Considering the multidimensional challenges in TB care and control in the SEA Region, it is imperative to promote effective civil society engagement to strengthen community response and make its voice heard against the TB epidemic. The role of CSOs and NGOs will become more critical in terms of establishing, consolidating and scaling up key community linkages with essential services, especially in the underserved, difficult-to-reach areas and with marginalized population groups across the country. The regional workshop on promoting roles of NGOs and civil societies in community-based TB care and control, Jakarta, Indonesia from 18-20 November 2013, provided an opportunity for participants from different countries in the Region to develop comprehensive community-based TB action plans based on WHO’s ENGAGE-TB Approach and to share and learn from mutual experiences which will help to provide inputs for TB and the programmatic management of drug-resistant TB (PMDT) in their own countries.

This report is intended to be shared with national TB programmes of the Member States, international organizations, national and local nongovernmental organizations (NGOs), community-based organizations (CBOs), faith-based organizations, patient-based organizations, and professional associations in order to promote broader partnership between the national TB programmes and the NGOs and CSOs which are working or willing to work for prevention, care and control of TB, especially at the community level.
Promoting the role of NGOs and CSOs in community-based TB care and control

Report of a regional workshop
Jakarta, Indonesia, 18–20 November 2013
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Acronyms

ACSM advocacy, communication and social mobilization
CCM country coordinating mechanism
CHW community health workers
CBO community-based organization
CSO civil society organization
CV community volunteers
DOTS directly observed treatment short course
DR-TB drug-resistant TB
FBO faith-based organization
FLD first line (anti-TB) drugs
GDF Global Drug Facility
GF Global Fund to Fight HIV/AIDS, TB and Malaria
GO–NGO Government–nongovernment
IPT isoniazid preventive therapy
JANTRA Japan–Nepal Health and TB Research Association
JEMM joint external monitoring missions
KHPT Karnataka Health Promotion Trust
M&E monitoring and evaluation
MDG Millennium Development Goals
MDR-TB multidrug resistant-TB
MoU memorandum of understanding
NCB NGO coordinating bodies
NFM new funding model
NGO nongovernmental organizations
NTP  national TB programme
PAL  practical approach to lung health
PLHIV  people living with HIV
PLWD  people living with disease
PMDT  programmatic management of drug-resistant TB
PPM  public–private mix
rGLC  regional Green Light Committee
RNTCP  Revised National TB Control Programme, India
SEA  South-East Asia
SEAR  WHO SEA Region
SHOPS  strengthening health outcomes through private partnerships
SLD  second line (anti-TB) drugs
SR  sub-recipients
TB  tuberculosis
TFI  Tobacco Free Initiative
WHO  World Health Organization
XDR-TB  extensively drug-resistant TB
1. **Background**

The World Health Organization South-East Asia Region (SEAR), with an estimated 4.8 million prevalent and about 3.4 million incident cases of TB in 2012, carries about 40% of the global burden of the disease. Five of the 11 states of the Region are among 22 TB high-burden countries in the world, with India alone accounting for more than 25% of the world's incident cases.

One third of the people estimated to have TB are either not reached for diagnosis and treatment by the current health systems or not reported to the NTP (national TB programme). Even among notified patients, TB is often diagnosed and treated late. In order to reach the unreached and find TB and drug-resistant TB (DR-TB) patients early in the course of their illness and prevent further emergence of DR-TB, a wider range of stakeholders already involved in community-based activities needs to be engaged. These include the nongovernmental organizations (NGOs) and other civil society organizations (CSOs) that are active in community-based development, particularly in primary health care, HIV infection and maternal and child health, but have not yet included TB in their priorities and activities.

NGOs and other CSOs are non-profit organizations that operate independently from the state and from the private for-profit sector. They include a broad spectrum of entities such as international, national and local NGOs, community-based organizations (CBOs), faith-based organizations (FBOs), patient-based organizations and professional associations. CBOs are membership-based non-profit organizations that are usually self-organized in specific local areas (such as a village) to increase solidarity and mutual support to address specific issues. CBO membership comprises community members themselves, so these organizations can be considered to represent the community most directly. NGOs and other CSOs engage in activities that range from community mobilization, service delivery and advocacy.
In the SEA Region, the national TB control programmes have unique partnerships with NGOs, CBOs, FBOs, and anti-TB associations. Many of these NGOs and CSOs work with the NTPs through a memorandum of understanding (MoU). They are also the sub-recipients (SR) of GF grants. They are active in TB care and control and other developmental interventions at the community level. Their strengths include their reach, spread and ability to engage marginalized or remote groups to increase case notification and prevent emergence of DR-TB. A more decentralized approach is needed that formally recognizes the critical role of NGOs and other CSOs as partners addressing gaps through support to community-based actions on TB prevention, diagnosis, treatment and care activities.

The implementation and scaling-up of community-based TB activities remains weak, despite the clear need, the documented cost-effectiveness of community-based TB activities, and the tremendous efforts that have been expended in recent years. Lack of effective collaboration between NTPs and NGOs and other CSOs and the absence of joint strategic planning, monitoring and evaluation is more the norm than the exception. Difficulties in measuring the impact of community-based TB activities and the lack of standard indicators have also been noted. The absence of operational guidance on engaging NGOs and other CSOs in TB prevention, diagnosis, treatment and care, including community-based TB activities has been mentioned as a barrier. In response, WHO produced the ENGAGE-TB Operational Guidance which describes how NGOs and other CSOs may integrate community-based TB activities into their work and how NTPs and NGOs may better collaborate.

The regional workshop on promoting the role of NGOs and CSOs in community-based TB care and control, 18–21 November 2013, in Jakarta, Indonesia, provided an opportunity for participants from different countries in the Region to develop comprehensive community-based TB action plans based on WHO’s ENGAGE-TB Operational Guidance and to share and learn from mutual experiences which will help provide inputs for TB and the programmatic management of drug-resistant TB (PMDT) in their own countries. The meeting was attended by 43 participants including national TB programme managers, officials from NGOs and CSOs, WHO TB staff from headquarters, the Regional Office and country offices.
2. Opening session

Dr Mohammad Akhtar, Medical Officer–TB, WHO Indonesia, welcomed all the participants and conveyed greetings on behalf of Dr Samlee Plianbangchang, Regional Director, WHO South-East Asia Region. In his message to the workshop, read by Dr Mohammad Akhtar, the Regional Director recognized and appreciated the unique partnerships of the national TB control programmes with NGOs and other CSOs in SEAR. He urged the participants to use the workshop as an opportunity to learn from the experiences of Member States in the Region to effectively plan the next steps to address community-based TB care and control. The Regional Director emphasized the need to “reach the unreached”, referring to one third of the TB cases that are either not detected or not reported (See Annex I for the full text of the message).

In his opening address, Professor Dr Tjandra Yoga Aditama, Director-General (Disease Control and Environmental Health), said that the goal of TB elimination can be achieved through partnerships, research, early diagnosis, better access to treatment, advocacy, and social mobilization. Professor Aditama emphasized the influence of CSOs, also known as the “third sector”— the government and private for-profit sectors representing the first and second sectors in global health. He noted that despite some efforts to engage CSOs in national TB activities, they are still not being recognized as legitimate partners in many countries at national and local levels. Strong motivation to respond better to urgent health and humanitarian needs has engendered a debate on how to formalize the significant, at times vital, contribution of CSOs in global health governance.

In conclusion, he said that the capacity of CSOs to function in difficult-to-reach, remote areas and conflict zones offers a unique opportunity for increased early TB case detection and treatment adherence through generating demand for services and scaling up of community-based care. If well planned, this will expand TB prevention, care and control beyond health facilities and in settings that cannot be easily reached by national programmes.

The general objective of the workshop was to promote the role of NGOs and CSOs in community-based TB care and control.
The specific objectives of the workshop were to:

- review the progress of community-based TB activities in Member States;
- identify the potential roles of NGOs and CSOs in improving care and control of TB;
- share updates on the technical guidelines to improve community-based TB activities under national programmes; and
- draft country-specific plans for effective scale-up of community-based TB, including programmatic management of drug-resistant TB.

