# Regional Framework for Advocacy, Communication and Social Mobilization



SEA-TB-333 Distribution: General

## Regional Framework for Advocacy, Communication and Social Mobilization



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#### **List of Abbreviations**

**ACSM** Advocacy, communication and social mobilization

**AIDS** Acquired immune deficiency syndrome

**ART** Antiretroviral therapy

**CBO** Community-based organization

**CCM** Country coordinating mechanism

**DOTS** Directly observed treatment short-course

**DST** Drug susceptibility testing

**FBO** Faith-based organization

**GFATM** Global Fund to Fight AIDS, Tuberculosis and Malaria

**HRD** Human resource development

**HSS** Health systems strengthening

**IEC** Information, education and communication

**IPC** Interpersonal communication

**ISTC** International standards for tuberculosis care

**KAP** Knowledge, attitude and practices

MCH Maternal and child health

MDG Millennium Development Goal

MDR-TB Multi-drug resistant TB (resistant to at least Rifampicin and Isoniazid)

**NGO** Non-governmental organization

NMA National Medical Association

NTP National tuberculosis programme

**OR** Operational research

**PAL** Practical Approach to Lung Health

**PCTC** Patients' Charter for TB Care

**PPM** Public–private mix

**PRSP** Poverty reduction strategy paper

**SEAR** South-East Asia Region (of WHO)

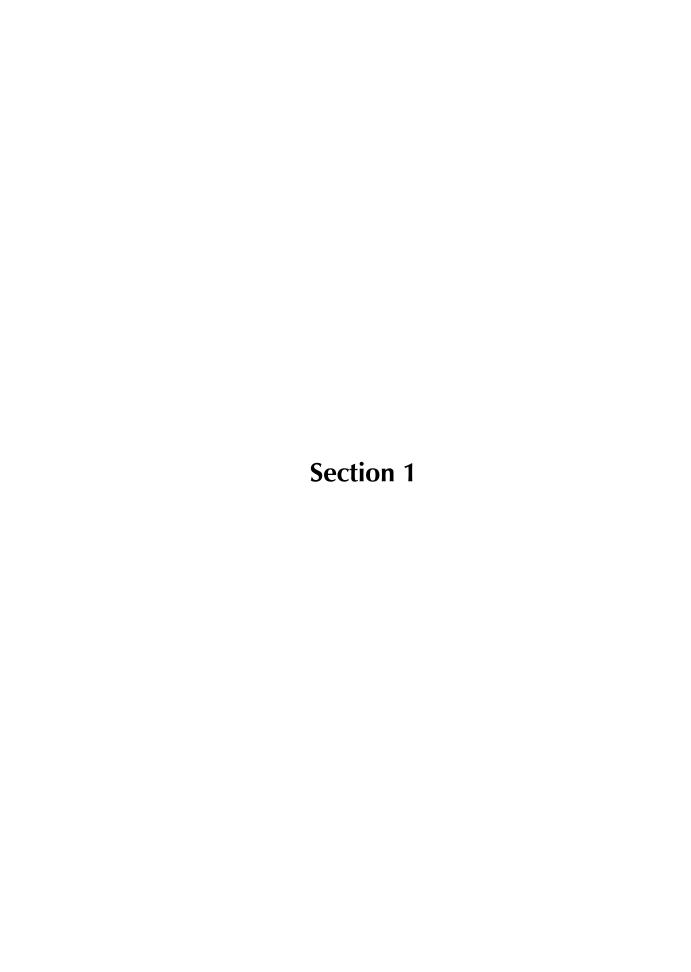
**SHG** Self-help group

**TB** Tuberculosis

**VHW** Village health worker

**WHO** World Health Organization

**XDR-TB** Extensively drug-resistant TB



## 1. Overview of TB situation in South-East Asia Region

Tuberculosis (TB) remains one of the most serious health and developmental problems in the South-East Asia (SEA) Region of WHO. The SEA Region, with an estimated 4.88 million prevalent cases, an annual incidence of about 3.2 million TB cases and about half a million TB deaths, carries one-third of the global burden of TB. Five of Region's 11 Member States are among the 22 high-burden countries, with India accounting for over 20% of the world's cases.

Of the 3.6 million people living with the human immunodeficiency virus (HIV) in the Region, roughly half are estimated to be co-infected with TB. Three of the Region's countries (Thailand, Myanmar and a number of districts in nine states of India) have rates of HIV greater than 1% in the general population and the highest HIV/TB co-infection rates in the Region. Available data suggest that the incidence of TB has been minimally affected by the HIV epidemic. However, the epidemic's impact on TB mortality has been much more substantial.

Levels of multi-drug resistance in terms of proportions are still low, at less than 3%; the population-weighted mean of multi-drug resistant TB (MDR-TB) across all the countries that have reported in the SEA Region is 1.7%-4.2% among new cases and 10.0 - 34.7% among previously treated cases. However, this translates into nearly 130 000 new MDR-TB cases each year.

Extensively drug-resistant tuberculosis (XDR-TB) has been isolated in samples from 6 countries in the Region - Bangladesh India, Indonesia, Myanmar, Nepal and Thailand. Given the widespread availability and use of second-line drugs, and as laboratory capacity to conduct second-line drug susceptibility testing (DST) increases, additional occurrences of XDR-TB are likely to be identified.

#### 2. The Regional Strategic Plan 2006–2015

The Regional Strategic Plan for TB Control (2006-2015) describes the future directions and focus of work for TB control in the Region. The targets and strategies in this document are consistent with the global targets and strategies, but focus on priorities most relevant to this Region and build on past experience.

The interventions are grouped under the following four strategic approaches:

- (1) Sustaining and improving the quality of directly observed treatment short-course (DOTS) to reach all TB patients;
- (2) Forging partnerships to ensure equitable access for all TB patients to an essential standard of care;
- (3) Establishing interventions to address TB/HIV and MDR-TB; and
- (4) Strengthening monitoring and surveillance to measure progress towards the Millennium Development Goals (MDGs).

In addition, every effort will be made to ensure that there are adequate finances and human resources to support the implementation of all the planned interventions. The focus for TB control is to achieve the TB targets under the MDGs in all Member countries by 2015. The interventions proposed in the plan enable countries to improve the quality of DOTS implementation, including improving laboratory services through phased expansion of culture and DST; introduction of additional facilities to better diagnose smear-negative, extrapulmonary and childhood TB; ensuring uninterrupted supplies of high-quality anti-TB drugs; enhancing case management through patient-centred community-based approaches; initiating and scaling up approaches to increase collaboration among all health providers for TB control; building capacity to effectively address TB-HIV and multi-drug resistant TB; and strengthening surveillance, monitoring and evaluation to more accurately determine trends in the TB epidemic in the Region, including levels of TB-HIV and drug resistance.

The plan recognizes that effective TB control necessarily depends on strong health systems, and proposes efforts to effectively streamline TB services within primary health care systems, optimize use of common resources for delivery of TB services alongside those of other programmes,

and adapt innovations in TB control to improve overall health service delivery, while at the same time adopting the successful approaches of other programmes to improve TB services.

With the implementation of the strategic plan, several milestones have been achieved in Member States in recent years.

## 3. Key challenges to implementation of Stop TB Strategy in the SEA Region

Member States of the SEA Region have varied socioeconomic and demographic profiles, leading to an equally varied challenges faced by TB programmes in each country. While considerable progress continues to be made, national TB control programmes still face a number of challenges, including uncertainties regarding sustainable financial and operational resources; limited technical and management capacity; weak national laboratory networks, procurement and supply management mechanisms which in turn are slowing the planned expansion of interventions for TB-HIV and MDR-TB. Although collaboration with other sectors is steadily increasing, the provision of care by all healthcare providers is not sufficiently linked to national programmes to make an impact at the national level. Low levels of community awareness also hamper the uptake of services, and there is increasing recognition that attention needs to be paid to the social, economic and behavioural determinants that impact TB, if national efforts to combat the disease are to succeed in the longer term.

Each country must therefore prioritize advocacy, communication and social mobilization (ACSM) activities according to the challenges it is facing. While ACSM activities cannot fully resolve all the challenges listed below, they can certainly catalyse efforts simply by drawing the attention of appropriate agencies or directly mobilizing resources and support through community action.

#### Pursuing high-quality DOTS expansion and enhancement

Low programme priority and sub-optimal fund allocation: Several SEAR countries are low- and middle-income countries. Financial resource constraints are a major factor affecting programme implementation and expansion of outreach, specifically in the Democratic People's Republic of Korea and Myanmar. Most low- and middle-income countries have been able to mobilize sufficient resources from different funding agencies for TB control. National governments meet almost half of the budgetary requirements to run national TB control programmes, while the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) covers almost a third of funding and bilateral agreements and grants make up the rest. Global initiatives such as UNITAID, the Global Drug Facility, the Green Light Committee, the Global Laboratory Initiative and the Stop TB partnership are helping mobilize resources towards achieving universal detection and treatment of all TB cases in the Region.

- Suboptimal supervision and monitoring of services accountability of the programme to those it serves. This is due to the variable political commitment and motivation of staff, leading to poor quality of services. Certain countries in the Region have conflict areas where supervision is limited by the security situation. However, in certain cases suboptimal supervision is due to lack of adequate resources or very difficult terrains, either in the entire country or parts of the country. Countries like Bhutan, Nepal and Timor-Leste hilly/mountainous areas, while Indonesia is a country of islands, making travel difficult. Therefore part of the problem can be addressed through ACSM, while another part requires different, logistical interventions.
- Migration: Most countries in the SEA Region have adjoining borders, and several of these are "porous," leading to crossborder migration. Migration is an issue for TB control because it leads to default and inaccurate counting of cases. Furthermore, from the patient's point of view receiving irregular treatment has the potential for developing drug resistance. Bangladesh, Bhutan, India, Nepal and Thailand encounter this challenge.

## Address TB-HIV, MDR-TB, and the needs of poor and vulnerable populations

> TB-HIV: According to the Global TB Report 2009, 5.5% of all TB cases notified in SEAR were tested for HIV status; 15% of TB patients tested positive for HIV; 37% of identified HIV positive

TB patients were started on Cotrimoxazole Preventive Therapy (CPT), and only 17% of identified HIV positive TB patients were started on antiretroviral therapy (ART) in 2007. TB-HIV collaborative activities need further strengthening in all Member States, especially Bangladesh, India, Indonesia and Thailand. This will require drawing the attention of programmes and all stakeholders to the existing situation and the potential threat from not addressing these challenges at this stage.

Despite strengthening of cross-referrals between TB and HIV programmes, the available data on HIV among TB cases remain insufficient, and there is an urgent need to scale up and report on the screening of TB cases for HIV infection, and vice versa.

MDR-TB: Despite the progress that has been made in some countries, the number of MDR-TB patients notified in 2007, and country projections of the number of MDR-TB patients to be enrolled on treatment in 2008 and 2009, fall far behind the expectations of the Global Plan. SEAR is one of the three regions with the highest number of MDR-TB cases, and targets set in the Global Plan are far above country projections (specifically India). Laboratory capacities in Member countries to perform cultures and DST are far below the requirement. To address the issue of MDR-TB, laboratory capacity would need to be strengthened by the introduction of newer technologies, specifically in Bangladesh, India and Thailand. Member countries would also need to scale up case management.

## Contribute to health systems strengthening (HSS) based on primary health care

Weak systems: TB programmes, being an integral part of health care systems, are as strong or as weak as those systems. Their success is dependent upon functioning referral, transfer and information-sharing mechanisms between various public and private health care providers. Health systems capacity requires strengthening specifically in DPR Korea, Myanmar and Timor-Leste. Health systems capacity is a cross-cutting issue, and it thus affords the opportunity to liaise with other health programmes of national interest to make a concerted effort in this regard. Some of the resource gaps will also need to be plugged by support from non-governmental agencies.

#### **Engage all care providers**

- Programmes leads to usage of non-standardized treatment regimens. Provision of care by private and other public sectors is not yet sufficiently linked to national programmes. Partnership with the private sector needs to be scaled up in Bangladesh, India and Thailand. Sri Lanka faces the specific challenge of the involvement of tea gardens. Each country needs to develop partnerships, although the nature and structure of these will vary from country to country.
- Though substantial progress has been made in the involvement of various sectors in TB programme, systemic documentation is lacking and there is little sharing of experiences for replication.

## Empower people with TB, and communities through partnership

- In general *low awareness about TB* and its treatment is prevalent in several countries in SEAR. Low awareness about TB leads to apprehension, misconceptions, stigma and discrimination. Coupled with a lack of awareness about services, this leads to low use and underperformance of the programmes. Media involvement in countries is variable, and even where it is occurring, there is a need to further strengthen these activities and tailor the messages to local context through community involvement. Communication activities are generally focussed on producing materials and providing information rather than incorporating more persuasive, behaviour-centred approaches. Stigma continues to lead to the isolation of patients and impairs effective referral, treatment and care.
- The poor bear a high burden of TB. Those in poverty, also have poor access to information and are therefore that much more difficult to reach with TB messages. Symptom that matters most (i.e. a persistent cough), do not usually trigger the search for help. Further, the symptom usually disappears within a few weeks of starting treatment, which can lead a person to stop treatment mid-course.

- ➤ Little community participation and ownership of services. The public health sector is limited in its outreach both in terms of geographical access and timings. This leads to high direct and indirect costs to the patient, even in situations where treatment services for TB are free. In several instances treatment observation is not convenient for patients living in remote areas. Community mobilization is required to increase the reach and cost effectiveness of treatment, overcome social barriers, improve patient acceptance of treatment observation and address lack of patient support that would otherwise lead to low treatment adherence.
- Insufficient attention to addressing social, economic and behavioural determinants that impact TB control. This is primarily because of low community involvement and poor understanding of community needs and the links with socioeconomic vulnerabilities. Without community involvement it will always be difficult for programmes to reach vulnerable and marginalized populations because of the inherent weakness in outreach of the public health system.

#### **Enable and promote research**

- Low priority is accorded to research for development and feasibility testing of newer technologies. These newer technologies need to be indigenized and adapted to local needs. Research is required not only to strengthen existing TB control activities (e.g. leading to effective implementation of DOTS through newer diagnostics), but also to confront the threat posed by MDR and XDR-TB.
- New research and promising results, if any, are not known among the masses or not understood because of technical jargon.

While several technical and financial resources are available within countries, they are not being adequately tapped. There is a need to bring together all stakeholders on a common platform at regional and country levels for efficient use of resources

The ACSM activities required to address each of these challenges, the target audience, and the agency undertaking each activity will differ from country to country.

It has also been observed in the SEA Region that though funds are allocated for ACSM activities in TB budgets, their actual use is low. The major reason is weak national and sub-national capacity to prioritize ACSM activities and plan and implement ACSM campaigns that are linked to TB programme needs. High-profile, well designed and sustained ACSM campaigns are required in order to have a substantial impact.

With this background, there is a need for a regional framework for ACSM that will provide strategic direction for ACSM activities to be carried out, at the regional as well as country levels.

#### 4. Need for ACSM framework

Advocacy, Communication and Social Mobilization (ACSM) are an integral part of TB care and control activities. They highlight and bring to focus key areas that are essential to control TB; mobilize resources required for these key areas through collaborative approaches; increase awareness about TB and the visibility of available services; and empower communities to be a partner, play a decision-making role and monitor the quality of services that they ultimately receive.

All countries in the SEA Region have adopted and follow the Stop TB strategy. ACSM activities are closely linked to all components of the strategy and catalyze the interventions linked to each and every component of the Stop TB strategy as highlighted in Table 1

Member States in the Region have varied requirements and priorities, and specific national plans therefore need to be developed within the agreed framework. This document aims to provide a general framework to Member States for drawing up their own ACSM strategic plans to complement and support implementation of the national strategic plans for TB control. Table 1 is intended as a guide in this regard for countries to identify and analyse gaps that can be addressed through a comprehensive set of ACSM activities.

