ADVOCACY, COMMUNICATION, & SOCIAL MOBILIZATION (ACSM) FOR TUBERCULOSIS CONTROL

A HANDBOOK FOR COUNTRY PROGRAMMES

World Health Organization

Stop TB Partnership

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About this Handbook

This Handbook is a guide to support the design and implementation of effective advocacy, communication and social mobilization activities in tuberculosis (TB) control at country level. As declared by the Stop TB Partnership's Advocacy, Communication and Social Mobilization Country-Level Sub Group in its "10-Year Framework for Action," a significant scale up of advocacy, communication and social mobilization (ACSM) is needed to achieve the global targets for tuberculosis control as detailed in the Global Plan to Stop TB 2006–2015.

Increased efforts and attention to TB are particularly essential with the growing emergence of multi-drug resistant (MDR) and extensively drug-resistant (XDR) tuberculosis. ACSM activities can support timely diagnosis and treatment completion, which will minimize the chances that resistant bacteria will evolve.

This handbook is primarily intended for staff that plan, organize and supervise TB control activities at the national level. Because tackling TB requires commitment and work at all levels, this guide can also be used by TB control staff at the provincial, state, and regional levels; by nongovernmental organizations (NGOs) and others involved in TB control, including communications officers, epidemiologists, program supervisors, TB medical specialists, nurses, bacteriologists, statisticians, health educators, logistics officers and trainers.

Health managers of refugee and displaced population camps, prisons and large private enterprises, such as factories and mines, will also find this handbook useful. Additionally, teachers in medical, nursing, laboratory and public health schools may find valuable information for training their students in effective, multi-disciplinary TB control.

This handbook was prepared for the Stop TB Partnership by the Academy for Educational Development (AED) and the Program for Alternative Health Technologies (PATH). The Stop TB Partnership is grateful for all the staff at AED and PATH and members of the ACSM at Country Level Sub Group who provided valuable input in the development of this publication.

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SECTION 1

Preparing to take action

Introduction

By the end of this introduction, the reader will understand:

1) what advocacy, communication and social mobilization (ACSM) is;
2) why it is essential to the Stop TB Strategy; and
3) how it can be used to identify and address TB control challenges.

1. What is ACSM?

The three terms – advocacy, communication and social mobilization – have been defined in many ways and are the subject of continued debate in the fields of public health and communication. For the purposes of this handbook, however, the definitions below apply.

Advocacy

At the country level, advocacy seeks to ensure that national governments remain strongly committed to implementing TB control policies. Advocacy often focuses on influencing policy-makers, funders 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 (MOUs), parliamentary debates and other political events, partnership meetings, patients' organizations, press conferences, private physicians, radio and television talk shows, service providers.

The different types of advocacy are described below.
- *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 TB-related topics regularly and in a responsible manner so as to raise awareness of possible solutions and problems.

Communication

Behaviour-change communication aims to change knowledge, attitudes and practices among various groups of people. It frequently informs the public of the services that exist for diagnosis and treatment and relays a series of messages about the disease – such as "seek treatment if you have a cough for more than two weeks", "TB hurts your lungs" or "TB is curable".

Effective behaviour-change communication and messages need to convey more than just the medical facts as, on their own, these facts do not necessarily motivate people to a visit a TB clinic or complete their treatment. The messages should explore the reasons why people do or do not take action on the information they receive, then focus on changing the actual behaviour by addressing the causes identified – social norms or personal attitudes for example.

Behaviour-change communication creates an environment through which affected communities can discuss, debate, organize and communicate their own perspectives on TB. It aims to change behaviour – such as persuading people with symptoms to seek treatment – and to foster social change, supporting processes in the community or elsewhere to spark debate that may shift social mores and/or eliminate barriers to new behaviour.

Social mobilization

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.

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 Patients' Charter for Tuberculosis Care (see Annex K) outlines the rights and responsibilities of people with TB. Initiated and developed by patients from around the world, The Patients' Charter 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.

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. 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 show, karaoke songs and contests. Other activities unique to a particular country or region may provide even better opportunities to engage and motivate individuals.

Although distinct from one another, advocacy, communication and social mobilization (ACSM) are most effective when used together. ACSM activities should therefore be developed in parallel and not separately.

