



**NATIONAL CONSULTATIVE MEETING OF PARTNERS  
PARTNERSHIP FOR TB CARE AND CONTROL IN INDIA  
Lemon Tree Premiere Hotel, 48, Sector 29, City Center, Gurgaon**

**4<sup>th</sup> – 5<sup>th</sup> April 2012**

**REPORT**

**Background and objectives:**

The **Partnership for Tuberculosis Care and Control in India** 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.

In a short time, the Partnership with more than 95 partners all over India has become a hub for disseminating information, creating visibility for India's national TB program, responding to TB related challenges and providing support to various stakeholders.

The National meeting of the Partnership is the general assembly of the Partnership where we chalk out strategies and help partners gain ownership of the Partnership. It is also a platform to introduce each partner to one another and exchange experiences and expertise.

This year the Partnership held a crucial consultation among its members to discuss a roadmap for its future. The consultation addressed very critical issues for the partnership, such as, the organization and framework for the partnership as an entity, its role in supporting the NTP and whether to register the partnership in order to be able to receive funds and improve governance.

There are 5 urgent matters that were taken up during the meeting;

- 1) Registration of the Partnership –opinion on pros and cons and deliberations on the processes and the way forward.
- 2) Defining the partnerships role in supporting national efforts and developing a 5 year strategy and first year work plan.
- 3) Seeking volunteers for using their expertise in various thematic areas and forming groups for each.
- 4) Positioning the Voice of the affected communities
- 5) Advocacy issues that needs immediate attention including advocacy for the partnership itself.

A working group had been formed to facilitate the process and support partners during the meeting. The group also managed to raise funds for the meeting **from Advocacy Partnership, UK, The Hindu and Lilly MDR-TB Partnership with support from Project Axshya of The Union.**

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

**Outcomes:**

**Primary outcome;**

- Evaluation of the partnership's structure and functions with solutions for improvement
- Decision on future stand of the Partnership in the next 5 years
- Increasing the involvement of affected communities

- Formation of thematic groups
- Identifying advocacy issues for the partnership

**Secondary outcome;**

- Increasing communication between partners and the Secretariat
- Enhancing Partner's responsibilities and ownership of the Partnership
- Strengthening of the relationship among all partners

**Organization:**

The event was organized by the Secretariat of the Partnership for TB care and control along with the working group for preparation of the national meeting (Annex 1).

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

**Proceedings:**

**4<sup>th</sup> April: DAY 1: Inaugural Ceremony.**

- Dr. Darivianca Elliotte Laloo, Partnership Secretariat welcomed the guest to the dais: Dr. K. S. Sachdeva, Addl. DDG, Central TB Division, Dr. Nevin Wilson, Regional Director, The Union SEA, Ms. Sheila Davie, Director Building Citizen Advocacy Project, Advocacy Partnership UK and Dr. S. N. Misra, Steering Committee member representing Dr. P.C. Bhatnagar Former chair, Steering Committee, Partnership for TB care and control in India. Guests were felicitated with bouquets by Ms. Manpreet Kaur, Partnership Secretariat.
- Dr. S. N. Misra gave the welcome address and an introduction to the goals of the meeting and its objectives (Annex 2). A round of self introduction followed by each participant stating the name of their organization and operational area.
- Dr. Laloo requesting the guests to light the lamp as an auspicious sign for the meeting.
- Dr. Nevin Wilson presented a perspective on civil society partnerships. 'The objective of why we are all here is to control Tuberculosis' states Dr. Wilson. He began with a brief history of TB care and control strategies from DOTs to the present strategies of networking and collaboration. He expresses that in spite of successes in TB care and control the incidence of TB remains the same. He spoke of the survey done by The Union for Project Axshya which had 4 top line findings; (1) 46% of patients who reported of TB were being treated by the private sector (2) more than half of the patients identified with TB was in the age group of 19-45 yrs, almost half were illiterate, in fact 1.3 % had an education level of graduate and above (3) out of the identified patients , almost 85 % used solid fuels in their house, and (4) 2/3<sup>rd</sup> of that group had a monthly income of less than 4000INR(80USD). This makes us ask where we look for TB. We need to partner with TB patients and empower them in order to be able to control TB. Let us not think of ourselves but think of those who we are here to serve - the TB patients. He then stressed the fact that civil society are fortunate to be given an opportunity through Global Fund and that it is up to us to sow this seed money and raise workers empowered with knowledge and awareness on TB. Project Axshya has processes which require partnerships like planning at village level, community systems strengthening, opportunities for advocacy and community awareness and supporting patient communities.
- Dr. Laloo then presented a brief on the media campaign year for the partnership which launched on World TB day 2011. The campaign involved training of partners on how to engage the media through an Eli Lilly funding project to The Union by REACH and IMCFJ media partners of the partnership. The trained partners then had to conduct their media

plans till World TB Day 2012. A prize is being given to the organization with the most sustained engagement with media during this campaign year.

