Background and objectives:

The “Partnership for Tuberculosis Care and Control in India” (the Partnership) brings together civil society across the country on a common platform to support and strengthen India’s national TB control efforts. It seeks to harness the strengths and expertise of partners in various technical and implementation areas, and to empower affected communities, in TB care and control. It consists of technical agencies, non-governmental organizations, community-based organizations, affected communities, the corporate sector, professional bodies, media and academia.

Developing a common understanding and agreement among the key stakeholders for involving partners in TB care and control at state and regional level is crucial to the Partnership’s strategy. Regional meetings for the Southern, Eastern, Central, Northern and North eastern regions were held at Chennai in July 2009, at Kolkata in August 2009 and Patna in February 2011, at Bhopal in September 2009 and Mumbai 2011, in Dehradun in July 2010 and in Shillong in September 2010.

These meetings have created a visibility of partners and provided a platform to initiate dialogue with the State and District level programme managers for TB care and control. Based on the results of previous meetings, the second meeting for the Southern region was organized at Hyderabad, Andhra Pradesh on the 28 & 29 April 2011.

The International Union against Tuberculosis and Lung Disease (The Union) South East Asia Regional Office host the Secretariat of Partnership and provide technical and administrative support.

Objective of the meeting:

- To develop a common understanding and agreement among the key stakeholders for involving Partners in TB care and control at state and regional level.

Outcomes:

Primary outcome;

- Issues related to civil society engagement identified and solutions to challenges explored with action that civil society can take
- Developed a work plan for increased participation of civil societies in RNTCP at the state and district level

Secondary outcome;

- New partners joining the Partnership increased
- Increasing communication between partners and the Secretariat
- Gaining ownership of the Partners of the Partnership
Organization:

The event was organized by the Secretariat of the ‘Partnership’, a coalition of civil society, private sector, technical and international organizations, formed in 2008 to support TB care and control in India. In coordination with Program for Appropriate Technology in Health (PATH) for partners working in the states of Andhra Pradesh, Karnataka, Kerala and Tamil Nadu.

Please visit [www.tbpartnershipindia.org](http://www.tbpartnershipindia.org) for information on the Partnership.

Proceedings:

28th April: Experience sharing:

- Dr Darivianca E.Laloo, Partnership Secretariat welcomed all the participants especially Dr. Udayasankar, STO, Tamil Nadu and Dr. Rama Rao, DTO, Andhra Pradesh who was representing the STO, AP. She gave a brief introduction of the meeting, its objectives and agenda (Annex 1, 2). This was followed by a self introduction of all participants.
- Dr. Laloo continued with an introduction to the Partnership, its objectives, its progress and future plans (Annex 3). She also represented The Union Global fund Team and gave updates on Project Axshya (Annex 4).
- Dr. C. Udayasankar gave an overview of RNTCP in Tamil Nadu and stressed the need to continue efforts to address MDR-TB in his state. He also questioned why in spite of achieving 85% cure rate the infection rate remains the same. He called on CSOs to continue their support to the program.
- Dr. Rao shared the success of the program in Andhra Pradesh and the collaborative efforts with all NGOs working on TB care and control in the state. He requested that for the coastal areas of AP there is scope for increasing involvement of civil societies along with the TB program and we should explore these possibilities.
- Dr. J. Subbana, Lepra Society- Blue Peter Public Health and Research centre presented their work of one decade which included their achievements and new schemes for rolling out MDR TB diagnostics (Annex 5). He mentioned their combined work in 4 states on MDR TB and TB HIV, new interventions like MLA sensitization as part of their ACSM initiatives, OR studies in Tribal Area, including Situation analysis of HIV, HIV/TB. Lab and field based studies.
- He then provided the status of MDR TB in India and the growing need to scale up all interventions. He also shared an interesting success story on partnering with national programme on the concept of Sample Transportation kit and a standard practice of documenting and publishing the study. He is pleased that Lepra is the first NGO whose lab technology has received an accreditation from the programme.
- Mrs. Vanajaa Augustine, Development Action Consortium Trust (DACT) introduced their organization and shared their experience in organizing a state level TB consultation of NGOs and program to address challenges and opportunities in TB services and access through a state network of NGOs (Annex 6). Some of the issues discussed were inaccessible remote rural and unreachable areas, late diagnosis due to no Lab technicians in certain areas, increase in co infection of TB with other diseases, no sputum collection centers in certain areas, NGOs not involved in implementing RNTCP schemes, lack of effective monitoring, increase in default rates and no major role of elected representatives in TB control. She also mentioned the suggested
activities to address these challenges such as health committee formed at panchayat level, organizing trainings of traditional healers and quacks on TB and involving them as DOT providers, involving private medical officers in RNTCP, involving more NGOs on TB and linking the state level network with the national and international level for advocacy. Mrs. Vanajaa also highlighted their experiences with Operational Research.