2. Why is ACSM essential to the Stop TB strategy?

The Stop TB global strategy, launched by the Stop TB Partnership in January 2006, has six major goals.

1) To pursue high-quality expansion and enhancement of directly observed treatment (DOTS) – short course.
2) To address the co-occurrence of TB and HIV, multidrug-resistant TB (MDR-TB) and other challenges.
3) To contribute to strengthening of health systems.
4) To engage all caregivers.
5) To empower people with TB and their communities.
6) To enable and promote research.

ACSM activities can be used to achieve all six goals. Incorporating ACSM activities as an integral part of reaching objectives set by national TB programmes (NTPs) is an effective approach to TB control. Over the years, ACSM has been used successfully to address four key challenges:

- improving case detection and treatment adherence;
- combating stigma and discrimination;
- empowering people affected by TB;
- mobilizing political commitment and resources for TB.

Examples of these success stories are provided throughout this handbook.

3. How to identify TB control challenges that can be addressed through ACSM

Tuberculosis control presents many challenges, such as:

- delayed detection and treatment;
- lack of access to TB treatment;
- difficulty in completing treatment;
- lack of knowledge and information about TB that can lead to stigma, discrimination and delayed diagnosis and/or treatment;
- stigma and discrimination that can prevent people from seeking care and diagnosis;
- misunderstandings and myths surrounding TB, including the belief that it is "untreatable";
- weak political support for TB programmes;
- insufficient funding for TB programmes.

Despite increased attention and funding in recent years, these challenges have been difficult to overcome. ACSM strategies however contribute to addressing many of them successfully.

Inadequate funding and lack of political will has slowed both the development of appropriate TB control policies and their successful implementation at the central, district and local levels. Even when good TB policies exist, there is often a gap between the policies and the programmes being implemented. Experience suggests that TB control services are negatively affected if there is no strong commitment from particular sectors of society, such as decision-makers, influential political and community leaders. TB programme planners therefore need to acknowledge the challenges related to insufficient political commitment and to consider how ACSM strategies can improve political will.

If people affected by TB can be involved in designing, planning and implementing control strategies, their concerns and the daily difficulties they face will be better reflected. As noted in the 10-year framework, "there is an urgent need for processes that will facilitate and empower communities most affected by TB to participate in, take ownership of and drive the agenda for the elimination of TB". Community empowerment has been shown to be effective in HIV/AIDS programmes and in implementing DOTS programmes.

Public stigma is often the reason people with TB do not seek diagnosis or care. Improved public education and awareness-raising initiatives about what causes TB, how it is transmitted and whether it can be cured can help to mitigate the stigma, not only among health-care workers but also among the general public.

Chapter 1:
Understanding advocacy, communication and social mobilization

By the end of Chapter 1, the reader will know:
1) how ACSM activities have been used to improve tuberculosis control; and
2) how an integrated approach, incorporating ACSM, is most effective.

1. How ACSM activities have been used to improve TB control

Decades of experience with a wide spectrum of public health programmes, including promotion of new behaviour and new medical products (such as contraceptives, drugs and vaccines), have shown repeatedly that ACSM creates positive behaviour change, influences decision-makers, and engages and empowers communities to change. NTPs need to develop ACSM strategies according to the specific epidemiological, socioeconomic and other realities of countries.

The following examples demonstrate how ACSM strategies have the potential to improve case detection and treatment adherence, reduce stigma and discrimination, empower people with TB and mobilize political commitment.

In both **Peru** and **Viet Nam** advocacy fostered political commitment and involvement at all levels and kept TB in the national spotlight. Mass media educated the public and motivated people to use services and complete their treatment. In both countries, all the personnel involved in the TB programme were given training in interpersonal communication and counselling to improve the relationship between provider and client and ensure completion of treatment. As a result, both countries noted that the rate of treatment abandonment decreased as the programmes progressed. Community mobilization activities educated the public and reduced stigma associated with TB while also creating a supportive environment for case detection and treatment. Over time, both countries met the WHO targets for TB control. This involved a long-term commitment: each country took almost a decade to reach the global targets.