- Ms. Sunita Prasad, Eli Lilly announced the joint winners for the media campaign, TB Alert India, NGO from Andhra Pradesh and Vivek Bicklang Saj-Jan Utthan Sansthan CBO from Bihar. Dr. Sachdeva then presented the award of a cheque of 10,000INR each to the winners along with a certificate.
- Dr. Sachdeva then delivered the inaugural address. He recalled the inception of the partnership and its journey since then. Dr. Sachdeva suggests that for better engagement of communities it would be best if we first identified the community and begin working through them. He also opines that receiving the Global Fund has been most helpful for community engagement and should be most thankful to donors. However we should look for more local level funding, individual level could be micro financing, etc needing us to work more at community level. He also mentions that public private mix in the government is mainly contracting services rather than a partnership. “True partnership is when we work for a cause”. It is time to think of government too as a partner through various government departments into the Partnership. Communities too should come at an equal level along with Government in a partnership. The Partnership could consider including more associations and professional associations into its membership along with physicians. He completes his address wishes the Partnership growth and strength and congratulates its achievements. He hopes Partnership can move forward from contracting in services to equal partners with the government.
- Dr. Nalini Krishnan, REACH then acknowledges the hard work of the Secretariat for the Partnership and on behalf of the Partnership presented a token of gratitude to Dr. Laloo and Ms. Kaur.

**Post tea session**

- Dr. Laloo requested some ground rules from the audience to be followed for the 2 days consultation. They were as follows;
  - 1) Mobiles to be kept on vibrate only mode
  - 2) Stick to time
  - 3) Keep observations short
  - 4) No repetitions
  - 5) Encourage new partners/ new ideas
  - 6) Volunteer translations into local language
  - 7) No self praise but should “Think India” ,Think TB”, ‘Think Partnership”
- Dr. Laloo then asked the participants what they think of ‘Partnership’. Responses were;

<ul style="list-style-type: none"> <li>• Sharing Knowledge</li> <li>• Mutual Understanding</li> <li>• Joining hands</li> <li>• Support</li> <li>• Networking</li> <li>• Synergy</li> <li>• Commitment</li> </ul>	<ul style="list-style-type: none"> <li>• Integrity</li> <li>• Teamwork</li> <li>• Shared Vision</li> <li>• Complimenting each other</li> <li>• Empowering</li> <li>• Agreement</li> <li>• Transparency</li> </ul>
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- Checklists for evaluating the partnership by partners were sent to all months prior, in preparation for the meeting (Annex 3) and data was compiled in an excel sheet (Annex 4).

- Responses were lukewarm total 25/ 90 partners submitted the checklists.
- Dr. Laloo presented the **results** of evaluating the **partnership function, infrastructure and outcomes** (Annex 5). Some **areas of improvement** were suggested to the leadership and management who need to consider these areas for improvement of the Partnership for TB Care and Control in India.
 

**Areas of Improvement include;**

  - Provide orientation to new partners by management.
  - Increase communication with partners and external stakeholders by leadership.
  - Improve processes to support implementation of objectives
  - Identify innovative ways to solve community health problems together
  - Improve ways to work together in the partnership
  - Structure allowing easy transfer and leadership change
  - Structure that allows partnership to receive funding
  - Increase access to resources
  - Improve system of referrals
  - Increase the involvement of practitioners with NTP
  - More coordination and communication between partners
  - Increase in efforts to create more state visibility of partners
- This was followed by some achievements of the Partnership in 2011 and January- March 2012.
  - **Membership** = 40 new organisations have joined the Partnership in 2011 by signing the Letter of Commitment (LoC) taking the total number from 55 in 2010 to 95 organisations strong by December 2011.
  - **Communication** =Partnership website [www.tbpartnershipindia.org](http://www.tbpartnershipindia.org) is updated regularly. Number of visitors in 2011 is 12204 visitors with an average of 25 - 30 visitors per day. Face book and Twitter has frequent updates and tweets. Newsletters are quarterly printed.
  - **Leadership:** 2 Steering committee meetings were held in 2011.
  - **Synergy:** A National Consultative meeting of Partners was held on the 6th and 7th January 2011. 4 Regional meeting of partners held in 2011.
  - An ACSM task force was formed in MP and a state level network of NGOs in Tamil Nadu.
  - Representatives from the Partnership participated and contributed in all the strategic working groups preparing for RNTCP Phase III
  - **Advocacy:** Partners of the Partnership along with several other civil societies have come together to issue a statement “A plea from civil societies in India on behalf of the millions affected by TB; Do not withdraw your support to saving lives” for Global Fund continuation.
  - The Partnership was represented in the Lille conference through various channels.
  - **Capacity Building:** Partners from the Partnership were trained on how to engage with media for TB care and control through a project funded by Eli Lilly.
  - **Service Delivery: Eli Lilly** funded a project to The Union. The Union gave 2 interventions to The Partnership to implement.
    - (i) Intervention 3 – Training of traditional healers in the states of Punjab, UP, TN and Maharashtra
    - (ii) Intervention 4 - Training partners on how to engage with the media

