditure for the poor
2. Only 2/3 of estimated cases reported or detected (late)
3. TB/HIV major impact
4. Emerging DR TB, with multiple resistace pattern
5. Un-engaged non-state practitioners and communities, and the private sector
6. Weak health policies, systems and services
7. Social and economic determinants maintain TB

Research awakening: old diagnostics, drugs and vaccines.

Under PRAGATI review consultative meeting with States will held, district identified based on agreed criteria (high TB, TB HIV, MDR_TB and low case finding) and action plan for same is in progress.

The session ended with a question answer by the participants.

After the launch break session Mr.Sashikant Nayak, ACSM consultant, Jharkhand discussed with participants on successes and challenges in TB care and control in States. He shared about various initiatives by RNTCP and by CSOs and the role of CSOs and how they can contribute towards TB care and control. Mr. Nayak described case studies from field**.** It revealed challenges for patients are different stages, as stated below:

- The programme tries to ensure health (TB) security, but could it be fruitful without social and economic security and psycho-social support
- Delay in diagnosis and treatment of infectious cases
- Contact screening and counseling services are missing
- Need to line list the traditional healers and sensitize them

Mr. Nayak explained how civil society can work closely with the ACSM in the state through the entire process, by helping to gather evidence and identifying barriers to services as well as suggesting good programmes or projects that can be scaled up.

In the open forum he discussed and guided the participants on raised questions.

After all these sessions partners shared about their activities in States and challenges and successes.

Mr. Diwakar Sharma, State Coordinator, REACH Call to action project presented about their activities in State.

He first discussed on how will change happen:

Change = TB gets more attention, more resources, more investment

Change will happen when:

- We are able to raise the profile of TB
- We are able to involve previously unengaged stakeholders
- We are able to expand the boundaries of conversations on TB
- We are able to support the public health system to fill gaps

Priority state of the project:

Odisha, Jharkhand, Assam, Rajasthan, Bihar and Uttar Pradesh

Strategic objective:

SO1: Coalition-Building, SO2: Resource mobilization (public and private sectors), SO3: Private healthcare sector, SO4: Civil society and affected communities, SO5: Policy advocacy, S06: Community models, S07: Raising the profile of TB.

Updates on Jharkhand:

- Draft state implementation framework shared with State TB Cell
- Discussions initiated with Jharkhand State Nutrition Mission to integrate nutrition and childhood TB
- Background research ongoing for addressing TB and Mining, TB and Gender, Corporate involvement, TB among tribal populations

- Request floated for proposals from state partners; shortlisting ongoing
- Official launch of TBC2A project has been done in Jharkhand on February 21 '17
- State coordinator appointed
- Letter of introduction issued from MoHFW to TBC2A project states
- Meetings initiated with MPs and MLAs to seek support for engagement in Jharkhand.
- Meeting with Corporates for their support towards TB care and control
- Convergence meeting with other line departments.
- Taking Ms. Deepika Kumari on board as a brand ambassador for TB.
- Talks has been initiated to take the Pharmacies for Advocacy on TB and TB Notification.

He urged the partners to work collaborately for the advocacy activities.

He also discussed about the implementation framework of project in Jharkhand.

Mr. Md. Hashmat Rabbani , India CCM member presented about India CCM, and his representation and role of CSOs. He shared about India has been allocated US$500,000,000 for HIV, TB, malaria, and building resilient and sustainable systems for health. He shared in TB India get 279,929,924 for the period of 1 January 2018 to 31 December 2020. He shared about the success in his CCM representation.

He discussed in CCM:

- Effective collaborative representation on the Country Coordinating Mechanism
- Full collaborative representation in India CCM
- Deepened collaboration eg Community Dialogue for NFM Concept Note
- TB KAP has been brought to the fore
- Increased visibility at policy making levels
- Success towards fruitful dialogue
- Effective engagement of civil Society in TB Control

- Discussion on Nutritional support to MDR Patients during treatment period (67th CCM Meeting on 14.12.2016)

Future plan for CCM:

- Formulate guidelines for the formation of patient organizations.
- Capacity building to become peer counsellors / peer educators
- Convergence, Strengthen and improve livelihood programs for TB Patients
- Tap funding agencies to provide for the projects/plans of different patient support groups
- Key populations, Gender, Rights, stigma and discrimination, Differentiated care delivery approach

The day 1 ended with group photograph.

Day 2:

Day 2 started with the recap session. The volunteer chosen from day 1 presented on day 1 various sessions and discussions.

Presentation and experience sharing from partners:

Partners shared their experience and activities in TB care and control.

Experience sharing by Lok Shakti Samiti:

Mr.Shyam Sundar Yadav from Lok Shakti Samiti shared about the activities conducted by Lok Shakti Samiti and about various initiative of District TB Forum. The district TB Forum members also helped TB patients with proper care and nutrition support. He shared the success story of TB patients who successfully cured.

Partners of Odisha presented their State scenario and activities conducted by partners and TB Advocates in the State.

CSO from West Bengal shared the initiative by the Axshya partner and TB forum members on distributing nutrition support to needy TB patients. He shared how they utilizing the local fund for distributing nutrition support for patients.

State wise groups were formed and the session to deliberate on current involvement of the community in the state and what are challenges and local solutions that can be done through collaborative action with civil society.

Group Work:

The groups were given an hour after which each state made a presentation of their deliberations. Mr. Diwakar Sharma facilitated the session. He talked about the SMART method and provided guidance to the participants to prepare action plan with objective, with specific activity and time period for complication of activity.

Bihar:

Objective, issues	Activity	Time Frame
Advocating for providing nutrition support for TB patients	Advocacy with political leaders, MP, MLAs (contacting 6 MPs and 15 MLAs) to raise question in the parliament. Discussion with MP and MLAs of concerned district's issue.	1st quarter
Transportation facility for TB patients for treatment support Remuneration for daily wages	Advocacy with Media, different government officials, DM, SDO	2nd and 3rd quarter

Odisha and West Bengal:

Media and political Advocacy:

- Sensitizing and advocating with journalist of print and electronic media professional.
- Submission of memorandum for nutrition support for DR TB patients
- Advocacy for involving CSOs in ACSM activities run by State department for strengthening community mobilization and participation.
- Advocating with political leaders to raise voice in the assembly for safeguard of TB affected community. At least sensitize 5 MPs and 10 MLAs
- Advocating for regular availability of medicine and fulfill of require health staff.
- To check TB-HIV migrants and provide local employment and income generation programme.

Chhattisgarh:

Issue	Activity	Timeline
To implement the nutrition support	Pilot level data collection	April-June

program in all over the State Special package for MDR TB patient Advocacy with DTO for involving CSOs in RNTCP activities and represent in various planning and review meetings Advocating with PRI members to organize special session on TB in Gram Sabha and other PRI meetings	Meeting with various MLAs. Submission of memorandum to Chief Minister. Submission of letter to DTO.	

The session ended with a recommendation from the participants to share the presentation with all PTCC partners as it would help in their area of work.

Ms. Sanchita discussed with participants on partnering with PTCC and contributing towards PTCC quarterly news letter.

Closing session

Ms. Sanchita thanked the group for their committed and enthusiastic participation over the two days of the meeting. All participants had an opportunity to express their views on the sessions, both verbally and through feedback forms.

She thanked all the people involved in the process of conducting the meeting.