(See Annex II and III for agenda and list of participants.)

3. **Overview: current situation, challenges and progress**

3.1 **TB burden and situation of TB control in SEAR**

The findings of the *TB Control in the SEA Region: Annual Report 2013* are that the burden of TB in SEA Region is high with 4.8 million prevalent cases and 450,000 deaths in 2012. The SEA Region has 26% of the world’s population, but accounts for 40% of the global burden of TB in terms of TB incidence.

The estimated number of cases of all forms of TB in 2012 was 3.4 million, with nearly 2.3 million cases reported to NTPs. In 2012, the number of cases of multidrug-resistant TB (MDR-TB) in the Region was estimated to be 90,000, of which 15,845 cases were registered for treatment. Case registration of MDR-TB has improved compared to 2011, when it was only 6,000. HIV-associated TB in the Region was estimated to be 170,000 with approximately 56,000 cases reported to NTPs in 2012. Prevalence of TB in the SEA Region decreased by about 40% and has shown over 50% decline in some countries, as compared to the baseline data of 1990s. The decline in TB incidence is less perceptible. However, the Region is on track to reach the MDG target of reversing TB incidence by 2015 and 50% reduction of mortality due to TB.
3.2 Updated Regional Strategic Plan for TB Care and Control: 2012–2015

The updated Regional Strategic Plan for TB Care and Control: 2012–2015 aims to support countries in their continued efforts to reach the TB-related MDG, making universal access to quality TB prevention, care and control services a reality for all persons living in SEAR. All 11 Countries of the Region have formally endorsed the Stop TB Strategy 2006 and based their subsequent updates of national strategic plans on its local adaptations.

3.3 National strategies and plans for implementation

The estimated rates of incidence, prevalence and mortality of all forms of TB in the Region continue to show a downward trend. NTP manuals and modules have been or are being updated in all 11 countries. Human resource plans to support national TB plans have been updated in six countries which include PMDT. National programme capacity for scaling up interventions under the Stop TB strategy has also been built in various technical areas.

3.4 Diagnostic capacity in SEAR

All countries have nation-wide networks of smear microscopy, but accessibility and quality still remain a challenge. Culture and drug susceptibility testing facilities are available in all the countries except Maldives and Timor-Leste. However, Maldives is an exception where treatment is case-by-case and diagnosis is at the supranational reference laboratory in Chennai, India. Most of the Member States in the Region are rolling out PMDT successfully. The Region has two supranational reference laboratories; one is situated in Bangkok, Thailand and the other at the National Institute for Research in Tuberculosis, Chennai, India. These two laboratories are overstretched and cannot meet the workload of the entire SEA Region. To reduce the burden and improve facilities in the Region, the process of accreditation of the National Tuberculosis Institute in Bangalore, India is ongoing.
3.5 Anti-TB treatment

Securing funding, procurement, distribution and management of first line (anti-TB) drugs (FLD) in all 11 countries is on target and there are no stock-outs. All countries are utilizing the Global Drug Facility (GDF) direct procurement services and GDF grants are also available for paediatrics in eight countries of the Region. Efforts are being made to counter issues such as limited number of treatment facilities, funding, procurement and short shelf life of second line drugs (SLD), available through the national programmes in Bangladesh, Bhutan, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka, Thailand and Timor-Leste.

3.6 Surveillance, monitoring and evaluation

All countries have very good reporting systems starting from the periphery up to the central level. The WHO Regional Office publishes the SEAR report annually, which is released on World TB Day. Reporting formats have been updated in line with revised WHO recording and reporting formats in all 11 countries, but these formats still require inclusion of civil society contributions to notifications and treatment success. Six countries in the Region have functional electronic data management systems. Further, in order to build capacities and train staff, training initiatives have been undertaken in Bangladesh, India, Myanmar, Indonesia and Thailand on managing information for action. The countries in the Region are constantly reviewing their TB care and control programmes through various mechanisms including joint external monitoring missions (JEMM) as per internationally recognized review standards. Upcoming JEMM in the year 2014 present an opportunity to strengthen the engagement of civil society in the national strategic plans of countries of the SEA Region.

Indonesia conducted its JEMM in February 2013. Nepal and Timor-Leste have concluded JEMM and are in the process of finalizing the reports. Thailand has also concluded its JEMM very recently with high level of commitment from key government officials. Further, Bangladesh, Democratic People’s Republic of Korea, Sri Lanka and Bhutan are planning a JEMM in 2014. Indonesia is currently undertaking its TB prevalence survey, while Thailand is on the verge of completion. Bangladesh, the Democratic People’s Republic of Korea, and Nepal are planning surveys for 2014.
3.7 Managing MDR-TB

More than 15,000 MDR-TB patients were registered for treatment in 2012, while this number was only about 5000 in 2011. However, much more needs to be done to detect MDR-TB cases and enrol them for proper treatment, as only 16% of the total estimated 90,000 MDR-TB cases in the Region were enrolled for treatment during 2012.

WHO SEA Region established a Regional Advisory Committee on MDR-TB (r-GLC SEAR) in May 2012 which has met four times so far. r-GLC SEAR provides guidance on new policies and strategies for PMDT in the countries of the Region. It also reviews and endorses country PMDT missions for 10 Member States of the Region for further scale-up of PMDT services.

Nepal has established ambulatory case management for MDR-TB throughout the country since 2005. India’s MDR-TB case management has expanded to all states and the country is using its national resources to improve availability of SLD. In Thailand, MDR-TB treatment is been provided at about 100 treatment units throughout the country and PMDT has recently scaled up. In Indonesia, MDR-TB case management is available at 13 referral hospitals and more than 380 satellite treatment centres. Bangladesh, Myanmar, and Timor-Leste have also started enrolling patients since 2008. Bhutan and Sri Lanka commenced enrolment in 2010. Bangladesh is expanding PMDT with its unique model of community engagement. Maldives continues to treat the few cases that occur on a case-by-case basis. The Democratic People’s Republic of Korea has started enrolling patients on SLD and the national reference laboratory is functioning well.

Limited capacity of laboratory diagnosis, low access to quality-assured drugs, limited numbers of trained personnel, non-availability of equipment at facilities and poor quality of care by providers were identified as challenges in the management of MDR-TB needing urgent attention.

3.8 Addressing TB/HIV

A comprehensive package of TB/HIV interventions is now available to over 1500 million people in the Region. Intensified case-finding is steadily
increasing at integrated TB/HIV counselling, testing and care centres. Infection control measures have been included in the national plans of Bangladesh, Bhutan, Democratic People’s Republic of Korea, India, Indonesia, Myanmar, Nepal, Sri Lanka and Thailand. Isoniazid preventive therapy (IPT) is not a part of policies in most countries of the Region. Despite significant progress made by countries, cross-referral mechanisms still need considerable strengthening. The roles and functions of coordination bodies need to be clarified and the number and quality of facilities providing TB and HIV services needs improvement.

3.9 Private–public and public–public partnerships

In the SEA Region, 25% of the cases are being notified from the private sector. The contributions of private–public and public–public partnerships to notifications are documented in most of the countries. However, the majority of patients in the countries of SEAR seek care outside of NTPs, and providers in other sectors often do not follow recommended TB diagnostic and treatment practices, particularly in terms of the SLD regimen (Source: Tuberculosis Control in the South-East Asia Region. Annual TB Report 2013)

3.10 TB and health system strengthening

Practical approach to lung health (PAL) implemented in Nepal (expansion phase), India, Indonesia and Sri Lanka has contributed to health system strengthening. Bangladesh is also in the phase for PAL implementation. It was recommended that TB programmes should be involved in decision-making on health reform processes. The lack of adequate workforce and overloaded staff is a crisis in most of the countries of the Region and needs attention.
4. Sharing of country experiences

Participants shared country-level experiences from the national TB control programme and the civil society perspectives.