**January – March 2012:**

  - Civil Society plea to G8 heads to not withdraw support to the Global Fund was sent to all G8 head of states

- Responses with assurance of continued support from the Prime Minister of UK and Germany Chancellor received.
- 4 new partners joined the Partnership
- Working group formed for planning the national meeting and raised fund for conducting the national meeting
- Partnership 'Call to action to enhance TB Care and control efforts in response to the DR-TB scare was sent out as a press release
- Media campaign year came to an end.
- World TB Day events by partners.

#### **Agenda point 1: Panel Discussion of registration**

- Dr. Nalini Krishnan gave an introduction to the matter of registering the partnership and requests the participants to speak their opinion on this matter so a consensus can be reached to decide the next step forward. She stated that we have grown into a huge network and it is time to structure ourselves to be able to function better.
- She then invited the panel for discussion on their take on registration of the partnership vs. its present loose structure.
- Prior to the meeting team 1 from the working group lead by Dr. Krishnan had circulated a concept note on registering the partnership with a request for vote from partners on their views on this matter (Annex 6) . **Total 16 votes were received with 13 for and 3 against registration.** As this was too small a count to make a final decision the group took this as a discussion point with the help of a panel who shared their experiences on legal vs. non binding networks.
- The panel consisted of Ms. Sheila Davie, Dr. K. Sachdeva, Dr. Vijay Edward, Mr. Mohanadoss, and Mr. Venkateswaran.
- Mr. Mohanadoss mentioned his background work with NGOs for 30 years and his stint as Steering Committee member. Initially there were a few partners and if any 2 unite they will have to follow the law of the land without any legal threat. **As we have 97 partners who have joined the need to explore going into legalities is now.** This is not a start of a business of profit making but we are supporting communities in an ever increasing population.
- Dr. Sachdeva is of the opinion that as the NTP realised that to achieve their goal the program cannot do without support from partners through whatever mechanism of partnering. As NTP has many partners it has limited resources and cannot organise resources. "We would rather have resources coming to us as a bonus. **We believe that the Partnership should be self sustaining and offer something to the program**". What shape the partnership takes is to be decided among partners. Partnership has not made NTP a partner but rather their mandate is to support program. **The vision of having NTP as a partner could be looked at and also inclusion of more professional associations.** Another suggestion is to **look beyond MDG and Stop TB Partnership strategy i.e. 2015 in the vision of the partnership.** If we **restrict to a time then we don't need registration.** If partnership really feels the need to get legislation because we **cannot work without it then only go for registration.** This will **depend on the role and objective.** Individual partners have their expertise and bid for resources. If the reason to legalise is to bid for resources then it may create conflicts among members. **Creating an identity is the first priority.**
- Dr. Nalini re-instates the importance of setting the identity for the partnership and re visit its vision and mission which will throw some light on some queries from Dr. Sachdeva. This would be good for the next day's discussion on the 5 year strategy and 1 year plan.
- Ms. Sheila Davie realises that **presently the partnership relies on goodwill and limited funding from The Union and this is not sustainable.** It is a reality that any organization that wants to operate needs funding and today the **funding needs to have credibility and recognition and be 'registered'.** To continue with their work the Advocacy Partnership had

to be registered to get funding in the UK and funds available for 5 years without going through the process of fundraising in between. The money often needs to be in place before the start of the work. As a member of the Coalition to stop TB in Europe, she recalls that the **organization fell apart after a few years as there was no funding**. They had started out with good intention of moving forward but the funding was missing to have the organization operate. Another example is the UK Coalition to Stop TB which has various member expertises and is very active with working groups and all this is due to the fact that they had the **funding in place even before they started**. **She advises the partnership to register when the opportunity presents itself.**