**Table 1:** Advocacy, communication and social mobilization support all components of Stop TB Strategy

	Components of Stop TB Strategy	Advocacy	Communication	Social Mobilization
1	Pursuing high-quality DOTS expansion and enhancement	Enhanced political commitment and prioritization of TB care and control	Policy advocacy for high-quality DOTS	TB control prioritization by community leaders
		Increased resource allocation for TB care and control	Increased awareness about TB and use of available services	Community empowerment and demand generation for quality services
		Strengthened programme accountability and responsiveness	Demand generation for quality services	Community involvement in providing TB services including contact tracing and default retrieval
		Human-rights-based policy approach	Improved patient/community interaction with health workers and health care system	Community partnership in ensuring accountability
2	Address TB-HIV, MDR-TB, and the needs of poor and vulnerable populations	Bring together various sectors for formulation of appropriate policies and their implementation	Community awareness about MDR-TB, XDR-TB and TB-HIV and prevention	Improved field collaboration and convenient services for TB- HIV co-infected individuals
		Increased political focus on MDR-TB, XDR-TB and TB-HIV	Awareness about available services to promote use	Community empowerment and demand generation for quality services
		Resource allocation for introduction of newer services, technologies, etc.	Demand generation for quality services	Community involvement in providing TB-HIV, MDR-TB and XDR-TB services

	Components of Stop TB Strategy	Advocacy	Communication	Social Mobilization
		Policy focus on marginalized, vulnerable and at- risk groups	Media focus on marginalized, vulnerable and at- risk groups	Community support groups amongst marginalized, vulnerable and at-risk groups
3	Contribute to health system strengthening based on primary health care	Enhanced political commitment to systems strengthening	Use of common communication opportunities for several related programmes	Usage of social capital/ community resources for provision of services
		Increased resource allocation for systems strengthening	Strengthened information system within and across programmes	Inclusion of community groups providing services in information network
		Strengthened systems, e.g. Procurement and supply management and management information systems, to support programme services	Outreach to community groups and local leaders	Community based support for TB and TB- HIV patients
		Linkages with social development programmes and other health programmes like HIV, maternal and child health (MCH), tobacco control	Sensitization to human resource needs	Formation of support groups of affected people
		Development and adoption of minimum standards for organizing TB services within health systems	Linkage of various community groups	

	Components of Stop TB Strategy	Advocacy	Communication	Social Mobilization
		Wider adoption of Practical Approach to Lung Health (PAL) and infection control measures		
4	Engage all care providers	Endorsement of International Standards for Tuberculosis Care (ISTC) by professional bodies including medical, paramedical and nursing associations	Adoption of ISTC by all sectors providing TB services	Use of private sector services for convenient DOTS services
		Professional bodies advocating with health care providers for quality care as per international standards	Discussions about TB care and control discussions in conferences and seminars	Community-led initiatives for involvement of all sectors
		Enforcement of rational drug use by regulatory authorities and prevention of prescriptions outside standard regimes	Promotion of rational drug use through communication	Community networks supporting rational drugs use
		Workplace policy for TB at business establishments	Involvement of business house leaders and workforce	Involvement of all sectors in national TB programme
5	Empower people with TB and communities through partnership	Prioritization of TB amongst local leaders	Community participation in message development	Partnership with community representatives at all levels
		Capacity building for mobilizing other community members	Community forums for message dissemination	Enhanced community contribution to TB care
				Trained community mobilizers

	Components of Stop TB Strategy	Advocacy	Communication	Social Mobilization
6	Enable and promote research	TB-related operational research (OR) in academic and research institutes	Linkage with academic/research institutes for research	Establishment of models for community- based services
		Promotion of investment in research through domestic and other funding sources	Linkages with funding organizations and demonstrating usefulness of investment in OR	Promotion of ideas from community on how to address access and other issues related to TB services

#### **Section 2**

#### 5. Regional framework for ACSM

**Vision**: Equitable access to quality diagnosis, treatment and care with dignity for all TB patients.

**Goal**: Strengthened planning, implementation and monitoring of ACSM activities in the Region, leading to adequate resource availability, enhanced awareness of all stakeholders and development of patient support structures within communities.

#### **Objectives:**

#### **Overall:**

- ➤ To contribute to the implementation of the Stop TB Strategy as integral part of related activities and catalyse achievement of TB-related MDGs by 2015
- To broadbase ACSM activities: active participation from all stakeholders including community representatives to maximize synergies
- > To strengthen ACSM capacity in the Region

#### **Specific to components:**

#### Advocacy

- ➤ To enhance political commitment to fully implementing the Stop TB strategy
- > To mobilize domestic and external resources for TB control

#### Communication

➤ To strengthen communication for appropriate awareness generation regarding TB care and control, and reduce stigma

#### Social Mobilization

To empower communities to play a greater, decisive role in TB care and control

The regional ACSM framework also advocates for a partnership approach for effectively implementing all components of the Stop TB Strategy. Partnerships are an important tool to mobilize resources and use them efficiently for an equitable, patient-focused national strategy.

Taking the above vision, goal and objectives into consideration, this document focuses on how ACSM can augment TB control activities in the Region. Although ACSM activities are presented individually, it must be remembered that they are in fact cross-cutting for all elements of TB care provision, and that in practice the activities overlap and complement each other.

#### 6. Advocacy

Advocacy activities support sustained quality TB care and control by mobilization of resources through collaboration with all sectors and stakeholders

Advocacy denotes activities designed to place TB control high on the political and development agenda, foster political will, increase financial and other resources on a sustainable basis, and hold authorities accountable to ensure that pledges are fulfilled and results achieved (WHO).

Advocacy often focuses on influencing policy-makers, funding agencies and international decision making bodies through a variety of channels: conferences, summits and symposia, celebrity spokespeople, meetings between various levels of government and civil society organizations, news coverage, official memoranda of understanding, parliamentary debates and other political events, partnership meetings, patients' organizations, press conferences, private physicians, radio and television talk shows, service providers.

There are different types of advocacy:

- Policy advocacy informs senior politicians and administrators how an issue will affect the country, and outlines actions to take to improve laws and policies.
- **Programme advocacy** targets opinion leaders at the community level on the need for local action.
- Media advocacy validates the relevance of a subject, puts issues on the public agenda, and encourages the media to cover TBrelated topics regularly and in a responsible manner so as to raise awareness of possible solutions and problems. Media can be used as an important tool to advocate and amplify voices, but it involves intensive training.

#### **Expected outcome**

The focus of advocacy activities at regional level will be to mobilize domestic and international resources for TB care and control. Even for countries that have secured funding through various external agencies, long-term financial sustainability of TB control programmes is a matter of concern. This gap will be bridged through advocacy activities that are expected to lead to greater country commitment of own resources and also access to available international resources through identification of various funding opportunities and securing necessary funds. At the Regional level, there will also be an opportunity for advocacy with ministries and other country representatives for continuing and emerging challenges related to TB. Advocacy activities will also lead to increased investment and focus on context-specific research. Through advocacy at regional level, Member States will be encouraged to adopt a human-rights-based approach and have a policy focus on marginalized, vulnerable and at-risk groups.

Another expected outcome of advocacy activities will be strengthening of existing partnerships at Regional level and forging of new partnerships with other stakeholders. Improved coordination and collaboration with multiple stakeholders will prevent duplication and lead to efficient implementation.

At country level, advocacy activities will lead to increased resource availability for programme needs through endorsed country strategic plans for TB, and control targets specifically for MDR-TB in alignment with the Global Plan. TB control programme priority will also lead to regular, systematic monitoring of TB control activities at all levels with multiple stakeholder participation. Regular monitoring of the programme will help motivate staff to adopt recommended practices as per national policy. There is expected to be systems strengthening through advocacy by developing and adopting minimum standards for organizing TB services within health systems. Wider adoption of PAL and infection control measures is also seen as one of the outcomes of advocacy activities. Incountry advocacy will focus on ensuring uninterrupted supply of quality logistics for TB care implementation. Systematic monitoring of programme activities will lead to efficient use of resources.

Countries may choose to have formal or informal partnerships that would lead to improved collaboration:

- Within govt ministries/departments
- ▶ Between programmes HIV/ MCH/others
- With community/ NGOs
- ➤ With affected patients/families and activist groups

Such collaborative efforts will channel resources available with other sectors and improve outreach of services. TB will be tackled not only as a medical problem but also as a social and economic problem. Advocacy with other sectors in the country will result in provision of standardized care to all TB patients.

It is important that TB care and control services in the country be patient-centred and provided as per the International Standards for Tuberculosis Care (ISTC). The evidence-based standards for TB care as articulated in the ISTC describe a widely accepted level of care that all practitioners, public and private, should apply in dealing with patients with TB or with symptoms and signs suggestive of TB. These include: prompt and accurate diagnosis; use of standardized treatment regimens of proven accuracy; appropriate treatment support and supervision until cure; monitoring of the response to treatment, and essential public health responsibilities such as reporting patients diagnosed and their treatment outcomes to national programmes. Further, rights and duties of TB patients are described in Patients' Charter for TB Care (PCTC). Continued advocacy

with various professional bodies would lead to endorsement of ISTC and PCTC, and their adoption in both public and private sector.

#### **Strategic directions**

- Addressing programme policy gaps through sustained, yearround advocacy activities. These gaps might be in the approach to service outreach; inclusion of various groups with focus on specific marginalized and vulnerable groups; and inclusion of various services that address TB in the most comprehensive way.
- Resource mapping and mobilization for TB control to meet programme needs in various countries.
- Innovative and context-specific advocacy messages. This includes generation and transformation of local data on epidemiology and economic impact of MDR-TB, XDR-TB and TB-HIV in advocacy messages.
- ➤ Joint monitoring of the programme by community representatives to increase accountability to those served. Most programmes are already undertaking reviews with external participation and with involvement of academic organizations outside the programme. They could also invite community representatives to participate in such reviews.
- Including human rights as an item in advocacy activities, with a specific focus on unreached, marginalized and vulnerable populations.
- > Strengthening collaboration between various stakeholders and multiple sectors at regional and country level, including those working directly on TB care and those working on other development activities.
- Pre-empt ACSM needs for introduction of newer technologies and tools for MDR-TB and XDR-TB. The programmes are prepared to launch the technologies quickly by reducing the lead time in convincing decision makers and subsequent resource mobilization.
- Collaboration with other sectors for HSS advocacy and involving various sectors in HSS plan and to address gaps.

- Promoting and disseminating standards for quality services based on ISTC and PCTC.
- Making a case for all inclusive integrated strategies such as PAL. This will not only strengthen health systems but also make them more cost-efficient by addressing multiple challenges through available resources.
- ➤ Greater participation of professional bodies in programme activities through advocacy with these bodies, including medical associations, nursing associations, paramedic associations, etc.
- At community level, advocacy with local leaders and creating a "movement for TB control" within communities.
- Promoting OR as a priority activity and mobilizing resources for research.

#### **Opportunities**

Several opportunities exist at Regional and country level for undertaking advocacy activities. These include:

At the Regional level, opportunities for international advocacy are available through meetings of the World Health Assembly (WHA), G8, GFATM board, development partners, South Asian Association for Regional Cooperation (SAARC), and the Association of Southeast Asian Nations (ASEAN). Commitments will be sought during such meetings from international partners and country heads to increased resource availability.

Additionally, global awareness/advocacy days like World TB Day, World AIDS day and World No-Tobacco Day are also opportunities for advocacy. While World TB Day is specific to TB and can be used to draw the attention of politicians, media and the community to TB control, other awareness days like those for acquired immune deficiency syndrome (AIDS) and tobacco could also be a platform for TB advocacy because of the close association of TB with HIV infection and tobacco usage.

Parliamentarian meetings, national partnership meeting and Country Coordinating Mechanism (CCM) meetings provide opportunity for the national programme to undertake advocacy activities. Though CCM meetings are held primarily to discuss proposals to GFATM, the meeting

could be used to promote TB control activities. The meetings are generally attended by senior bureaucrats and national and international stakeholders represented in the country and hence provide an opportunity for discussion of key issues related to the programme.

In addition, there could be meetings and workshops specifically organized for TB and/or other sectors. These could include meetings of professional bodies or trainings and workshops where people related to health care could be sensitized to challenges related to TB control and what actions can be taken.

For media advocacy, sensitization and trainings can be organized to train print, TV and radio journalists to cover issues on TB. Meetings for press, journalists or TV correspondents can raise issues related to TB control.

Advocacy messages should be focused for the targeted group and should project:

- Severity of the situation in local context and why immediate action is required, and specifically challenges in access to services and/or continuation of services
- Populations/groups that are most afflicted, and the socioeconomic consequences of TB
- Cost-effectiveness of DOTS strategy and why investment in TB control is the best investment
- Use examples from other areas

## Advocacy activities to strengthen components of Stop TB strategy

#### Pursuing high-quality DOTS expansion and enhancement

#### Regional

The Region will focus on advocacy with:

National tuberculosis programmes (NTPs) and Ministries of Health and Ministries of Finance

- UN bodies including WHO
- Multilateral and bilateral donors
- Professional/academic organizations
- Community-based organizations and patient groups
- ➤ TB and/or TB-HIV activists
- Academic and technical organizations
- Media agencies and social marketing experts with international presence
- Governmental organizations with regional presence

This will involve working with several partners looking at commonalities between TB and other priority programmes towards reaching the MDGs such as health systems financing innovations, comprehensive human resource development (HRD), poverty reduction strategies, service reforms, common fiduciary arrangements, and budgetary support approaches such as franchising, health insurance, etc. It will also involve engaging NGOs and academic partners in looking at health systems management to develop and implement best practices.

The efforts would include establishing country and NGO links with regional resource mobilization efforts and developing a resource mobilization action plan supported by a strong advocacy, communication and media strategy in line with the Regional strategy. This will also involve stakeholder profiling, including listing "aid themes" of development and supporting countries in accessing resources. Most development partners, especially bilateral donors, have specific agendas or aid themes for financial support as part of their mandate. However, applicants—especially NGOs—may not be completely aware of this and hence are not able to access funds. Profiling of funding agencies will help implementing agencies better access and use available funds. Advocacy efforts will assist countries in obtaining resources for TB services among population groups requiring special consideration through international initiatives such as the GFATM.

Advocacy with ministries of health and finance will be aimed at improved funding for priority public health programmes including TB, and addressing TB control as part of poverty reduction processes such as

poverty reduction strategy papers (PRSPs) and initiatives such as the Highly Indebted Poor Countries initiative. Assistance will also be provided to countries in evaluating and disseminating information on the impact of TB control on poverty alleviation. This will constitute an important component of the advocacy message for investment in TB control.

The Region will encourage countries to have a national ACSM strategy and plan for TB control, including a budget for civil society and community participation in TB care. The countries may need to form a national multisectoral team or task force to work on the national policy, strategy and plan. The team's responsibilities would include: analysing the initial situation, identifying all stakeholders, having discussions with people with TB and communities to design a "model" for their involvement, and providing support for formulating policy by the national TB programme.

Regional guidance on involvement of community representatives in monitoring will be made available for countries, as well as support through organizing forums for discussions among programme managers and rights activists.

#### **Country**

Country advocacy activities will complement regional efforts for the inclusion of TB control under priority health programmes in sector-wide planning frameworks at national level and as part of PRSPs and HPIC initiatives; and opportunities for sharing successful approaches in building core public health functions. The advocacy efforts will extend to local governments/subnational administration to ensure adequate funding and services for TB control.

Policy and action for community monitoring of programme performance. This is done through advocacy at subnational level with programme managers and community representatives. As at the national level, community representatives could participate in review meetings (generally held quarterly) and supervisory activities. It is also essential to ensure a human-rights-based approach in delivery of services by advocating adoption of a Patients' Charter.

Country programmes will need to engage with key agencies and highnet-worth individuals and institutions, especially those with the potential to influence policy at key economic/policy forums.

The programmes will develop focused advocacy messages for:

- Politicians and administrators
- Development partners
- Opinion leaders
- Community leaders

## Address TB-HIV, MDR-TB, and the needs of poor and vulnerable populations

#### Regional

Advocacy with relevant ministries and stakeholders to draw attention to the problem of TB-HIV, MDR-TB and XDR-TB and for increased resource allocation without curtailing resources for basic DOTS. Introduction of newer technologies for diagnosis and case management of MDR-TB patients requires huge financial inputs. Although several agencies support these initiatives, domestic commitment is equally important for successful implementation and sustaining of these activities.

In countries and areas with high HIV prevalence, steps to respond to the needs of the increasing numbers of female patients will include greater collaboration with services that cater primarily to women such as **MCH** programmes and the involvement of women's groups and organizations in TB care and prevention.