4.1 Bangladesh

Current level of community and civil society engagement

Dr Nuruzzaman Haque, Deputy Director, DGHS, provided NTP’s perspective on TB care and control in Bangladesh, which has witnessed greater engagement of community; NGOs and CSOs post-1993 in DOTS era. Presently, NTP is partnering with 46 NGOs and other international development partners for TB control and prevention. Key areas of NTP-NGO partnership are participatory planning and joint review, resource mobilization, community engagement, health system strengthening, capacity-building and advocacy, communication and social mobilization (ACSM).

Community contribution data estimates 45% referrals during Q1–Q3, 2013. The treatment success rate in the 2011 community-based DOTS was
as high as 93%. Bangladesh is also implementing community PMDT since 2012 to further integrate the community with the TB care services. NTP aims to collaborate with the National Nutrition Programme to support patients with nutritional deficiencies. Sustainability and scaling up of community engagement and lack of effective guidelines and tools still remain a challenge for TB control and care in Bangladesh.

**TB care and control role of civil society**

Md. Akramul Islam, Associate Director, Health Nutrition and Population Programme, BRAC described some of the specific roles played by civil society in TB care and control, which is not only limited to demand generation, but extends to bringing services close to the communities. High disease burden of TB with lack of infrastructure and human resources and insufficient demand for utilizing TB control and care services among vulnerable population create a need for NGO and CSO engagement in Bangladesh. NGOs and CSOs are closely working with the Ministry of Health and Family Welfare with a shared vision to achieve the goals identified by the Government.

BRAC supports the NTP by engaging with frontline community health workers (CHW) (Shwasthya Shebika), for community mobilization, case notification, ensuring DOT, treatment completion and follow-up sputum tests. Further, arranging outreach sputum collection centre, providing nutrition and livelihood support to poor and vulnerable people and introducing incentives for health workers for treatment compliance are BRAC’s specific TB control interventions. Strengthened GO–NGO partnership in rural and urban areas and launch of social protection scheme has significantly increased case notification and treatment success rates in the past decade.

### 4.2 Bhutan

**Current situation of civil society engagement in TB control and care**

Mr Tashi Dendup, Programme Officer, National TB Control Programme reflected the situation of civil society engagement in Bhutan. To ensure community engagement in NTP, a DOTS Committee was established.
However, taking the limited number of TB cases in the community and cost-effectiveness into consideration, the Committee was dissolved. Involvement of NGOs and CSOs in TB control and care in Bhutan is extremely limited and the country has come up with the CSO Act only in 2007.

Considering the importance of engaging NGOs and CSOs in health service delivery, one of the objectives of the National Health Policy 2010 was to foster GO–NGO partnership. Country level data to gauge civil society engagement in TB care is not available due to lack of monitoring mechanism. However, improvement in primary health care services and in knowledge and attitude about health care is largely attributed to village health workers and community action groups. Capacity-building and increased funding to support community system coupled with recent developments like the CSO Act are creating an environment conducive for greater engagement of NGOs and CSOs in TB control and care in the country.

4.3 India

**Partnership for TB Care and Control to support and strengthen India’s national TB control efforts**

Dr Reynold Washington, Managing Trustee, Karnataka Health Promotion Trust (KHPT) highlighted work of India’s civil society network. The network has more than 180 partners, representing various sectors across 19 Indian states. Based on the discourse of various GO–NGO consultations, the Government of India has communicated its expectations from civil society partners to supplement the efforts of Revised National TB Control Programme (RNTCP). These include: assistance in notification; spreading awareness about ban on serological tests for TB diagnosis; engagement with private practitioners and community pharmacists; capacity-building of NGOs and CSOs; innovation interventions for the urban poor; and community engagement and research on RNTCP priorities. The engagement of civil society with diverse core competencies in a unified manner with the Government of India in its TB care and control efforts is an opportunity for achievement of the shared goals. However, paucity of funds
to sustain activities and changing Government attitude towards civil society still remain a challenge.

**Specific initiatives to combat TB and support state-level TB control initiatives in Karnataka**

Dr Reynold Washington informed that The University of Manitoba and Karnataka State AIDS Prevention Society established the Trust in 2003. KHPT had been closely working with the Government of Karnataka on their intensified programmes for HIV and TB.

KHPT is working on market-based partnerships for health and strengthening health outcomes through the private partnerships (SHOPS)–TB Project and the model is based on universal adoption of standards of TB care. Capacity-building initiatives are carried out through a network of colleges and based on the completion of training, the participants receive credits which are recognized by the Karnataka Medical Council. Diagnosed patients, urban slum populations and diabetes co-infected. Communication interventions within the community are focused on spreading awareness in the community about what they should expect from private practitioners. Further, community members work to increase the access of facilities; teach methods of sputum collection and carry the sputum cups for testing, which reduce two visits to one. Community volunteers (CV) also accompany the members to the testing/diagnosis centres. DOTS-Mitra is a telephone helpline to disseminate information about DOTS. The helpline works for reducing stigma about the DOTS treatment by providing information in an anonymous way.

### 4.4 Indonesia

**Current situation of NTP and community engagement**

Dr Dyah Erti Mustikawati, Programme Manager, National TB Control Programme, said that Indonesia is one of the high TB burden countries of the Region with a population of 247 million. The NTP has been successful in implementation of basic DOTS, but one of the major challenges is that 30–40% of the affected people seek health care from private practitioners, out of which an unknown number does not follow the standard treatment.
This creates a need for a comprehensive model of public–private mix (PPM) which aims to provide quality TB care to the unreached population and prevent MDR-TB.

Indonesia had a high treatment success rate of more than 90% in 2012; however, some of the provinces show a success rate of as low as 43%. Further, to ensure quality management of TB by private providers, NTP has mandated notifications and created pilot models in eight provinces.

With intent to optimize and boost the achievement of universal access towards quality TB care and to increase case notification and maintain high quality TB care, NTP is taking rapid strides for wider engagement of NGOs and CSOs. However, the level of community engagement in the country is still limited in scope and is mostly on local advocacy and DOTS implementation (community case-finding and holding, treatment support). Future action in the country should focus on strengthening of Stop TB Partnership Forum, Indonesia, to engage broader CSOs and community and development of national CSO plan, which covers broader issues such as ACSM, support service delivery to unreached population and strengthen capacity of CSOs and community on advocacy and community funding mobilization through various resources.

**Indonesian Association against TB**

Dr Henry Diatmo, PPTI (The Indonesian Association Against Tuberculosis), said that NGOs and CSOs in Indonesia have a strong presence and structure at all levels. Some CSOs have private clinics and good linkages with policy-makers. The Stop TB Partnership Forum Indonesia was also created to be a movement to accelerate social and political action to stop the spread of TB. Community health services have played a crucial role in implementation of DOTS strategy to achieve the national target. In addition to this, communities have also assisted in case-finding and referrals, observing treatment and disseminating awareness-raising information. However, the recording and reporting system to measure community contribution is not yet established and there are limited resources to support cadre activities.
4.5 Myanmar

Current situation of civil society engagement in TB care and control

Dr Sithu Aung, Assistant Director (TB), National TB Control Programme, Department of Health, said that In line with STOP TB strategy, NTP had been working closely with local and international civil society organizations, bilateral agencies and WHO for promoting community partnerships. NTP was also working with medical associations to promote PPM. Draft guidelines for community-based TB care had been developed together with implementing partners and technical support of WHO. Starting from the second quarter of 2011, community-based TB care activities in the country were currently being implemented in 167 townships with GF budget. To improve TB control activities in unreached areas, NTP had been engaging with local NGOs and CSOs in community-based care activities since 2011. Contribution of local NGOs and CSOs to all forms of TB in catchment areas was 2.2% of the total cases in 2012. However, Myanmar still faced challenges in covering the northern and north-western parts of the country under community-based TB care. Further, lack of reliable monitoring data and motivated trained volunteers were other issues facing the country.

