

Promoting civil society engagement in TB control: African and Asian perspectives

Mahaballipuram, Tamil Nadu, India

14th-17th September 2010





Target TB is a UK-registered charity working towards its vision of a world free from TB. The charity was set up in 2003 in response to the global TB emergency and its mission is to address the health, social and economic impact of the global TB epidemic amongst vulnerable and marginalized groups.

Target TB works in partnership with local organisations in developing countries, directly supporting communities affected by TB. Through our projects, we train community volunteers and government health workers in TB control. We carry out awareness raising activities to empower

people to protect themselves from the disease and reduce TB stigma. We identify people with TB symptoms and link them to testing and treatment facilities and provide patients with support throughout treatment. We also work to influence those in positions of power to bring about lasting changes that make a real difference to people affected by TB worldwide.

We prioritise working with organisations in areas with high levels of TB and poverty, where health facilities are poorly developed and government services are under pressure to meet demand. We currently support initiatives in Africa and Asia.

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RATIONALE FOR THE MEETING

During Target TB's strategic planning for the period 2009-12 we asked partners for feedback on how we work together. All expressed a keen interest in meeting with each other to share ideas and learning. Our Southern-based partners have a large amount of accumulated experience on TB control and we recognise that we need to develop opportunities to use this learning more effectively.

This meeting and workshop in India was aligned with our current strategic objective of building links with organisations and developing mutually beneficial partnerships. Holding this meeting in India, which has

the highest TB burden in the world and where Target TB's partners carry out a considerable amount of work, was also felt to be a relevant contextual setting.

The meeting was held between 14th and 17th September 2010, at Ideal Beach Resort, Mahaballipuram, Tamil Nadu. Participants of the meeting were generally the head of the organisation and the person in charge of implementation, usually a junior level management staff member. 23 participants from 12 partner organisations across 6 countries (India, Malawi, Timor-Leste, Uganda, United Kingdom and Zambia) were present.

MEETING SCHEDULE

DATE	SESSION/ACTIVITY
Monday 13 th September	Arrival of participants Welcome dinner
Tuesday 14 th September	Introduction to the meeting Sharing experiences, challenges and differences: Theme 1: Health research (presentations from DACT, MAAS, IMF) Theme 2: Innovation in TB programmes (presentations from AID, Raphael, Zatulet) Theme 3: Organisational development (presentations from Bwafwano and SRFIM) Focused discussions on: reporting to donors; in-country fundraising; service delivery
Wednesday 15 th September	Raising the profile of partners' TB control efforts and how to lobby and influence key TB decision makers at national levels Dr. Bobby John, Global Health Advocates, Guest Facilitator
Thursday 16 th September	Sharing experiences, challenges and differences: Theme 4: Partnerships and networking (presentations from Klibur Domin, AKS Hope, Blossom Trust) Group discussion on building partnerships and strengthening Target TB's partner networks Peer discussion groups on organisational development Focused discussions on: history of Target TB; MDR-TB; organisational development; relationships with National TB Programmes (NTPs)
Friday 17 th September	Visit to TB Research Centre

TARGET TB AND ITS PARTNERS: PARTICIPANT INFORMATION

Agnes Kunze Society (AKS), India

AKS is a community based NGO working to reduce the levels of TB in Dehradun district, Uttarakhand State, India. AKS focuses its work on supporting the needs of poor and marginalized slum communities, creating awareness about TB, reducing stigma and encouraging people to access the healthcare they need. In addition to their TB work, AKS are also involved in providing health services to People Living with HIV, education and support to vulnerable children, vocational training and general development of slum dwellers.

Participants:

Mr Lawrence Singh (Project Coordinator)
Mr Sanjeev (Community Head)

Alternative for India Development (AID), India

AID is a registered NGO in India working in the states of Jharkhand, Bihar, Uttar Pradesh, Chattisgarh, Orissa and Tamil Nadu, to empower the poor and help them gain access to basic education, health and livelihood improvement with gender and social equality. AID works at the grass roots level in Jharkhand and Orissa, building the capacity of tribal communities around TB control and providing mobile TB screening services to remote regions.

Participants:

Dr. K. T. Arasu (Director)
Dr. P. K. Sahu (TB Project Manager)
Lita Rani (Advocacy Officer)

Blossom Trust, India

Blossom Trust is a registered non profit organisation in India, founded in 1993, initially focusing on community development (particularly women) through art and culture. Blossom Trust is a partner of the Indian Government's Revised National TB Control Programme (RNTCP). They implement community based TB control activities throughout Virudhunagar district, Tamil Nadu, with activities being supported by a large number of volunteers and members of Blossom's women's self help groups.