- Dr. Vijay Edward a founding member of the partnership begins by questioning whether by registration, will we get anything done especially in India. **The partnership needs to define what the expected outcomes are and relook at the vision, mission statements and strengthen them first.** Speaking on the **pros of registration** like income and stability ,funding, standing in national and international society, good mileage, high level advocacy and political will. **Cons of registering** are governance by boards and since each partner is already answerable to their board may cause conflicts and danger of splitting up. If we do go for registration these issues should be kept in mind. Dr. Edward then cited some examples of organizations like ILEP which registered abroad and functional in India. He opines that we could look at other examples of existing organization before looking at registering.
- Mr. Venkateswaran, IHBP began with a brief background of his organization as it is a program, not a registered entity being funded by USAID. He does **not agree** that registration is related to creditability and inability to raise funds. He recalls his experiences working with partnership, alliances and strengthening them. He questions the reasons for registration; is it the need to mobilise resources or to get opportunities to represent TB related issues. Is the purpose of the partnership to mobilise resources and /or implement or to build on collective capital and advocate, or both or neither. Mr. Venkat states that a **partnership is a platform**, should it seek representation in another platform. Mr. Venkat adds to the **cons of registration** such it may bring members into legally conflicting situations, may bring the partnership in competition with its members. He adds that **anon registered alliance is loosely bound by guiding principles** – organization have the freedom to decide their level of engagement as the it could be restrictive or controlling. Some of the **options** could be (a) partners park resources, indicate how much and for what (b) revolving secretariat (c) organization housing the secretariat should have greater stake or greater involvement and (d) set the purpose and clarify the agenda. The need to look at Visibility, Vitality, Viability and Vibrancy. Would registration help us work together and will the leadership improve as these are the areas we still have low score.
- Dr. Nalini summed the panel’s thoughts and then opened the discussion to the audience. Mr. Subrat Mohanty reminiscence on the working group who has prepared the vision, mission statement at the beginning of the partnership and how things have changed since then and the need to relook at the statements. He asks the partners if they are satisfied about the growth of the partnership and if they are why there is a need to change it.
- Mr. Man Mohan Sharma, VHAP believes that with registration we can **prove our work** more. Dr. Srivastava, SIR adds that as a partner he is very happy about the partnership and its work even if his organization is registered and working on many health issues. He states that as we are **working with government** a legally registered organization is often **more creditable** with them hence is essential to go into registration. **Bylaws to look** into preventing conflicts of interest and monopoly. Recommendations to form **state chapters** of the partnership and SIR are ready to form the Uttar Pradesh chapter.
- Mr. Swamy, TB Alert India feels that we need to ask what the **role that the partnership** will play is, is it a passive or dynamic, is it a professional role or maintain status quo. With the example of FICCI who have one aspiration and not for profit for the benefit of its partners

and its cause partnership should have an aspiration and **move ahead actively in advocacy**. The government does not invest in the NGO sector but more in businesses and partnership should become a professional organization and think of registration as it is for the movement and the country. Today the partnership is suffering due to lack of funds and when Global Fund stops what happens. **A corporate approach** is best for the partnership for **sustainability**. With the **present scenario** we will remain **passive** and will not make a difference in our entire lifetime.

- Dr. Daisy Lekharu, PSI India cites the example of CII and FICCI and shared her experience being in the federation; **partners take ownership of the federation** and pitch in their own resources to attend meetings. Fund raising mechanisms for the partnership could be set in place to operate and maintain it for sustainability. A **resource pool** would be beneficial.
- Dr. S. N. Misra, Futures believes that registration is not the only option but could be a **middle path and frame the bylaws and agenda carefully**. The workings of the partnership have been good and all stakeholders have put in their best however situations and expectations are changing, and they may not be fulfilled without the partnership getting registered. Secondly even to organize this conference we had to look for resources so we need to have resources to be able to look beyond 5 years. The **Partnership needs to limit its goals to what it can do** and what partners can do so as to avoid competition with its partners. **A formal structure which has sustainability and don't need to beg for funds**. He asks what compels the membership to grow from 13 to 97 in the last year, it's obvious that something is attracting them and if they want to contribute that commitment should be present. A further deliberation is needed to take a decision on the issue taking all the thoughts from this meeting. There are **ways to register without affecting the partners**.
- Ms. Sunita Prasad, Eli Lilly & Co notes that partners have different expertise and they have a level playing field but need to **define the force that is holding them together**. A suggestion could be an **organization who can build capacities** to contribute to the program. Memberships are open to even the government but how do they see it. What do we see the future as and we need to sustain the efforts and build capacities.
- Mr. J.M.Singh, MSS states that the partnership has been a good experience for him. He recalls that in the beginning **partners managed their own expenses** for attending meetings as there was no money available and questions the 95 members that would they pay for their own expenses. An **ideal partnership is self sustaining** and for registration the partnership should think about its structure and the road map.
- Dr. Laloo shares the experience of presenting the partnership at international conferences, what are its added values to the NTP. **Efforts as a group so far has been reactive** but the values we have are unity through a shared vision, trust among partners with transparency, collaboration through service, capacity building of partners. The indicators of success are qualitative and not quantitative. She cites the example of Uganda and their journey from a loose network into a registered body and is proactive. Another example is PHILCAT who is a registered body and is doing good work without conflicts among members. Other partnership networks CII, IMA all doing excellent work on the shared goal. To avoid conflicts the partnership needs a neutral body "broker" who can **help solve the issues** among partners. In every partnership there are risks and benefits and partners help each other in completion of the shared goal. As the Secretariat also it has been difficult to answer on the present outputs of the partnership with the limited finances constricting other activities. The request for partners to volunteer their own resources to attend meetings is not easy as the partnership also have a huge number of community based organisations with limited resources. Partners need to think of what motivates them to go into the partnership. In reality to conduct any activity you need funds. Presently the partnership with support from The Union has funds for only 4 activities i.e. website maintenance, newsletter, regional meetings and steering committee meetings. To have any other outputs you need resources

for e.g. even to conduct an advocacy issue you need money to connect partners and to produce and send any material. **Funding is not the reason to get registration but it definitely is one of the points to do so.**