Regional activities will include helping countries to develop and promote strategies to ensure equity in access to TB services among the poor, especially in urban and remote areas, prisons and marginalized population subgroups. Attention also needs to be paid to addressing gender-specific differences in TB epidemiology and barriers to effective care. In the Region as elsewhere in the world, the ratio of males to females with active TB shows a male predominance. Studies in the Region have shown that this reflects the epidemiology of disease rather than differential access to health care. However, a different picture is emerging in countries

with a higher prevalence of HIV, such as in Thailand and in parts of Indonesia, where greater numbers of TB cases are being notified among young women aged 15-24 years. TB control among migrant populations will be addressed through advocacy activities to promote cross-border collaboration via inter-country forums and Regional associations such as SAARC and ASEAN, and by developing guidelines and training materials to operationalize cross-border TB control activities.

#### Country

Along similar lines as regional activities, national programmes will undertake in-country advocacy for increased focus on emerging challenge of TB-HIV, MDR-TB and XDR-TB. For this purpose, the programmes will develop advocacy messages inclusive of local, country-specific data. The data will highlight the gravity of situation, the gaps in addressing it and how country productivity can be improved by investment in TB control. Advocacy will aim for adoption of locally relevant newer technologies which involve diagnosis and treatment specifically for MDR-TB and XDR-TB.

National programmes in Member States will undertake TB care and control advocacy activities tagged with HIV, MCH, poverty alleviation, housing, social development, gender discrimination, environment and tobacco control. This will not only bring synergies but also help increase programme outreach among vulnerable communities. For this purpose, country programmes will undertake identification of unreached groups and their needs and devise need-based innovative strategies with involvement of representatives from such groups.

### Contribute to health system strengthening based on primary health care

#### Regional

The Region will contribute to HSS through advocacy with ministries of health and ministries of finance, backed by technical assistance for services in accordance with ISTC. Advocacy will also be undertaken with donors to fund HSS plans to support TB control. As already discussed, TB control is integrated with general health systems in most countries, so it is important to have a strengthened health system to support TB control.

There will be advocacy with various ministries and departments outside health to support procurement and supply management, health management information systems, and infrastructure. The activities will aim at encouraging departments to make systems transparent, accountable and stronger, and how this can bring efficiency and cost-effectiveness for the whole system

#### Country

One of the key activities for ensuring equitable access to TB care and control is HSS. However, this is a cross-cutting issue and beyond the influence of a TB programme or any programme alone. Hence a coordinated effort by several national programmes to strengthen health systems, including placement of qualified trained staff and provision of quality equipment and consumables, is important for improving access and outcome of programmes. It is also critical that TB services are effectively positioned and streamlined within basic health care services during the process of health systems development, in order to optimize both the implementation of TB control services and the contribution of TB services to strengthening health services as a whole. National treatment programmes will need to join forces with other programmes and stakeholders involved in health systems development to strengthen human resources, increase health financing and improve health systems management through:

- Organizing meetings of relevant sectors and stakeholders
- Coordinating advocacy efforts with several national programmes to strengthen health systems
- Advocating for adoption of policy standards as per ISTC
- ➤ Including cross-cutting HSS plans in funding proposals
- ➤ Advocating for adoption of local policy standards
- Advocacy messages that include the cost-effectiveness of comprehensive approaches

#### **Engage all care providers**

#### Regional

Advocacy with professional bodies, NGOs, universities and academic institutes, e.g. medical, nursing and pharmacies, will be undertaken at the Regional level. The latter are important to ensure that basic TB control principles are included in pre-service training curricula. These activities will be undertaken directly, and the Region will also support countries in developing messages for various professional bodies, including medical and paramedical associations.

In several countries health care is imparted through organizations and departments not directly controlled by the ministry of health. These include industries, railways, prisons and police. Hence reaching out to other ministries will also be key to the overall success of advocacy activities

Most of the corporate sector has captive population that seek health care from specific outlets, either directly managed by corporate houses or in liaison with them. It is important for these health facilities to provide DOTS for TB care that will benefit not only the individuals but also work towards improving productivity. The corporate sector will be approached for DOTS at workplaces.

#### Country

For involvement of various sectors, national programmes will focus on professional bodies, NGOs, universities and academic institutes such as medical, nursing, and pharmacy. This is along similar lines as regional activities, but with greater work at the micro level. The programmes can undertake dialogue with individual institutions for their involvement in TB control as per the national strategies. They could also invite representatives of professional bodyies to programme review meetings to enhance confidence and include their views.

Similarly, drug regulatory body representatives can be invited to programme review meetings to apprize them of programme needs. This could include over-the-counter sale of anti-TB drugs, curbing sale of loose drugs, etc.

In addition to service provision as per the country guidelines, the corporate sector could be involved in programme review meetings and offer technical support for establishing DOTS in business establishments.

## Empower people with TB, and communities through partnership

#### Regional

The Region will aim for greater involvement of community representatives in regional meetings. This could include patient groups working at regional level, community-based organizations and other formal and informal community leaders working for TB control.

Further, capacity building of activists/community representatives to empower them for effective engagement and contribution in TB care will be undertaken. For this the Region will also contribute to policy development towards greater involvement of TB-afflicted individuals and groups and guide Member State strategic planning for advocacy with communities.

#### Country

The national programmes will ensure greater involvement of community representatives in programme meetings at national and subnational level. The representatives can directly convey their needs and expectations to the programme and vice versa. This will help advocacy of TB control among local leaders.

Providing opportunities and a platform to bring together National TB Programme managers, civil society and community representatives for regular dialogue will result in community ownership of the programme, leading to community-led initiatives.

Programmes will identify and mobilize opinion leaders within communities. These people could be formal and informal leaders, but mostly informal leaders such as school teachers, postmen or village elders whose opinions are respected by communities.

#### **Enable and promote research**

#### Regional

The Region can provide technical assistance on OR to countries on locally identified priorities. It can also undertake advocacy with:

- Donors for fund allocation for OR
- Academic and research institutes at regional level for promoting OR

The advocacy activities are carried out by articulating benefits from OR through the use of results from earlier studies. Specific examples of OR need to be included in these messages.

#### **Country**

Countries should advocate for OR to address identified local challenges and priorities. At the country level, advocacy can be undertaken with:

- Donors for fund allocation for OR
- Academic and research institutes in the country to promote OR

On similar lines as the Region, country advocacy for OR can be carried out by articulating benefits from OR by using results from earlier studies, citing specific examples.

#### Challenges to effective advocacy

- Politicians and administrators are busy with numerous activities
- Competing priorities If it is not a priority, it doesn't get an opportunity. There are also more "glamorous" health interventions that rapidly attract attention.
- ➤ Too much or too little technical components and data in messages data on extent and impact of TB not available
- Objective of advocacy not clear
- Relationship between poverty and TB not clearly shown

### 7. Communication

Communication is used to generate appropriate awareness regarding TB and TB control services, to remove misconceptions and promote use of available quality services

The term "communication" is used to mean the process people use to exchange information about TB. Communication may be used for programme information, advocacy, and social mobilization. In this chapter, communication primarily refers to activities that generate awareness about TB and its available services, i.e. programme communication, although all awareness generation activities complement advocacy and social mobilization activities and hence cannot be seen in isolation.

All communication activities make use of some form of media or channel of communication (e.g. mass media, community media, and interpersonal communication [IPC]). While much of the communication effort on TB is concerned with transmitting a series of messages to people affected by the disease, nearly all communication practitioners stress that to be effective, communication should be understood as a two-way process, with participation and dialogue as key elements. Feedback is another important component of a successful communication campaign. The recipient of the message should be able to comment on content and show whether the message has been correctly received.

#### Expected outcome

Communication messages will support **policy advocacy** for high-quality DOTS. This overlaps with advocacy efforts, but as has been mentioned, communication is overarching.

The messages will lead to increased awareness about TB, TB-HIV coinfection, MDR-TB and XDR-TB, and use of available services that will lead to removal of misconceptions, reduction in stigma and better use of services. This will also lead to demand generation within communities for quality services.

Communication also involves sharing programme information among various stakeholders. Programme information includes technical and management aspects as well as expenditures. Sharing information leads to increased transparency and accountability. Improving transparency leads to

greater accountability and enhanced trust between various stakeholders, which in turn will lead to greater participation of by multiple partners.

There should be a media focus on marginalized, vulnerable and at-risk groups and their rights including accessibility to services. Greater media coverage for TB and services because of communication efforts will increase visibility of the programme, an important precursor for advocacy and social mobilization. There will also be greater attention to newer challenges and opinion building around these challenges through communication campaigns.

The communications process will involve greater community participation in message development and use of community-based forums for message dissemination. This will also lead to linking of various community-based groups.

Communication activities within the TB programme will also be aimed at strengthening of information systems within and across programmes, sharing international experience and best practices with programme managers, and supporting them in adopting these experiences according to respective programme needs. Within countries there will be sharing of success stories to motivate managers and workers.

Communication messages will lead to sensitization of policy-makers to human resource needs, both in terms of quantity and qualifications. This could also include sensitization on training needs for existing staff.

Information on ISTC will be made available to all sectors providing TB care and control services and establishment of linkages with professional bodies, other ministries, the corporate sector and other stakeholders through sharing of data and progress reports.

Linkages with academic/research institutes will be established for research and with funding organizations for demonstrating the usefulness of investment in OR.

#### Strategic directions

Identifying and using opportunities for message delivery, which would include specific events accompanied by regular, synchronized mass media campaigns, community media and

- IPC. Using mass media approaches to reach larger sections of the population and increase visibility of TB as an issue.
- Gaining media attention for TB and its control, as media has important role to play in dissemination of messages. It is also important to have a quality focus in communication messages. This will also include media sensitization to have regular articles/features on TB and related issues.
- Using community media approaches such as citizen journalism or participatory radio programmes. While more complex, these can be very effective for facilitating participation and community empowerment. Secondly, these approaches are particularly useful for deployment in specific geographical areas ("mediadark" areas) or cultural/social contexts (poverty, special ethnic groups). Process-oriented approaches also allow for flexibility and adaptation, and generally encourage/extend dialogue within communities.
- > Strengthening Interpersonal communication (IPC) by health staff—an important component of communication at the point of health care delivery and for ensuring patient adherence.
- Raising awareness regarding newer challenges through various academic and social forums and groups.
- ➤ Having contextual messages that are culturally sensitive, gendersensitive and socially acceptable. These should avoid technical jargon as far as possible and be simple to understand.
- Prawing examples from other successful communication programmes like polio. Some of the lessons from the polio programme that can be incorporated are:
  - Communication is evidence-driven and linked to the work itself.
  - Communication should be contextual and ever-evolving.
  - Communication flows: what is important is how people receive information and what they do with it, rather than the tools themselves.
  - Paying attention to politics is critical to devising communication and mobilization processes.
  - Participation and two-way communication are key.

(Health Communication: Polio Lessons; Paul Mitchell, Manager, World Bank Development Communication Division)

- Strengthening communication component of information systems and developing communication strategies for information dissemination, including plans to communicate for and through community-based groups
- Documentation and dissemination of data on available human resources and infrastructure vis-à-vis requirements. This will support communication on systems strengthening.
- Raising awareness about:
  - Standards of care and patient rights
  - Why DOTS is the standard of treatment for TB
  - Importance of regular and uninterrupted treatment
  - Rational drug use
- ldentifying and involving socially influential personalities and opinion leaders for message dissemination.
- Communicating research priorities to academic/research institutes, and activities involving documentation and dissemination of research results.

## **Opportunities**

Any interaction with a relevant organization or individual is an opportunity for communication. Specific events provide the necessary platform for communication. These include new developments/findings in the field of TB, such as new technologies and drugs. These opportunities are generally found at the Regional level. However if some country has been involved either in development or even testing the implementation, the country can use this as an opportunity for communicating not only about the new development but also its necessity.

New opportunities exist for public debate and for highlighting voices and perspectives of poor people through radio talk shows, community media, etc. More open and democratic media provide important new opportunities to place pressure on governments to more effectively and urgently address poverty-related issues such as TB.

At national and subnational levels, the launch of new services/milestone achievement in the form of new DOTS service delivery centres, and the expansion of services for testing/management of MDR-TB or TB-HIV collaboration mechanisms, are opportunities for communication. Information dissemination could be done through mass media or meetings organized for the purpose, e.g. with partners/stakeholders.

World TB Day and other international awareness days can be an opportunity to organize communication events. This could be through mass media or mid-media such as community fairs, parades, school events and other culturally relevant local events. A press conference inviting journalists could also be organized to mark such events. However, communication activities will not be limited to such events and will be undertaken all year round.

Sessions organized during conferences, seminars and workshops for health care professionals. Such events or a communication kiosk can help disseminate information on the latest developments in the field of TB control and international best practices.

Political gatherings attract huge crowds. People expect to be informed on social development issues and TB control, being a social issue, will be well received at such gatherings. Motivated leaders could deliver important, key messages on TB and its curability. Other places of regular mass gathering such as religious institutions, community festivals and fairs are also an important platform. Using traditional folk media would help deliver messages in forms acceptable to the community and which they can identify with. community leaders and faith-based organizations (FBOs) are in constant touch with the community, and people look towards them for guidance on various issues concerning daily life. Regular community-based activities by NGOs/CBOs entail direct contact with the community and provide an important opportunity for message dissemination. Similarly, self-help groups (SHGs) are constituted by community members themselves and hence are close to the general population. All these can be use as a direct platform to interact with community.

Schools and other educational institutes disseminate health-related information to students. It should be ensured that correct knowledge about TB and its prevention are part of the curricula.

Any visit to a health centre by patients is opportunity for IPC. The doctor or any paramedic should be able to deliver information on health care topics of relevance to patients, including TB and specific queries on disease and treatment if the patient is chest symptomatic.

It is important to ensure coherence of messages from various sources and that contextual messages are culturally sensitive, gender-sensitive and socially acceptable. It is also important to choose a mode of communication based on the target group and the nature of the message intended:

- ➤ Mass media electronic/print for generic messages
- Health care providers for patients through IPC at the point of service
- NGOs, CBOs for community and patients, through IPC
- Professional bodies for medical and paramedical workers
- Corporate sector for their workers
- Community participation in message dissemination community discussions

# **Communication activities to strengthen components of Stop TB strategy**

## Pursuing high-quality DOTS expansion and enhancement

### Regional

The Region undertakes regular communication through various media on all aspects of TB control including cost benefits of existing strategies. This would be further enhanced to include press releases tagged to all important developments, as well as distribution of fact sheets containing important information about the disease. The activities will be strengthened by using latest technologies for awareness, such as interactive TB-specific websites and social networking sites promoting two-way communication.

Communication activities will be aimed at improving networking between country programme managers of the Region and other regional

stakeholders. This can also be part of the ongoing activities which involve programme managers' meetings at the regional level.

The Region will provide technical assistance on incorporating "quality" content in messages to strengthen country-level communication activities. This will include workshops/trainings for IPC skills-building at national level and training of national-level trainers.

Workshop will also be held for media agencies, social marketing agencies and other agencies involved in message dissemination on how to make the messages coherent and how to track and report TB-related issues and features. This will also help develop a comprehensive regional communication plan to support national programmes. Training programmes will be conducted for young and senior journalists on TB and related issues. Advocacy with owners of media houses to help mainstream TB coverage in the media.

#### **Country**

For improvement in communication activities, national programmes in Member States will identify behaviour-related challenges through knowledge, attitude and practices (KAP) surveys, and develop communication messages to address these challenges.

The message will be disseminated using mass media, mid-media, community media and local innovative media to raise awareness on various aspects of TB and services available for control. A focused campaign will involve targeted communications identified groups/unreached populations using innovative approaches to include and amplify the voices and concerns of the target groups. While developing and disseminating messages, it will be important to initiate dialogue with opinion leaders, celebrities and community groups to involve them in spreading TB-related messages. These activities will also involve work with communities and TB patients to understand their concerns.

Countries will hold national and subnational workshops for IPC skills-building to cover different groups such as the corporate sector, SHGs, umbrella organizations and other forums that have direct interaction with the community. Regional activity will be aimed at building the capacity of trainers who will further engage at country level to disseminate skills.