In **Colombia**, a mass-media campaign resulted in an increase of 64% in the number of direct smears processed by the laboratories and an increase of 52% in the number of new cases of positive pulmonary TB, as compared to the pre-campaign level. This demonstrates the key role of communication in improving TB control. In **Viet Nam**, the NTP ensured that all messages about TB – regardless of whether they were through interpersonal communication or community-based media such as local theatre – were consistent. Evaluations of the programme revealed that 80% of the people responding to a nationally representative survey knew that TB was a communicable disease, could list basic TB symptoms, knew TB was curable, and understood that they should go to a government health centre for treatment rather than trying to treat symptoms on their own.

Experiences in **India** demonstrate the value of community involvement and mobilization in linking DOTS clinics with private health providers and volunteers to diagnose early and complete treatment.

In **Nigeria**, after discovering that some health-care workers preferred not to be posted to TB clinics, periodic "enlightenment" seminars and workshops on TB and TB treatment procedures were held for medical personnel. Anti-stigma training and education helped to ensure that health workers (both providers of TB services and administrative staff) received accurate information on TB and developed greater sensitivity to the needs of people with TB. Nigeria also held community-based rallies and church services to dispel rumours and reach people with messages about TB.

Experiences in **Mexico** and **Peru** strongly demonstrate that using social mobilization to fight TB can bring about changes that influence social development in other ways. Intensive activities were sustained over time in both countries. These included advocacy, mass media, local media, counselling and community mobilization. Peru collaborated with community surveillance units and mothers' groups to create links between health facilities and the community and to develop materials that would appeal to people with TB. Mexico designated "champions" in most states to lead and participate in activities to keep TB programmes visible and to engage communities. Notably, political will to improve TB control was strong in both Mexico and Peru – a factor that increases the chance of ACSM activities being successful.

Viet Nam reached out to community-based organizations such as associations of elders, farmers associations, women's unions and youth unions to organize activities and serve as peer educators. **Ethiopia** tapped into "TB clubs" to provide peer support that was shown to eventually boost treatment compliance.

In the Western Cape of **South Africa** limited health-care access was viewed as a significant obstacle to reducing TB cases. Farm workers in the Boland Winelands district sponsored a community member to attend lay health-care worker training. Armed with new-found skills and primary health-care knowledge, the lay health-care workers conducted monthly weighing and TB screenings, referred people with TB symptoms to the local clinic, administered DOTS treatment, supported families affected by TB, treated minor ailments, and educated the community to give them an understanding of basic health issues. This social mobilization effort has led to a significant increase in compliance with treatment.

Health workers stimulate people to talk to each other about TB issues. TB action committees involving employers, employees, farm lay workers and community resources such as schools, churches, social workers, NGOs, health representatives and the agricultural private sector have been formed. These committees address lifestyle challenges faced by the farming community by organizing and developing capacity-building events, recreational and health promotion activities for women, men and youth.

In **Brazil**, government officials in the states of Rio de Janeiro and São Paulo helped to establish nongovernmental organizations (NGOs) and to get existing HIV/AIDS NGOs engaged with TB. This included the São Paulo State Forum of AIDS NGOs that supports 180 community-based organizations in fighting HIV/AIDS. Groups in both states have initiated efforts to engage and educate the broader public to give them an understanding of TB and the relationship between HIV and TB.

2. Why an integrated ACSM approach is most effective

The experiences described above show the need for an integrated approach – incorporating ACSM – to maximize impact. As shown in Viet Nam and Peru specifically, integrating communication activities into all TB control programme activities not only led to meeting global targets for TB control, but also helped combat various obstacles along the way, such as political and environmental challenges and long-standing stigma among health-care workers and the general public.

"...ACSM creates positive behaviour change, influences decision-makers, and engages and empowers communities to change."

Chapter 2:
Developing a TB strategy incorporating ACSM

By the end of Chapter 2, the reader will have learnt how to assess strategic ACSM needs for a TB programme.

To develop an effective TB strategy that incorporates ACSM activities begin by obtaining accurate information on the country's TB problem. Much of this can be done through a very basic situation analysis – ideally by the NTP or another national authority that has the technical cooperation of WHO, NGOs, other international organizations and people affected by TB. A needs assessment tool has been developed by the Stop TB Partnership to assist in country-level planning. Though not specifically intended to assess ACSM needs, this tool provides an idea of what a needs assessments would involve. Chapter 4 addresses needs assessments specifically for ACSM.