- Dr. Prakash Kudur from Karnataka Health Promotion Trust (KHPT) provided an overview of the organization’s TB-HIV related activities (Annex 7). He shared the various projects that KHPT are involved with such as Sankalp-Avahan which reaches 60,000 Female sex workers and 22,000 MSM in their operational areas, Samastha – HIV prevention, care and support, and Spruha along with NACO for GF round 6 where they provided technical support to KSAPS.

- Fr. Anto Chalissery, CHAI- Kerala introduced their work and highlighted the work done by CHAI in Wayanad district, Kerala under Global fund Round 9 (Annex 8).

- Mr. P.K.Swamy, TB Alert India closed the morning sessions with a presentation on TB Alert’s work on TB through its various partner NGOs (Annex 9). He highlighted some of the challenges faced during implementation of the projects and gave the audience some points to ponder on such as:
  - Need for development of TB Information Materials / Facilitation
  - Materials for RHCPs, TB Forum & MDR support groups in local language
  - Need budget allocations for follow up meetings for TB Forums & MDR support groups
  - Need to have soft skill Training programs for SSRs, TB forums and MDR Support Groups
  - Involvement of cured TB patients in all interventions yielding greater results
  - Need for Formal and regular Training to SSRs – on Program & Finance aspects of Axshya Project.

- Post lunch, Mr. Shiva Shrestha shared PATH’s work on TB care and control. Some of the key areas are lab strengthening, air borne infection control, capacity building on ACSM, PPM efforts in AP for involving pharmacists for referrals of TB suspects and sharing workshops on MDR-TB with innovative home based care for MDR TB patients.(Annex 10)

- Dr. Laloo facilitated the formation of the three working groups program with equal participation from the NGO sector and the government department to begin brainstorming on three different topics namely:
  1. Group A – Service Delivery , Facilitated by Dr. Subbanna, LEPRA
     (i) Improving sputum collection centres
     (ii) Counseling in TB programmes
  2. Group B - ACSM, Facilitated by Mr. Shiva Shrestha, PATH
     (i) Innovations and dissemination of IEC materials
     (ii) Recognition and acceptance of CSOs by the local government
  3. Group C - PPM, Facilitated by Dr. Franklin Santanthony, IDF
     (i) Over the counter prescription of TB treatment by pharmacist and unlicensed service providers
     (ii) Sub optimal involvement of the non formal service providers in urban areas.

- The objective is to collect evidences from the field on solutions for these challenges and back up the recommendations on what civil society can contribute to address them. The document has
been submitted to Central TB Division in February 2011 for inclusion into the RNTCP phase III planning.

- Group activity began with group members gathering in 3 clusters to brainstorm on the topics and preparing their results to be presented the next day.

29th April: - Group presentations with Panel discussion

- Manpreet welcomed back the participants and presented a recap of Day 1 of the meeting.
- Dr. Laloo welcomed Dr. Sarabjit Chadha, Project Director, Global Fund Round 9, The union and also Dr M S Srinivas Rao, STO AP who dropped by the meeting to wish all participants success in their endeavors and also said a few words on the program in Andhra Pradesh.
- Dr. Laloo requested the participants to form state-wise groups, discuss and decide on action-points for responding to the issues identified through the discussions on the first day of the meeting. Each state presented priority areas for action after a deliberation of thirty minutes. The salient points from presentations are listed below.

**Andhra Pradesh:**

- Sensitization of all NGOs on RNTCP schemes: - NGOs who are really working actively on health issues specifically on TB, HIV/AIDS will be identified and included in the sensitization program by one of the NGO partners in the state who has the expertise in RNTCP.
- Sensitization of District level authorities: - Collectors and DMHOs have to be sensitised on all RNTCP schemes so they can sanction the schemes to the right NGOs.
- Discuss issues in Review meetings: - problems, advices and other issues can be shared and discussed at review meetings as it is the right place as both Government officials and NGOs are present in these meetings.
- Capacity building programmes to DOT providers: - ASHA workers, AWWs, private practitioners and social workers who are DOT providers have to be included in capacity building programmes like soft skills trainings, health issues and others.