Participants:

Mrs T. Mercy Annapoorni (Director)
Mrs J. Reeta Kodeeswaran (TB Project Coordinator)

Bwafwano Home Based Care Organisation (Bwafwano), Zambia

Bwafwano is a Zambian NGO established by community members in 1996 to build the skills and capacities of communities living on the outskirts of Lusaka in the prevention and management of HIV/AIDS and TB. Bwafwano has grown into a much larger organisation which now offers integrated programmes in TB, HIV/AIDS, OVC, integrated health and survival skills, older people, nutrition, maternal and child health and education, and operates in four districts.

Participants:

Mrs Beatrice Chola (Executive Director)
Mr Isaac Phiri (Programmes Officer)

Development Action Consortium Trust (DACT), India

DACT is an NGO based in Theni district, Tamil Nadu, India, supporting a large integrated health and women's development programme through a network of grass-roots NGOs. DACT aims to socially, economically and politically empower poor and marginalized communities through focused projects supporting women's federations, strengthening Panchayat Raj Institutions and equipping the community to participate in health.

Participants:

V. R. Vanajaa (Director)
J. Singaraj (Senior Programmes Officer)
David Jones (TB Programme Manager)
S. Kasi (Advocacy Officer)

IMF (International Medical Foundation), Uganda

IMF is a Ugandan registered NGO working towards making high quality medical care accessible to the most needy in Uganda through the implementation of various healthcare interventions targeting disadvantaged communities. IMF currently runs community-based interventions with projects addressing TB, family planning, HIV and other STIs, community-based health insurance and training of community level health workers.

Participants:

Dr. Edith Nyangoma (Physician and TB Coordinator)

Klibur Domin, Timor-Leste

Klibur Domin is a registered NGO in Timor-Leste (East Timor) established shortly after the country's independence in 2000. Klibur Domin provides a comprehensive TB control programme including a 25 bed in-patient facility for seriously ill TB patients, the country's only Multi-Drug Resistant (MDR) TB treatment facility, and a mobile community outreach programme supporting case detection and community based DOTS in rural communities. In addition to its TB work, Klibur Domin provides in-patient care to orthopaedic patients and community based rehabilitation for people with disabilities.

Participants:

Mr Joaquim Soares (Director)

Maharashtra Association of Anthropological Sciences (MAAS), India

MAAS is an academic NGO based in Pune, Maharashtra, India. MAAS is involved in training in research methodology, health and development through course work, seminars, symposia and workshops. The Centre for Health and Development unit of MAAS has expert researchers in disciplines including medical anthropology, health and social science, public health and epidemiology.

Participants:

Mr Saju Joseph (Health Research Scientist)

Raphael Ryder Cheshire International Centre (Raphael), India

Raphael is a registered NGO working in Uttarakhand State, India. Its mission is to provide relief and rehabilitation to people affected by leprosy, disability and TB, irrespective of caste, creed or religion. Raphael provide a 26-bed specialist in-patient facility offering high quality care to seriously ill TB patients who cannot be treated in the community. The hospital serves rural communities from Uttarakhand and surrounding states as one of the few dedicated facilities in the region.

Participants:

Dr. J. P. Gupta (Superintendent of TB Hospital)

Sue Ryder Foundation in Malawi (SRFIM), Malawi

SRFIM is a Malawian registered NGO working in Ntcheu and Balaka districts. SRFIM provides medical rehabilitation and nursing care to people with physical disabilities and/or chronic illnesses (epilepsy and asthma). SRFIM's aim is to enhance the quality of life in rural communities where access to health services is limited. Community based programmes raising awareness about TB and malaria aim to ensure these rural communities have access to vital health information and services.

Participants:

Mr Kibble Ngalauka (Executive Director)

Target TB, UK

Target TB has a vision of a world free from TB. Target TB was established in 2003 in recognition of the global TB emergency, and focuses its work on supporting some of the poorest and most vulnerable people in Africa and Asia to access quality TB testing, treatment, and vital additional support services. Target TB works in partnership with 13 civil society organisations across 7 countries in Africa and Asia.