- Dr. Nalini thanked the panellists and partners and summarised their thoughts. She added that and even if this discussion is not to decide registration or not, **more deliberations** are needed to move this forward. She appeals to all partners to respond to emails so we can move forward.

**Post Lunch session:**

**Agenda point 5: Advocacy**

- Toolkit on Advocacy for TB /MDR-TB was shared with all participants by Lilly MDR-TB partnership and Ms. Sheila Davie, Advocacy partnership,Uk.
- The session on Advocacy began with a presentation from Ms. Sheila Davie on the importance of Advocacy. ( Annex 7)
- Advocacy points ; meeting decision makers on a one to one basis, a group from a coalition should be meeting a single decision maker as it is a powerful way to influence, patience and persuasion and not being put off by setbacks are what you need and finally documentation and follow up. Advocacy is a process that brings about change for TB control with commitments from government and politicians. It is distinct from communication which is creating behaviour change of public and social mobilisation which is bringing people together for community participation. For successful advocacy it needs a critical issue to work on with a compelling vision e.g. the StopTB vision which is to end TB in my lifetime. Advocacy needs the 3 ‘Ps’ -persuasive messages and powerful requests, passion to see change and powerful speaking and partnerships. Sheila gave some examples from the Stop TB Partnership. Sharing experiences are strong messages by patients telling their own story. Working together can become a powerful force, impossible to ignore and that is what is aimed for.
- Partnership for TB Care and Control in India could **become a powerful advocacy force for TB** in India but is not there yet. If they do not it then who will speak out particularly at the national level. This group should not only be a partner of the national program but be an influencer and also **challenge the program** to ensure they deliver on promises at all levels. People’s life depends on it and the group should do it.
- Mr. Venkateswaran and the IHBP team facilitated the discussions on **developing an advocacy plan.** (Annex 8). He began by asking participants **(a) to identify an advocacy issue by citing some examples like; childhood TB (agreed), quality of health services, etc (b) who to advocate to e.g. family, government with specific demands of each issue. (c) What action would you like the identified stakeholder to take.** Pairs were requested to be formed and each pair given an Index Card and a color marker pen. Participants then asked to discuss with their partner one issue that they would like to be the **ADVOCACY ISSUE OF THE YEAR** for the partnership to advocate for at the national level.
- The pairs worked and the issues that came out were:

	<b>Advocacy Issues</b>	<b>No. Of Votes</b>	<b>Who to advocate to</b>
1	Nutritional support	8	Global Fund /USAID/ RNTCP/ Planning Commission/ Finance
2	Childhood TB	13	
3	Funding/ Fund raising for the partnership / NGO schemes/etc.	<b>33</b>	

			ministry
4	Treatment protocol & Quality of Treatment	<b>29</b>	Health Ministry, Health Minister, State Health Secretary, MOHFW, District Collector, DDG- TB, Ministry of Pharmaceuticals, private providers etc.
5	HIV/TB – New diagnostic and Treatment	3	
6	TB in Women	5	
7	Increasing awareness of policy maker	1	
8	Occupational hazards in TB	1	
9	Community Support for MDR TB	2	
10	Engaging traditional healers	2	

- Participants then were asked to cast their votes on which of the issues they feel strongly about by sticking dot stickers on the issue (see table). The session was fun and interactive and partners enjoyed contributed.
- The **two advocacy issues** most voted on which the partnership will focus on for the year are **Funding/ Fund raising for the partnership / NGO schemes/etc.** and **Treatment protocol & Quality of Treatment**. The group began the work to identify the decision maker/ influencer who we need to influence by breaking into groups of four. The group was then asked “identify one key person/ institution they would like to focus on for the advocacy issue” and clustered the decision maker by the advocacy issue( see table).
- Mr. Venkat then informed the participants that the next step is about decision making. Keeping in mind the busy schedule of the decision maker what would be the advice to him for one action to be taken on the above mentioned issues. He asks the groups “If you were to advice the decision maker on **one decision/ action** you want the person to take/ make for one advocacy issue, what will be your advice to him?”
- Advice to decision makers:

#### **Treatment protocol & Quality of Treatment**

- For standard treatment protocols we will like the DDG-TB/MOH to recommend banning the sales of OTC 2<sup>nd</sup> line drugs and instruct use of standard guidelines for treatment by private practitioners
- For accessing quality treatment of TB we will like Health Minister to monthly review of the program and identify gaps of accessing TB quality treatment by RNTCP staff.
- For quality of TB treatment we will like the DDG-TB to ensure appropriate allocation of funds in areas of basic laboratory facilities at grass root levels along with continuous and non spurious drug supply mediated through co-ordination (involvement) of NGOs.
- For treatment/TB Elimination we will like the Union Minister to make a strong political will to declare the target year and exhort all TB partner NGOs and Govt. bodies to work in a synergy to reach the goal.
- For universal standardisation of TB treatment we will like the DDG to make TB a notifiable disease.
- For improving the treatment protocol we will like the Union Minister of Health to smooth and consistent drug supply to all service points
- Towards achieving universal access for TB care and services, we will like the Union Health Minister to approve (i) expansion of TB diagnostic and treatment services in all the government sector health systems  
(ii) Expansion of TB diagnostic and treatment services into private/NGO sectors across India
- For protocol and quality of Tb treatment we will like DTO/DTCO/CMO/STO/CTD to provide quality drugs, ensure proper regime through resources (HR, Infrastructure & Equipments), Follow up mechanism and ensure engagement of grass root level service

providers e.g. RHCPs. Pharmacies, CVOs, traditional healers in a BIG way as PARTNERS!

- Dr. Laloo then read the names of the organizations that had filled up their names for the advocacy group thematic area on the charts around the hall. (Annex 9) and announced that there are some funds available for the group to begin their work on advocacy contributed by Ms. Sheila Davie. The work done by Mr. Venkat's advocacy session could be taken forward by the Advocacy group after they have selected their leader.
- The day ended with Mr. Swamy making an announcement about the CCM elections for the TB seat nominations and request for all partners to vote. The partnerships have also sent in 16 nominations for the seat of the affected communities for TB.

### **5<sup>th</sup> April: DAY 2:**

- The day began with a recapturing of the sessions on Day 1 by Dr. Daisy Lekharu, PSI.
- **Agenda point 3: Thematic groups**
- Dr. Abhijeet Sangma gave an introduction to Thematic groups, their purpose, membership, benefits of forming a group, benefits of the group, themes to focus, operation of the groups, funding of activities, support from Secretariat, aims of the group and role of the group conveners. Possible ways of establishing the groups. The groups should be highly active, well connected, knowledge-rich, innovative and operationally relevant. ( Annex 10)
- The **6 Thematic groups** are:
  - (1) ADVOCACY
  - (2) PPM
  - (3) Service Delivery
  - (4) Women and childhood TB\
  - (5) TB-HIV
  - (6) Operational Research
- **Agenda point 4: Voicing the affected communities**
- Mr. Subrat Mohanty, The Union spoke to the participants about affected communities with a few examples of TB champions identified from project Axshya. He mentioned the stigma the patients go through and many other issues hence the need for support groups to nurture and care for patients and we should encourage the **support groups** to come forward. Throughout the course of treatment advocacy is needed with family, community, public health facilities, health workers, etc. **Capacity building** of patients to become community volunteers and advocates. Capacity building of TB health staff at all levels on soft skills like how to counsel patients and cited some examples of how the training on soft skills have helped the health workers. Documentation is important and a strategy on **involving patients** is very important. Through Project Axshya the formation of District TB forums has been a good step in empowering the community as the members consist of patients and community volunteers and influencers. They are acting as an **advocacy group** for TB patients by submitting memorandum to the politicians for issues like nutrition support, etc. Other opportunities like India CCM, Global Fund community board and Stop TB Board.
- Mr. Azad adds that the government schemes should be availed to and also find out from other countries about exposure of patients.
- Ms. Shanta, co infected patient from the rainbow TB forum spoke of her team and their work. She recalls the time when TB patients wanted to attend the World TB Day function in their district and was sent off by the DTO who insulted them. The elders left but the youth of the group rallied and decided to work on patient issues. They formed the Rainbow TB Association

and registered their organization and have 525 members with 11 leaders from 11 blocks in the district. They have monthly meetings and have starting activities like looking for new cases and also default retrieval. They **arrange income generation activities and collecting rice bags for TB patients to help improve the nutrition of people**. Challenges of **stigma and discrimination** are still present in the community and hospital as well. They are aware of the free treatment but they have to be given on time, as irregular supply will lead to discontinuation of treatment. The team would like to **unite with District TB forums** being formed in the state and make it a **state level initiative** to fight for the rights of patients and other activities. Ms. Shanta mentioned the requirements that are **needed; trainings on communication with patients and training on counseling for children affected with TB**. She encourages more TB leaders among patients who will participate at such forums and their voices can be heard at the state and national level with opportunities being provided for them. The **need for space for meetings** is important as presently they are meeting at leaders houses. She **thanks the Partnership** for giving her this opportunity to be heard and voice patients' challenges.

