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

A HANDBOOK FOR COUNTRY PROGRAMMES

World Health Organization

Stop TB Partnership

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

A HANDBOOK FOR COUNTRY PROGRAMMES

WHO Library Cataloguing-in-Publication Data

Advocacy, communication and social mobilization (ACSM) for tuberculosis control : a handbook for country programmes.

1. Tuberculosis - prevention and control.
2. Behavior therapy.
3. Patient advocacy.
4. Consumer participation.
5. National health programs.

I. World Health Organization.
II. Stop TB Partnership.

ISBN 978 92 4 159618 3 (NLM classification: WF 200)

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.

December 2007

Table of contents

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 sure all partners have accomplished their action items; this will foster greater ownership of activities and promote accountability. Establish communication channels and use them frequently.*

Involve people who show leadership characteristics, such as the ability to obtain resources, solve problems and promote collaboration and equality among members. *Members with political knowledge, administrative or communication skills, access to the media and to decision-makers can also be valuable.*

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.*

As with most aspects of ACSM activities, working with partnerships is not static. Programme officers should always be looking for – and considering – new partnering opportunities.

5. Create and manage budgets

It is important to create a realistic ACSM budget at the beginning of the partnership. This should reflect pre-planning and intended activities. Partners should understand the overall budget for the activities as well as the budget for the respective components in which they are involved. Make sure adequate funds are allocated for:

- meeting and work space;
- formative research;
- material and product development (including pre-testing) and production;
- material distribution and storage;
- staff and consultants (specify the amount of time needed);
- revisions to materials and activities, based on feedback from implementers;
- process and outcome evaluation;
- payment of external technical or creative experts as needed;
- miscellaneous costs of the partner organizations such as transportation, telephone and postage.

It is also helpful to prioritize programme activities in case funding is reduced. Make a breakdown to show the steps involved in each activity that is being considered; provide resources for each step.

Partner organizations can augment existing resources in various ways. For example, some partners might be able to contribute by photocopying materials while others may be able to donate office space for meetings. When planning ACSM activities, draw up a checklist of activities, products and other resources that might be needed. If the NTP does not already have some of these services or items, identify potential organizations that might be willing to donate them.

“It is important to create a realistic ACSM budget at the beginning of the partnership. This should reflect pre-planning and intended activities.”

CASE STUDY no. 2

Private sector collaboration in Cambodia

The Pharmacists Association of Cambodia (PAC) is the NTP’s main private-sector partner in Cambodia. PAC’s role has been to mobilize registered pharmacies and encourage pharmacists to identify and refer people suspected of having TB to DOTS services. PAC also facilitates pharmacy staff training, oversees monthly supportive supervision activities, and coordinates and communicates with the public sector within the operational districts where the project is active.

PATH provided technical assistance to strengthen the PAC team – four staff members led by a senior member – in project management, project implementation and advocacy. This assistance included the development of strategies, workplans, PAC terms of reference and the budget.

The municipal health department, which regulates all private-sector activities, developed a memorandum of understanding with the NTP early in the project. The memorandum of understanding stipulates that each pharmacy agrees to:

1) participate in the DOTS activities of the TB public–private mix network in Phnom Penh;
2) cooperate with NTP, the municipal health department, operational districts and related organizations until the end of the pilot activity;
3) participate in training and workshops related to Stop TB;
4) in accordance with national TB guidelines, provide and disseminate accurate information about TB to people suspected of having the active disease;
5) refer all clients with potentially active TB to a public health facility providing TB services;
6) complete the referral coupon before referring any client to a service;
7) keep records of any referrals made and provide this information to project coordinators every month; and
8) agree to be supervised by the project coordinators and staff of the operational districts, the municipal health department and partner organizations.

During an orientation workshop, the memorandum of understanding is shared with the private-sector pharmacists who provide feedback.

The revised memorandum of understanding between the municipal health department and the providers is signed at the start of each training session. It is also used by the PAC team as a tool to measure performance during supervisory visits. The use of the memorandum of understanding as a management and monitoring tool has been adapted by the provincial health departments and is now used by all private providers in the TB public-private mix network.

SECTION 2

Core development process

Chapter 4:
Conducting a situation /needs assessment

By the end of Chapter 4, the reader will know how to conduct a situation or needs assessment for ACSM activities by:
1) identifying challenges, priority populations and key behaviours
2) relating "ideal behaviours" and goals
3) identifying factors and activities to enable ideal behaviours
4) considering the assets and context of partners and related programmes
5) considering the research methodologies that will be needed
6) using assessment findings
7) creating strategic objectives for ACSM.

Before planning ACSM activities make an assessment of the needs. The Stop TB Partnership's advocacy and communication checklist can be used in assessing these components of the NTP. Reviewing this checklist (see Annex B) might help identify strategic ACSM activities.

The needs assessment process should begin by identifying the challenge to be addressed. This important first step enables programmes to focus on the types of information that need to be gathered, the types of populations they want to focus on, the key behaviour they want to affect –or the changes they want to effect – and how best to promote change.

1. Identifying challenges, priority populations and key behaviour

Many challenges identified in Chapter 2 can be addressed by ACSM. Once the NTP identifies the challenges to address, the next steps are to identify priority populations to reach with advocacy, behaviour-change communication and social mobilization efforts.

NTP staff members have often targeted groups where TB detection and control rates need to be improved. In many countries, the populations most at risk of catching TB include individuals suffering from narcotics addictions, indigenous groups and ethnic minorities, migrant workers and people living in poverty, in prison or with HIV/AIDS.

The following questions help determine which populations should be influenced to change.

- Which populations have the highest rates of TB?
- Which groups usually delay diagnosis or treatment – such as drug/alcohol users, indigenous populations, homeless individuals, migrant workers, people in prisons/jails or people living in poverty?
- Which individuals begin DOTS but often do not complete treatment?
- What common factors are present in programmes where individuals are diagnosed, begin DOTS, complete their treatment and are cured? What has worked, why and how?

Answers to the following questions can help guide TB advocacy efforts.

- Which individuals can either change policies or allocate funds for TB prevention and control?
- Who has supported or opposed TB control efforts? What have these individuals said publicly?

The following questions will obtain information to inform social mobilization activities.

- Which communities have large populations affected by TB? How have these communities been affected by the high rates of TB? Describe the characteristics of these communities. Identify respected community leaders or social organizers.
- Do medical/health service facilities exist in the community? What services and care do they provide? What TB services do they provide? Who visits the health centres?
- Where do people learn about health issues? Where do people gather when they have questions? Who do they ask for information? Do local media or other news sources exist?
- Do any businesses in the community employ large numbers of people? If so, have these businesses provided any TB screening, treatment or resources?

Once information on the priority groups has been gathered, ACSM planners must determine how to engage the populations effectively. Planners identify key behaviour that affectsTB; they then examine the factors that motivate people to change as well as the barriers they may encounter in making such changes. Other factors not related to a patients' behaviour, such as poorly trained health-care workers administering DOTS, can also contribute to the problem.

The table on p.16 provides questions– with space to write the answers – to help analyse key behaviour in identified populations. Create a separate table for each population/ group.

Answering the above questions may help to rule out certain segments of the population. This should make it easier for a programme to decide on message development and dissemination and to ensure that programme resources are spent effectively.

In some cases, initial research and assessment of information needs may have uncovered adequate information about the affected population, particularly if knowledge, attitude and practice (KAP) surveys or other behavioural studies have already been conducted. For ACSM interventions, KAP survey results can help identify key behaviours. If there is not enough existing information about the affected population, the NTP team will need to decide what types of information may be needed and determine how to obtain it. This could be something simple like interviewing or observing people in the affected population.

2. Relating "ideal behaviour" to goals

It is helpful to determine how "ideal behaviour" relates to the overall goals of the NTP or ACSM activities. For example, the ideal behaviour of going to a health-care provider at the first signs of possible TB infection relates directly to the NTP goal of increasing the case-detection rate for TB. Planners should make sure that the ideal behaviour they want to promote in their messages and activities is somehow connected to the goals of the NTP.