## Address TB-HIV, MDR-TB, and the needs of poor and vulnerable populations

#### Regional

Media sensitization on TB-HIV co-infection, MDR-TB and XDR-TB is a key communication activity. This includes Regional-level meetings with journalists, media agencies and social marketing agencies. Activities will also include sensitization on needs of special groups and vulnerable populations so that the programmes can effectively address them.

The Region will help countries generate relevant local data with regard to new and emerging problems that confront TB control and also provide technical assistance on incorporating quality content in messages.

One of the important innovative activities at regional level will be building communication skills of marginalized and vulnerable groups so they can be empowered to convey their concerns to appropriate authorities.

#### **Country**

As at the regional level, national programmes will undertake media sensitization on TB-HIV co-infection, MDR-TB and XDR-TB.

Strengthening communication for emerging challenges will involve development of contextual messages using local data to make them more effective and easier to identify with. Standards of care can be disseminated among physicians and communities in the form of information sheets, booklets or brochures.

## Contribute to HSS based on primary health care

#### Regional

Regional workshops on communication channels and their effective use will be aimed at using communication opportunities for several related programmes and increasing the efficiency of messages.

The Region will also provide a platform for experience sharing on community involvement in various countries. Available information from other countries can be used to develop similar models, and community resources can be used to fill in gaps for HSS.

One of the important activities in communication for HSS is inclusion of human resource and infrastructure data in performance reports. This data will include existing staff positions and training status against actual needs. This will attract the attention of senior policy-makers to HR and infrastructure issues.

#### Country

For systems strengthening, national programmes will develop messages for dissemination on common forums and through common media. As at regional level, this will also include country workshop on communication channels and their effective use. To make communication more effective, the programmes will also maintain a database and inventory of communication materials produced.

Community resources are important for completing public health systems. Programmes at national and subnational levels will initiate dialogue with opinion leaders, celebrities and community groups for using community resources to support health systems.

To attract the attention of politicians and senior policy-makers, it is important to present human resource and infrastructure data on needs vis-à-vis availability. Such data can be disseminated through programme management and performance reports.

For effective dissemination and increased outreach of messages, especially among the younger generation, programmes will explore newer and innovative communication technologies as at the Regional level to establish communication links between various stakeholders and health providers. This will improve efficiency and promote synergies.

## **Engage all care providers**

#### Regional

Communication materials developed at regional level will help in dissemination of successful public-private mix (PPM) models involving private physicians, both from the Region and some replicable global

models. Successful models of corporate sector involvement will be disseminated to the programme and representatives/associations in the corporate sector. These models can then be adapted to the local contexts of various countries.

As part of the regional communication strategy, the latest WHO guidelines and recommendations will be circulated among representatives of all sectors to make them aware of the latest developments and international recommendations for TB control.

#### Country

National programmes will be involved in adaptation, translation and dissemination of ISTC and PCTC among medical, nursing and pharmacy colleges, universities and professional associations.

Communication activities at national level will be aimed at consensus building through dialogue on evolving operational guidelines and policies for involvement of other sectors in TB control. There will also be dissemination of a policy on rational drug use among pharmacies, professional bodies and community representatives.

For effective PPM, there will be information exchange with the corporate sector on workplace practices, involvement in programme review meetings and provision of technical support for establishing DOTS in business establishments. Programme information can be shared through newsletters, quarterly reports and other programme publications, to apprise partners of progress and achievements.

# Empower people with TB, and communities through partnership

#### Regional

When a communication strategy is developed, it will be important to have inputs from community representatives to get the beneficiaries' perspective on barriers to access.

The Region will attempt to have enhanced community leader participation in regional meetings. Regional meetings are an important

platform for communication among various stakeholders. Participation of the community will ensure a direct exchange of ideas and expectations.

#### **Country**

One of the key factors in the success of communication campaigns is involving community representatives in message development workshops. This helps make messages contextual and culturally sensitive. Community ideas will also balance social, political and cultural dimensions with the technical content of messages, making messages more acceptable and enhance community ownership of them. Countries will use traditional and folk media for message dissemination at the community level to increase acceptability of messages.

Dissemination of PCTCs through community forums can be undertaken by the programmes. While translation and adaption can take place at the national level, the actual dissemination should be through community-based meetings and discussions at all levels.

Community guidance on communication plan development will help identify barriers to access and encourage community participation. Empowering communities in communications to convey their issues, and using innovative community-based media approaches like citizen journalism and participatory radio, will help to improve quality and outreach of services.

## **Enable and promoting research**

#### Regional

The Region will provide assistance to countries to develop OR protocols and methodologies for assessing efficacy of communication techniques.

The Region will also engage in communicating and highlighting successful models and how they can be used as a basis for OR, adapting them to local context and priorities.

#### Country

The national programme will hold dialogue with academic and research institutes to promote need-based research that is relevant in the local

context. This will involve communication of programme needs and research priorities. The institutes will also communicate their needs, challenges and resource requirements for the purpose.

Picking and highlighting stories and case studies from the field and imparting a human face to messages is an important area for strengthening. Studies not only promote research and bring out best practices, but also help encourage and motivate the staff at subnational level, especially programme managers.

Communication messages will include using media to disseminate new research to broader audiences in an easy-to-understand format.

## Challenges to effective communication

- One-way communication
- > Top-down approach
- Generic messages not focused on specific groups with low access
- Stereotyped messages that do not generate interest; recipients do not identify themselves with the message; not sensitive to local culture
- Technical jargon in messages
- Incoherent messages from a variety of sources
- > Languages and dialect, visual illiteracy

## 8. Social mobilization

Social mobilization involves all stakeholders to empower communities and generate support for all those in need of TB services—diagnostic or treatment—for sustainability and community ownership

Strengthening TB programmes in a sustainable way requires involvement at many levels: individual, community, policy and legislative. A single effort has less impact than collective effort. Social mobilization brings together community members and other stakeholders to strengthen community participation for sustainability and self-reliance. Social mobilization

generates dialogue, negotiation and consensus among a range of players that includes decision makers, the media, NGOs, opinion leaders, policy makers, the private sector, professional associations, TB-patient networks and religious groups.

Social mobilization is based on the principle of social justice. Social justice generally focuses on the social, political and economic aspects of problems and their respective solutions. It refers to organizing society such that the common good, to which all are expected to contribute in proportion to their ability and opportunity, is available to all the members for their use and benefit. Promoting and respecting social justice means contributing to a society in which all members, regardless of their social, political economic and religious background, have basic human rights and equal access to their community's resources. Applying these fundamental principles is essential for promoting greater responsibility for health within a society. The recognition or neglect of these principles will often determine social will succeed whether work in the arena fail. (WHO/HTM/TB/2008.397)

At the heart of social mobilization is the need to involve people who are either living with active TB or have suffered from it at some time in the past. Empowering TB patients and the affected community helps to achieve timely diagnosis and treatment completion, especially among families of TB patients. The PCTC outlines the rights and responsibilities of people with TB. Initiated and developed by patients from around the world, the PCTC makes the relationship between patients and health care providers a mutually beneficial one. Implementing the concepts of the Charter at all levels is an important social mobilization component for better TB control. For the PCTC to be mutually beneficial, it has to be endorsed by all—doctors, nurses and other health-care providers.

Social mobilization works on the philosophy that a community's problems are best understood by the community itself and that it has the potential to resolve them. TB patients and their communities are involved in TB control from planning to implementation and monitoring the quality of services is their right and not a privilege. Community involvement in TB control results in improved awareness and greater use of services, leading to shorter delays in seeking care, and improved case detection and treatment success rates. Community involvement in TB control efforts is essential if stigma and misconceptions are to be overcome and self-referral is to

improve. In this context, the PCTC was developed to promote a patient-centred approach. It sets out the ways in which patients, communities, and health providers can work together to improve both the use and responsiveness of services.

Reaching specific population groups such as slum dwellers, the urban poor, internal migrants and prisoners requires special strategies. A wide range of care providers based in communities and other government ministries and departments will need to be targeted, including the informal sector, which is often used by the poor and marginalized. Proper referral and information systems to allow for the movement of patients between different geographical areas will need the involvement of communication and information management experts as well as NGOs and CBOs.

Mobilizing resources, building partnerships, networking and community participation are all key strategies for social mobilization. Specific activities include group and community meetings, partnership sessions, school activities, traditional media, music, song and dance, road shows, community drama, soap operas, puppet shows, karaoke songs and contests. Other activities unique to a particular country or region may provide even better opportunities to engage and motivate individuals.

The link between poverty in TB has to be clearly understood. The Region is home to a disproportionately large number of the world's poorest people. It also carries the highest burden of TB. There is a growing body of evidence from the Region that shows that TB exacerbates poverty through unemployment, poor coping strategies such as reduction in food intake, and withdrawal of children from school, and social deprivation further reducing access to basic needs including health care. While addressing the adverse social and economic determinants of health will gradually lead to a reduction in TB incidence, the increased availability of quality TB control services would more immediately and substantially contribute to a reduction in both the incidence of TB and poverty.

In addition, political unrest, wars and natural disasters which cause large, unexpected and uncontrolled population movements result in a breakdown of services and social support networks which add to poverty and increase vulnerability. TB programmes need to link with emergency and humanitarian action programmes to determine rapid response interventions to restore TB service in these situations.

Recognizing the need to break this strong link between TB, poverty and social deprivation, the broad interventions proposed are:

#### **Expected outcome**

Social mobilization efforts will lead to prioritization of TB control by community leaders and other representatives that will enhance community participation and ownership of the programme through community empowerment. Empowerment takes place when people share the opportunities and responsibilities for action in the interest of their own health or of other issues important to their life (WHO/HTM/TB/2008.397). The community also becomes involved in monitoring of the quality of services that it is supposed to receive. The community itself demands TB services, defines goals, and participates in decision-making.

Beyond demand generation, there is also active community involvement in providing TB services such as contact tracing and default retrieval. A system of community support structures for patients and their families will be created through community support groups for TB patients that may consist of volunteers, local formal and informal leaders, present and cured TB patients, faith-based organizations, and members of SHGs. The visible effect is a greater number of countries reporting community volunteer involvement in TB services at Basic Medical Units.

Social mobilization makes TB services patient-centric. Countries will adopt the PCTC and demonstrate community oriented policies and services. This adoption takes place not only at the central policy level but also at the subnational implementation level at all health facilities. The process starts with communication activities, involving translating the Charter into the local language, disseminating it and displaying it at all appropriate places. National and subnational managers are sensitized to the Charter and motivated to adopt it in policy and in practice.

Social mobilization will improve collaboration between various implementation partners, civil society and community members, leading to convenient services for TB-HIV coinfected individuals. There will also be greater community involvement in providing MDR-TB and XDR-TB services. Collaborative efforts should be based on promoting ideas and concepts from the community itself on how to address access and other

issues related to TB services, and using the social capital/community resources for the provision of services.

The community should lead initiatives for involvement of all sectors, including using private sector services for convenient DOT services. This would also lead to establishment of models for community-based services through partnership with community representatives at all levels. Community partnership will ensure accountability of services to those they are meant to serve. Such partnerships can be sustained and strengthened by including community groups providing services in information networks.

#### Strategic directions

- Continuous dialogue between NTP, stakeholders and community is the first step in getting the community's perspective on TB care services and how to improve them. Continuous participation by the community will enhance its role in planning, implementation and monitoring of TB care and control services, which will eventually build trust between the programme and recipients of services.
- Involving community in policy and decision-making, service provision and monitoring of services.
- > Strengthening linkages with community groups involved in TB care and involvement of various community groups, SHGs and groups of HIV positive people.
- Community mobilization by increasing awareness on TB-HIV, MDR-TB and XDR-TB.
- Strengthening community resources through trainings and capacity building.
- Mobilizing private sector for DOTS and DOTS-Plus at grassroots level through community demand for these treatments in the private sector.
- ➤ Community monitoring systems on sale of TB drugs from pharmacies and availability of over-the-counter drugs and non-standard regimens.
- Mobilizing workers' unions and other health care recipient groups in various sectors.

- Continuous dialogue and interaction with community representatives so that members contribute to policy issues and discussions.
- Community empowerment for research and community-led innovation in research.

#### **Opportunities**

Social mobilization starts with greater involvement of community members in existing activities such as regional meetings of NTP managers, where both the programme and community representatives can be invited for joint consultation on implementation challenges.

Several social development programmes and projects, specifically those linked to MCH, have their own community networks. Establishing links between the TB programme and such projects will help leverage existing community support structures for TB care and control.

Community gatherings and events such as community fairs are important for both communication and social mobilization.

Regular NGO activities at which they interact with the community can also be used for community sensitization and mobilization for TB care.

Regular programme staff trainings that are generally part of the ongoing TB control programme should be used for sensitizing staff on the need and methods for social mobilization.

Self Help Groups, FBOs and religious institutions are connected with the community, and their networks can be used efficiently to mobilize communities. Support groups of people living with HIV exist in almost all countries in the Region. These can be trained on issues around TB so they can advocate and support collaborative TB-HIV activities.

It is important for countries planning social mobilization activities to ensure that plans are converted into action at ground level.

The key to success of the social mobilization approach is to allow ideas for mobilization to germinate within communities. Communities are best positioned to find solutions for barriers to access TB control, though they may require some external support for implementation of those solutions.

## Social Mobilization activities to strengthen components of Stop TB strategy

## Pursuing high-quality DOTS expansion and enhancement

#### Regional

The Region will work towards social mobilization by providing a platform for discussions between community members and programme managers.

There will also be capacity building workshops and involvement of community members in discussions on policy issues at regional level. Such workshops will provide an opportunity for sharing experiences from various countries and replicating successful models. Attempt will be made to have greater representation of community groups/community-based NGOs at regional Stop TB meetings.

Member States will be technically supported by the Region to develop projects that involve civil society organizations and have social mobilization as one of the key interventions. The GFATM already encourages proposals with its Dual Track Financing mechanism. Other bilateral agencies will also be encouraged to have similar provisions in their funding mechanisms. Support will be mobilized for piloting and scaling-up DOTS in special settings such as in large urban areas, workplaces and closed communities through social mobilization and "marketing" approaches to create demand, enhance use and increase participation in delivering services.

The Region also plans to hold training of trainers and workshop on community- based DOTS.

In this regard it has also been noted that there is very little documentation of ongoing social mobilization activities in Member countries. The Region will work towards collecting, publishing and sharing successful international community-based models from inside and outside the Region.

#### Country

To ensure social mobilization at country and subcountry levels, platforms will be established for discussions between community members and programme managers at each level. This would include involving community leaders in programme manager and stakeholder meetings.

Member countries will organize capacity building workshops for subnational managers on ways to involve community representatives and how to monitor and report such activities. This will help translate policy into practice and promote community involvement and monitoring at the service delivery level.

National and subnational programme managers will ensure that community members participate in policy and review meetings at various levels. It may not be necessary to organize separate meetings with community leaders for programme monitoring, but regular programme monitoring meetings can involve community representatives.. Programme reviews should invite participation of community/civil society representatives to help share lessons and increase community awareness of programme activities.

## Address TB-HIV, MDR-TB, and the needs of poor and vulnerable populations

#### Regional

International experience in improving collaborations among various stakeholders to address TB-HIV, MDR-TB and XDR-TB will be shared among Member States so that best practices can be adopted.

The Region will also provide need-based technical assistance for:

- Development of community-based care models for TB-HIV, MDR-TB and XDR TB
- Development of appropriate country strategies and community mobilization plans
- ldentifying unreached populations and developing approaches to address gaps through community-based approaches

#### **Country**

At country level it will be important to undertake community-based message development and dissemination on the danger that incomplete/irregular treatment will lead to development of MDR-TB and XDR-TB. Preventing drug resistance will also involve training community members in counselling and default retrieval. This will be part of community support activities for TB patients in general.

To improve outreach of the programme to vulnerable populations, the first step would be situational analysis, identification of vulnerable groups and training them on symptomatic identification and referral for appropriate treatment to prevent drug resistance. Establishing support community groups in unreached populations will help improve access and quality and reduce stigma. Involvement of people with TB and communities can be explored and adapted to address other special challenges such as refugee settings and internally displaced people, and MDR-TB activities in group settings or ethnic minorities that may be harder to reach in terms of geographical or cultural access.

## Contribute to HSS based on primary health care

#### Regional

To contribute to HSS, workshops for programme managers and community representatives on strengthening community resources and their use in TB care will be organized. International experience in strengthening systems through community involvement and involvement of community groups will be shared through these workshops and other regional meetings of programme managers and stakeholders.