4.6 Nepal

Community engagement in TB care and control

Nepal has a huge burden of TB and because of larger population density, the concentration of TB cases is more in the districts neighbouring the Indian border. To overcome the difficulty in accessing MDR-TB care, NTP and partners have established 80 DR treatment centres and sub-centres in all five regions of the country. In addition, 10 DR-TB hostels have been established to admit for care those patients living far away from any treatment centre. The performance of NTP is good, as case-finding and treatment success has increased compared to early 2000; but the case-notification rate is still stagnant.

At present, community engagement in TB care is at the district level and below, primarily through health management committees and DOTS committees and most of the NGOs and CSOs also operate at the district
level. Members of the community are trained by the district health office and play a critical role in referring TB suspects from the community to the nearby microscopy centre, supervising DOTS for patients who cannot attend DOTS clinic, counsel and motivate TB patients for the full course of treatment, visit irregular TB patients’ houses and participate in ACSM activities at the local level. However, there is still a need to increase the level of involvement of NGOs and CSOs in TB care and control which has mainly declined due to limited funding.

**TB care and control by NGOs**

Mr Ram Sharan Gopali, Executive Director, Japan–Nepal Health and TB Research Association (JANTRA), said that JANTRA is a national NGO which complements the Government of Nepal’s efforts in providing TB care services. Activities carried out by JANTRA included providing patient-friendly DOTS services as early in the morning as 08:00, free sputum examination, mapping of existing DOTS centres and supervising TB treatment by trained volunteers. In order to facilitate community engagement in TB activities, JANTRA is working towards community empowerment through ACSM which includes door-to-door visits, school health programmes and community meetings.

Community contribution to referrals/notifications, DOT and treatment success in the country is facilitated by cured TB patients working as volunteers and nutritional support for poor TB patients in some pocket areas. Further, creating opportunities for participation of NGOs and CSOs in planning and implementation of interventions under NTP and recognition of their contributions are crucial recommendations to keep them motivated.

**4.7 Sri Lanka**

**Current situation of community engagement**

Dr Nirupa C Pallewatte, Consultant Community Physician, National Programme for TB Control and Chest Diseases, said that the prevalence and incidence of TB in Sri Lanka is low as compared to other countries of the Region. High literacy rate, gender equality, and enthusiasm of government
and society over health issues make community engagement comparatively easier in the country.

The majority of persons are referred to chest clinics through public health institutions. However, the amount of self-referrals is good and 25% of patients are attending chest clinics on their own. CHW are extensively engaged in DOTS delivery. Coordination at all levels between public and private sectors, nongovernmental organizations and civil societies is present in Sri Lanka. Further, it is important to incorporate a sense of ownership and belonging in the community.

**TB care and control**

Dr KK Sooriyaarachchi, Vice-Chairman of the Ceylon National Association for the Prevention of TB which started its operation in 1944 before the implementation of NTP-Sri Lanka, made a short video presentation on the work carried out. The Association is now working closely with the NTP with the support of donations and without any external funding.

### 4.8 Thailand

**TB care and control**

Mr Booncherd Kladphuang, Public Health Technical Officer, Bureau of TB, noted that significant progress had been made in engaging all care providers in Thailand. The PPM network in the country included the Bangkok Metropolitan Administration, government hospitals (at all levels), university hospitals, private hospitals, NGOs and CSOs, the corporate sector, prisons, military and police. Around 3000 people with TB were detected and notified by non-NTP providers in Thailand in 2012.

The district hospital serves as the basic management unit for TB control, performing sputum smear-microscopy to diagnose TB, maintaining the TB register, and supervising treatment. Persons may also be diagnosed with TB at other health-care facilities, including those operated or partially supported by the government and those operated by private entities. Such additional health-care services are widely available in Bangkok and a few other metropolitan areas, but less so in most provinces. However, there is significant scope for strengthening engagement of hospitals in the private
sector as well as those outside the purview of the Ministry of Public Health. Currently, 80% of private hospitals do not notify TB cases to the national TB programme.

**Role of civil society in TB care and control**

Dr Nang Sarm Phong, World Vision Foundation of Thailand, said that his organization was mainly working with migrant population with support from frontline social networkers and migrant health volunteers. Working through migrants had been effective in building trust, overcoming language barriers and reducing stigma and discrimination. The organization acts as a bridge between the government facility and the migrant population by community health posts and its network of volunteers. The community health post provides services such as TB screening, sputum collection, health education. However, lack of freedom of movement of migrant workers had been one of the key challenges faced when working with such a population group.

**4.9 Timor-Leste**

**Community engagement**

Mr Antonio Da Cruz dos Santos, Regional Supervisor, NTP, said that his country was engaging the community in TB control through suspect referral and DOT provision family health promoter. NGOs and CSOs are also widely engaged in advocacy, case-finding and management of cases as per NTP guideline. The country also involves community leaders and TB patients in advocacy for TB care and control. NTP works in close collaboration with NGOs and CSOs and these organizations are empowered through active involvement in the decision-making bodies and steering committees. However, family health promoters are volunteers for many other programmes, so their time commitment to the TB programme is not sufficient for complete engagement. Financial sustainability of NGOs and CSOs involved in TB care and control in the country is also a challenge.

Poor infrastructure and transport make it almost impossible for people in remote villages to access life-saving diagnosis and treatment for TB. Family health promoters and local NGOs and CSOs are necessary to find and treat patients and to provide health education to remote communities.
Klibur Domin Foundation, a local NGO in Timor-Leste, has a mobile clinic to transport volunteers and health workers to outlying villages to identify patients, start them on treatment, and ensure successful completion of treatment.

4.10 Discussion

- The prime roles of NGOs and CSOs in community should be to raise voices and convey the needs of communities to the policymakers and implementation agencies. In most countries, NGOs and CSOs are becoming service providers by getting engaged with NTPs, which is not their true role. Therefore, it is crucial to empower NGOs and CSOs so that they continue to bring perspectives of patients and ground realities to wider attention.

- It is important to bring in influential and active private participation in the PPM committees at state and district levels to ensure productive and regular meetings and equal participation from both private and public sectors. This has been dealt with effectively in Bangladesh where the district-level committees are chaired by a civil surgeon and there is strong participation from the private sector.

- In case of limited NGO and CSO existence or engagement at the grass-roots, trained village health workers can be instrumental in reaching the unreached and identifying people with symptoms. This model has been successfully implemented in Bhutan, where the role of civil society in TB care and control is still limited.

- In PPM, most country programmes tend to engage with tertiary, secondary or primary health care levels. However, it is also important that efforts are made and actions taken to engage general practitioners and other service providers who are involved in screening, diagnosis and treatment of tuberculosis.

- To achieve and ensure universal coverage, patients should be provided with choice of multiple PPM options at all levels where they could be diagnosed (i) in the public sector and continue treatment; (ii) in the private sector through a public sector laboratory and continue treatment in private sector; (iii) in the private sector in a private sector laboratory, and continue treatment with public sector medication.
Promoting roles of NGOs and civil societies in community-based TB care and control

- Motivation of village and community level workers can be sustained by giving them cash incentives or sending them for training and educational field visits. In order to ensure motivation and contributions from the grass-roots level workers, steps are being taken to fix minimum wages for the workers in Bhutan.

- Engagement of multiple stakeholders can facilitate case-finding and quality treatment. The model of engagement of pharmacists in community-level meetings with suitable incentives for referrals in Nepal has been critical in complementing NTP’s efforts. Further, NTP Indonesia is also working closely with pharmacist associations for ensuring universal health coverage.

- With limited availability of funds for TB care and control, the sustainability of NGOs and CSOs working on TB remains a question. However, countries such as Indonesia are examples where TB control projects were initiated as far back as the 1960s, only with the strong commitment of active civil society groups and religious institutions such as mosques, who disseminated awareness in communities without any major sources of funding.