Some examples of "ideal behaviour" are outlined below.

For the general public or at-risk populations:
- going to a health-care provider at the first signs of possible TB infection;
- going to the proper facility to get tested for TB if a family member, friend or someone they work with has the disease or if they have been exposed to the disease in other ways;
- initiating and completing DOTS treatment if they are diagnosed;
- taking medicine every day, even after they feel better;
- practicing good hygiene, like covering the mouth when laughing or coughing.

For health-care providers:
- following the correct protocols for treatment of TB – this includes knowing how to administer DOTS and what treatment path to take in the case of MDR or XDR TB;
- following proper infection-control procedures in the health-care facility;
- counselling people with TB on the types of behaviour that will prevent the transmission of the disease to others (e.g., covering the mouth when they laugh or cough) and providing guidance on how to best comply with the TB treatment.

The **cough to cure pathway** helps identify ideal behaviour and factors that affect it. This tool lists the ideal steps to take, from the identification of symptoms to the completion of treatment, such as to:
- seek timely care;
- go a DOTS facility;
- get an accurate diagnosis;
- begin treatment;
- persist in getting treatment; and
- complete treatment.

The cough to cure pathway shows how the interrelationship between individual behaviour, social factors and DOTS services affect treatment-seeking and completion. It also identifies the individual, group and system barriers or facilitating factors that may hinder or help an individual's ability to complete each step. Annex A has more information on the cough to cure pathway.

3. Identifying factors and activities to enable ideal behaviour

The cough to cure pathway can also help in identifying motivators or enabling factors that facilitate an intended behaviour change or barriers to ideal behaviour.
- What influences a person with TB to stay on, or veer off, the cough to cure pathway?
- What are the barriers to continuing along the pathway?
- Do any personal, social and/or system-wide obstacles exist (e.g., does TB stigma or a lack of nearby health facilities prevent people from seeking diagnosis or care)?
- Are the knowledge, attitudes or practices of the people with TB or the health providers preventing people from completing the pathway (for example, do people neither recognize the symptoms of TB nor know that they should seek care in the first place? When do people begin to feel better? Do they consider themselves "cured" and stop treatment before the DOTS regimen is finished?)

- What ACSM objectives are realistic for the target population?
- What is the behaviour or policy that needs to be changed?
- How willing is this population to make that change?
Note: In many cases a population cannot make a behaviour change until a policy change is instituted or a new or improved product has been developed. If the NTP cannot affect (or effect) the change that might be needed (such as development of new treatments for TB), consider other priority groups or objectives.

- Will achieving** this/these **ACSM objective/s** [as identified above] **with this population contribute to attaining the TB programme goal?
- Will the desired changes in behaviour, policies, funding levels or other objectives make a worthwhile contribution to programme goals?

***- To what extent would members of this population benefit from different ACSM interventions/efforts?** Note: Some parts of the population may already engage in the desired behaviour or may be on the way toward implementing a necessary policy change.*

- How effectively can this population be reached through available resources and channels?
- Will mass communication (e.g., mass media, public events) reach the intended population best, or will something more interpersonal – like one-on-one skill modelling – better help these individuals make a change in behaviour, opinion or policy?

- To what extent do other populations influence the primary priority group?
- Whose opinions matter to the group being influenced? Is it possible to influence them?

- To what extent can progress be measured?
- Is it possible to gather information on the desired change?
Note: It is relatively easy to gather information in the case of policy changes, increases in funding or passage of new laws. It might not be as easy to measure whether misconceptions related to TB still abound. (For more ideas on ways to measure progress, see Chapter 9.)

Identifying what people care about also helps in tailoring messages and interventions to resonate with the group in question. For example, in a culture that places a great value on caring for family members, messages can emphasize the importance of staying healthy, and getting diagnosed and treated, so as to be better able to take care of the family. If a population trusts traditional healers, messages might state that these individuals endorse DOTS. Or, if certain people tend to avoid care in public health facilities, messages can emphasize that care can be obtained at specific types of private sector facilities.

ACSM activities need to enable ideal behaviour. This means that a variety of activities should be undertaken to address the diversity of barriers to TB prevention and control.

As a general rule, advocacy activities aim to address:

- structural or systemic issues (such as the lack of community DOTS programmes);
- communication interventions;
- individual and social barriers (such as stigma, risk perception and knowledge among populations and health staff); and
- social mobilization activities that promote changes throughout a community or priority group.

The activities chosen, whether in the areas of advocacy, communication or social mobilization, should mean something to the people who are to be influenced or affected. That means reaching these people where they already are. For example, when education on TB treatment is needed for migrant populations, communication activities and materials should be provided where the migrants live and work, through people they interact with on a daily basis, and not at clinics. Such a strategy has been employed successfully by HIV/AIDS programmes in educating truck drivers about HIV prevention at highway truck stops or roadside clinics.

Chapter 5 provides additional guidance on how to match activities and strategies to goals; it also describes examples of activities that can be used to meet the goals.

4. Considering the assets and context of partners and related programmes

To maximize available resources and increase the impact of ACSM activities, consider what partner organizations can contribute. Partners and related programmes (such as HIV/AIDS programmes) can offer useful platforms from which to launch ACSM activities or distribute material; their existing activities may also be used to reach people with TB. Consult members of the Stop TB Partnership first. Also, consider:

- organizations and individuals that may have a connection to priority populations such as community groups, faith-based organizations, local schools and universities, professional organizations, traditional healers' groups, women's unions and youth unions;
- the regional office of the International Union Against Tuberculosis and Lung Disease; and
- TB patient–activist associations that may have valuable experience working with stakeholders and networks and/or access to community resources.

An often-neglected source of support is the private health sector. In some countries, people are increasingly going outside public health facilities for diagnosis and treatment for various illnesses. Private sector providers (both "for-profit" and "not-for-profit") are often geographically and culturally closer to the community than the state-run services. Engaging with these private providers and building on their existing assets and networks might help to make ACSM activities for TB sustainable and allow for greater geographical impact.

Organizations that could assist with advocacy, social mobilization and information-dissemination activities could be the large-scale networks of national/international NGOs and civil society organizations that are actively fighting poverty and working to address the Millennium Development Goals, such as the *Make Poverty History* campaign. Other coalitions of organizations that could assist with advocacy and social mobilization or, at least, serve as a source of experience and "lessons learnt", include NGOs, trade unions and community-based groups that may also be engaged in national and regional interventions to address the Millennium Development Goals.

5. Considering the research methodologies that will be needed

Several research methodologies can help programme planners identify problems, resources and strategies. Quantitative and qualitative methods differ in their respective underlying approaches, tools and techniques. Participatory assessments engage respondents in shaping the questions that will be asked.

Quantitative methods include surveys on knowledge, attitudes and behaviour. Closed-ended questions are asked through questionnaires distributed to a random sample of individuals. The individuals questioned can be from target populations and sometimes from a control group also.

Qualitative methods focus less on precise measurement of predetermined questions and more on a holistic understanding of complex realities and processes. The methods include focus groups, informal interviews, in-

depth interviews, participant observation and visual media such as photography and video. Questions are broad and open ended; they change and develop over time.

Participatory assessments are particularly useful when trying to promote change at the community level. Participatory assessments ensure that the social, cultural and economic conditions of the community are included. By sharing in the selection and design of research projects, communities gain skills and are in a position to make use of the results in future health-care activities. In this way important health issues can be activated and sustained by the community.

6. Using assessment findings

Consider how the assessment findings can be used for ACSM activities. Some uses are described below.

Use findings in advocacy

- Integrate KAP statistics into TB information materials and media packages distributed to mass media, journalists and key decision-makers.
- Educate political leaders and encourage them to draw attention to the fight against TB-related stigma in their public addresses.
- Show knowledge gaps or identify populations with special needs.