#### **Country**

Systems strengthening at country level can be undertaken by linking with community-based groups to mobilize human and other social capital resources required for ensuring and monitoring equity in access to all. This will start with subnational consensus discussion on using community resources and infrastructure to complement the public health services. National programmes will need to involve all stakeholders in planning, implementing, obtaining resources for and monitoring community-based approaches for better TB control.

Complementing public health systems by using mechanisms for community-based care, such as local storage to ensure an uninterrupted supply of drugs and diagnostics, will be useful to bridge gaps, especially in remote and inaccessible areas or where the existing infrastructure for TB control services is poor.

While national programmes will not be able to address all the systemsrelated issues in isolation, collaboration with other social development programmes/projects and including TB in their agenda will help tap available resources. Similarly, several countries have social welfare schemes which are not directly part of the TB control programmes. Linking of TB patients to such schemes will form an important component of social mobilization activities to support TB patients through the existing systems.

## **Engage all care providers**

#### Regional

Regional workshops for representatives of professional bodies will help build consensus and promote country-level engagement of all care providers. Greater participation of private sector and ownership will require involving private sector representatives in regional reviews and external monitoring missions. The Region will also be involved in sharing international recommendations on workplace policy with workers.

#### **Country**

Social mobilization for engaging all care providers will essentially involve engaging the private and corporate sector as an essential element, and representatives of the community responsible for health. Workshops/meetings with the private and corporate sector at national and subnational levels as part of community strengthening will help private providers identify with the community and sensitize them to community needs. On the other hand, generating community awareness for need of appropriate and complete treatment for TB will help drive demand for quality services from all care providers. Community sensitization on rational use of drugs will help limit substandard prescription and will increase availability of TB drugs through private pharmacies.

To ensure quality services through corporate sectors and other workplaces, the national programmes will organize sensitization programmes through workers' unions and groups.

## Empower people with TB, and communities through partnership

#### Regional

Partnerships to empower people with TB will be promoted through involvement of stakeholders and community representatives' participation

in regional meetings; seeking community guidance on strategies for social mobilization at regional and country levels, and technical assistance for translation of the PCTC Charter into local language, and its dissemination and adoption.

#### **Country**

Empowerment at country level can be initiated by sharing programme information and meetings with community representatives and making them part of the programme processes. At country level also it will be important to seek community guidance on policy and strategies for social mobilization.

At the implementation level, mobilization activities will involve formation of community support groups as an interface between the programme, the community and TB patients. Formation of associations of cured TB patients is also an important component of the activity. Existing community groups and volunteers that have a broad base and trust within community should be identified and involved. Mainstreaming the involvement and partnership of people with TB and HIV and communities can potentially increase the social ownership of any aspect of TB and HIV care and control. TB programmes can build on the experience and collaborate with civil society initiatives on HIV. This can provide a strong basis for community-based advocacy for improved TB-HIV services in areas with a significant HIV burden. The overall idea is to promote community-based TB care, addressing barriers by engaging TB support groups and patients and consider patient enablers to promote treatment adherence.

## **Enable and promoting research**

#### Regional

Research on social mobilization in the Region will be promoted through documentation and dissemination of successful community-based approaches for wider replication, including successful examples of community empowerment in ensuring equitable access to TB control services.

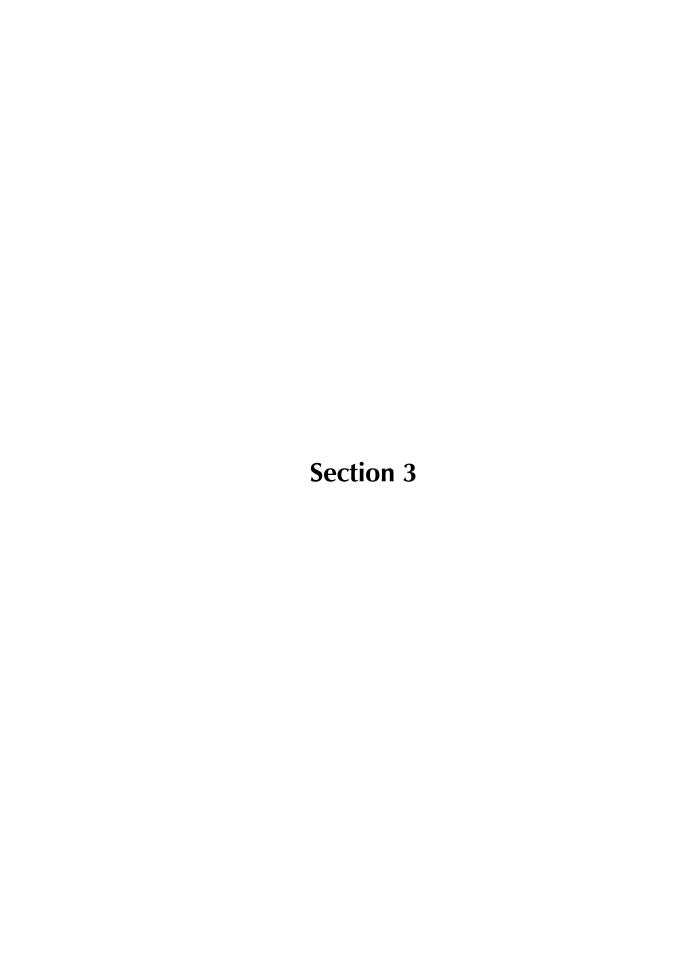
#### **Country**

Countries will promote research by training community members in research and providing a platform for community members to share ideas for research. National programmes will also conduct operational research linking care-seeking diagnostic delays and unfavourable outcomes with socioeconomic data, assessing gender-specific barriers to accessing services, and improving user-friendly and community-based approaches to provision of DOTS services.

Disseminating results of successful and socially relevant research through community-based groups and forums will encourage further involvement of community level stakeholders in relevant research.

## Challenges to effective social mobilization

- Community taken for granted (top-down approach)
- Community not recognized as an equal and valuable partner
- Activities appear manipulative rather than participative
- Mistrust and apprehension about hidden expectations
- > TB control and care perceived as the responsibility of the medical world alone
- Easy access to other forms of treatment/care and cultural acceptability of providers practicing alternative/traditional medicine
- ➤ Continued volunteer work with no incentive, disparity in incentives for similar work with governmental/non-governmental schemes or other schemes within government health programmes.
- Programme structure not geared to meet demand generated by mobilization activities



## 9. Partnerships

Partnerships are essential for efficient and sustainable patient-centric TB care and control services, especially in resource-constrained settings

A partnership may be defined as agreement between individuals and organizations to work towards a common goal with shared vision and responsibilities. There is generally a consensus on issues being dealt with, and motivation levels are high. In the case of TB care and control, a partnership will have a shared vision of TB elimination, and partners undertake joint activities to promote synergies of efforts.

Partnerships are an outcome of ACSM and a means to enhance Stop TB strategy:

Advocacy – Advocacy efforts with various UN bodies, development partners and ministries are required to encourage them to contribute to partnerships.

Communication – Ongoing dialogue is an antecedent to a meaningful partnership.

Social Mobilization – Any partnership that is meant to serve community is incomplete without community representation.

On the other hand, partnerships can also play an important ACSM role for TB care and control in the programme, in addition to implementation support for country TB control strategies.

National TB control programmes need to continue to engage a wide range of stakeholders both within the health sector and other sectors, to ensure that the distribution and coverage of DOTS is equitable across all geographic locations and reach various socioeconomic groups. Engaging with several partners requires close attention to their activities and providing support and guidance to ensure that all activities serve their intended purpose. Partners need to be provided with relevant information, reports on achievements, a forum for regular interaction, and opportunities to share experiences and develop consensus on joint activities towards a common goal.

#### Why have a partnership?

Partnerships are an instrument to tap diverse resources—technical, financial, human and physical infrastructure—to fill gaps in programme implementation. Partnerships can be viewed as a means of maximizing benefits. The incentives for working in a partnership are not limited to monetary benefits; they include specific skills derived from the learning experience, greater collective capacity to respond to the problem, and increased quality of solutions. Various resources available through partnerships include:

- ➤ Technical resources through technical agencies, academic institutions, professional bodies located within countries
- Public and private human resources, including NGOs and other civil society organizations, health care providers, community volunteers
- Financial resources, which can be harnessed through development partners, corporations and business houses
- Public and private physical infrastructure, including for-profit and not-for-profit organizations, health facilities, community-based groups

In resource-constrained settings, partnerships are a mechanism to induce synergies and avoid duplication. A variety of agencies work for TB care and control in a country, and often some do not know what the others are is doing. This can lead to duplication of efforts and waste of resources. Working together will help avoid duplications and create a synergy of coordinated efforts.

Through partnerships, a platform is available for shared responsibility and decision making for TB care and control, where all partners feel the needs to directly or indirectly support the cause.

A dialogue between the programme and other stakeholders, including the most marginalized, will lead to a common understanding and consensus for addressing challenges. This will help create an inclusive strategy and action plan for programme needs and civil society needs. This would help all partners to have a shared vision and confidence in how their individual efforts are contributing to the larger goals of the programme. Partnerships allow programmes to get diverse views and perspectives on challenges faced by the programme, creating a holistic picture. By listening to various community voices and stakeholders, the programme can gain an idea of their needs and expectations. Gaps in service delivery will also be highlighted. On the other hand, the community and stakeholders will also get a better picture of programme views on service delivery, existing constraints and efforts to improve service delivery.

Through partnerships, programmes can share information on their achievements. Partners can share their experience on a common platform. This promotes transparency and builds trust amongst stakeholders. Thus partnerships act as an interface between programme, stakeholders and community. The partnership can carry the voice and opinion of multiple stakeholders and community members to the programme managers, and vice versa.

#### What works well

**Mutual respect and recognition**: All partners come with different strengths and varied experience. It is essential that in partnership this diversity is recognized and respected so that everyone feels included. Shared decision making leads to greater understanding and commitment. Commitment has many dimensions and is related to the extent to which participating organizations have endorsed or adopted the common mission or carried out activities in the name of partnership. The key to success is to identify bona fide partners who could also be respected leaders in the effort. Partnerships are more likely to be durable when the commitment of individual members is strong.

**Information sharing with the partners:** Communication is a binding force for the partnership. It is essential that partnership activities are regularly shared with all partners. To accomplish this task there is need to:

- ➤ Have a focal point responsible for regular communication to which all partners have a good relationship
- Share information with all partners and the programme, through:
  - Newsletters
  - E-mails
  - Meetings

**Frequent discussions/meetings with partners and other stakeholders**. All important decisions should be consensus-based, and it is important to involve all stakeholders in discussions prior to arriving at decisions.

Clarity of roles and responsibilities. Partners have their own core strengths, and responsibilities within partnership can be defined accordingly. It is also important to have defined governance structures that help manage the partnership efficiently.

**Forward thinking**: The partnership structure should not only be able to manage the present but also plan for the future.

(Steps for setting up a national partnership – refer: A Pocket Guide to Building Partnerships: WHO/HTM/STB/2003.25)

#### Keys steps to building partnerships

- (1) Undertake a situation analysis of the programme. Identify gaps or requirements that need to be filled and list all potential partners who can contribute in these areas to fulfil the programme's goals.
- (2) Identify the strengths, weaknesses, opportunities and threats; consider what potential partners could contribute, including:
  - Technical, training or management expertise
  - Leadership capabilities
  - Ability to be team players
  - Contribution to the direction and purpose of the partnership
  - Ease of communication
  - Partner resources (facilities, human resources)
  - Cultural and language background
  - Any drawbacks in involving them
- (3) Shortlist the most promising partners and define their roles in the programme. Share the programme goals and vision with them.

- (4) Discuss the programme with them and explain why they should partner programme efforts. Address any concerns they may have in joining the programme.
- (5) Obtain consensus on a common plan: targets, objectives, areas of responsibility, use of operational guidelines, procedures and timeframes. If required, help build the capacity of the partner.
- (6) Implement agreed activities according to the plan.
- (7) Sustain dialogue. Network and share information regularly with all partners on progress being made, any problems that need to be resolved and how they may maximize their contribution.
- (8) Evaluate progress.
- (9) Document lessons learned and experiences. Share these with the partners. Appreciate and praise successes and work towards accepting failures jointly.
- (10) Broaden the partnership and scope of work as the programme grows

#### Hosting a secretariat

Once a partnership is established, it must have a management structure to support it, give direction and establish a shared agenda. This can be done through a secretariat. Some of the expected characteristics of a secretariat are:

- ➤ The partnership could be registered as a legal entity in the country, or the secretariat may be housed in an organization that has legal status in the country.
- Dedicated staff that are the pivotal point for the partnership, with clear job descriptions that are agreed upon by all members. The Executive Secretary who heads the secretariat must have the trust of partners and must have good communication and diplomatic skills in addition to having recognized capabilities in the fight against TB.
- While it is essential that strong leadership is provided to the partnership, the function of secretariat is to support the partnership and not own it.

- The host organization should ensure that secretariat represents a value addition to the partnership work.
- Funding may need to be arranged for the functioning of secretariat. This funding should ideally be neutral. However, partnerships should also work towards self-sustainability.
- ➤ The secretariat should be reviewed/audited independently to ensure its transparency and accountability to the partnership.

### Possible implementation roles of different partners

#### Public sector departments:

- Education: training teachers and educating children about TB; including TB in school health campaigns; including TB awareness education in non-formal education and adult literacy programmes.
- **Social welfare**: possibly offering food subsidies and social assistance to families of TB patients
- ➤ **Labour**: promoting treatment and prevention at the workplace; ensuring that work environments are not places in which TB is easily transmitted.
- ➤ **Defence and police**: promoting treatment and prevention within these forces; coordination and collaboration between their health facilities, where available, and those of the national TB programme.
- **Women's welfare**: raising awareness through organized women's groups and ensuring supportive environments for women to seek and complete treatment more readily.
- **Youth and sports**: promoting TB awareness among young people.
- ➤ Media/communications: raising public awareness and helping shape public attitudes and opinions about people with TB, making the communities aware of how they may participate in control, and informing people about public policies and facilities that are in place to treat TB.

## Other governmental and nongovernmental programmes within the health sector:

- Referring TB cases
- Sharing expertise where TB is associated with other illnesses
- Developing complementary public health messages
- Sharing resources and support structures at the community level
- Making better use of manpower and financial resources

#### NGOs:

- Providing community-based care
- Training health care workers and volunteers to provide DOTS
- Generating awareness and educating the community on prevention and treatment
- Involving the community in implementing DOTS
- Conducting operations research
- Playing a major role in advocacy and in mobilizing community support

#### Private sector:

- Referring patients to the public sector from private dispensaries, clinics and hospitals, and/or providing DOTS services in partnership
- Undertaking research and development of drugs and simpler diagnostics
- Maintaining a healthy work environment to prevent the spread of TB

#### Academic bodies, professional associations:

- Influencing health policy and practices at political and decision making levels
- Educating all health professionals on national guidelines for the diagnosis and treatment of TB

Assisting in setting codes of ethics and maintaining standards, especially in research for TB control

#### International/regional organizations and associations:

- Mobilizing resources and providing technical assistance to national programmes
- Promoting innovative approaches, including intercountry collaboration for TB control
- Coordinating national laws, standards and regulations on crossborder movement

#### Media:

- Disseminating evidence-based information
- Educating the public and specific interest groups on TB
- Influencing attitudes and behaviour with regard to TB
- Advocating and communicating with policy makers to influence decisions relating to TB control

#### Opinion leaders (political, religious, traditional, etc.):

- Influencing attitudes and behaviour of and towards people with
- Influencing policy decisions relating to TB control

#### Communities:

- Supporting TB patients and their families by fostering positive attitudes and non-discriminatory practices
- ➤ Involvement in planning, problem-solving, monitoring and reviewing TB programme initiatives

#### Patients and their families:

Ownership of their health through active involvement to ensure that any affected member of their own family is treated properly until cured

The table below gives examples of the roles that different in-country partners can play in ACSM.