4.11 Current challenges in SEAR

Ms Blessina Kumar, Chair, Global Coalition of TB Activists, presented the results of an online mapping exercise which was conducted with NGOs and CSOs to identify the current challenges in SEAR. Majority of the NGOs and CSOs participating in this exercise were from India. However, there was participation from Bangladesh, Indonesia, Myanmar, Nepal, and Sri Lanka also. The main activities carried out by these NGOs and CSOs

<table>
<thead>
<tr>
<th>Challenges highlighted by NGOs and CSOs:</th>
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<tbody>
<tr>
<td>• activism and advocacy not a priority;</td>
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<tr>
<td>• stigma and ignorance;</td>
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<tr>
<td>• language barrier;</td>
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<tr>
<td>• advocacy not a budgeted activity;</td>
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<tr>
<td>• government bureaucracy;</td>
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<tr>
<td>• lack of information required for advocacy;</td>
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<tr>
<td>• low political commitment;</td>
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<tr>
<td>• lack of cohesiveness among TB organizations;</td>
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<tr>
<td>• lack of information, education and communication resources;</td>
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<td>• lack of funds.</td>
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</table>
were in the area of TB/HIV, primary TB-DOTS, MDR-TB, with a very few organizations working on TB research. The findings of the study revealed that almost all the organizations were working with individuals affected by TB, TB/HIV, and MDR-TB, and a large majority of them knew individuals with potential to be activists. It was also interesting to know that almost half of the participating organizations felt that they had ample resources to be effective.

Some of the specific challenges highlighted by the NTP managers of all the 11 Member States of the SEA Region during the recent NTP managers’ meeting in Thailand, Bangkok were also shared.

<table>
<thead>
<tr>
<th>Country</th>
<th>Challenge</th>
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<tbody>
<tr>
<td>Bangladesh</td>
<td>• No specific challenge identified; unique partnership exists</td>
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<tr>
<td>Bhutan</td>
<td>• CSOs not keen on engaging in TB care and control or being a part of NTP</td>
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<td></td>
<td>• Limited opportunities of funding</td>
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<td></td>
<td>• People living with disease (PLWD) are part of working groups but do not participate in the meetings</td>
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<tr>
<td>Democratic People’s Republic of Korea</td>
<td>• Limited NGOs and CSOs but there are only women’s groups, youth groups or household doctors</td>
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<tr>
<td>India</td>
<td>• Addressing the issue of TB in urban slums</td>
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<td></td>
<td>• Engaging with the private sector, specially the practitioners</td>
</tr>
<tr>
<td>Indonesia</td>
<td>• Monitoring and evaluation plan has to be stronger</td>
</tr>
<tr>
<td>Maldives</td>
<td>• Limited NGOs and CSOs working in TB care and control</td>
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<tr>
<td></td>
<td>• TB in migrant population</td>
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<td></td>
<td>• Detecting patients</td>
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</table>
Promoting roles of NGOs and civil societies in community-based TB care and control

<table>
<thead>
<tr>
<th>Challenges highlighted by NTP managers</th>
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</thead>
<tbody>
<tr>
<td><strong>Country</strong></td>
</tr>
</tbody>
</table>
| Myanmar | • Representation on country coordinating mechanism (CCM)  
• People living with HIV (PLHIV) but also affected by TB  
• Revising the membership of the Technical Strategic Group to include more PLWD  
• Strong HIV groups but not for TB  
• Sustainability of initiatives is a big challenge |
| Nepal | • Hard-to-reach populations |
| Sri Lanka | • Limited number of NGOs and CSOs working in TB  
• Very low involvement  
• NTP not able to provide a platform for involvement |
| Thailand | • Capacity-building of key stakeholders is required at multiple levels.  
• Limited levels of awareness on TB  
• Challenge to integrate TB into existing work  
• Human resources  
• Coordination needed  
• Urban setting |
| Timor-Leste | • Limited involvement of NGOs and CSOs  
• Limited management, financial and HR capacity of civil society. |

4.12 Summary

Mr Thomas Joseph, Consultant, Community Engagement, Global TB Programme, WHO Headquarters, summarized the discussion and discourse of the day. The main focus was as follows:

- role and contribution of NGOs and CSOs in early detection and treatment success;
reaching the unreached and harnessing civil society partnerships to extend the impact of current efforts;

promoting the role of CSOs in TB care and control.

The country experiences shared by the CSOs and NTP representatives converged well and were also reflective of the dialogues which happened during the recent meetings of NTP managers. Some of the specific points highlighted during the country presentations were:

value of community engagement and reach of CSOs;
mechanisms to support CSO engagement;
limited understanding of CSO engagement in some countries;
extensive use of community structures like village development committees or health committees;
role of village and CHW in community TB care and control;
innovations by CSOs and NTPs, such as assisting in taking samples; flexibility in clinic timings to suit communities and nutrition support being provided to TB patients;
role of NGOs and CSOs in communicating the voice and needs of the community to the policy-makers.

The existing challenges discussed were specifically related to:

extending the reach of the current initiatives and going beyond current partnerships and organizations to new NGOs and other CSOs to improve case-detection and notification rates as well as treatment success;
reaching specific groups such as migrants and mobile populations;
addressing stigma and negative attitudes;
recording and documenting community contributions.
5. Guiding principles on promotion of roles and responsibilities of NGOs and civil societies in the integration of community-based TB activities

5.1 TB - the opportunity in our lifetime

Ms Blessina Kumar, Chair, Global Coalition of TB Activists, stressed upon the urgency to counter TB globally. She said that there had been a total of 45% reduction in TB mortality since 1990 and 56 million people had been treated for TB and 22 million lives saved since 1995.

Advances in reducing TB prevalence, mortality and incidence had been achieved. However, most cases of TB continue to be in lower-income countries and the majority of cases of MDR-TB continue to go undiagnosed and untreated. A total of 1.3 million people died of TB in 2012, out of which 40% of the deaths were in SEA Region. If the current annual pace of decrease is not accelerated, reducing TB incidence from current global levels (125/100 000) to the target (10/100 000) would take until 2180. (Source: Global TB Report 2013)

Figure 2: The road to 10/100 000 TB incidence
Globally, there are 8.6 million estimated TB cases, but only 5.7 million cases are getting diagnosed and treated. So there are 3 million missing TB patients. WHO estimates that 75% of the "missing" TB cases are in just 12 countries: Bangladesh, China, the Democratic Republic of Congo, Ethiopia, India, Indonesia, Mozambique, Myanmar, Nigeria, Pakistan, the Philippines and South Africa.

TB has a drastic impact on households, resulting in loss of income and huge economic liability. However, recent studies suggest that return on investment for TB case-finding and treatment is the highest as compared to other health interventions.

Between the years 2005 and 2011, a total of 1.5 million lives were saved due to TB and HIV integration. There was a 25-fold increase in cases detected and treated due to prioritized interventions in vulnerable populations. Detection and treatment has doubled through engagement of civil societies and communities. The international community must accelerate efforts and invest more in the fight against TB today to drive progress tomorrow.

5.2 Linking tobacco prevention and cessation with community-based TB activities

Dr Rim Kwang IL, Medical Officer–TB, WHO Regional Office for South-East Asia described the scope of tobacco control and cessation to address TB through a community-based approach.

Worldwide, approximately 1.3 billion people currently smoke cigarettes or use other tobacco products with nearly 70% of them living in developing countries. Total global prevalence in smoking is 29% (47.5% men and 10.3% women over 15 years of age). Tobacco use is the leading preventable cause of death. More than 6 million people die every year from tobacco use.

The WHO monograph on TB and tobacco presents a strong base of evidence which describes the linkage between TB and the use of tobacco products. Tobacco smoking substantially increases the risk of TB and death from TB and more than 20% of global TB incidence may be attributable to smoking.
WHO-recommended policies to combat tobacco and TB, which include strong coordination between national TB and tobacco control programmes and promote implementation of smoking cessation procedures through PAL pilot project are being implemented in Bangladesh, India, Indonesia, Nepal and Sri Lanka.