**Karnataka:**

<table>
<thead>
<tr>
<th>What?</th>
<th>How?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 List out non member NGOs including grass root level</td>
<td>Use information available ,STOs,DTOs office, WHO consultants, Google, yellow pages,etc.</td>
</tr>
<tr>
<td>2 Understand the nature of NGOs work and appraise about the Partnership</td>
<td>Appraise potential partner NGOs about the partnership, collect information through the internet, telephone calls, emails requesting them to fill a form and send to the Partnership</td>
</tr>
<tr>
<td>3 Prompt them to be members</td>
<td>Advocate with the potential partners. Present members to call a meeting of all partners at the state level and possible district level.</td>
</tr>
<tr>
<td>4 Initiate the formation of network of</td>
<td>Initiate formation at the grass root level – block</td>
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</tbody>
</table>
TB cured patients at state and district level through CSOs and other stakeholders and state level.

| 4 | Work for increase media involvement |

**Tamil Nadu:**

- State-level IEC materials to be produced jointly by State, District and NGOs working on TB. Message could be;
  - 2 weeks continuous cough for immediate diagnosis and free treatment approach the nearest PHCs and General Hospitals.
  - This will be telecast in Doodarshan, Cable TV, Posters, toll free phone numbers and voice sms.
- Toll free number for TB counselling, Voice SMS for TB information
- Awareness through public places like beauty parlours, transport workers for sensitization to the general public.
- District level review of TB work by government officials and NGOs (RNTCP and others)
- Gram Sabha positive speakers of TB.
- Marketing of anti-Tb drugs by private sector should be banned
- Tamil Nadu education department; cover page and syllabus – TB information should be included.
- RNTCP vacancies should be filled immediately
- Increase of scheme budget allocations for RNTCP.

**Post-tea break**

- Representatives of each of the groups (Service Delivery, ACSM, and PPM) from day 1 shared the outcome of group-discussions. Presentations are included separately. Key points and issues discussed in the wider group post-the presentations are presented below.

**Group 1: Service delivery (Annex 11)**

**Panel members:** Dr. Rama Rao, DTO AP (Chair), Dr. Srinivas Govinarajulu, GLRA, Dr. Prakash Kudur, KHPT, and Dr. Franklin Santhanthy, IDF.

**Group members:** Dr. J. Subbanna, Dr. Srinivas, Dr. Dyson P. Misquitta, Dr. C. Udaysankar, Ms. T. Mercy Annapoorni, Mr. P. Hrishi, Mr. P. T. Mohanadoss, Mr. A. K. Soman, Mr. Hari Singh, Mr. David Jones, Mr. T. L. Nandagopal, and Mr. N. Gangadharam.

The group discussed two issues (1) Sputum collection centres and (2) Counselling for TB patients.

1. **Sputum collection centres;**
   - The group deliberated on the challenges of sputum collection centers and the recommendation of (a) revising schemes with budgets for effective transport and (b) Involvement of private labs in efficient collection, transport of specimens and tracking/dissemination of results.
The proposed action by civil society to run sputum collection centers in remote / difficult terrain, urban slums and other settings where access to microscopic and molecular diagnostics (including diagnosis of drug resistant TB) is sub-optimal was further discussed on. Some of the key points on supporting the above action are:

- Volunteerism
- NGO identified for larger area by RNTCP can facilitate process
- Transportation issues
- Fast track NGO scheme approval process
- Speedy clearance of grant-in-aid disbursements on time
- Uptake of these schemes should increase
- Incentive for transport in inaccessible hilly / remote / tribal areas should be doubled / more
- Enhancement of amount – need based budget
- Annual increment o be introduced for NGO schemes grant-in-aid (in line to mitigate inflation)

2) Counselling for TB patients;

The group deliberated on the counseling for TB patients and the recommendation of mandatory counseling using patient charter at DMC / PHC with specific budget and deliverables. The proposed action by civil society to undertake counselling of patients with available resources is supported with key points such as:

- RNTCP should be the first point of initiation of counseling
- NGOs should support RNTCP in training in soft skills; strengthen counseling through training and support.
- Full time counselor a must for DOTS Plus site (In Patient ward) - NGO can be given this role
- Scheme for counselors can be developed for NGOs and incentive similar to ICTC counselors can be used as benchmark
- Counseling module for TB & DR-TB to be developed and translated into local language (incorporate patient charter)
- Counseling staff or person/NGO to support RNTCP in counseling

The additions from the larger audience have been included in the presentation.

Group 2: ACSM (Annex 12)

Panel members: Dr.P.Anand Kumar, WHO consultant, TN, (Chair), Mr. Mohanadoss, DLRH, Dr.J.Subbanna, LEPRA, Ms. Mercy Annapoorni, BLOSSOM.