 Table 2: Possible ACSM roles of country-level partners and stakeholders in TB care and control

Expected output/ outcome	_		Sustained services	Improved standards of care	Accountability and transparency		Stigma reduction, improved case detection rate	Promoting evidence based best practices		Improved treatment adherence	Promoting patient-focused services - improved outcome	Patient-friendly services
Other health programmes sp HIV/AIDS control	К		Collaboration for patient cross- referral	Liaison with TB programme to ensure ISTC	Collaboration for information sharing		Coordination for awareness generation activities	Sharing relevant programme information		Counselling support specifically in case HIV positives	Sharing experience in social mobilization	Multiple services under same roof
Corporate sector	- 1		Peer pressure for following national strategy	Adopting PCTC	Sharing workplace information		Awareness generation among workers	Documentation of Documentation of innovation and innovation and best practices best practices		Incorporating TB control in corporate social responsibility	Workplace support structures	Coordinating with programme for patient convenience
Professional bodies	1		Advocacy with health care providers	Endorsing ISTC and PCTC	Independent data validation		Conferences and seminars	Documentation of innovation and best practices		Discussing community perspective in technical meets	OR	Watchdog for patient rights
Media	Н		Opinion building	Promoting PCTC	Highlighting achievements and challenges		Awareness generation through media	Articles and short films on TB control amplifying community voices		Interactive sessions for communities and community- based media	Highlighting patient needs	Watchdog for patient rights
Academic institutes and technical organizations	C	56	Generating evidence for advocacy	OR on implementation of ISTC and newer technologies	Independent data validation	roles	Awareness amongst medical and paramedical students	Analysing practices and developing models	ı roles	Training on counselling and social support	OR - improving accessibility and acceptability	Integrating technical guidelines with patient-centric approach
NGOs/CBOs (other than direct health care)	F	Advocacy roles	Advocacy with local leaders and groups	Promoting PCTC	Joint monitoring of services	Communication roles	Awareness generation through IPC	Documentation of innovation and best practices	Social mobilization roles	Patient and family support through counselling	Community support groups	Watchdog for patient rights
Health care providers - public and private	E		Advocacy with local leaders and groups	Adopting PCTC	Adequate maintenance of records	3	Awareness generation through IPC	Documentation of innovation and best practices		Complete information to patient on treatment	Patient-centred services	Delivery of patient-friendly services
Programme managers	D		Motivating health workers	Incorporating ISTC in programme guidelines	Monitoring & support supervision		Ensuring coherence of messages	Guiding documentation in alignment with programme needs		Guiding field workers on IPC with patients	Regularly reviewing community involvement	Providing platform for community members to express their views on TB services
International technical organizations	С		Advocacy with the programme	Technical advice on implementation of ISTC	External evaluation		Incorporating international technical data in messages	Building capacity for documentation		Technical aspects of community- based projects	Advocating with other sectors	Interface with patient/
Development partners	8		Advocacy with ministries	Support implementation of ISTC	Independent data validation		Supporting media campaigns	Creating avenues for innovation		Supporting community-led initiatives	Encouraging projects with community involvement	Reviewing projects for community approach
UN bodies incl. WHO	A		Advocacy with ministries	Support implementation of ISTC	Independent data validation		Technical assistance on focused message development	Sharing international best practices		Integrating TB control in other social development projects	Sharing international experience from various sectors in social mobilization	Supporting community approach
			-	2	3	0	4	in		9	7	00

The table can be used in two ways:

- (1) Left to right How ACSM contribution from various stakeholders would contribute to TB control e.g. activities in from A 6 – K 6 will lead to expected output/outcome in L 6.
- (2) Right to left In case of identified deficiency to programme performance what ACSM action can be taken, e.g. for L 4 (stigma reduction and improving CDR), activities A 4 to K 4 will be essential.

It should be borne in mind that activities in various cells are illustrative and not mutually exclusive, e.g. improved treatment outcome overlaps with patient-friendly services. So efforts to improve treatment outcome need also to make TB services patient-friendly.

## **Partnership activities**

#### Regional

The Region will advocate for wider linkages between NTPs, other ministries, departments and related programmes and will also promote the development of national policies for wider intersectoral collaboration, based on evidence of the value of these collaborations.

Need-based support will be provided to countries to have a partnership approach and where required, a partnership policy. This would include initiatives by partners to establish country-level partnerships in all countries with opportunities to contribute to TB care and control. Efforts will be made to make TB partnerships inclusive of HIV control and other relevant programmes and to share platforms to deliver messages.

The Region can promote and assist in developing broader approaches across multiple health fields including TB, to engage with a wider range of providers and stakeholders. The activity encompasses engagement with a wide range of partners and stakeholders who can help facilitate implementation of policy and legislation, and share best practices in building core public health functions, effective financing schemes, service delivery strategies, sector-wide planning frameworks, medium-term expenditure frameworks and poverty reduction strategies. Coordination

with various partners will also help minimize parallel administrative, reporting and monitoring systems.

Such partnerships will help devise common responses to challenges and opportunities associated with decentralization, civil society engagement and accountability, etc.

Several countries in the SEA Region face the challenge of addressing TB among migrant populations. Regional forums, e.g. SAARC and ASEAN will be used to develop mechanisms for cross-border collaboration and coordination at national and subnational levels. Working groups can be formed under these umbrella forums.

#### **Country**

Member States in the Region will be encouraged to develop a partnership approach, and with agreement of all partners to translate this into a partnership policy. This may be the start-up for establishing a functioning partnership at country level. Concurrently the programme or a major stakeholder in the programme may initiate an exploratory meeting with all potential partners. The countries could also begin with establishing national inter-agency coordination committees or equivalent bodies under the stewardship of ministries of health, with representation from all relevant sectors and partners to provide direction for policies, planning and implementation of joint interventions.

In country context, partnership would imply:

- Representation of all relevant stakeholders in an inclusive way
- Sharing of a common plan and resources

#### Partners could include:

- > NTP, other national health and social development programmes
- UN bodies, including WHO country office
- Country representative of multilateral and bilateral donors
- Professional/academic organizations
- NGOs, community-based organizations and patient groups

- Academic and technical organizations
- Media agencies and social marketing experts

Once the partnership is established, shared resources and responsibilities are important. Roles for ACSM can be taken up by various partners depending on their core competencies, as described in table 2. Depending on the local situation, the countries could consider establishing partnerships at all levels of programme implementation, i.e. from the central to the most peripheral level.

Whatever the structure of the partnership, it must be a functioning entity. There should be a clear roadmap for partnership activities and the partners. Once established, the partners should consider establishing partnership goals in alignment with country and global Stop TB strategy goals. A partnership strategy should then be developed to accomplish relevant targets for the partnership

The partnership should adopt guidelines for implementation including mechanisms to jointly ensure quality of TB control activities through partnerships. Partners bring various technical and implementation strengths that could be harnessed to improve the quality of the programme.

# **Section 4**

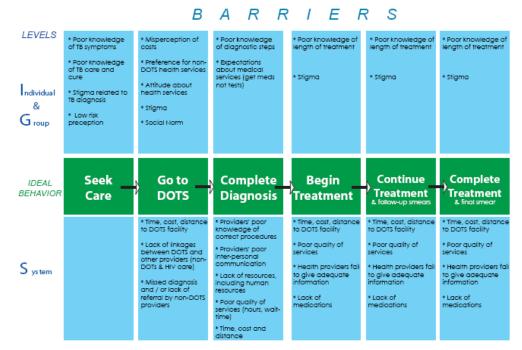
# 10. Planning and Implementing ACSM

During planning and implementation of ACSM activities, the following key priorities for the Region will be kept in mind:

- (1) Sustaining and improving the quality of DOTS to reach all TB patients
- (2) Forging partnerships to ensure equitable access to an essential standard of care to all TB patients
- (3) Establishing interventions to address TB-HIV and MDR-TB
- (4) Strengthening monitoring and surveillance to measure progress towards MDGs.

Steps in Planning and Implementation of ACSM include:

- (1) **Identification of challenges** Based on desk review/surveys:
  - Using programme data. This includes case notification rates, treatment outcomes and programme management reports
  - Using gap analysis tool "cough-to-cure pathway". After identifying the indicators where the programme is underperforming, cough to cure pathway will provide guidance on barriers that might be contributing to underperformance. Barriers might exist at individual, community or systems levels.
- (2) **Prioritization of challenges** What needs to be addressed first? Most countries work in resource-constrained settings and it resources may not always be available to address all the challenges. Programme managers will know what challenges can be most easily and quickly overcome, addressing a wider group of people/situations.
- (3) Identifying Stop TB strategy element that needs to be strengthened. Each challenge can be classified under a corresponding element of the Stop TB Strategy which helps improve the programme performance.



#### From Cough to Cure: A Path of Ideal Behaviors in Tuberculosis Control

- (4) **Identifying appropriate activities** to meet those challenges and strengthen Stop TB Strategy components.
- (5) **Resource mapping** Available financial and technical resources must be mapped. This includes NGOs and CBOs, who may be best suited for implementing certain activities, especially at grassroots level.
- (6) Action plan An action plan will include listing activities and setting a time frame for their completion. The time of launch/organization of certain activities can be synchronized with important events and other opportunities. An action plan also needs to identify cost centres involved in each activity and match the activity with the available budget. A list of possible cost centres as examples is available in the chapter on resources and tools required
- (7) **Deciding on indicators** Technical and corresponding financial indicators that will help monitor the performance and, if required, make mid-course corrections to activities. A suggested list of indicators is provided later in this document.

(8) **Monitoring, evaluation and review** of strategies. Constant and periodic review of all ACSM activities is important as with any other programme activity.

#### **Challenges to successful implementation of ACSM activities**

- Low ational and subnational capacity to plan and implement ACSM campaign
- Programme managers apprehensive about activities and their monitoring
- Suboptimal collaboration within health department and with other sectors on ACSM activities
- ➤ Limited data/ studies on KAP and on successful models
- Stand-alone approach to ACSM rather than as integral part of TB control

**Table 3:** Checklist for planning ACSM activities

Target group/ audience	Objectives of ACSM activities	Challenges	Key messages/focus areas	Message delivery options
		Advocacy		
Political leaders and policy- makers	Enhanced political commitment     Greater fund allocation     Monitoring of programme at the highest level	Competing priorities Busy schedule of leaders Lack of clarity in message	TB and MDR- TB burden in the country TB control is a development issue Intricate link between TB and poverty Cost-benefit analysis of TB control Consequences of neglecting TB	Parliamentarian meeting Ministerial review of the programme Individual meetings with ministers and senior bureaucrats
Government departments	Collaboration with NTP Sharing of resources HSS	Lack of information on TB No platform for meeting	Introducing synergies through collaboration Cost-effectiveness of collaboration Creating a platform for regular meetings Adoption of PAL	Ministerial review of the programme     Inter-agency meeting     Country Coordination Mechanism (CCM) meeting

Target group/	Objectives of ACSM	Challenges	Key messages/focus	Message delivery
audience	activities	- J	areas	options
UN bodies	Greater attention to TB control     Linking of development activities with TB services	Infrequent     opportunities for     dialogue	<ul> <li>TB control is a development issue with wide implications</li> <li>Development programmes can collaborate specifically for cross-cutting areas</li> </ul>	UN meetings Ministerial meetings with UN agencies Newsletter
Donors/funding agencies	Enhanced and sustained commitment to TB control	Global economic situation     Emerging challenges requiring funding diversion     Changing priority of donor countries	Financing TB control is an investment with high yield Cost-benefit analysis Tangible outcomes of investment	Meetings     Quarterly/annual reports     Newsletter
Academic institutions and professional bodies	Adopt and teach standardized treatment regimen for all TB cases     Undertake and support TB research	Professional ego Conflicting messages from various sources Lack of local evidence Funding for research	DOTS as gold standard for treatment     Available global/ local evidence     ISTC and PCTC     Priority research areas	Newsletter     Workshops     Conference     NTP trainings     WHO/technical guidelines     Joint monitoring
International agencies	Greater     collaboration     with the     programme     Technical and     financial     assistance     Sorting out     cross- border     issues	Mandate of international organizations     Ability to work in local context     Limited grassroots presence	TB anywhere is TB everywhere Efficacy of programme activities Sharing international experience	Meetings     Joint monitoring     Facilitation of     trainings
Media	Sustained coverage of TB situation     Highlight programme achievements and gaps     Motivating policy-makers and communities	Competing priorities for coverage Making a media "story" out of facts	TB as a social disease National and subnational TB burden Current programme activities and how quality is being ensured Success stories	Journalists' training and workshops     Press release/ media briefing
Opinion leaders	Commitment to TB control Motivate and support community Create supporting environment for TB patients	Lack of social relevance in messages No involvement of community in message production and dissemination	TB and MDR- TB burden in local area Intricate link between TB and poverty Consequences of neglecting TB TB services available	Meetings and workshops     Community events     Focus group discussions

Target group/ audience	Objectives of ACSM activities	Challenges	Key messages/focus areas	Message delivery options
			through the public and private sector Community collaboration in TB care	
Communication Local leaders	Increase	Identification of	Achievement	Quarterly/annual
Locarieaders	awareness regarding TB and available services Develop confidence in programme and available services To further motivate communities	<ul> <li>problem in local context</li> <li>Apprehensiveness about quality of services through public sector</li> </ul>	and gaps in implementation Local success stories Community leaders can be part of monitoring system determining quality of services	Quarterly/annual report     Message from cured TB patients     Joint monitoring of local services
Communities	Early referral	<ul> <li>Community</li> </ul>	Curability of	Mass media
	and diagnosis  Stigma reduction  Social support for patients	perceptions  Cultural values and norms  No involvement of community in message production and dissemination Conflicting messages from various sources	the disease Symptomatic identification and sputum testing Need for treatment observation	Display/print media Interaction in groups Street theatre Focus group discussions
Patients	Patient- friendly treatment observation Treatment adherence	Convenience of DOTS centre location Friendliness of DOTS provider/other health staff Lack of counselling skills	Available DOTS options     Need for regular and complete treatment     Follow-up     Need for treatment observation	Patient groups  Patient groups
<b>Social Mobilization</b>				
Stakeholders and CBOs	Mobilize community     Active involvement of community representatives in monitoring service delivery	<ul> <li>Lack of adequate/ accurate information on TB</li> <li>Apprehensiveness about partnership with government/ programme</li> </ul>	<ul> <li>Community         benefits of         DOTS and         DOTS-Plus</li> <li>Allaying         apprehensions         through         dialogue</li> </ul>	Stakeholders     meeting at     national and     subnational level     Newsletter
Communities	Early referral and diagnosis     Stigma reduction     Social support for patients	Communities     seen as passive     recipients of     services rather     than active     partners     Social dimensions	Creation of social support structure     TB is a social issue     TB is curable     Contribution to	Local media     Community     meetings     NGOs/CBOs/FBOs     Village heads/     teachers/postmen/     other opinion

Target group/ audience	Objectives of ACSM activities	Challenges	Key messages/focus areas	Message delivery options
Patient groups	<ul> <li>Convenient</li> </ul>	of the disease not a priority with programme managers  • Accessibility of	TB care will decrease the spread and will benefit all members of the community Everyone can contribute DOTS can be	leaders  Opinion leaders
and families	DOTS  High quality services  Treatment adherence	services     Cultural beliefs     Opportunity costs	arranged close to home Need for complete and regular treatment Ambulatory treatment minimizes costs and wage loss Untreated TB has dire consequences	Peer group Various forms of media IPC

# 11. ACSM capacity building

#### Areas for capacity building

**Planning** – The components of an effective ACSM plan and how to develop an ambitious but practical plan that can be implemented with available resources.

**Implementation** – When implementing the ACSM plan it should be clear who does what, when and where. This is common to implementing any project but is especially relevant to ACSM activities because it is difficult to attribute outcomes to specific activities. Hence, clarity on implementation brings clarity in assessing the outcomes. Again, implementation of ACSM activities should not be seen as parallel to other programme implementation but as complementing the programme efforts

**Monitoring and evaluation** – It is important to monitor process, outputs and outcomes. Process monitoring helps evaluate the progress and strategies and any unforeseen outcomes of activities. This helps mid-course corrections to the implementation plan. Similarly outputs help monitor achievement of targets, and initial outputs may also help forecast cost-

efficiency. Outcomes are community-based changes observed due to the activities. Programme- and project-specific outcome indicators may differ.

**Documentation of results** – It is often the case that documentation and publication of results from ACSM activities is not available in a comprehensive form. This makes it difficult to assess what works and what does not, and as a result models are not replicable.