Countries in the SEA Region are taking up strong and innovative initiatives such as PAL/TFI collaboration in Nepal and TB-tobacco integration in India to counter the dual burden of diseases. These pilot projects have shown success and great potential based on the initial results available.

5.3 Discussion

There is a large base of evidence about the direct association of smoking with TB. However, the effect of tobacco use on MDR-TB treatment has not yet been established. Therefore, more research is required to gather this critical evidence.

The rate of re-initiation of tobacco smoking among TB patients on completion of treatment is high and needs to be addressed with strong counselling and cessation assistance facilities.

6. WHO’s ENGAGE-TB approach

Over the past five years, TB case detection has stagnated and about a third of the estimated cases are either not diagnosed or not reported. NGOs and other CSOs can play an active role to address this gap by integrating TB prevention, diagnosis and care into their work. NTPs need to reach out to NGOs, collaborate with them and encourage them to include TB in their strategies and activities. NGOs and other CSOs should foster their collaboration with the NTPs and align their systems in order to enhance the prevention, diagnosis and treatment of TB in the communities they are serving.
NGOs and other CSOs could integrate TB into their community-based work in many ways, without trained medical staff. It is particularly important for them to do so when they are working with high-risk populations, such as PLHIV and the very poor, people living in congested environments, urban slums and prisons, people who use drugs, sex workers and migrant workers (Source: Integrating community-based tuberculosis activities into the work of nongovernmental and other civil society organizations; WHO publication 2012).

The operational guidance describes the community-based actions and collaborative processes that need to be undertaken by NTPs, NGOs and other CSOs to strengthen NGO and CSO engagement in community-based TB activities. The ENGAGE-TB approach recommends a horizontal approach, promoting integration of TB services into other sectors of health and development. It also defines two core indicators for measuring the contribution of communities to key TB outcomes through one national recording and reporting system. These relate to case notifications that can be attributed to community referrals and treatment success rates of those supported by communities.
ENGAGE-TB proposes six areas to facilitate the engagement of NGOs and other CSOs in community-based TB activities. The ENGAGE-TB approach emphasizes the value of collaboration between NGOs and other CSOs and the NTPs or equivalents. ENGAGE-TB emphasizes close alignment of systems, especially in TB monitoring and reporting, to ensure that national data adequately capture the contributions of communities. It was also highlighted that some of the countries, including the Democratic Republic of Congo, Ethiopia, Kenya and the United Republic of Tanzania, are currently implementing the ENGAGE-TB Approach and have prepared national guidelines based on WHO's operational guidelines. This has resulted in many new NGOs and CSOs in these countries now integrating TB into their work.

6.1 Discussion

- NTPs in many countries have gone out a long way to initiate discussion with NGOs and CSOs, but due to lack of resources, it is difficult for the NTPs to ensure that these NGOs are effectively carrying out TB care and control activities. Therefore, it is extremely important to establish NGO networks and NGO coordinating bodies (NCBs) to keep that energy alive in the new NGOs and CSOs working on TB.

- NCBs should be given initial support and guidance by NTPs so that they can bring in more members. NTPs can help to create an enabling environment for NGOs to work on community-based TB prevention and care. Further, NGOs and CSOs who have experience of TB care and control can provide guidance or mentorship for the newly engaged NGOs.

- Integration of various programmes at the level of governments could be an uphill task, as these programmes are even implemented by different ministries, but instead of structural integration there can be programmatic integration. One example of such integration could be village/community health workers, so that while screening for maternal health, they can also screen mothers for TB.
There have been instances where the country level NGO and CSO networks have tried to engage more NGOs and CSOs but have not been successful. It is important to understand that this is the start of this movement and coalitions would grow.

Making use of the existing structure and NGO and CSO networks is equally important.

Despite all the efforts, there are still 3 million unreached TB cases and case detection has been stagnant at 67% for the past 5–6 years. There is great need for civil society organizations and communities to be engaged in TB care and control activities. The centrality of CHW and CV was highlighted. NGOs need to come together in NCB and meet at least quarterly with NTPs. An enabling environment needs to be created to support NGOs in TB. Two core indicators measuring community contributions to case notifications and treatment success need to be monitored through a single national monitoring system. This summarizes WHO’s ENGAGE-TB approach.

7. Group work

The participants were divided into four groups to discuss the existing challenges and possible opportunities for NGO and CSO engagement in community-based TB activities vis-a-vis the ENGAGE-TB guidance on the following three topics:

- creating an enabling environment for increased community engagement;
- enhancing community engagement to improve success with DR-TB;
- ensuring data collection on community contributions at facility level, aggregated at district/provincial level and reported at national level.
The problem areas and gaps identified are summarized below:

<table>
<thead>
<tr>
<th>Creating an enabling environment for increased community engagement</th>
<th>Community engagement to improve success with DR-TB</th>
<th>Ensuring data collection on community contributions at facility level, aggregated at district/provincial level and reported at national level</th>
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<tbody>
<tr>
<td>• TB considered a biomedical disease rather than a socioeconomic issue</td>
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<td>• inadequate NGO–NTP partnerships and interactions;</td>
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<td>• lack of national strategy plan and guidelines for engagement of civil society;</td>
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<tr>
<td>• lack of NGO and CSO coordinating bodies for cohesive action</td>
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<td>• community contributions largely unrecognized with current database systems;</td>
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<tr>
<td>• limited capacity-building and funding opportunities for NGOs and CSOs.</td>
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<tr>
<td>• lack of training and capacity-building of CSOs for MDR-TB;</td>
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<td>• weak mechanism to trace patients lost to follow up;</td>
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<tr>
<td>• horizontal approach and limited multisectoral involvement;</td>
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<tr>
<td>• lack of physiological, social, economic and nutritional support for TB patients;</td>
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<tr>
<td>• stigma associated with TB and MDR-TB;</td>
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<td>• MDR-TB survivors’ engagement in community mobilization is an unexplored tool.</td>
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<td>• lack of periodic reporting leading to unrecognized community contributions;</td>
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<td>• limited pilot programmes for evidence generation and documentation of success stories;</td>
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<td>• lack of understanding of operational definition of community indicators among stakeholders;</td>
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<td>• insufficient human resource capacity at facility level.</td>
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The recommendations from the groups were further discussed and the final outcomes reported under the workshop recommendations.

### 7.1 Summary

In summary, Ms Blessina Kumar, Chair, Global Coalition of TB Activists, highlighted the remarkable consensus that groups had during the
presentations and discussions. Countries of the Region are thinking in a similar way and comparable ground realities also form a basis for similar interventions to counter issues related to TB care and control. The uniqueness and comparative advantage that the NGOs and other CSOs and communities have in reaching hard-to-reach populations and the importance of governments and civil society working together were reiterated.

8. **Effective planning on promoting roles of NGOs and other civil society organizations in community-based TB care**

NTPs and civil society representatives from nine participating countries, Bangladesh, Bhutan, India, Indonesia, Nepal, Myanmar, Sri Lanka, Thailand and Timor-Leste presented their country action plans based on the discussions held during the workshop. These plans were particularly developed with an aim to increase community engagement, report data related to community contributions and improve collaboration to deal with DR-TB.