Group members: Dr. Rama Rao, Mr. Shiva Shrestha, Dr. Michael, Ms. Vanajaa, Mr. Kunasekran, Mr. Sreeram, Dr. Prakash, Mr. Patil, Ms. Reeta, Mr. Ronald, Mr. P.S.R. Kanakambaram.

The group discussed two issues – (1) Innovations and dissemination of IEC materials (2) Recognition and acceptance of CSOs by the local government

Key points from the presentation and discussion thereafter are presented below.
<table>
<thead>
<tr>
<th>Challenge</th>
<th>Recommendation</th>
<th>Action by CSO</th>
<th>Evidences</th>
<th>Additional recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distribution Channels of IEC materials</td>
<td>Proper distribution and dissemination of IEC</td>
<td>Development of key Messages for each target groups</td>
<td>Existing evidence of designing appropriate IEC messages and materials and advocate with State TB Office to adopt it</td>
<td>- Concept of counseling on TB to be strongly addressed, training on soft skills, counseling skills</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Supporting the distribution channel by taking up follow up</td>
<td>- Communication messages should also provide information to link with social welfare schemes.</td>
</tr>
<tr>
<td>Role of DOTS provider to include IEC dissemination at strategic locations</td>
<td>Establish two way communication</td>
<td>DOT Provider is not adequately trained, hence he/she is not part of IEC activities at community level</td>
<td>Communication messages should also provide information to link with social welfare schemes</td>
<td></td>
</tr>
<tr>
<td>Patients, charter for TB care to be made available local languages</td>
<td>Facilitate distribution and dissemination and provide feedback about community response</td>
<td>Evidence of translating the Patient TB charter into local language (Hindi) Dissemination patient TB charter through Patient Provider meeting and support groups</td>
<td>Patient TB charter should be disseminated with A/V methods Prominent display in the PHC etc</td>
<td></td>
</tr>
<tr>
<td>Recognition and acceptance of CSO’s by the local government</td>
<td>Joint sensitization and advocacy to increase the visibility of ACSM efforts</td>
<td>Joint efforts by RNTCP and CSOs to sensitize the local authorities</td>
<td>NGO’s are not part of DTCS and other meetings including IEC development workshops</td>
<td>Involvement of CSOs in TB programme review at Block and district level</td>
</tr>
</tbody>
</table>

- The group added a few pointers that they felt was needed such as:
  - Need of training on ACSM to all the NGO partners and government
  - Challenges in being part of ACSM schemes for NGOS
i. The Grant in Aid allocated is not sufficient for NGOs who desire to do only particular NGO scheme

ii. Small NGOs cannot really partake in RNTCP Schemes

iii. Only NGOs who have other funding sources and other Project on hand are able to involve in RNTCP Schemes.

iv. There is delay in processing of MoU and release of budget.

   - Need to involve educational institutions and NGOs in designing and developing IEC materials

• The larger audience made a few remarks and included a few suggestions such as:

**IEC materials:**

*Print media:* NGOs to be involved by RNTCP in developing local specific IEC material using bottom up approach is solicited

*Electronic media:* Video clippings involving prominent film personnel giving TB related messages.

*Mass media Activities:* Street plays to create awareness on TB. NGO can be involved in organizing street plays and IEC stalls can be organised at community level.

*Support group and provider-Patient meetings:* organized at community level and discuss about Patient Charter. Bulk messages using mobile telephony including voice messages on TB.

*National & State TB Helpline like “104” in Andhra Pradesh.*

**Advocacy:**

- At Central, State and District level by Steering Committee.
- Advocacy with Principal Health Secretary, Director of Health and District collector to review RNTCP at State and district level.
- Advocacy with other line departments like transport, Women’s federation, etc.
- Inclusion of health education particularly about TB in text books of high school.
- Trainings : DOT providers and Para medical staff to be trained on TB and also provide with IEC material for local dissemination

**TB Patient Charter:**

- Translation in local language, suggested that charter in 19 languages by CTD. Can contact State/District /CTD for procurement
- Developed in Audio visual method to reach out to the uneducated
- Feedback from the community for revising and improvising IEC materials.

**Group 3: PPM (Annex 13)**

**Panel member** : Dr.C.Udaysankar, **STO TN** (Chair), Mr.Hrishikesh Polisetti, **Sivananda Rehabilitation Home**, Dr.Dyson Misquitta, PATH and Ms. Vanajaa Augustine, DACT.
**Group members:** Dr. P. Anand Kumar, Ms. A. Sridevi, Mr. V. Chellamuthu, Mr. Samuel Vincent, Fr. Anto Chalissery, Fr. M. Lawrence, Mr. S. Krishnamurthy and Dr. S. Franklin.