**HRD for ACSM** – Training on various components of ACSM is important at various levels.

**Operations Research** to assess efficacy of ACSM and community models. This will also help in proper documentation of results.

#### **ACSM** capacity building activities

#### Regional

- Assist countries in development of an annual ACSM budgeted workplan with identified priorities, target groups and expected outputs/outcomes.
- ➤ Technical needs assessment of countries based on ACSM strategic plan and other ACSM felt needs in the Region.
- Support countries in development of ACSM training plans. Assist Member countries in adopting and piloting appropriate ACSM methodologies and approaches through tools development, training, technical advice and information exchange.
- > Strengthen capacities of ACSM implementing agencies in documentation and impact evaluation. Develop research methods and instruments for formative research and ACSM impact and outcome evaluation.
- > Creating opportunities for information sharing, especially best-practice models amongst NTPs and other stakeholders.

#### **Country**

Support subnational units in development of an annual ACSM budgeted workplan with identified priorities, target groups and

- expected outputs/outcomes. Develop and implement a national advocacy and communications strategy for nationwide campaigns including the use of mass media and traditional point-of-service health education.
- Workshops and training for ACSM implementation for subnational programme managers and officers in charge of ACSM.
- Strengthening national and subnational partnership for ACSM implementation with defined roles. Partnerships can play an important role in ACSM through shared responsibilities and resources and by imparting credibility to the messages delivered.
- Strengthen capacities of ACSM implementing agencies and community groups in documentation and impact evaluation.
- Information sharing, especially best-practice models amongst national stakeholders:
  - Visits to sites
  - Joint review meetings
  - Interactive website
- Formation of an ACSM task force at various levels with defined tasks for outreach.
- Conduct formative research and communications pre-testing; Conduct quantitative pre- and post-intervention surveys.

#### Develop a capacity building plan to include:

- ➤ Tools for capacity building for all relevant stakeholders, such as standardized training material and flow charts; consider methods appropriate for adult education.
- Plan for educational activities and related tools addressing stigma and discrimination.
- Identify the people responsible for conducting training.
- > Ensure ongoing training to address staff turnover.

#### Indicators for strengthened ACSM capacity

**Staff positions** for ACSM at central and subnational levels. It is recommended that there will be at least one staff position for ACSM responsible at the national level. Depending on the scope of activities, population covered and available budget, there could be subnational ACSM positions as well. Staff must be well qualified and experienced in identifying the role of ACSM activities in TB care and control.

**Bottom-up planning for ACSM in countries**. National plans are based on micro-plans developed at subnational level. While overall guidance is provided from the central level, actual implementation activities are decided by peripheral units that feed into the national ACSM plan. These plans also should include inputs from other stakeholders.

#### An **annual ACSM budgeted workplan** with:

- Identified challenges and priorities,
- Target groups
- ➤ Role assignment for partners
- Expected outputs/outcomes

**Needs-based trainings** for national and subnational staff. This would be decided by roles and responsibilities of programme staff at each level. Trainings on ACSM should also be imparted to other private and civil society partners, community leaders and volunteers.

**Research articles** in journals and presentations at international conferences regarding ACSM models, are a comprehensive indicator for strengthened capacity in ACSM.

## 12. Monitoring ACSM activities

(Meant only to be an indicative list. For further details see Stop TB planning framework/monitoring and evaluation toolkit/ACSM handbook)

Monitoring processes as well as outcomes.

- ➤ The table below provides examples of monitoring of ACSM projects. Indicators to be used for monitoring will vary with the project and the expected outcome for which the activities are undertaken.
- From a TB control programme point of view, outcomes are measured in the form of change in case detection rates and treatment success rates. However, from an ACSM project point of view, the outcome could measured in terms of population changes for which the specific activities have been designed.
- Several factors play a role in bringing about the outcomes, and it is often difficult to attribute changes to a specific activity or even a group of activities. The only way to assess value addition of ACSM activities is comparison in time, i.e. before and after activities were undertaken, or in terms of geography, i.e. areas where activities are being undertaken compared with those where the activities are not being undertaken.
- The monitoring frameworks should also remain open to outcomes beyond what was expected.

**Table 4:** Suggested indicators for ACSM activities

Activity	Process indicator	Output/ outcome indicator
Advocacy		
Sensitization of leaders for increased allocation of resources	<ul> <li>Number of meetings held</li> <li>Number of politicians/local leaders sensitized</li> <li>Number of TB-related questions raised in house of representatives</li> </ul>	<ul> <li>Increase in allocation of financial resources for TB control</li> <li>Cross-cutting – Newer health posts established or the existing ones strengthened with posting of additional staff</li> <li>Number of laboratories strengthened – availability of microscopes, trained microscopists, quality lab reagents</li> </ul>
Strengthening collaboration with other sectors	<ul> <li>Number of meetings held</li> <li>Number of partners attending the meeting and sectors represented</li> </ul>	<ul> <li>Newer entities adding TB control to their agenda</li> <li>Newer DOTS facilities in other sectors</li> <li>Partner participation in ACSM activities</li> </ul>

Activity	Process indicator	Output/ outcome indicator
Establishment of national partnership	<ul> <li>Partnership policy in place</li> <li>Exploratory meeting between potential partners</li> </ul>	<ul> <li>National partnership formed based on a partnering agreement including vision, goals and objectives, role and responsibilities of each partner and governance structure agreed and signed by all partners</li> <li>Partnership contribution to national policy issues on TB control</li> </ul>
Communication		
Raising awareness about TB	<ul> <li>Number of times message is broadcast on radio/television</li> <li>Number of times articles appear in the print media</li> <li>Other awareness generation activities organized</li> </ul>	<ul> <li>Message recall in general/target population</li> <li>Change in awareness noted by preand post-campaign KAP survey</li> <li>Decrease in stigma after the campaign</li> <li>Increase in knowledge of TB – signs and symptoms, need for early screening, free treatment, location of DOTS services, side effects, and treatment adherence.</li> <li>Increase in number of chest symptomatics approaching health facilities after hearing/reading the message</li> </ul>
Sensitization of journalists	<ul><li>Number of sensitization meetings held</li><li>Number of attendees</li></ul>	Increase in coverage to TB as a social issue in press
Social mobilization		
Greater involvement of community in provision of TB services	<ul> <li>Dialogue between programme managers and community members at various levels</li> <li>Number of community support groups formed and involved</li> <li>Capacity building of</li> </ul>	<ul> <li>Number of community volunteers engaged in provision of DOTS services – referral, counselling, default retrieval and DOTS</li> <li>Contribution to case-finding and treatment adherence</li> <li>Number of health centres reporting community volunteer involvement</li> <li>Number of monitoring meetings</li> </ul>
NGOs/CBOs in programme monitoring	NGOs/CBOs in monitoring through trainings	held by programme im which NGOs/CBOs participated  Contribution of NGOs/CBOs to decision-making process

A monitoring and evaluation plan for ACSM activities should be developed at the planning stage itself. This will help to:

- Monitor performance regularly through process indicators
- Indicate potential problems in execution
- ➤ Help to make any required mid-course corrections
- Keep track of resource use
- Inform the outputs/outcomes of the activities

### 13. Resources and tools required

List of resources and tools that would be required at regional and country level to undertake ACSM activities. The list can be adapted to local contexts and to the actual implementation plan. The list also includes examples of some of the cost centres that should be kept in mind while preparing the action plan and budget

#### Regional

- Human Resources
  - ACSM focal point at Regional level to coordinate activities, review progress and provide/coordinate technical assistance for ACSM activities
  - Consultants to support various aspects of ACSM
- Database of organizations and individuals actively involved in ACSM
- Annual ACSM plan developed in partnership with stakeholders
- Portal for information sharing with stakeholders
- Literature on best practices and models
- Advocacy and communication material design, production and distribution
- Budget for ACSM cost centres
  - Staff hiring
  - ACSM Regional workshops

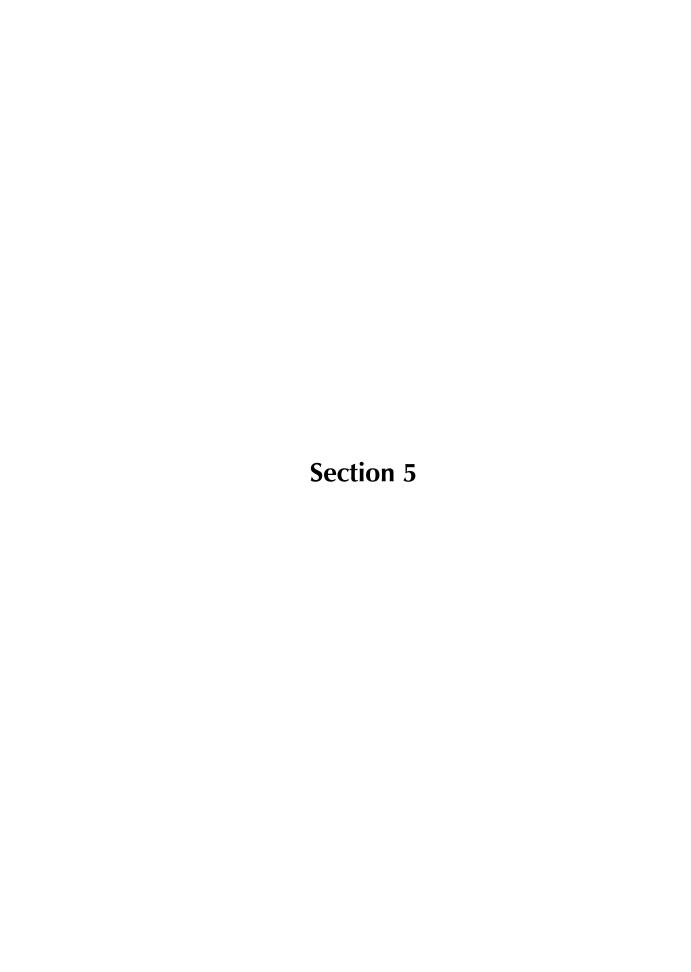
- Advocacy meetings with country representatives,
- International meetings like ASEAN and SAARC coordination for TB advocacy
- Regional ACSM trainings
- Enhanced participation from stakeholders in regular Regional meetings
- Publication and distribution of advocacy materials and other technical material to be used for ACSM
- Country support missions, monitoring missions and developing country strategies
- Documentation and publications of experience in the Region;

#### **Country**

- National- and subnational-level focal ACSM person/s
- National trainers for training and guiding subnational ACSM activities
- Portal for information sharing with various stakeholders
- Database of organizations and individuals actively involved in ACSM
- Involvement of mass media and social marketing agencies
- ➤ Networking platform with various stakeholders, including NGOs, CBOs and FBOs
- Development of an annual plan inclusive of ACSM in partnership with various stakeholders
- Partnership policy and guidelines for involvement of various sectors
- Guidelines on involvement of communities
- Design, development, production and dissemination of ACSM material
- Literature on best practices and models
- Monitoring tools for implementation and progress of ACSM activities

- Budget for ACSM cost centres
  - Staff:
    - Hiring of staff
    - Workshops
    - Trainings
  - External technical assistance,
  - Development and dissemination of policy documents ACSM, partnership policy, etc.
  - Advocacy material production and advocacy meetings at various levels
  - Adaptation, translation and printing of ISTC and PCTC
  - Publication and distribution of information, education and communication (IEC) materials, e.g. pamphlets, brochures, flipcharts
  - Celebrity events and messages,
  - Media outreach:
    - Press meetings
    - Journalist training
    - Mass media campaign
  - Community activities, e.g:
    - Creation of SHGs, patient support groups and sustenance
    - Community events for awareness, e.g. street theatre, mobile cinema, cultural and arts events, community announcements, street rallies and other innovative and interactive methods
    - Peer education meetings
  - Monitoring activities, routine supervision
  - Needs assessment baseline studies, KAP studies
  - Developing OR protocols
  - Analysis of results of ACSM activities and dissemination
- ➤ Budget for partnership activities cost centres
  - Exploratory workshop/s with all partners

- Follow-up meetings with partners
- Meetings to prepare operational plan, partnering agreement and basic structure of the partnering initiative and drafts
- Setting up the secretariat of the partnership
- Meetings of the governing bodies and partners on a national/regional level (in large countries).
- Workshop for staff employed by partner organizations on the implementation of the operational plan according to each service delivery area
- Monitoring and evaluation of the activities implemented by partners under the corresponding service delivery area.
- Communication of partnership activities through website/newsletter/ media activities
- Institutionalizing the partnership (registration and related costs), maintenance of books of account and annual audit costs



# 14. Transforming statistics into key messages and stories (WHO/CDS/STB/2000.1)

#### Three types of messages and stories are generally effective

- Stating the extent and effects of the problem
- Showing what can be done about the problem
- Documenting the impact of TB on the individual

#### Remember: Local statistics and stories generally have the most impact.

- Use statistics to develop a list of key messages and stories that can be used depending on the target audience. The messages and stories should support the successes, identify gaps and set out the next steps in your TB programme, and they should be a call for action.
- If possible, use comparisons to illustrate your point.

#### **Examples**

Research has shown that stories about people's lives being affected by TB have a greater influence on public opinion and attitudes. A key element in the success of a media or public awareness campaign is its ability to convey a personal message about TB, how it affects real people and what we can do to improve the situation.

#### Human interest story

<u>Message</u>: TB and AIDS is a deadly combination. But TB is curable even for people living with HIV/AIDS. We need to act today to prevent further suffering.

Story: When Somachi, a 27-year-old single school teacher from northern Thailand, came to the hospital four years ago he only hoped that

the doctor would give him some medicine for his fever and cough. After seeing the doctor and getting his sputum check-up, the young teacher was told that he had to undergo treatment for tuberculosis. But the diagnosis did not end there. In the eye of the doctor there was a possibility that he was HIV-positive. Somachi entered DOTS (Directly Observed Treatment, Shortcourse) and started feeling better. The hospital began to give him counselling and asked him to have a confidential blood test. Somachi took a few days to decide before he took the test. The result was HIV-positive. Now Somachi is cured of TB and takes regular antiretroviral treatment that helps him lead a healthier life

# 15. Using epidemiological data to identify strategic needs in Indonesia (Advocacy, communication and social mobilization (ACSM) for tuberculosis control: a handbook for country programmes; WHO 2007)

The first-ever Indonesian National Tuberculosis Prevalence Survey in 2004 estimated that TB prevalence, as determined by the number of sputum-smear positive cases was 104 per 100 000, with regional differences in the Java–Bali, Sumatra and eastern Indonesian regions. To reduce this burden, the Indonesian Ministry of Health used a variety of ACSM strategies to identify specific populations that might benefit from targeted outreach. A secondary analysis used epidemiological data from the national prevalence survey to identify the populations by determining environmental and behavioural risk factors of specific groups of individuals.

Results from the secondary analysis indicated that people were more likely to be diagnosed with TB if they were:

- older
- living in the eastern provinces of Indonesia, particularly in rural areas
- men
- living in urban areas

- less educated
- living in a less "healthy" house (for example, a house with poor illumination and ventilation or no septic tank, sewage system or trash management).

Study results indicated that the risk of TB infection in children was two times higher if their family history included contact with people with TB, compared to families with no contact. Children from lower-income families were less likely to obtain TB medicines compared to children from higher-income families, probably because of the availability of disposable income to pay for the medical consultation and other costs associated with care. (Anti-TB drugs themselves are supposed to be available free of charge.) As a result of this epidemiological investigation, the Indonesian strategic plan to Stop TB 2006–2010 focuses on expanding DOTS in the remote eastern provinces specifically. This plan was designed to reach underserved populations through social mobilization, and one of its six objectives is to increase community participation in implementing the TB control programme and increase the demand for good-quality TB diagnostic and treatment services.

To raise awareness of TB, especially among key groups, Indonesia plans to form a strong network of TB communicators over the next five years. Mass media campaigns will use culturally tailored TB messages with the aim of strengthening the ability of patients and communities to demand access to good quality TB services and mobilize support for TB control. These grassroots campaigns are expected to significantly increase the use of TB diagnostic and treatment services, especially in the hard-to-reach eastern region. To fill knowledge gaps related to TB, various communication materials (brochures, posters, leaflets and audiovisual materials) will highlight important topics such as TB prevention for children in families where at least one family member has already been diagnosed with TB.