8.1 **Country action plans**

|------------|----------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------|
| Bangladesh | • informing NCB to increasingly involve NGOs and CSOs in integrated community based TB activities;  
• including this agenda in the next quarterly monitoring meeting at all levels. | • reviewing and modifying the existing management information system;  
• scaling up of electronic data management system to all districts;  
• developing standard operational procedure for engagement of NGOs and CSOs. | • revising NSP and securing appropriate budget allocation;  
• strengthening joint monitoring and supervision under the leadership of NTP. |
## Promoting roles of NGOs and civil societies in community-based TB care and control

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<tbody>
<tr>
<td>Bhutan</td>
<td>• organizing sensitization and awareness workshop for NGOs and CSOs;</td>
<td>• joint/planning exercise for GF NFM proposal;</td>
<td>• training of TB coordinators and NGOs and CSOs on basics of TB;</td>
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<td>• including NGOs and CSOs strategic interventions into the TB NSP;</td>
<td>• holding regular consultative or review meetings;</td>
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<td>• introducing recording and reporting system to capture data on engagement of NGOs and CSOs.</td>
<td>• conducting joint monitoring/supervision activities;</td>
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<td>• encouraging NGOs and CSOs to raise funds.</td>
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<td>India</td>
<td>• increasing experience sharing, learning and coordination meeting between NTPs, States and NGO and civil society partners;</td>
<td>• strengthening existing NGOs and CSOs partnerships by engaging NGOs and CSOs working in other health issues</td>
<td>• increasing government ownership and stewardship to adopt ENGAGE-TB approach.</td>
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<td></td>
<td>• capacity-building of local NGOs and CSOs.</td>
<td>• devising effective mechanism of resource pooling between civil society and RNTCP.</td>
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<tr>
<td>Indonesia</td>
<td>• creating platforms for introducing ENGAGE-TB to key partners, civil society and stakeholders;</td>
<td>• developing national guidelines of ENGAGE-TB;</td>
<td>• incorporating ENGAGE-TB component in the next NSP.</td>
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<td>• including and implementing community contribution indicator in the NTP-TB surveillance system.</td>
<td>• developing NGO and CSO coordinating body;</td>
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<td>• establishing TB commissions.</td>
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<td>Myanmar</td>
<td>• establishing NCB with approval of MOH; &lt;br&gt;• finalizing and disseminating revised guidelines for community-based TB care; &lt;br&gt;• involving existing and new NGO and CSO partners in NTP quarterly work plan meetings; &lt;br&gt;• strengthening of joint supervision and monitoring activity with focal persons and supervisors of NGOs and CSOs; &lt;br&gt;• procuring infection control materials like N-95 masks to be made available to NGOs in PMDT project sites.</td>
<td>• seeking guidance from MOH and technical support from NTP and WHO for selection of expansion of new townships for NGOs; &lt;br&gt;• training and capacity-building for existing and newly engaged NGOs; &lt;br&gt;• conducting periodic evaluation to recognize achievements, limitations, constraints and NTP interaction with NCB.</td>
<td>• sustaining activities of NGOs and CSOs with funding from existing and potential donors; &lt;br&gt;• strengthening and harmonizing supervision and M&amp;E system of NGOs in line with NSP and national M&amp;E system.</td>
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<tr>
<td>Nepal</td>
<td>• mapping of potential NGO and CSOs working for health and development; &lt;br&gt;• strengthening the membership of TB Control Network of Nepal; &lt;br&gt;• organizing meetings of potential and interested NGOs/CSOs; &lt;br&gt;• reviewing existing recording and reporting forms, supervision checklists to community contribution;</td>
<td>• increasing CSO contributions by signing MoUs between CSOs and NTP; &lt;br&gt;• strengthening supervision and monitoring systems</td>
<td>• ensuring community contribution in NSP and new funding proposal; &lt;br&gt;• ensuring that community contribution is routinely included in NTP progress updates, disbursement requests and annual report; &lt;br&gt;• organizing a national level CSO seminar.</td>
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<td>Sri Lanka</td>
<td>• advocating for community and civil society engagement in the World TB Day.</td>
<td>• including NGO and community engagement in NSP and in funding proposals;</td>
<td>• strengthening support for diagnostic services;</td>
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<td></td>
<td>• initiating discussions to identify roles and responsibilities of NGOs CBOS;</td>
<td>• training the representatives of NGOs and CBOs on TB care and control;</td>
<td>• involving family members of TB patients in income generation projects.</td>
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<td></td>
<td>• setting up an activity plan based on their roles and NTP objectives;</td>
<td>• creating awareness among community especially among marginalized populations, urban slum dwellers, temporary migrants, drug addicts, and estate populations.</td>
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<td></td>
<td>• establishing NCB at national and regional levels;</td>
<td>• conducting regular NTP and NCB meetings to strengthen coordination at national and provincial levels.</td>
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<tr>
<td></td>
<td>• conducting regular NTP and NCB meetings to strengthen coordination at national and provincial levels.</td>
<td>• expanding the NGO/CSO network at national and community levels;</td>
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<tr>
<td>Thailand</td>
<td>• identifying at risk populations, major CSO/NGOs through situation analysis by NTP;</td>
<td>• ensuring financial and resource mobilization;</td>
<td>• sustaining CSO and community engagements for a long term.</td>
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<td>• developing policy and guideline for national TB commissions;</td>
<td>• promoting health insurance system for risk groups;</td>
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<td>• establishing NGO and CSO coordination bodies at the national level;</td>
<td>• developing web-based MIS;</td>
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<td>• organizing frequent NCB-NTP meetings;</td>
<td>• training and capacity-building of staff to ensure effective utilization of the newly introduced tools.</td>
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<td>• developing procedure, tools and guideline to deal with DR-TB;</td>
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<tr>
<td>Timor-Leste</td>
<td>• building capacity of NGOs and CSOs for strengthening ACSM campaign, stigma reduction and patient support;</td>
<td>• developing national policy and strategy for effective engagement of civil society and community;</td>
<td>• piloting of planned activities in one district and scale up in the future;</td>
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<td>• strengthening the single national reporting system.</td>
<td>• developing or adopting training curriculum for all members;</td>
<td>• including community contribution especially on case notification and treatment success in revised current electronic registration;</td>
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<td></td>
<td>• organizing a meeting with TB technical working group CCM and Minister of Health for the adoption of WHO ENGAGE-TB;</td>
<td>• establishing interministerial committee to provide support to community engagement in TB and providing socioeconomic support to patients and their families;</td>
<td>• including budgetary provisions for community engagement in TB in next round of GF.</td>
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<td></td>
<td>• identifying and mapping all NGOs, INGOs, CSOs in all districts;</td>
<td>• advocating at community level to reduce stigma, ensuring availability of drugs and supplies for diagnosis and treatment;</td>
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<td></td>
<td>• developing NGO coordinating bodies (NCB) at national level;</td>
<td>• increasing financial and human resources at facility level for effective implementation of community engagement and contributions.</td>
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<td></td>
<td>• recording, analysing and disseminating current data on community contributions.</td>
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8.3 Discussion

- NTPs and civil society partners should explore other funding avenues besides the GF such as STOP-TB partnership’s Challenge Fund which offers smaller grants specifically for community-based activities.

- NGOs/CSOs at all levels should be encouraged to join the listserv of the Global Coalition of TB Activists, as these platforms disseminate regular information on opportunities of funding and other TB updates. They can also join WHO’s ENGAGE-TB mailing list.

- Awareness about TB in the community should grow collectively with demand for services; if not, it may result in increase in stigma. Such examples come from the National AIDS Control Programme in India, where in some parts, there is still a lot of HIV stigma among doctors.

- Community involvement as per the ENGAGE-TB approach is not only engaging new NGOs, but is also continuing to empower communities and strengthening the effort of NGOs and CSOs already involved.

9. Conclusion and recommendations

9.1 Conclusion

Efforts to reach the MDG-related targets have resulted in significant progress in the Region over the past few years. However, the Region still bears more than one third of the global burden of TB. Considering the multidimensional challenges of TB care and control in Member States of the SEA Region, it is imperative to promote effective civil society engagement to strengthen community response against the TB epidemic and make the community voice heard. The role of CSOs will become more critical in terms of establishing, consolidating and scaling up key community linkages with essential services, especially in the underserved, difficult-to-reach areas and with marginalized population groups across the country. To facilitate effective realization of the goals of national TB programmes, countries
should explore all possible opportunities to engage CSOs, non-formal and private health-care providers to promote comprehensive coverage and ensure effective TB prevention, early diagnosis and prompt treatment. It must also be recognized that NGOs and CSOs will themselves need support to build various capacities in order to contribute effectively as actors and advocates in TB control.