Participants:

Nikki Jeffery (Director)

Morris Lab (Programme Development Manager)

Clare Shaw (Programme Officer)

Zambia Tuberculosis and Leprosy Trust (Zatulet), Zambia

Zatulet is a registered NGO in Zambia supporting government efforts in the fight against TB and HIV. Zatulet's main activities are community based TB control programmes which operate through 13 local branches in 5 provinces. Zatulet's extensive network of trained volunteers carry out TB case finding in the community, link patients with government health centres for diagnosis and provide comprehensive community based care and support for those on treatment.

Participants:

Mrs Charity Habenzu (Programmes Director)

Mr Mazuba Mutinta (TB Project Coordinator)

REPORTING BACK ON THE MEETING'S OBJECTIVES

Objective 1: To provide a forum in which African and Asian NGOs working on TB control can share skills, experiences and learning to benefit their work

This was the first meeting of its kind where representatives from all of Target TB's partner organisations came together in one place to share experiences and learning on their work. With grass roots organisations facing high demands on their time delivering services at the community level, opportunities for attending meetings on sharing experiences and learning with others are often lacking. This meeting provided a much needed space for Target TB's partners to meet with similar organisations working in other regions and countries on TB control programmes and share their experiences.

Activities were planned within the meeting timetable to maximise sharing of experiences, knowledge and learning between Target TB's partners. Participants presented on four key thematic areas which generated a significant amount of discussion both within facilitated sessions, and informally.

Partner presentations focused on the following thematic areas:

- Health research
- Innovations in TB programmes
- Governance and accountability
- Partnerships and networking

Group discussions followed each of the presentation themes, enabling participants to discuss the subject in greater depth. The groups then fed back to all on their discussions and key learning points.

Ad hoc focused group discussions on Multi-Drug Resistant TB (MDR-TB) and managing relationships with National TB Programmes (NTP) were also held as the group identified these as important themes for discussion. Partner representatives with good experience in these areas were asked to lead a facilitated discussion on these issues.



Mercy Annapoorni, Director of Blossom Trust, India, presented to the group on her experiences under the theme of partnerships and networking.



Participants present their feedback from group discussions.

Objective 2: To improve the ability of African and Asian NGOs to share their experiences and learning with other TB stakeholders and key decision makers

Dr. Bobby John led a 1-day facilitated session on advocacy which for many participants was a highlight of the week, and a theme which all were keen to gain insight into. The session focused on how to go about advocacy to influence policy and decision makers, particularly for civil society organisations like Target TB's partners who are working at the grass roots level and rarely get opportunities to input into national level decision making forums.

"Advocacy – Bobby John's talk has given me an altogether different perspective...looking at and into the TB problem...how the TB problem can be approached from different perspectives"

For many participants, advocacy was a new area, and one which Target TB is keen to build partners' capacity on, to enable more sustainable improvements in TB control at national and international levels. Through this session participants gained greater understanding of and insight into how to plan advocacy activities in order to maximise their effectiveness. Previous discussions on the value of health research also fed into this objective, with participants noting how health research studies could be of great value in providing evidence of impact, enabling them to engage with and convince decision makers using strong, credible information.

FACILITATOR PROFILE

Dr. Bobby John, President of Global Health Advocates, India, facilitated the 1-day session on advocacy. Dr. John worked for five years in a small village hospital in Western India as a surgeon and obstetrician. Subsequently, Dr. John established World Vision's India countrywide HIV/AIDS initiatives.

In 2002, he joined the Swiss-based Global Health Advocates as its Southeast Asia Director, and subsequently became its President. He works closely with various national governments and non-governmental agencies in the region to establish, fund and manage transparent, comprehensive national health and education programmes aimed at eradicating AIDS, TB and malaria. Dr. John sits on the Board of the Global Fund and serves as the high-burden country advocacy advisor for the ACTION (Advocacy to Control TB Internationally) project.



Facilitator Dr. Bobby John discusses advocacy with the Target TB partner network.

Objective 3: To build more effective and beneficial relationships between Target TB's partners

The meeting was important in building long lasting relationships between Target TB's partners, most of whom had never met each other before. The meeting enabled partners to genuinely feel part of a larger network, meeting with their peers who face many of the same challenges in delivering TB control programmes. Whilst historically the relationship between Target TB and its partners has just been two-way, now a third dimension has been added, with partners now establishing relationships with each other, independently of Target TB leading or facilitating this process. Throughout the meeting there were formal and informal opportunities for partners to get to know each other.

ORGANISATIONAL DEVELOPMENT: A COMMON CHALLENGE

Throughout the meeting, discussions with participants highlighted how organisational development can be a key challenge for NGOs. The burden of work to deliver TB programme activities at the community level, combined with often limited funding, results in many organisations lacking the resources to address this important area.