Use findings in communication

- Create specific messages to inform the public about TB and the benefits of completing treatment.
- Design interpersonal communication and counselling training for health workers.
- Develop educational materials and messages to encourage family members of people with TB to take an active role in care.

Using findings in social mobilization

- Raise awareness of TB prevention, symptoms and treatment by ensuring that programme staff go to community events that are well-attended by people at high risk of TB.
- Generate community dialogue during village or community meetings to discuss factors affecting TB diagnosis and care.
- Employ the media channels that the KAP survey has identified as the most accessible and preferred by members of the group you want to reach.

7. Creating strategic objectives for ACSM

A strategic objective states how a goal will be achieved. A few example strategic objective statements are given below.

- Increase awareness of epidemiological status of TB and the sociodemographic profile among decision-makers in governments.
- Increase support for TB services among local leaders.
- Increase knowledge of TB care services (the location, no costs involved) among specific populations, such as miners or seasonal migrants.
- Reduce stigma related to TB and people affected by TB in peri-urban communities.
- Increase knowledge of “incentive programmes” (e.g. transport and food vouchers) offered by TB services among rural populations.
- Increase risk perception of TB in specific neighbourhoods or areas with high rates of TB but low diagnostic and treatment rates.
- Educate maternal health clinic workers to know how they can incorporate TB services into their programmes.

Statements such as the above can be used to develop messages and activities, and to help remind the NTP and partners of the goal of ACSM efforts.

“By sharing in the selection and design of research projects, communities gain skills and are in a position to make use of the results in future health-care activities.”

CASE STUDY no. 3

Needs assessment to support implementation of the national TB programme in Ukraine

In Ukraine, the TB programme’s needs assessments collected data through quantitative and qualitative methods. Baseline data from several specific populations residing in Donetska oblast and Kyiv city were collected to assess programmatic gaps in the implementation of the NTP. This formative research aimed to explore the needs, behavioural practices, and knowledge of select populations, clarify the best channels and formats for providing TB information, and evaluate client satisfaction with the performance of their doctors. The assessment techniques included:

- a KAP survey among the general public and among open market vendors, food bank clients and former prisoners;
- focus-group discussions with people living with HIV and AIDS; and
- an exit survey among patients undergoing TB care.

The exit survey focused on evaluating client satisfaction with client-provider communication. Patients often cited poor interaction with providers as a reason for the delay in seeking TB diagnosis or for stopping TB treatment. They suggested that establishing rapport between the health worker and the patient was a critical element of the communication activities of TB control. Effective communication depends on the patient’s ability to understand the terms the health worker uses and to respond in words and language the health worker understands. The health worker must treat patients with respect and sympathy, listen to them and express interest in their welfare and recovery, and simplify questions about issues the patient may not understand. Most doctors in Ukraine have never received counselling or communication skills training and client-provider communication does not include psychological support and counselling.

Focus group discussions on TB services, conducted with people living with HIV and AIDS, identified a need to improve collaboration and integration between the TB and HIV services. The needs assessment thus led to the development of a three-day training course in effective communication and counselling for TB doctors. This training covered: 1) interpersonal communication, 2) steps in effective counselling, 3) counselling on TB, and 4) diagnostic counselling and testing of TB patients for HIV. The three-day course uses participatory methods including role-play exercises with video playback and discussion.

This course was given to TB carers in Kyiv city and Donetska oblast and has been incorporated into the national TB strategy as a key intervention to reduce diagnostic delay, increase case detection and improve treatment adherence.

Chapter 5:
Designing ACSM interventions

By the end of Chapter 5, the reader will know how to:
1) design effective ACSM interventions by matching NTP goals with appropriate ACSM activities;
2) assign roles and responsibilities and coordinate activities;
3) set and follow realistic timelines.

1. Design effective ACSM interventions by matching NTP goals with appropriate ACSM activities

Linking ACSM goals with activities strengthens overall programme effectiveness. Several ACSM approaches can be considered for TB. Decisions on which approach or combination of approaches to use should take into account the benefits and risks, the time frame and the expertise and financial resources needed for effective implementation. Annex C provides a list of ACSM goals (indicators).

The table opposite[1] shows a few NTP goals and examples of ACSM approaches and activities that can be used to meet them.

2. Assign roles, responsibilities and coordinate activities

As part of determining roles and responsibilities, undertake an honest assessment of available resources in the NTP and among the partners. In many cases, an existing platform such as an HIV/AIDS programme that provides resources or counselling to people co-infected with TB and HIV (or their caregivers) or a health-related seminar for policy-makers, can be used to conduct activities and distribute messages on TB. The NTP should draw up a table to show the roles and responsibilities assigned then ensure that everyone involved in the activity has access to it and agrees to their respective assignments.

A sample table to help coordinate various players and their responsibilities is provided below.

Organization Name & Type of Organization	Contact Person/ Contact Information	Activities Responsible For	Timeline/Due Date for Activities	Status
1)				
2)				
3)				
4)				

[1] Adapted from *The Role of Health Communication in Achieving Global TB Control Goals: Lessons from Peru, Viet Nam and Beyond*. Health Communication Partnership, Johns Hopkins Bloomberg School of Public Health/Center for Communication Programs, 2004.

NTP GOAL	ACSM APPROACHES	ACTIVITIES & CHANNELS
Gaining political commitment for TB control	• Educate national policy makers and political leaders about the health and economic benefits of TB control. Aim to have TB declared a national health priority • Educate local and community level authorities to encourage them to contribute to TB control efforts • Solicit support of international and national partners	• Seminars and briefing meetings • Print information (letters, fact sheets) • Events around World TB Day and other occasions.
Improving case detection	• Raise public awareness about TB • Reduce stigma against people with TB and correct misconceptions about TB infection by actively involving current and former TB patients • Help health workers, communities and individuals identify TB cases • Encourage individuals to seek care from appropriate sources • Target hard-to-reach populations (prisoners, urban poor, homeless)	• Formative research to determine best messages and approaches • Mass media including radio and television • Distribution of print materials at community meetings or events • Interpersonal communication and counselling training for health workers • Community mobilization activities
Increasing treatment success and discouraging the spread of MDR TB	• Give people with TB hope of complete cure • Encourage people with TB to seek treatment from appropriate sources • Provide materials to counsellors • Encourage people with TB to complete treatment even if they improve before treatment ends • Make people with TB aware of possible side effects and where to seek care if present • Encourage health workers, family and community members to directly observe people with TB taking their medicine • Engage people who are fully recovered to encourage people currently affected by TB to complete treatment	• Interpersonal communication and counselling training for health workers • Mass media including radio and television • Extensive distribution of print materials at health care facilities • Community mobilization activities • Peer education at community or interest group meetings

3. Set and follow realistic timelines

Allocate time wisely when designing ACSM activities. Create a timeline with realistic expectations. Consider the preparatory activities that need to be addressed first, then identify the subsequent sequence of activities involved. Estimate how long each activity will take.

Many factors can accelerate or slow down ACSM activities and must be considered when creating a timeline. Some factors might include conflicting partner schedules and unavailability, delays with producing and printing materials, holidays or other observances, unexpected illnesses among key personnel, and political transitions or civil society unrest. Think about occurrences or conditions that have created delays in the past, and factor those into the timeline.

Chapter 6:
Developing ACSM messages and concepts

By the end of Chapter 6, the reader will understand how to develop messages and concepts by:
1) targeting messages appropriately;
2) using credible messengers of information;
3) considering appropriate logos, slogans and other creative aspects;
4) developing a guide to use messages and concepts creatively in ACSM materials and activities.

The TB messages disseminated should be consistent and relevant across all channels and activities. The more the messages reinforce each other across channels, the better the results will be. Consistency makes the ACSM strategy effective – ensure that the health-care provider, the community mobilizer and the radio announcement all give the same key information. This does not mean creating only one message for everything. It means, rather, identifying key points that every message should convey, no matter how it is communicated.