- Dr. Laloo request ideas on how the partnership can bring voices like Shanta to the fore and get their voices heard. Mr. Swamy believe there are 2 ways that the partnership can do ;(i) get CTD to issue a circular to include District TB forums at state and district level and (ii) NGOs working at grass root level to take up with District TB forums to involve more patients with the **district level program planning**. Ms. Merci Annapoorni, Blossom Trust plans to organize all the district level forums in Tamil Nadu and make it a state level forum totally representative of patients. They will be done in the entire district and the preliminary work has started in Tamil Nadu. She request partners to encourage formation of patient groups in their work areas.
- Mr. Shishir suggest like GIPA coordinate in NACO SACS, similar can be thought for TB for continuous voice. IHBP is going to work on capacity building of patients as requested by Ms. Shanta. Dr. Laloo closes the discussion by suggesting points for action (a) **inclusion of these District TB forums in the partnership** (b) **partner organization to advocate for the formation of patient group and include them in district planning. Discussions to continue via emails.**

**Agenda point 2: Role of partnership and 5 year strategy.**

- Dr. S.N. Misra invited his team members to help him facilitate the discussion on the 5 year strategic plan for the partnership. The points to consider or remember:
  - Revisit Vision and Mission statements
  - Beyond the Project "Axshya"
  - Partnership activities
  - Wish list of Stakeholders
  - Sustainability
  - Management Structure

<b>What we have.....</b>	<b>What we do .....</b>	<b>What we can do.....</b>
A network of Partner institution	Enrollment of new partners	Promote /strengthen TB forums
A Memorandum of Understanding and Commitment	Compilation and dissemination of TB and partners news	State level / regional Secretariats on a rotational basis reporting to the national level
A 2 member secretariat	Meetings and Workshops	TB Coordinator at state level
A Steering committee	Contribution to National planning efforts	Invite ILO to join – Workplace policies

Reactive working groups	Capacity building among partners	Promoting stakeholders meeting to strengthen the program
We also have a group of very committed and vociferous professionals	Advocacy	Develop TB spokesperson and promoting ambassadors
	Main streaming	Inter departmental collaboration
	Collaboration	Partnership represented internationally
	Fund raising	Documentation- State health
		Disseminate information to block level, use of state level fora
		Taking partnership beyond NGOs

What we should do....	
Act as a think tank	Honours/ recognition for partners
Act as an interface	Workplace policies
Technical capacity building/ workshops	Reporting- Nationally
Fundraising	Involve multi stakeholders for TB discussion
Advocacy ( Use of media)	Resource centre
Share of best practices through summits	Promote research and disseminate new findings
Networking	Goodwill ambassadors for TB
Campaigns addressing stigma & discrimination	Mainstreaming with other departments
Increase visibility of the partnership	Branding of PTCC
Promoting the affected community	capacity building of partners

- Participants were asked to give examples on what the partnership can do as a united force. The suggestions were added on a flip chart under “What we can do....”( see above table)
- Partnership should not go into implementation but should raise funds for partners to implement.
- Dr. Laloo stresses the importance of partners to take ownership of the partnership as this partnership belongs to the partners and not only the secretariat. Partners need to feel responsible and be able to contribute to the group. Responding to emails is the first step.
- Dr. Misra states that depending on the type of work, structuring of the partnership is the next steps. He shared a wish list for one of our stakeholders. They are;
  - Partnership to include in the agenda to initiate advocacy with politicians (MPs, MLAs, Ward Counsellors, elected PRI members) (**Advocacy**) – **can be done**
  - Partnership to strongly support and start initiatives for advocacy to ban serological tests of TB and over the counter selling of Anti-TB drugs and antibiotics at state/district level (**Advocacy**)- **can be done**
  - There is strong need for active participation and work towards developing programmatic linkages with the corporate hospitals (**Advocacy**)- **can be done by secretariat**
  - Partners can contribute in great deal for reaching difficult-to-reach areas/population groups where program has limited/no reach (**Implementation**) – **partners can do it**
  - Issues like TB control and care in URBAN set ups and TB and migration should also be included in the agenda on priority (**Implementation**) – **partners can do it**
  - Partnership can create resource of key information about the TB situation of the districts located at the interstate/international borders of the country that is easily accessible to the national programme and other partners active in the area (**Information**) – **can be done**