The group discussed two issues – 1) over the counter prescription of TB treatment by pharmacist and Qualified Medical Doctor prescribing non-DOTS, and (2) Sub-optimal involvement of the non formal service providers in urban areas.

1) Over the counter prescription of TB treatment by (a) pharmacist and (b) Qualified Medical Doctor prescribing non-DOTS

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Recommendations</th>
<th>Role of CSOs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>By Pharmacist</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Commercial Motive</td>
<td>1 to 1 training / Sensitization; Displaying a Statutory notice issued by the govt, “DOTS-Sure Cure for TB” – Available free of cost. Advising people against the trend using Mass Media</td>
<td>Promoting IEC activities</td>
</tr>
<tr>
<td>May not be aware of complications of TB</td>
<td>Awareness through trainings and should establish rapport with RNTCP and CSO. Make Pharmacists as DOTS providers Yearly gathering of pharmacists to get their experiences with RNTCP</td>
<td>Co-ordination and monitoring</td>
</tr>
<tr>
<td><strong>By qualified medical doctor prescribing non-DOTS</strong></td>
<td></td>
<td></td>
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<tr>
<td>Commercial motive</td>
<td>Circular issued by District /Corporation Health Authorities to prescribe and adhere to DOTS treatment</td>
<td>Facilitate advocacy for policy making</td>
</tr>
<tr>
<td>Disregard/lack of conviction to use DOTS</td>
<td>Training through experts; Sharing scientific papers</td>
<td>Co-ordination</td>
</tr>
<tr>
<td>Lack of awareness to prescribe DOTS</td>
<td>1 to 1 - training / Sensitization Take support from IMA</td>
<td>Co-ordination</td>
</tr>
<tr>
<td>Lack of linkages with RNTCP</td>
<td>Establishing linkages through RNTCP</td>
<td>Co-ordination</td>
</tr>
<tr>
<td>Reluctance to be a DOTS provider</td>
<td>Cite examples of best DOTS providers/ case studies etc; Recognition of work done</td>
<td>Co-ordination</td>
</tr>
</tbody>
</table>
2) Sub-optimal involvement of the non formal service providers in urban areas:

- Registered Medical Practitioners
- Traditional healers / Quacks
- Para-medical staff

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Recommendations</th>
<th>Role of CSOs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>By Registered Medical Practitioners</strong></td>
<td>- Decreased involvement of RMPs in RNTCP&lt;br&gt;- Inhibitions about the RNTCP methods or Bias over other branches of medicine&lt;br&gt;- Rigidity to their system of medicine</td>
<td>- Awareness and motivation about RNTCP&lt;br&gt;- Involve RMP into RNTCP&lt;br&gt;- Persuasion to adapt to RNTCP through a licensed medical practitioner who is following DOTS&lt;br&gt;Using the services of Specialists to whom, RMPs refer in case of difficulty.</td>
</tr>
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</table>

| **By Traditional Healers/Quacks** | - Not aware of the risks of TB and delay in treatment<br>- Fear of losing patients and losing practice<br>- Fear of being subjugated to other systems of medicine | - Sensitize the traditional healers for the early referrals<br>- Patient would come back for DOTS | - Facilitation<br>- Enabling traditional healers/quacks to become DOTS providers |

| **By Para-medical Staff** | Sensitization to reinforce their important role with regard to:<br>- Case finding,<br>- Treatment compliance,<br>- Follow up and rehabilitation | - Establish linkages<br>- Ensure proper disbursement of incentives to the DOTS providers |

- Lack of involvement, despite a) the faith placed on them by the patients and their families<br>b) their greater accessibility to the community

- Sensitize to reinforce their important role with regard to:
  - Case finding,
  - Treatment compliance,
  - Follow up and rehabilitation
  - Motivate them to be DOT providers

**Recommendations**

**Role of CSOs**

- Identify the licensed medical practitioner
- Persuade and motivate the RMP
- Facilitation
- Enabling traditional healers/quacks to become DOTS providers
- Establish linkages
- Ensure proper disbursement of incentives to the DOTS providers

- Mr. Shiva Shrestha, PATH then summarised the 2 day meeting and mentioned a few of the important points discussed (Annex 14) followed by Dr. Laloo who gave the Vote of thanks and the southern regional consultative meeting of partners came to an end.
- Six (6) new organizations signed the LOC and joined the Partnership for TB care and control.