In view of the above discussions, the following recommendations were made:

**9.2 Recommendations for NTPs in Member States:**

- develop and expand a community engagement strategy and support for NCB in NSPs and concept notes for GF, while ensuring broad participation of CSOs in the development of these instruments;
- recognize NGOs and other CSOs as valuable partners in addressing TB care and control;
- forge partnerships with CSOs based on mutual respect;
- organize national and provincial/state consultative meetings to invite the participation of NGOs in TB activities and encourage formation of NGO coordinating bodies;
- ensure regular (quarterly) meetings of NTP and NGO coordinating bodies at all levels;
- undertake situational analysis to identify gaps and opportunities with NGOs and other CSOs;
- jointly develop enabling policies and procedures; tools and guidelines including training materials needed for capacity-building of newly engaging organizations;
- ensure the progress of community engagement in national plans can be tracked, preferably by making it a budgeted activity;
- recognize services rendered by the community;
- include CSOs in policy, strategy, planning, development and monitoring and evaluation mechanisms.
9.3 **Recommendations for NGO, CSOs and civil society:**

- form/strengthen NCB/networks for community-based TB at national and provincial levels;
- develop capabilities to engage in community-based TB services;
- consider implementing part or all of the full range of community-based activities in prevention, care and treatment support;
- integrate community-based TB into existing programmes of work and not create a new vertical programme;
- support NTP in joint monitoring and evaluation of programmes and interventions to showcase impact of community engagement on TB care and control;
- ensure effective engagement of cured TB patients and local media in all community-led local advocacy initiatives;
- provide regular feedback to facilities and NTPs on availability and quality of services.

9.4 **Recommendations for WHO, technical and development partners/donors:**

- provide technical support to Member States in the SEA Region for development and implementation of national strategic plans to create an enabling environment for increased NGO and civil society engagement in community based TB activities;
- provide technical support to countries to effectively use the ENGAGE-TB approach for promoting community engagement, integrating TB services into other sectors and monitoring community contributions;
- encourage and support Member States to include CSOs in all formal monitoring and evaluation mechanisms;
- support Member States to conduct relevant operational research that will feed into future policy development.
Annex 1

Message from Dr Samlee Plianbangchang, Regional Director, WHO SEA Region

(Read by Dr Mohammad Akhtar, Medical Officer–TB, WHO Indonesia)

Ladies and gentlemen,

I have great pleasure in conveying greetings from Dr Samlee Plianbangchang, Regional Director, WHO SEA Region, and in welcoming you on his behalf to this regional workshop.

As Dr Samlee is unable to be here today, I have the honour to deliver his message. I quote.

“The World Health Organization’s SEA (SEA) Region, with an estimated 5 million prevalent and about 3.5 million incident cases of TB in 2011, carries about 40% of the global burden of the disease. Five of the 11 Member States of the Region are among the 22 TB high-burden countries in the world, with India alone accounting for more than 25% of the world’s incident cases.

One third of people estimated to have TB are either not reached for diagnosis and treatment by the health systems or are not being reported. Even among patients who are identified, TB is often diagnosed and treated late. In order to reach the unreached and find TB and drug-resistant TB patients early in the course of their illness and prevent further emergence of drug resistant TB, a wider range of stakeholders involved in community-based activities needs to be engaged. These include the nongovernmental organizations (NGOs) and other civil society organizations (CSOs) that are active in community-based development, particularly in primary health care, control of HIV infection and in maternal and child health, but have not yet included TB in their scope of priorities and activities.

NGOs and other CSOs are non-profit organizations that operate independently from the state and from the private for-profit sector. They
include a broad spectrum of entities such as international, national and local NGOs, community-based organizations (CBOs), faith-based organizations, patient-based organizations and professional associations. CBOs are membership-based non-profit organizations that are usually self-organized in specific local areas (such as a village) to increase solidarity and mutual support to address specific issues. For example, these include HIV support groups, women’s groups, parent–teacher associations and micro-credit village associations. The membership of CBOs is comprised entirely of community members, so these organizations can be considered to be directly representing the community. NGOs and other CSOs engage in activities that range from community mobilization, service delivery and advocacy.

In the SEA Region, the national TB control programmes have a unique partnership with NGOs and other CSOs, many of whom are working with them through MoUs. They are, also sub-recipients (SR) of the GF. They are active in TB care and control and other developmental interventions at the community level, taking advantage of their reach and spread, their ability to engage marginalized or remote groups to facilitate case notification and prevent emergence of drug-resistant TB. A more decentralized approach that formally recognizes the critical role of NGOs and other CSOs as partners addressing gaps through support to community-based actions on TB prevention, diagnosis, treatment, and care activities is needed.

I am certain that this workshop will facilitate in developing a comprehensive community-based TB plan to cover a wide range of activities contributing to prevention, diagnosis, improved treatment adherence and care that positively influence the outcomes of drug-sensitive, drug-resistant and HIV-associated TB. The activities also include community mobilization to promote effective communication and participation among community members to generate demand for TB prevention, diagnosis, treatment and care services.

I am also confident that this workshop will contribute towards a better understanding of our needs and in improving our response to more serious forms of TB in our Region. I would urge that we use this opportunity to learn from the experiences from countries in this Region and elsewhere to effectively plan the next steps to address community-based TB care and control. I would conclude by expressing my sincere gratitude to the
Government of Indonesia for agreeing to host this important event in Jakarta.”

Unquote

I will, of course, apprise the Regional Director of the outcome of this workshop. In conclusion, I wish you all fruitful deliberations and a pleasant stay in Jakarta.

Thank you.
Annex 2

Agenda

(1) Overview of the situation, challenges and progress in TB in the Region and country experiences on involvement of CSOs

(2) Guiding principles on promotion of roles and responsibilities of NGOs and civil societies in the integration of community-based tuberculosis activities:

   - Situational analysis: identifies specific needs and tasks for integrated community-based TB activities
   - Enabling environment: a mutually enabling legal and policy environment based on the principles of equality and mutual respect
   - Guidelines and tools: national operational guidelines for community-based TB prevention and care; template of partnership; training curriculum
   - Task identification: to increase synergy and effectiveness
   - Monitoring and evaluation: in assessing the quality, effectiveness, coverage and delivery of community-based TB activities
   - Capacity-building: strengthening capacity and sustaining engagement of NGOs and CSOs

(3) Drafting plans for effective scale-up of community-based TB including programmatic management of drug-resistant TB

(4) Conclusion and recommendations
Annex 3

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Promoting roles of NGOs and civil societies in community-based TB care and control

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Considering the multidimensional challenges in TB care and control in the SEA Region, it is imperative to promote effective civil society engagement to strengthen community response and make its voice heard against the TB epidemic. The role of CSOs and NGOs will become more critical in terms of establishing, consolidating and scaling up key community linkages with essential services, especially in the underserved, difficult-to-reach areas and with marginalized population groups across the country. The regional workshop on promoting roles of NGOs and civil societies in community-based TB care and control, Jakarta, Indonesia from 18-20 November 2013, provided an opportunity for participants from different countries in the Region to develop comprehensive community-based TB action plans based on WHO’s ENGAGE-TB Approach and to share and learn from mutual experiences which will help to provide inputs for TB and the programmatic management of drug-resistant TB (PMDT) in their own countries.

This report is intended to be shared with national TB programmes of the Member States, international organizations, national and local nongovernmental organizations (NGOs), community-based organizations (CBOs), faith-based organizations, patient-based organizations, and professional associations in order to promote broader partnership between the national TB programmes and the NGOs and CSOs which are working or willing to work for prevention, care and control of TB, especially at the community level.