1. Targeting messages appropriately

Messages must be relevant to the various groups they target. Each group may have a different level of knowledge of TB so target messages according to their respective level. Messages should address the action or change that the intended audience is ready to make – for example, a message to people who have never heard of DOTS should not encourage them to start treatment immediately. It should rather focus on raising the awareness of DOTS with the aim of moving the group toward getting treated. Look at the stages-of-change model (in Annex E) to understand the stages in changing behaviour: pre-contemplation, contemplation, preparation, action and maintenance.

Even if a group is motivated by a message, other factors may limit their ability to adopt the proposed behaviour or take the recommended action. For example, at-risk individuals might not seek testing or treatment because they are afraid of being stigmatized by their communities.

Accurate and clear messages are the most credible. Advice and information on treating TB changes rapidly so scientific accuracy is vital. This is particularly problematic with MDR-TB and XDR-TB where recommended treatment regimens, as well as access to treatment, frequently change.

Messages should be simple and contain very few, if any, scientific terms. Include only information that is necessary for priority groups to take the desired actions or decisions. Do not include information on disease physiology, research debates or sponsoring organizations.

Consider the written and visual literacy levels of the target audience. Many people cannot understand health materials written in technical language, particularly if their literacy skills are low. Make specific choices on the writing style, vocabulary, typography, layout, graphics and colour. These choices affect whether the message is read and how well people with varying degrees of literacy will understand it.

2. Using credible messengers of information

All messages conveyed should be credible. The audience must trust whoever delivers the message – whether it is someone in authority, a celebrity or a group member. It is necessary to know who is trusted to give advice about health or TB; the needs assessment should have gathered this information. A person's credibility will be linked to the message he/she delivers. The right person to deliver a message highlighting TB as a public health problem, for example, might not be the appropriate person to deliver a message on trying to reduce TB stigma. A celebrity might be a good choice for the message on raising awareness of TB, but a person cured of the disease would be a better choice for the message on the stigma of TB.

Messengers can be individuals or organizations. TB programmes can collaborate with credible organizations, such as women's unions or religious institutions, and emphasize their involvement. When a message involves using TB drug treatment, it is best to use a trusted and unbiased source. If people perceive an ulterior motive, such as a pharmaceutical company with a profit-driven interest in the treatment, they may dismiss the message.

It is good to ask representatives of the target group whether a particular messenger is well-liked and relevant to the issue. In many cases, the most effective messengers may be members from trusted social networks such as clubs, neighbourhood or other local groups.

3. Considering appropriate logos, slogans and other creative aspects

Logos, slogans and other graphic representations can help unite different ACSM activities that occur over a long period of time. These creative elements will help establish programme recognition and trust, while distinguishing its activities from those of competing programmes or messages.

Wherever possible, use the same graphic identity in all ACSM activities – for example, use the same or compatible colours, types of illustrations and typefaces in all printed materials. Include a logo in all materials. Graphics and messages should not send different signals; they should reinforce each other and follow the overarching ACSM strategy. No matter how creative, compelling or wonderful a slogan may be, do not use it if it does not fit with the strategy statement, objectives and/or identified audience.

In developing a logo or a slogan it is necessary to consider cultural norms associated with the images to be portrayed. The symbols, metaphors, visuals (including clothing, jewellery and hairstyles), types of language and music used in materials all convey aspects of a culture. Use ideas that reflect local customs and ways of talking when you describe and identify TB.

It is important to acknowledge and understand a priority group's culture. It is not always necessary or even advisable, however, to develop separate messages and materials for each different cultural group. Pre-testing messages, concepts and images before they are distributed helps to identify those that resonate across groups and to recognize situations where different messages or images may work better. The time spent to test and refine messages is always worth while; it ensures that the messages and images are well received, effective and, most importantly, inspire positive change.

4. Developing a guide to use messages and concepts creatively

The next step is to create a "map" or "blueprint", sometimes called a creative brief, to give to implementers or creative staff – the writers or designers. The brief is to give simple directions to help them create images, logos, designs and messages that should connect with the target audiences. Ideally, there should be a brief for each intended population because it is likely that the messages will differ for each.

An effective brief summarizes what is known and allows creative staff to identify several approaches that could effectively convey the intended messages. A vague, loosely worded brief can confuse the creative staff and lead to poorly constructed messages and ineffective products and activities.

A worksheet for compiling a creative or strategic brief is provided in Annex F.

"Logos, slogans and other graphic representations can help unite different ACSM activities that occur over a long period of time."

CASE STUDY no. 4

A tale of a Kenyan family and TB

Kenya's National TB Communication Strategy promotes strong links between mass media, interpersonal media and the community. In the absence of known stakeholders and personalities, a "virtual family" called the Rahisi family in a fictitious Kenyan town has been created. The Rahisi family members are expected to serve as the official spokespersons for all communications related to TB, appearing in all selected media and materials.

The members of this family, through their humorous interaction and conversations among themselves and with their neighbours, friends, doctors and others in the community, reflect a range of predicaments related to TB in the age of HIV/AIDS. Over the long term, the goal is for the characters in the family to become culturally popular spokespersons and demonstrate the best possible response to TB risk and disease.

The family includes parents, at least one child under the age of 10, and two adolescents (male and female, between the ages of 16 and 24). One develops active TB. The reactions of the family exemplify both the thoughtful, questioning approach to health and TB and also the irrational, fear-based and life-threatening responses. All exchanges rely heavily on humour to sustain interest and allow for sensitive handling of death-related issues.

The family's scenarios are depicted in short role plays (each less than three minutes in length) designed for radio and closed-circuit television. Each scenario explores a single aspect of TB or the response to it. Clear, accurate information and motivational success stories form the main content. Following is a sample scenario.

I forgot my pill today: The forgetful father and his assistant at work. Today the father has forgotten nearly everything he needs: his wallet, his handkerchief, his socks are mismatched, his umbrella is at home, and he has forgotten to bring his TB pills. His assistant lends him money, a handkerchief, a new pair of socks and a spare umbrella. But he tells him that he cannot give him his missing TB pills. Just then the man's school-age son runs in with the pills saying, "Daddy, didn't you forget something important?"

Chapter 7:
Developing ACSM materials

In this chapter, the reader will learn how to develop effective ACSM materials by:
1) understanding the cycle of developing materials: draft–pre-test–revise;
2) identifying materials needed for different activities;
3) selecting appropriate materials;
4) hiring "experts" to develop materials;
5) pre-testing materials;
6) revising materials based on pre-testing and other feedback.

1. Understanding the cycle of developing materials: draft–pre-test–revise

Developing initial drafts of materials and pre-testing them ensures that the messages are effective and reflect strategic guidelines. Pre-testing allows planners to learn early in the process which messages, products or activities will be most effective with the intended population. Knowing this will save time and money as it will ensure that ineffective products are not mass produced and distributed.

Pre-testing helps NTP programmes to ensure that people understand the messages in the materials and that the intended population draws the desired interpretations. Pre-testing also offers an important opportunity for communities and other interested parties to become involved in the ACSM process early on and to share what they believe will work or not work. Communities or individuals affected by TB should be brought into the process even earlier to help create the materials. Staff and partners with technical expertise should also be consulted to ensure that all scientific and technical information is correct.

Once results from pre-testing have been compiled and analysed, materials can be revised to reflect the feedback received. While pre-testing can improve the effectiveness of materials, there is no guarantee that activities and supporting materials will achieve their intended goals. Pre-testing can provide an indication of the strengths and weaknesses of materials, but it cannot definitively determine what will or will not work.

2. Identifying materials needed for different activities

Several different types of materials can be developed to support ACSM activities. Examples of materials required for different activities are provided in the table on the next page.

Selecting channels that will be effective in reaching intended populations is important. Leaflets placed in clinic waiting rooms, for example, will not encourage more people to go to clinics to get diagnosed and treated for TB. Place materials for intended populations in locations where the target audience normally goes, such as markets, bus stations, train stations, taxi and truck parks, schools, places of worship, workplaces, union halls, community buildings where meetings are held, and in front of the homes of village elders or other places where people gather informally.