The situation analysis should gather basic information on different TB issues in each region of the country. The information required includes:

- demographics and socioeconomic status;
- epidemiology of TB in the country;
- the political environment;
- other TB control activities in the country (focus on what is effective and what is not working – such as why some activities are successful and why they work, as well as why other activities do not work as well as anticipated).

Once this type of information has been collected, NTP managers and technical staff can determine the programme goals and the most significant constraints to TB control, then consider how ACSM activities can help.

The analysis might reveal a wide range of challenges that should be addressed, such as:

- the DOTS strategy not being implemented;
- the TB programme not being a high political priority;
- an increasing prevalence in MDR-TB;
- an increase in the prevalence of HIV/AIDS that is directly affecting TB morbidity and transmission of TB infection.

The questions in the table below focus on how to overcome these challenges and assess the issues. Space is provided to answer the questions.

What obstacles prevent implementation of interventions or preventive actions?
Why do these obstacles exist?
How can these obstacles be removed?
What opportunities exist for addressing these obstacles?
Who "controls" these opportunities?
What must be done to "capture" these opportunities?

Five tools that help with strategic assessment are described below. Annex A contains more information on each.

- **The P process:** Created by Johns Hopkins University, the P process lays out a logical framework for a communication intervention – analysis, strategic design, development and testing, implementation and monitoring, evaluation and re-planning. The process has been applied to a wide range of health issues.

The communication-for-behavioural-impact (COMBI) approach: Developed by the WHO Social Mobilization and Training Team, this approach aims to mobilize social and personal influences to prompt behaviour change and maintenance at individual and family levels.

- Johns Hopkins University's **outcome map** to strengthen the DOTS strategy: This planning tool matches communication responses to programme needs and outlines key planning and measurement indicators. The outcome map retrofits communication interventions onto the well-established but medically-oriented DOTS strategy for TB control. It enhances DOTS to include demand generation for high quality DOTS services and suggests strategies to encourage adherence and treatment completion.

- The **communication for social change approach** advocated by the Communication for Social Change Consortium: Through public and private dialogue people define who they are, what they need and how to get what they need to improve their own lives. This approach uses dialogue that leads to collective problem identification, decision-making and community-based implementation of solutions. It is communication that supports decision-making by those who are most affected by the decisions being made. This is especially appropriate for strategies where social mores – such as stigma – act as a barrier to behaviour change.

- The **"cough-to-cure" pathway** is another tool that can be used to guide the strategic planning process. Developed by the Academy for Educational Development (AED), the pathway helps TB control programmes identify where drop-outs are occurring. It identifies six steps to ideal behaviour in TB control and the most common barriers at the individual, group and system levels. It is based on the idea that understanding the behaviour of people living with TB is fundamental to designing interventions to strengthen NTPs, including communication interventions. More details on the pathway are provided in Chapter 4 and Annex A.

Ultimately, decisions on which strategies and approaches are most appropriate need to be taken at country level within the context of the NTP.

"To develop an effective TB strategy that incorporates ACSM activities begin by obtaining accurate information on the country's TB problem."

CASE STUDY no. 1

Using epidemiological data to identify strategic needs in Indonesia

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; and
- 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.

Chapter 3:
Maximizing skills through partnerships

By the end of Chapter 3, the reader will understand the importance of collaborative management skills to:
1) identify and involve stakeholders;
2) assess and build capacity and resources;
3) assign roles and responsibilities;
4) manage partnerships;
5) create and manage budgets.

To carry out ACSM activities successfully, it is important to review the unique skills and resources that the NTP already has, then assess what additional skills might be needed and how to obtain them. Because TB is such a multisectoral, multilevel health problem, effective TB control programmes must establish and nurture partnerships to maximize contributions from different organizations. The NTP might want to consider hiring specific ACSM staff with management skills to lead these activities.

Decentralized health services also require planning and managing ACSM at district and community levels. Evidence and experience suggest that the scarcity of skills in ACSM at the district level contributes substantially to implementation problems. In addition, staff at public and private health institutions, NGOs and community-based organizations need technical support in planning, implementing, monitoring and evaluating ACSM.

There are several steps to maximize collaboration, such as the following.

1. Identify and involve stakeholders

The first step in collaborative management is to identify and involve stakeholders. In addition to the NTP, organizations of people affected by TB, technical institutions, donors and private organizations are also involved in TB control. Collaborating with these organizations is crucial because in many countries the NTP may not have the resources, knowledge nor the capacity to develop and carry out ACSM strategies and activities.