- Operation research (focusing mainly on behavioural aspects of the TB patients/suspects) (**Research**) – **Research group to guide but done by implementing partners**
- **The Vision of the Partnership:** Achievement of the TB-related targets of the Millennium Development Goals and the Stop TB Partnership in India through a unified response from civil society and multiple stakeholders.
- Partners felt the need to simplify it and generalised, remove MDGs, partnership should work in alliance with Stop TB Partnership. No vision statements should state someone else’s mission but should have its own vision shares Dr. Edward. It should be understandable and straight forward. A small group will work on the Vision draft share with all for comments and suggestions in a timeline.
- **The Mission of the Partnership:**Contribute to India’s TB control efforts through a unified response from civil society and all other stakeholders, in line with a common national goal
- The Mission could remain the same.
- **Core Values** :The value system at Partnership is founded on:
  - Mutual trust and respect
  - Willingness to contribute to the Partnership
  - Belief in Partnership Vision and Mission
- Dr. Laloo stresses the need to work as a group and try and not push in underlying interest, take ownership and be accountable as a group, to look at the goal of reducing TB. It’s only if partners think collectively will the partnership be strengthened. If we put our self interest forward then we are thinking with blinders on. Partnership is all about building relationship and collaborating. These could be some of the values added to the listed above.
- Mr. Subrat seconds Dr. Laloo’s words and believes that at the end of the day partners should say “THIS IS MY PARTNERSHIP”. Dr. Edward reinstates that partners should get out of the” what will I get out of it” mindset for partnership is all about giving.
- Dr. Misra summarises the decisions and asks the partnership what structure should it take based on the above “what we should do”. There have been additions to the functions and can all this be done with the present structure or the need to change to be able to accommodate them. Mr. David suggested relooking at the criteria’s for membership as this group could expand to other diseases. The name might need to change if other diseases are included.
- Dr. Laloo also requests the group to work on the TOR for the Secretariat, what can it do and what not.
- The question ‘do we function as a loose network’ then came up. Mr. Swamy suggests we get hold of donors to provide funding to the partnership, approach corporates, etc. Should a membership fee be introduced? Can partners think of a nominal amount?
- Points of agreement : work/functions, structure and membership fees , to an extent agreement of formal registration but need to deliberate further as there is no awareness of what needs to be done to go into a formal structure which may take time to fully understand by all partners. Decision on this moved further. Partners to go back and discuss with their organization and submit their thoughts on a given deadline.
- The follow up actions:
  - **Working Group to further deliberate on all points raised**
  - **Circulate a working draft**
  - **Develop an interim plan**

**New Structure – within 3-4 months**
- Registration could be done without restricting any partner’s freedom. Dr. Misra then thanked the participants.
- Dr. Laloo announced that as partners were aware of the group of partners who stepped us as working group for preparing the national meeting, a working group to on the next steps is being formed. She invites partners who can volunteer time, resources and ideas to be part of the group. Interested partners can submit their names to the Secretariat. A post national meeting

is to be held with the working group and advisors like Dr. Giuliano Gargioni, Team Leader, National and Global partnerships, Stop TB Partnership, Geneva. Dr. Wilson, the Union, DDG-TB on the 20<sup>th</sup> April 2012 to frame the way forward for the partnership.

- Ms. Sunita Prasad states the **way forward** based on the discussion of the 2 days;

#### Agenda 1: Registration

- Working group will deliberate further
- Prepare a working draft and circulate to all
- Prepare a draft of vision and share

#### Agenda 2: 5 year strategy and 1 year plan

- Work on a 1 year plan based on 6 thematic groups decisions
- 5 year strategy to be decided based on decision of point 1

#### Agenda 3: Thematic groups

- Groups to choose leader and what they plan of action (POA) / work plan for the year and submit to Secretariat in 2 weeks
- Secretariat to send all names for all groups and to respond accordingly

#### Agenda 4: Voicing affected communities

- Inclusion of District TB forums in the partnership
- Partners to advocate for patient groups in every district and include them in the administration of the state
- Formation of state level forum
- Tamil Nadu model to be shared with partners

#### Agenda 5: Advocacy

- Advocacy group to begin work on advocacy issues discussed on day 1
- Use advocacy tool kit provided
- Some funding available for advocacy work

- Dr. Laloo thanked Ms. Sunita and request partners to be regular with the communication and be proactive with what partnership should be doing. Discussion could begin on how to access internal funding rather having to depend on external donors, new innovations on diagnostics could be examples that the partnership could look at.
- Documentation is important to highlight all the excellent work partners are doing and this needs to be sent to the secretariat. Use the various channels available for communication. Encourage more media engagement for this all matters in making a difference in the life of Ms. Shanta and other TB patients.
- “Partnership should be about sharing strengths and competencies, sharing risks and also benefits at the end of the day”
- The 2 day national consultative meeting of partners ended with a vote of thanks from Ms. Manpreet to all partners, donors (Advocacy Partnership, UK, Eli Lilly, The Hindu and Project Axshya of The Union), the hotel, administrative team of USEA, and guests.



Thanking you