3. Selecting appropriate materials

Development and production of materials can be time consuming and costly. Before taking this step, determine whether new materials are necessary.

Communication materials such as booklets, leaflets, posters, public service announcements and videotapes may already exist; they may have been produced in the planning phases. Check for existing materials through clinics, the ministry of health, NGOs, trusted Internet web sites and local universities. If you find any, decide whether they are useful as they are or whether they need to be modified.

In reviewing existing materials, ask the following questions:

- Are the messages accurate, current, complete, and relevant?
- Are the format, style, cultural considerations and readability level appropriate for the targeted audience? If not, could they be modified easily?
- Will the materials meet the communication objectives?

Pre-testing can help answer some of these questions. If possible, check each item with the group that originally produced it to find out:

- results of any pre-testing (be sure to ask which groups the materials were pre-tested with);
- effectiveness of the materials to date;
- any advice or recommendations related to the programme's ACSM needs.

In deciding whether to use existing materials, ask the original producers several questions.

- Are the materials available?
- Can the NTP have permission to use the materials? Modify them? Would reprinting be easy?
- Are they affordable?
- How have they been used?
- How have they been received?
- Is there any information about their effectiveness?

ACTIVITIES	MATERIALS
Meetings with policy makers (e.g., meetings with law makers to advocate for increased TB funding)	• Fact sheets • Presentations, other visual aids such as slides, photos, posters • Letters • Briefs that summarize data
Outreach to media (e.g., to promote World TB Day, awareness campaign)	• Letters to the editor • Opinion-editorial write-ups • Press releases • Public service announcements, live-read scripts/ announcements • Summaries of key findings, articles (and authors)
Public awareness activities (e.g., increase awareness/reduce misconceptions about TB, reduce stigma)	• Informational booklets, leaflets/flyers, posters • Radio and television spots (live-read scripts or produced public service advertisements)
Peer education and training (e.g., for health care workers and communities to identify TB cases, provide the proper care/treatment)	• Training modules • Fact sheets • Flip charts/flannel boards • Instructional posters/wall paintings/job aids • Videotapes
Presentations at seminars or other gatherings (e.g., with decision makers or health care professionals)	• Presentation slides or other visual aids such as photos • Displays (including posters, photographs, real objects, models)

Pre-test existing materials with the intended audience. Even if the materials are not appropriate, you may gain valuable information that will help in modifying them or developing new materials.

Developing new materials will probably be costly. Choose formats that the programme can afford and make sure that there is enough money to print, distribute and promote sufficient copies to meet your needs.

4. Hiring experts to develop materials

If the NTP decides to develop new materials, it might be necessary to work with health communication or design experts – either within the NTP or on a contract basis. It might seem easy to design and create effective, eye-catching materials that deliver the intended message(s), but this is not always so. Materials might be technically correct but, if the intended group does not notice or relate to them, they will be ineffective. Managing the relationship with the team of creative professionals and consultants is therefore a critical factor in producing effective materials.

When working with an advertising agency or other external consultant, consider the experience and previous products of the professionals who will staff the effort. Additional guidelines on how to select and work with external advertising agencies can be found in a resource called *How to Select and Work with an Advertising Agency: Handbook for Population and Health Communication Programmes*[2].

The creative brief (described above in Chapter 6) explains the ACSM strategy to ensure that the outside organization understands the constraints and follows the instructions. Consultants should understand the objectives and concerns of the NTP as well as all that has been learnt about the intended population, particularly sensitive issues, as well as key content points and other aspects that should be conveyed in the messages and materials.

Other issues to consider are the type of pre-testing and approval that will be required, when the pre-testing will occur, how long pre-testing will take, how many rounds of revisions will be made, and whether the creative consultants observe the pre-testing. If they listen to the reactions and concerns of the target population it will help them develop messages and materials that use appropriate language and ideas.

Even if outside organizations are not used, the internal team (ideally led by a communication expert) will need to consider all the issues involved in pre-testing materials.

[2] Available on the Internet at *http://www.jhuccp.org/pubs/fg/2/2.pdf*

5. Pre-testing materials

As mentioned, pre-testing materials helps to ensure that the intended messages are understood. Although colleagues can add useful input, testing the materials with intended group members will give a sense of their reactions. People who do the pre-testing may be internal or external researchers, communication experts or members of the creative team that has been hired or assigned to develop the materials.

Pre-testing is not necessarily expensive. There are low-budget methods and money-saving strategies to review materials among intended groups, such as those outlined below.

Lower-cost options for pretesting

- Conduct focus groups in DOTS clinics with health staff and people living with TB.
- Share materials with TB "clubs" or other TB groups.
- Have communities or those affected by TB design, develop and test materials and messages (for the general community).

Other ways to reduce pretest costs

- Work with partner organizations to recruit participants and conduct tests (e.g., a place of worship, a clinic, patient educators' clients).
- When testing with many respondents, keep the questions short and focused; use close-ended or multiple choice questions as much as possible (for easier analysis); and develop codes in advance to quantify responses to open-ended questions.
- Avoid over-testing (pretests should answer questions, not gather new opinions).

Follow the steps below to plan and conduct a pre-test:
A. Determine test objectives
B. Choose methods
C. Identify, screen, and recruit respondents
D. Draft test instruments (discussion guides, questionnaires)
E. Conduct the pre-test
F. Analyse results.

A. Determine test objectives

Formulate research objectives for the pre-test. Write specific objectives to provide a clear understanding of what the programme wants to learn from whom. Pre-testing can also help to answer questions about alternate ways to present information, questionable inclusions or depictions and reviewer conflicts regarding content, format and appearance. Describe which segments of the intended group should be included and/or excluded.

B. Choose methods

Several research methods can be used to test messages and materials. The choice of method depends on the research objectives, the materials, the target group and the amount of time and resources available for pre-testing.
There are many different ways to pre-test concepts, messages and materials with intended group members, such as:

- focus groups (face-to-face or telephone for audio materials);
- in-depth interviews;
- interviewer-administered surveys/questionnaires – by telephone, through central-location intercepts, or other face-to-face scenarios;
- theatre testing where a large group responds to messages via questionnaire;
- observational studies paired with exit interviews – for instance, observing how much time people spend examining informational leaflets while waiting in a clinic then, as they exit, asking what they learnt and whether they found it useful;
- Readability assessments to see if printed materials are easily understood.

"Gatekeeper" or expert reviews can also allow health officials or leaders of the NTP to provide their input. Health communicators often ask gatekeepers (e.g., partner organization leaders, public service directors, physicians and teachers) to review materials. This provides input from people close to those who need to be reached and also increases the likelihood that the gatekeepers themselves will use the materials with the intended population. If the graphic style or illustrations depart from what gatekeepers or other reviewers expect, focus on this when testing draft products with the intended group. Use favourable responses from the pre-testing to persuade gatekeepers to accept the selected approach. Gatekeeper reviews, however, should not be used as a substitute for pre-testing materials with members of the intended group.

Choose additional reviewers carefully. Reviewers may be subject experts, communication specialists, representatives of the intended group, TB control specialists and partners; they should have relevant knowledge and represent a range of expertise. In some cases, reviewers with other skills or view points may be important, such as legal professionals, law enforcement officials, social workers, school personnel or clergy.

Explain exactly what reviewers are expected to do and what they should not do. Give them guidelines, a list of questions to answer for example. Do not be discouraged by too much criticism, whether it is constructive or destructive. Keep in mind that NTP and ACSM programme planners are not required to act on all the comments received.

Allow sufficient time. Reviewers need time to do a thorough job and the creative professionals require time to make thoughtful and careful revisions.

C. Identify, screen, and recruit respondents

Develop guidelines on recruiting people. A sample of a recruitment instrument is provided in Annex G.

Another useful resource is *The Handbook for Excellence in Focus Group Research*[3]. Written to take into account situations in developing countries, it provides a sample screening questionnaire and other focus-group instruments such as discussion guides and sample focus-group reports.