Focused discussion groups were held with directors and operational staff to discuss common organisational development challenges they face in their work. The discussions were revealing in how difficult it can be to adequately resource and spend time on organisational development, despite recognising the importance of this in developing sustainable and effective organisations. Common challenges reported included board representation and engagement, personnel recruitment and management, and delegation of authority.

"A highlight for me was the sharing of different experiences and how others solved their challenges...it will be easy to apply similar approaches to our own situations."



Beatrice Chola, Executive Director of Bwafwano, Zambia, shares her feedback with the rest of the group.



Participants worked in small groups with people they had never met before to share views and experiences.



Isaac Phiri (left), Programmes Officer from Bwafwano, Zambia, gets to know Vanajaa, Director of DACT, India.

VISIT TO TB RESEARCH CENTRE

Target TB and its partner network were honoured to visit the TB Research Centre in Chennai, a World Health Organisation Collaborating Centre for TB Research and Training, and a Supranational Reference Laboratory. Senior staff from the centre gave a warm welcome to our partner representatives and gave presentations on different aspects of the centre's work including research into new TB diagnostic tools, new and more effective TB treatment regimens and research into some of the social and economic aspects of the disease including gender, stigma and nutrition. After the presentations there was a very interesting question and answer session, followed by a tour of the laboratory facilities. The centre staff demonstrated new TB diagnostic tools in action including fluorescent microscopy and culture facilities for diagnosing drug-resistant TB.



Staff from the TB Research Centre explain to Target TB partners the work they are doing to culture TB samples for drug resistance testing.

CONCLUSIONS

For Target TB this meeting marked a step forward in the development of our work. The meeting highlighted that through our international partnership network we are making significant contributions to TB control and global health. Target TB's partners are a diverse group of organisations, with different skills, knowledge and experience. This offers opportunities to transfer expertise within the network and for members of the network to work together more closely towards common goals.

TB is one of the world's biggest killer diseases, yet there are relatively few civil society organizations working on TB control in a focused way. Whilst individually Target TB's partners are making great achievements to address TB, working together we could achieve even more. This is vital to help us step up our efforts to help control this preventable and curable disease.

RECOMMENDATIONS

Participants provided extremely positive feedback, with calls for this type of meeting to be held more regularly, enabling partners working in different areas, regions and contexts to share experience and learning. Key recommendations and learning points for Target TB and its partner network arising from the meeting included:

- There are opportunities for greater joint working between partners, enabling them to share their diverse skills and expertise to achieve common goals.
- There is a need to develop advocacy plans for Target TB's network which all partners are involved in developing and actively engaged with.
- Organisational development is a common challenge for NGOs to address, and Target TB partners are keen for further support to enable them to address this important area.
- Participation in regional and national level networks are important forums through which Target TB's partners can share the impact of their work at community level and raise the profile of their organisations with key stakeholders.
- Building capacity in health research and including this aspect within TB programmes can help Target TB and its partners to demonstrate impact and draw out best practice information.

PARTICIPANT FEEDBACK

"...the meeting was extremely interactive and highly participatory, resulting in valuable contributions from all participants. The facilitators did a fantastic job in putting together a meeting of such magnitude considering the diverse background from which participants came."

"Thank you so much for everything. The workshop was an eye opener and I learnt quite a lot about TB and what others are doing. I have learnt that TB needs a careful and well calculated approach to make an impact at all levels."

"We would like to thank Target TB for facilitating this dialogue on TB control among its partner organisations. The meeting was a platform upon which future discussions among partners will be anchored."

"I wish to thank you for the opportunity accorded to us to attend the Partners Meeting and also to meet and share with our friends from other countries. It was a wonderful experience that will last for a long time to come."



Target TB and its international partner network.

ACKNOWLEDGMENTS:

- To all participants for their active engagement throughout the meeting, and for travelling significant distances to make this a truly international event.
- To Dr. Bobby John for facilitating an excellent session on advocacy and providing his expertise free of charge to Target TB's network.
- To staff at DACT and AID for their support with logistics, which enabled the meeting to run smoothly.
- To the Commonwealth Foundation for providing funding which enabled us to make this meeting a reality.
- To Joe Newbiggin and Cathy Haenlein, Target TB interns, for their help with meeting logistics and designing this report.
- To Big Lottery Fund and Comic Relief for their support, which enabled other partner representatives to attend this important meeting.
- To the TB Research Centre, Chennai for their welcome and openness in sharing their work and achievements towards global TB control.