# 16. Examples of ACSM activities in the Region

Bangladesh (WHO/HTM/TB/2008.397)

#### 1. BRAC community-based TB care model

At the core of TB control and other essential primary health care services are female community health volunteers called *shastho shebikas*. They are chosen from village organizations – BRAC female micro-credit schemes containing 40-50 members per village. Each *shastho shebika* is responsible for about 330 households – they visit each household every month to provide primary health care services, including TB control. *Shastho shebikas* are allowed to sell medicines at an agreed price and are motivated by performance-based incentives. They receive 3-4 days of training and monthly refresher courses to serve as directly observed treatment providers. They usually spend about two hours daily working as health volunteers.

When a *shastho shebika* encounters a person suspected of having TB, she provides a sputum container, which is then taken to one of BRAC's smearing centres a few kilometres away. BRAC staff members visit the smearing centres once a week, fixing slides and taking them to a laboratory for sputum smear examination.

If the examination is positive, BRAC contacts the *shastho shebika* and provides a weekly dose of medicines for the intensive phase of treatment and several months' supply for the continuation phase.

People with TB go daily to the *shastho shebika*'s home to receive directly observed treatment. If a person with TB does not turn up, the *shastho shebika* is obliged to go to his or her home. If a person with TB still has problems in adhering to treatment, *shastho shebikas* have to report this to the village authority, which will contact the person with TB to encourage them to continue treatment.

#### 2. The Damien Foundation community-based care model

Unlike BRAC, the Damien Foundation mostly uses the existing function of village doctors as treatment supporters. They usually earn a living by selling medicine, but they do not charge consultancy fees and are often a villager's first contact when they seek care.

Village doctors are laypeople with six months of government training. One village doctor covers a population of about 5 000. One in five village doctors becomes a directly observed treatment provider too (also called a fixed directly observed treatment provider). Fixed directly observed treatment providers identify people suspected of having TB, who are given sputum cups to take to diagnostic centres themselves. Microscopy centres are located at government-run *upazila* (subdistrict) health centres or Damien Foundation clinics. Fixed directly observed treatment providers have responsibility for following up sputum examinations. They obtain medicines from the health centres.

People with TB are expected to come to the *upazila* health centre every two weeks, where the Damien Foundation staff members ensure that treatment is not interrupted.

If a person with TB misses a second visit to the health centre, Damien Foundation staff members visit the person with TB at home, accompanied by the fixed directly observed treatment provider.

People who have had TB are encouraged to join TB clubs. After forming a TB club, members receive annual refresher training. Their responsibility is to refer people suspected of having TB for a sputum check, and they often accompany them. In some cases they may also become directly observed treatment providers.

#### Bhutan

Involving Village Health Workers: Bhutan's strong Village Health Worker (VHW) programme was introduced by the government in 1978 and formally established in 1998 under the Department of Public Health. It has since been integrated into the health system, emerging as a successful outreach initiative. As of today, there are 1250 VHWs spread out in all 20 districts of the country's three regions. Most of these districts are situated in remote and

hard-to-reach areas. What binds the health workers together is their singular objective of helping people access services in as efficient and economical a manner as possible.

Serving as health counsellors, VHWs provide a link between the community and the health system. All VHWs are volunteers, and they are either nominated by the community or sign up of their own accord. They receive training on basic health care, and how to assist with deliveries, identify health problems and make referrals, besides helping with advocacy.

In the case of TB, VHWs play a critical role by monitoring treatment status of the TB patient. Based on the list of names given by the village headman, they visit the concerned households and remind the person about going to the health centre. They also keep checking the status of other family members to see if they need screening.

#### Democratic People's Republic of Korea

Household doctors - Since 2008, the detection rate of new smear-positive cases in DPR Korea has gone up to nearly 75-80%. The concept of household doctors has worked extremely well in the case of DPR Korea and has boosted the health profile of the entire nation. It has yielded results on the ground and has emerged as a viable and sustainable concept and is now one of DPR Korea's biggest success stories in the health sector. Household doctors are basic country-level TB doctors who fan out through the length and breadth of the nation to look after TB cases. The concept of household doctors has been prevalent in DPR Korea since the 1950s, with each doctor mandated to look after 120 households. By training them on TB, the NTP has succeeded in expanding its human resource base by as many as 10,000 doctors. Until household doctors became involved in TB care in 2007, ambulatory treatment was not provided.

#### India

(http://www.tbpartnershipindia.org/about.asp accessed 04 December 2010) *Partnership of civil society*: The "Partnership for Tuberculosis Care and Control in India" (the Partnership) brings together civil society across the country on a common platform to support and strengthen India's national TB control efforts. It seeks to harness the strengths and expertise of partners in various technical and mplementation areas, and to empower affected

communities, in TB care and control. It consists of technical agencies, NGOs, CBOs, affected communities, the corporate sector, professional bodies and academia. Currently the Partnership includes 24 partners.

The Partnership's vision is to support India's Revised National Tuberculosis Control Programme and achieve the TB-related targets of the MDGs and the Stop TB Partnership in India through a unified response from civil society and all other stakeholders, based on shared values of mutual trust, respect and a willingness to contribute to this common vision. It seeks to synergize civil society to contribute to TB care and control in India in line with common national and international goals.

The Partnership's objectives include: advocating with national, state and district authorities and with all existing and potential stakeholders on TB control; developing a dynamic and comprehensive strategic plan for civil society participation; mobilizing resources and interfacing with donors to support partner activities; coordinating partner activities and providing tools, information and platforms to share successes, lessons, constraints and innovations; facilitating need-based technical support for partners; promoting the ISTC and PCTC as internationally accepted standardized tools; increasing the visibility of India's national TB programme and promoting community ownership; and expanding the Partnership to harness all available resources for a self-sustaining TB control movement in India.

In a short time, the Partnership has become a hub for disseminating information, creating visibility for India's national TB programme, responding to TB related challenges and providing support to various stakeholders.

#### Indonesia (WHO/HTM/TB/2008.397)

1. Community participation in TB in urban setting – Yayasan Syahrullah Afiat in Jakarta: Yayasan Syahrullah Afiat is an NGO that runs a health centre in Jakarta. Since 2003, Yayasan Syahrullah Afiat has implemented a TB prevention and control programme using the DOTS strategy. Yayasan Syahrullah Afiat was also a subrecipient of a GFATM grant in 2006. At the time of the visit, the health centre was treating 105 people for TB and 7 people for TB and with antiretroviral therapy.

The centre had established a partnership with the Ministry of Health, which provided drugs, and with other private clinics that referred people

suspected of having TB to them. The health centre had a set of community volunteers attached to it that provided good coverage in their catchment area. Each volunteer supported several primary health care programmes within a 2 km radius of their home. Community volunteers promoted TB control through youth organizations and gave talks at schools and religious meetings. People with TB received drug supplies in the health centre and usually had two treatment supporters: a family member responsible for daily support and drug collection and a community volunteer who visited each person with TB weekly.

Each volunteer could support up to 10 people with TB at a time. The health centre had organized quarterly meetings for people with TB, treatment supporters, community volunteers and nurses, where they discussed TB-related issues, and monthly meetings between community volunteers and nurses.

2. Community participation in TB control – Ninik Mamah in West Sumatra: Ninik mamah in West Sumatra province are traditional leaders, often responsible for their extended family. One district involves ninik mamah in TB control work through puskesmas (health centres). Ninik mamah were initially approached by health centre staff, trained about TB and encouraged to identify and refer people suspected of having TB to the health centre. They provide support to family members who become treatment supporters to people with TB. Ninik mamah promote free TB treatment at religious gatherings too, and they have reported a change in public perception of the disease.

Puskesmas reported an increase in case finding in the first year of ninik mamah involvement. Previously, the population was not aware of freely available treatment, which resulted in significant diagnostic delays. Lately, many more people with TB have referred themselves for treatment.

In most other areas of Indonesia, the treatment registration fee can be waived only for poor people.

#### Maldives

Community involvement: During the mass TB-leprosy survey initiated in 1976 in Maldives, all diagnosed patients (TB and leprosy) were treated by the island chief. This was a groundbreaking move in a country heavily

influenced by the island chief. The patient was made to swallow pills in front of the undisputed head of the community. Lists of those found to have TB were handed over to him and he was thoroughly briefed about the treatment schedule (for a year). Clear colour coding was done to avoid any confusion since the island chief was in a similar way handling leprosy treatment too. If the patient had to leave the island, even for a short period of time, he had to first seek permission from the island office and wait for the official transfer letter. The pills would then be sent to his/her destination and if the patient left the island to proceed to an atoll, where good fishing was forecasted, he would be treated through the boat captain who would debrief the island chief. In 1979 the responsibility of treating TB patients was handed over by the island chief to the family health workers or community health workers who were based at the atoll capital, where the health centre was located.

In 1995, the mobile team approach was launched. This entailed a centrally operated team carrying out a package of activities similar to the TB-leprosy mass survey team. The activities of three mobile teams included all primary health care activities including TB case follow-up, contact tracing and active surveillance in case detection. It provided orientation and on-the-job tracing to the family health workers and community health workers to enable them to carry out tasks effectively in a more decentralized and cost-effective manner, with regular follow-up and case holding along with supervision.

#### Myanmar

The National TB programme began implementing an approach promoted by WHO and partners five years ago, to link with private health care providers through PPM. This was done by involving the National Medical Association (NMA), which has a membership of over 7 000 general practitioners and specialists. The NTP began by inviting the central level of the NMA to meetings to acquaint them with what the programme was doing, and what it had achieved in terms of finding and treating TB patients. The NTP then worked with the NMA to develop a plan to orient and involve GPs and specialists in the programme across the country. Starting with five townships, the programme and the MMA worked on mechanisms for GPs to refer people with cough and symptoms of TB whom they wanted screened for TB to government facilities. This allowed patients to receive treatment with their preferred doctor free of cost, with the patient then only having to pay for

transport every two months to attend the government facility for follow-up lab tests. This scheme is now contributing to the detection and treatment of an additional 20% of TB patients annually.

#### Nepal

Village Health Workers supporting MDR-TB treatment - Nepal has five administrative regions and 44 sites scattered across the country where treatment for MDR-TB is available. Enrolment of MDR-TB cases started in September 2005 using a standardized treatment regimen. By the end of August 2007, 343 patients had been enrolled. Initial treatment results showed 245 patients having completed six months of 2<sup>nd</sup>-line drug treatment, of which 80% were smear- and culture-negative, 5% remained smear- or culture-positive, 4% had died, 7% defaulted, and 4% did not have full culture and smear data. DOTS-Plus was performed at five DOTS-Plus centres and 21 DOTS-Plus subcentres. However well organized, full DOTS was not taking place in the continuation phase. Most patients, being from socioeconomically disadvantaged sections of society do not have the capacity to finance their relocation to areas where the DOTS-Plus treatment is available. Also, daily transportation to and from a DOTS-Plus centre or subcentre is likely to be too expensive. Involvement of village health workers for supporting DOTS in the continuation phase has helped reduce default and improve treatment outcomes.

#### Sri Lanka

Cured patient as advocate for DOTS: 25-year old Janaki Liyanajayawardana lives in Kotawella Rambukkana, which is 15 km from the town of Kegalle. She developed a low-grade fever, cough and chest pain, and after shopping for treatment for several months and losing her savings, she was diagnosed as having TB. Her treatment continued for six months at a chest clinic. When the medicines began to take effect and a few months later her condition started improving, people began to once again, befriend her and seek her advice in the event of their not being well. They had by now begun to see her as a kind of expert on medical matters, especially those relating to chest pain, cough and low-grade fever.

Around this time Liyanajayawardana decided to go back to the chest clinic and work there as a volunteer. Her contribution was found to be valuable. Officials and doctors realized that she could be a good advocate for them and be instrumental in reaching out to others like her who were unaware of their TB status and therefore excluded from the national programme. Seeing a concrete role for herself in what was to be a national campaign and national cause, she decided to immerse herself full-time in spreading community awareness. As a kind of "TB ambassador", Liyanajayawardana went through a rigorous schedule of talking to people, visiting communities, conducting home visits, giving messages via the media, appearing on television spots, newspaper advertisements and posters and hoardings. Talking of her own experience, she counselled people on how to overcome stigma and guided families on how they could support and handhold the TB patient. She also advised people on what kind of doctors to go to and who to avoid.

#### Thailand

Successful integration of TB-HIV activities through advocacy: The TB-HIV Policy necessitated a three-pronged strategy that included:

- Establishing a TB-HIV coordinating mechanism for joint planning, surveillance of HIV among TB patients and joint monitoring and evaluation
- Embarking on an intensified TB case-finding exercise among HIV infected persons and providing HIV counselling and testing for all TB patients
- Providing treatment and care (ART, CPT) to TB-HIV patients.

Substantial progress was made in implementing TB-HIV collaborative activities throughout the country, and this received a further boost with the establishment of a National Working Group for TB-HIV. In addition, the NTP provided guidance for collaborative TB-HIV activities. Routine HIV screening was recommended nationally for all registered TB patients, and improved identification of HIV-infected TB patients, together with effective linkage to care and treatment, helped to significantly reduce TB mortality rates.

In spite of a long history of high HIV prevalence, it was a challenge to get the TB clinic staff in Thailand to support the HIV initiative. The success of the TB-HIV strategy thus took immense coordination and commitment. In Thailand, TB patients are treated in 800 hospitals under the Ministry of Public Health, of which 400 private hospitals are under authority where

different components of TB-HIV activities have been successfully juggled to create the right fit.

While most TB clinics have special HIV staff, there were smaller clinics where the TB staff was trained on HIV counselling by the HIV staff. Staff strength in majority-TB clinics in Thailand includes one physician and two nurses at the district hospital. In most hospitals the TB clinic and HIV testing centre are located separately, but in some hospitals they may function as part of one group, depending on the available infrastructure.

#### Timor-Leste

Organized involvement of Village Health Workers - SISCa (Serviço Integrado da Saúde Communitária – the Portuguese name for integrated health outreach programme) is a monthly health clinic that is temporarily positioned at a designated suko (village) and is managed and run by a battery of Village health workers (VHWs). Ignorance, geographical constraints, social and economic access are the biggest deterrents in warravaged Timor Leste, where people try to barter their local crops such as pumpkin and papaya or a home-reared chicken for a ride to the hospital from someone who has a vehicle. In this country, distance is measured not in kilometres but in hours. The presence of SISCa and the VHWs is thus a lifeline for villagers. They throng the mobile clinic, flood the VHW with guestions, look at her equipment and IEC materials with curiosity and try to understand their symptoms as they seek affordable treatment options. The VHW, who is often a woman, is in some cases also a DOTS provider. The SISCa has gradually helped bridge geographical challenges (islands, mountains, no roads) by increasing awareness in the community through health education and promotion, active case-finding and contact investigation while simultaneously involving the community and religious organizations. TB control is prioritized in SISCa, and steps taken include suspect identification, referral for sputum examination, sputum collection, communication of TB diagnosis, health education and patient support and case holding.

Tuberculosis (TB) remains one of the most serious problems for health and development in the South-East Asia (SEA) Region of WHO. The Region has an estimated 4.88 million prevalent cases, an annual incidence of about 3.2 million TB cases and about half a million TB deaths, which equals one-third of the global burden of TB. Five of the Region's 11 Member States are among the 22 high-burden countries. Of the 3.6 million people living with the human immunodeficiency virus (HIV) in the Region, roughly half are estimated to be coinfected with TB. There are nearly 130 000 new MDR-TB cases each year. Extensively drug-resistant tuberculosis (XDR-TB) has been isolated in samples from six countries in the Region.

Member States have varied socioeconomic and demographic profiles, leading to varied challenges faced in each country. Considerable progress is being made, but national TB control programmes still face uncertainties regarding sustainable financial and operational resources; limited technical and management capacity; and weak national laboratory networks and procurement and supply management mechanisms. These factors are slowing the planned expansion of interventions for TB-HIV and MDR-TB.

Advocacy, communication and social mobilization (ACSM) activities are required to address each of these challenges. The target audience and the agency undertaking each activity will differ from country to country. Though funds are allocated for ACSM activities in TB budgets, their actual use is low. High-profile, well-designed and sustained ACSM campaigns are required in order to have a substantial impact. Thus, there is a need for a regional framework for ACSM that will provide strategic direction for such activities at the regional as well as country levels.



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