Another helpful tool is a more recent publication, *A Skill-Building Guide for Making Focus Groups Work*, produced in 1955 by the Academy for Educational Development in Washington DC, 1995.

D. Draft test instruments (discussion guides, questionnaires)

Ideally, the creative team or communication expert heading the development of materials should be involved in developing the discussion guides or questionnaires that will be used to ask questions and gather information during the pre-testing. Questions should assess the areas outlined below:

[3] *The Handbook for Excellence in Focus Group Research* by Mary Debus, available on the Internet at *http://www.globalhealthcommunication.org/tools/60*

- **Content:** Understanding the content, accuracy of information presented, credibility of the people expressing themselves through the material, and the kind of reactions evoked by the content.
- **Form:** The interest generated by the materials and the technical quality.
- **Materials:** The reaction to formats that have been used, the technical environment necessary to use the material and the useful life of the material.

Annex H has sample guides for focus-group discussions and Annex I has sample questions for pre-testing printed and other materials.

E. Conduct testing

If possible, have the creative team, content experts, partners and gatekeepers (including TB programme decision-makers) present at some focus-group discussions or interviews. Observations made during pre-testing or concept exploration often pinpoint comments or recognize trends that are important for the creative development of the materials. These responses improve the team members' understanding of an intended group's reactions and can illustrate, more vividly than any report, the need for simple language or the power of a particular creative approach.

F. Analyse results

Use the test objectives set forth in Step A to analyse the findings at the beginning of the process. Were the objectives of the pre-testing met? Consider what was found and what was not; sometimes what is not stated by a participant is very important.

Avoid over-generalizing the findings. For example, if 50 of 100 respondents in an intercept test do not understand sections of a pamphlet, it does not necessarily mean that 50% of the total intended group will be confused. The lack of understanding among the pre-test respondents suggests, however, that minor revisions may be needed to make the pamphlet easier to understand.

A problem often encountered in analysing results is the interpretation of the reactions of a respondent to a sensitive or emotional subject, such as stigma related to TB. Respondents may become guarded when reacting to materials and hide their true concerns, feelings and behaviour. Those pre-testing and analysing the results must therefore examine and interpret responses carefully.

6. Revising materials based on pre-testing and other feedback

Revisions that will be made to materials are usually included in a report on the testing process. Such a report should comprise the sections outlined below.

- **Background:** Who was tested? Why? How? What lessons or results were anticipated? Describe each in detail.
- **Highlights:** Summarize the main points that emerged in answer to the research questions during testing.
- **Findings:** Describe the findings. Where appropriate, describe participants' reactions, quote participants and use examples from the test documents to support the findings.
- **Conclusions:** Describe patterns that emerged or significant differences observed between groups. If no patterns are apparent, more research may be needed.
- **Recommendations:** Suggest revisions for materials or planned approaches based on findings and conclusions.
- **Annexes:** Include copies of test instruments used, such as discussion guides, screening questions and questionnaires.

In most cases, the ideal person to prepare the report is a team member with a health communication background. If such a person is not available, the pre-test researcher may be able to report on the findings but may not be in a position to draft useful recommendations. Involve the creative team to recommend solutions or revisions.

If major changes are made to a message or product, based on the original pre-test results, consider pre-testing again if resources permit. In most cases, however, revisions based on the pre-test findings and the recommendations of the communication or creative experts involved in the process will not need to be tested again.

"A problem often encountered in analysing results is the interpretation of the reactions of a respondent to a sensitive or emotional subject, such as stigma related to TB."

CASE STUDY no. 5

Developing IEC materials for health centre staff working in TB programmes in Cambodia

To successfully implement DOTS, interactive approaches that promote community participation and discussion to raise community awareness of TB prevention, diagnosis and adherence to treatment are essential. Local health centre personnel, as trusted and respected community members, are ideally positioned to lead such awareness activities.

With funding from the US Agency for International Development's IMPACT project, PATH provided technical support to the Cambodian NTP's information, education, and communication (IEC) team to develop a communication training curriculum and handouts for public health-care providers working in TB DOTS programmes. The training curriculum seeks to strengthen providers' interpersonal communication skills and promote the effective use of supportive materials such as flip charts and other health promotion tools to educate people with active TB. It uses participatory methodologies such as small group discussions, games, case studies and practical sessions with peer feedback.

PATH's approach was to walk the NTP staff through the process of developing IEC materials, following five essential steps: 1) assessment, 2) message development, 3) pre-testing and revision, 4) production, and 5) dissemination and monitoring. This approach enabled the NTP IEC team to build its capacity to develop appropriate materials by applying their newly acquired skills to produce a final product that they could use.

Step 1 was to conduct an assessment with public health-care providers to determine the kinds of information and tools that would be preferred by them. The assessment relied on focus-group discussions and individual interviews and provided information for step 2, the development of the first draft of the curriculum and accompanying tools. Step 3 was to pre-test the materials with two different groups: one group, the health staff working in DOTS programmes; the other, the potential trainers. To do this, the team conducted focus-group discussions during which the content and duration of each session of the curriculum was pre-tested and revised. They then conducted a second round of focus-group discussions to review the changes and finalize the content.

In step 4 a designer was hired and a mock-up presentation of the curriculum was prepared. This was pre-tested with the provincial and operational district TB supervisors who would be the trainers. Based on their feedback, the training curriculum and handouts were finalized and shared with the NTP manager, key ministry of health personnel and relevant TB partners for their final approval. Following this approval, the final versions of the curriculum and handouts were printed and disseminated in step 5.

To develop the national IEC training team's skills in delivering workshops, PATH conducted a training-of-trainers workshop using the curriculum and handouts. Following this initial training, the IEC team, with oversight from PATH, trained all the TB supervisors in 24 provinces. Since 2006, the IEC team, in collaboration with TB provincial supervisors and with continued support from PATH, has trained health staff working in DOTS in 15 out of the 24 provinces.

At the start of the training phase, a monitoring plan was developed to allow continual adaptation of the curriculum and handouts, based on feedback from participants and the experience of trainers. This ensured that the materials optimally meet the needs of both groups. For example, a local NGO may adapt the curriculum and accompanying materials for use with community health workers. The materials can be revised electronically and printed as needed to minimize the costs. This capacity-building process has produced a set of useful and popular tools that can be easily adapted for specific uses.

SECTION 3

Implementation and evaluation

Chapter 8:
Implementing ACSM activities

In this chapter, the reader will understand the steps required to implement ACSM activities, including:
1) learning how to address logistics and the role of partners during implementation;
2) understanding issues related to launching activities.

1. Learning how to address logistics and the role of partners during implementation

When implementing ACSM strategies, pay attention to logistical details – the "how," "when" and "who" – of planned activities. Many details can be addressed and coordinated by TB programme staff. Planners will also coordinate with partner organizations and volunteers to carry out activities successfully. Before officially "launching" ACSM activities, planners should produce an implementation plan that addresses the three key areas: partner roles, public relations and distribution issues.

Partner roles

Planners should define the roles, relationships and responsibilities of all implementing partners. This will avoid misunderstandings and ensure that expectations are realistic and achievable. Such coordination will maximize resources and synergies between partners while avoiding duplication.

All organizations need to know who is responsible for the different tasks involved in rolling-out communication activities, including distribution, funding procurement, information systems, management, monitoring and evaluation, resource allocation, supervision, training and other functions. Organizations collaborating as part of a network, coalition or "franchise," should be included in this planning.

The table below can be used to plan what needs to be done, who/which organization will lead each activity, when an activity needs to be initiated or completed, and the types of materials or resources and support that might be needed.

ACSM activity	Organization responsible / contact person	Activity start date & completion date	Materials and other resources needed	Status

Not all NTP staff members will know the details of the planned ACSM activities. All staff and partners should be informed of the ACSM interventions and should review the roles of each organization. For example, if nurses are supposed to give an educational brochure to clients, they need to know how best to incorporate the brochure into visits or in their interaction with clients. Clinic managers might need to be explicitly told to put posters up and set brochures on the tables in the waiting rooms. Do not assume that everyone knows what to do, even if it seems obvious.