Sometimes ACSM skills and resources may be found in organizations outside the health arena. It is worth while considering whether such groups – with insight into local social and cultural approaches based on knowledge from working and empowering communities – could either help and participate in TB activities or even be brought in as consultants to strengthen the local and national capacity for ACSM.

If an official partnership with other organizations is formed, the NTP does not have to lead it. This could be done by one of the other organizations in the partnership that has appropriate experience.

2. Assess and build capacity and resources

Stakeholders and other organizational partners come with skills, experience and resources. It is important to assess the types of skills, strengths and other resources available among these partner organizations and to assess any deficiencies or needs within the partnership that should be addressed and filled.

Meanwhile, to avoid duplication of effort, research any related activities that partner organizations or others may be conducting in the country. Some assessment questions are outlined below.

- Does a TB partnership already exist in the country?
- What existing platforms or programmes (such as HIV/AIDS or malaria programmes) could be built on?
- What resource groups – such as media professionals, production agencies, patient organizations, NGOs and other professional groups in the country – could help plan, develop and implement ACSM?
- Is money available for TB activities in the country? What sources exist?

The 10-year framework recommends seeking support (skills and finances) from multinational and national commercial corporations. Such public–private partnerships can benefit NTPs substantially and provide good public relations for the corporations concerned.

At the same time, TB advocates must have access to technical advice from appropriate agencies to build and sustain ACSM capacity. This may include contacting the public relations/communications staff from the ministry of health, United Nations organizations and other specialized ACSM training agencies to assist either with data collection and access or with implementing activities.

3. Assign roles and responsibilities

Developing a partnership plan helps in assigning roles and responsibilities to the various stakeholder organizations. Responsibilities can include running the day-to-day functions of the ACSM initiative or organizing a specific event. Institutions should lead activities related to their own particular area(s) of expertise. Specific responsibilities for partners could be to:

- participate in strategic planning and in designing ACSM activities;
- create a plan for monitoring and evaluating activities;
- make connections with political leaders;

- give presentations to key decision-makers;
- create advertising about the programme's priority themes and messages;
- purchase advertising time and space;
- underwrite communication materials or activities developed with the NTP;
- print, promote and distribute materials;
- sponsor publicity and promotional activities;
- develop a list of key media contacts;
- develop relationships with health reporters and other media contacts;
- engage TB-affected community members in the development and implementation of ACSM activities.

A staff member should be designated to identify and involve stakeholders and coordinate roles and responsibilities.

4. Manage partnerships

The person selected to coordinate work with all partners should be:

- a good time-manager who is able to balance several components of ACSM initiatives at once;
- a team player who is:
  - able to work with other organizations;
  - willing and able to negotiate;
  - willing to share credit for success.

Above all, frequent two-way communication is essential to productive partnerships. Following are some guidelines that can be used to create and maintain successful partnerships. Space is provided to write some thoughts on addressing them.

If possible, formalize the relationship to create greater commitment. *Formal arrangements include written memoranda of understanding, by-laws, mission statements and/or regular reminders of the partnership's purpose and progress.*

Make the responsibilities of each organization and its staff clear. *In particular, people need to know who will give direction. Consider writing sample job descriptions or draft a memorandum of understanding for each partner.*

Structure aspects of the partnership's operation. *Consider electing officers, forming standing committees or having regularly scheduled meetings with written agenda and minutes. Expect and support action, not just discussion, at these meetings. Circulate action items that result from meetings among partnership members. Follow up to make*

Create and reinforce positive expectations by providing information on the partnership's progress. *Optimism and success sustain member interest; report even small successes.*

Formalize accountability and develop criteria for judging whether partners are honouring their commitments.

Be flexible about partners' needs and constraints. *Losing prospective partners by not making compromises or not considering an organization's needs can limit the effectiveness of interventions and activities.*

Provide training to help members complete their tasks. *For example, partners may need to learn how to be effective advocates for programme issues.*

Involve members in the ACSM endeavour and in decision-making. *Also give them credit for successes and other tasks that they accomplish.*

Evaluate the effectiveness of the partnerships periodically and make necessary changes. *Conduct a process evaluation of how the partnership functions and assess its impact on the health problems being addressed.*