Clear expectations and communication about what partners will do, when and how they will do it are critical. NTP staff should work closely with partners to prepare for implementation. Partners should be given tasks that are reasonable; the easier it is for the partners to participate, the more likely it is that they will complete their assigned tasks. Partners should have copies of materials, talking points, display racks for brochures and other aids. Most importantly, planners should listen to and address partners' suggestions and concerns where possible, acknowledge partners' contributions and thank them publicly when appropriate.

As activities continue, a regular coordinating mechanism, such as weekly or monthly meetings, should help partners assess and maintain progress. Informal communications can also track activities.

2. Understanding issues related to launching activities

Outreach to the public can be a major part of launching ACSM campaigns or activities. Many organizations hold a "kick-off event" to introduce their activities to the media and the community. This can be a press conference or any other event that spotlights the TB situation and programme and motivates public commitment from national and global authorities.

Other launch events could include activities such as:

- a walk or parade
- a health fair
- an expert panel discussion including people living with TB
- a concert/entertainment event
- a disease-screening event
- a celebrity appearance.

The event should meet three criteria: it must attract members of the priority populations; it must communicate key messages; and it must be considered sufficiently newsworthy by the media for it to be covered. Planners should decide in advance which media outlets to target – local or national outlets, television or radio.

Designate one partner (or person) – and a backup – to address and respond to potential questions from partners and communities. This person, in most cases the NTP director, can serve as the programme's spokesperson. He/she should be prepared to respond as needed and should ideally have some training in media relations that offers guidance on how to effectively communicate with journalists and other members of the news media. Skills in media relations can also help in talking to journalists, to interest them in covering the events and perhaps even becoming partners or advocates of the cause. Direct all calls or communications that require any type of public comment to this person.

Create talking points to help the spokesperson(s) to explain to the media and others who might ask questions about why the activity is taking place.

Talking points can include other information such as:

- facts about TB, including local statistics
- how the programme is addressing the problem
- why these approaches have been chosen
- responses to foreseeable objections to activities and interventions.

If there is news coverage, planners should be prepared to provide follow-up information; if the coverage conveys anything incorrect or misleading, they need to talk to the media and clarify any misconceptions. Even if there is no follow-up to provide or misconceptions to clarify, it is still advisable to contact the reporters covering the event and thank them for their interest. This helps to build a relationship with the media that can continue to be useful in promoting the programme's activities.

Distributing materials is another key part of a launch. Consider the issues opposite.

Who are the partner organizations and how do they contribute to the programme or ACSM activities specifically?
Do additional partner organizations and volunteers need to be recruited to carry out activities?
What are the dissemination activities or platforms? Confirm that they are still viable and appropriate.
Will radio, television or other media materials be given to media outlets, either as public service announcements or as paid advertisements?
How many copies of each product will be needed? Estimate the potential demand. Produce enough copies to be able to replace the materials as they are used up.
Is there a plan for tracking inventory?
Is there a place to store supplies?
Does everyone on the team know how to distribute the materials? Clearly state what needs to be done with materials so that they do not get forgotten, unused, in a box.

CASE STUDY no. 6

Implementing ACSM in Kenya

The National Leprosy and Tuberculosis Control Programme (NLTP) of Kenya, the custodian and primary stakeholder on all matters related to TB control and prevention, has approached the subject of ACSM holistically. Recognizing that the needs, approaches and target audiences of advocacy and communication are significantly distinct from each other, the NLTP began development of a national TB communication strategy and a national advocacy strategy in 2003.

The national TB communication strategy drew from, and built on, TB assessments and research dating back to 2002. In the absence of a national KAP survey, several community-level workshops were conducted to allow the NLTP to gain qualitative insights into knowledge and attitudes to TB, especially in relation to HIV. These workshops led to a draft TB communication strategy that was validated by a multilevel review process.

This review and validation process engaged TB stakeholders from different levels of government, civil society and the nongovernmental sector. Two national-level review workshops brought district and provincial-level TB staff together – one was held in Nairobi, the other in a province. In a three-day process, participants in the workshops went over the strategy document word by word and made recommendations and changes. The Interagency Coordination Committee of the NLTP, whose members include donors and implementing agencies, reviewed the strategy drafts at the penultimate stages.

The final national TB strategy document, entitled Lights of Hope, provides a broad and evidence-based framework that allows the NLTP and other NGOs communicating on TB and HIV to align themselves with national objectives and to synchronize and optimize activities, interventions and messages.

Kenya's TB advocacy strategy reached its final stage in late 2007 and will soon be converted to action. Future activities include identifying organizations to implement the communication strategy, developing campaigns and messages, and building capacity to carry out community-level interventions and other activities recommended by the strategy.

Chapter 9:
Monitoring and evaluating ACSM activities

In this chapter, the reader will learn about methods for monitoring and evaluating ACSM activities.

For **monitoring**, the reader will learn about:
1) conducting short-term and long-term monitoring and tracking;
2) recognizing problems via feedback from the field; and
3) making mid-course corrections based on feedback.

For **evaluation**, the reader will learn about:
1) types of evaluations;
2) setting evaluation goals;
3) determining suggested indicators;
4) developing an evaluation plan;
5) selecting monitoring and evaluation methodologies;
6) developing and pre-testing data-collection instruments; and
7) writing an evaluation report.

1. Monitoring

1.1 Conducting short-term and long-term monitoring and tracking

Before ACSM activities begin, create monitoring mechanisms to receive feedback on the interventions and identify any problems early. Although it is impossible to anticipate every problem, a monitoring system will help identify difficulties quickly so that they can be addressed. Determine the roles of partners in solving problems. "Process evaluation" is the day-to-day monitoring of ACSM activities and operations. Determine the objectives of a process evaluation prior to establishing the monitoring mechanisms.

The objectives should focus on:

- whether ACSM activities are on track,
- how close they are to meeting the projected timeline and budget, and
- whether staff members understand and perform their roles correctly.

The objectives can also assess the effectiveness of each partner in disseminating materials or carrying out other assigned tasks. The specifics of the intended ACSM activities will determine the elements and objectives to be included in the process evaluation.

Examples of questions that can be used to monitor progress towards objectives are listed on the next page.

"Before ACSM activities begin, create monitoring mechanisms to receive feedback on the interventions and identify any problems early."

How many people participated in activities?
How many responses were received? How do they compare to those received in the months leading up to the activity? What were the responses?
How did the programme respond to enquiries? Was appropriate action taken in each case?
How many materials were sent out or otherwise disseminated?
How many materials were given to each of the partners? How many materials were disseminated by these partners?
Were staff and partners adequately trained to carry out their roles effectively? Did they perform their roles correctly?
Are there any currently pending events, legislation or policies that might affect the programme or ACSM activities? ***How many messages were sent to law-makers or other decision-makers? How many letters were written? How many meetings were held? How many articles were published in newspapers, magazines or other publications?***
How many news stories appeared as a result of public relations efforts?
Have political conditions changed since the initiative was planned?
Were all activities carried out on budget and according to the expected timeline? If not, why?
How were the activities managed? Were workplans followed? How well did staff perform their duties? Were relations among partners successful? Were donors kept apprised of activities? Were logistics well managed? Were other resources well managed?
Have the knowledge, attitudes, awareness or opinions regarding TB changed in the intended group? Where can these changes be observed or obtained?

Once objectives have been determined, select monitoring and tracking mechanisms. Some suggested sources of information for tracking the various components of ACSM activities include:

- inventory of materials;
- distribution list;
- activity reports;
- public diaries;
- television and radio logs;
- media-clipping services;
- staff surveys or focus groups;
- partner feedback;
- timeline and budget assessments;
- news and information searches;
- legislative tracking systems; and
- attitude or household surveys.

It is not enough to collect this monitoring data only once. Planners need to review, analyse and discuss it regularly – monthly, bimonthly or quarterly – depending on the particular circumstances of the organization(s) involved. For some types of information, such as data from household surveys, it may make sense to collect information less frequently – either every six months or annually.

Planners should also decide whether to conduct internal programme team reviews or joint reviews with community groups and/or other partners.

In addition to identifying areas that need attention or adjustment, monitoring also identifies successes. Celebrate successes with those involved. Each success, however small, contributes to a growing sense of confidence and accomplishment and motivates partners and other ACSM participants to continue their efforts. Successes also highlight areas in which capacity is being strengthened.

1.2 Recognizing problems via feedback from the field

Responding to relevant information in real time allows a programme to improve immediately, rather than realizing in retrospect what it should have done.
The following strategies for effectively using feedback from the field can be implemented:

- Involve key decision-makers, stakeholders and TB advocates in helping to analyse and use feedback;
- Use process evaluation to uncover problems or opportunities for the ACSM intervention during implementation;
- Conduct preliminary evaluations to identify potential improvements and highlight and share successes before the completion of ACSM activities; and
- Use summative research to make future ACSM programme decisions part of a process rather than just an end point.

1.3 Making mid-course corrections based on feedback

The ACSM planning and implementation process is circular. Feedback from the field might indicate programme areas or ACSM interventions that should be changed, expanded or phased out.

Consider also what might be added. For example, should new developments in TB treatment be addressed? Has anything changed about the intended population, the community or the TB control programme that necessitates creating new goals and objectives?

Consider the feedback questions below when deciding whether mid-course corrections are necessary.

- Have goals and objectives shifted as activities have been conducted? If so, revise the original goals and objectives to meet the new situation.
- Are particular objectives not being met by programme or ACSM interventions? Why? What barriers are being encountered? How can the barriers be overcome?
- Has a strategy or approach met all its objectives or does it seem not to be working at all? Consider ending that tactic.
- Is there any new intervention or treatment information that should be incorporated into the messages or design?
- Which strategies or activities have not succeeded? Review why they do not work and determine what can be done to correct any problems.

Identifying successes can also lead to mid-course corrections. If certain activities have been shown to be successful, planners might consider focusing on them and discontinuing those that are less successful. Following are some questions to help assess the value of successes.

- Which objectives have been met? What activities have succeeded?
- Should successful activities be continued and strengthened because they appear to work well or should they be considered successful and subsequently discontinued?
- Can successful activities be expanded to apply to other groups or situations?
- What were the costs (including staff time) of different aspects of the ACSM intervention?
- Do some activities appear to work as well as others, but cost less?
- Do programme funders need evidence of ACSM success to continue funding activities?
- Have the results of the activities been shared with the

TB programme leadership and partners? With funders, advocates or other stakeholders?
• Do the assessment results show a need for new activities that would require establishing partnerships with additional organizations?

Consider the above questions with regard to problems encountered and successes achieved, then identify new strategies, target different intended groups and revise ACSM activities and products to accommodate new approaches, new tasks and new timelines.

2. Evaluation

At some point all programmes need to ask the question, "How effective were the ACSM strategies?" This is the time to reflect on what has been achieved, what has worked and what has not, and to make recommendations to improve future efforts. A summative evaluation will not only help to answer these questions, but also to demonstrate to funders and partners the effectiveness of activities.

2.1 Types of evaluations

There are two types of summative evaluation: outcome evaluation and impact evaluation.

An **outcome evaluation** measures how well the ACSM intervention has met its objectives and what should be changed to improve future ACSM activities.

Follow the steps below to conduct an outcome evaluation:

- determine what information the evaluation must provide;
- define the data to collect;
- decide on data collection methods;
- develop and pre-test data collection instruments;
- collect data;
- process data;
- analyse data to answer the evaluation questions;
- write an evaluation report; and
- disseminate the evaluation report.

When conducting an outcome evaluation the limitations and constraints can include:

- limited funds;
- limited staff time or expertise;
- length of time allotted to the ACSM intervention and its evaluation;
- restrictions on hiring consultants or contractors to conduct the evaluation;
- policies that limit the programme's ability to collect information from the public;
- difficulty in defining or establishing consensus on ACSM objectives;
- difficulty in isolating the effects of ACSM intervention from other influences; and
- a perception by funders or others involved in the programme that evaluations are not valuable.

These constraints can often be overcome. However, if a programme faces several constraints, it might be advisable to conduct a small-scale evaluation. This would be more valuable than a poorly conducted large-scale evaluation.

Impact evaluation connects behaviour change to health or social outcomes. An impact evaluation answers the question: "Did the people who adopted new actions or behaviour experience improved health and well-being related to their TB status?" Impact evaluations are not often used by planners of ACSM activities – mostly because of the high costs usually involved in carrying them out successfully. However, evaluators can select a few programmatic objectives to measure, such as changes in the rates of treatment completion or increases in case detection.

2.2 Setting evaluation goals

To set evaluation goals, first determine who wants to learn from the evaluation. This will be primarily the stakeholders involved in ACSM activities or those with a direct interest in the programme. Other interested parties – such as the broader community, the various levels of the health system, people from the municipal/district/regional/national governments and donors – should also be invited to suggest evaluation goals or participate in other ways. There may also be people and organizations that are interested in learning from the evaluation although they may not have been directly involved in the process. Potential future partners might also be invited to participate, to provide an external perspective and to further their understanding of the approach used and its results.

List individuals and organizations interested in participating in the evaluation. Remember that they need not be physically present; they can contribute questions or thoughts on aspects that they are interested in learning about. (Do not promise to incorporate all their questions into the evaluation, as time and resources will be limited. Try to address concerns not included in another way.)

After deciding on who should be involved, determine what they want to learn from the evaluation. This will often link to their roles in the effort, such as a donor wanting to know whether the money that was invested was well spent, or a policy-maker wanting to know whether a media campaign improved TB diagnosis rates in the community.

It is important to determine which aspects of the outcome evaluation plan best fit with the programme's priorities. It is rare for an ACSM programme to have adequate resources to evaluate all its activities. Some specific questions to ask in setting up objectives for an evaluation are outlined below:

• What are the ACSM objectives?
What should the members of the intended group think, feel or do as a result of the ACSM activities, in contrast to what they thought, felt or did before?
• How is change expected to occur?
Will it be slow or rapid? What measurable intermediate outcomes – steps toward the desired behaviour – are likely to take place before the behaviour change can occur?
• How long will the intervention last?
What kind of changes in attitude, awareness, behaviour or policy, for example, can be expected in the time period? Sometimes, when the outcomes are measured, activities or interventions will not have been in place long enough for objectives to have been met.
• Which outcome evaluation methods can capture the scope of the change that is likely to have occurred?
When sample sizes are small (usually due to funding constraints), the evaluation is said to lack statistical power and only fairly large changes will be statistically significant. Programmes should consult a statistician to make sure that the size of the sample is adequate to measure the amount of change that they expect to see.

2.3 Determining suggested indicators

Changes in the evaluation indicators, or key outcomes to be measured, indicate whether objectives have been achieved. Select the indicators that identify where ACSM initiatives have been the most successful or where additional work is needed. Link indicators to the objectives set during the planning process. All indicators must be measurable.

Individual-level indicators measure:
- knowledge;
- attitudes;
- beliefs;
- behaviour;
- stage of willingness to change; and
- demographics.

Community-level indicators use data from organizations, public agencies or other groups to show trends occurring on a larger scale. A key method of tracking community-based indicators is to observe people's behaviour or relevant factors in the community. Community-based indicators measure changes in:
- policy and regulation;
- information accessibility;
- behaviour;
- social norms, including stigma; and
- presence or mobilization of social networks.

Community-based indicators are usually less expensive and time-consuming to track because data are collected from a few sources rather than from many individuals. However, the information gathered might not be as relevant to TB programme objectives.

2.4 Developing an evaluation plan

At a minimum, an evaluation plan should answer several key questions, as outlined below:

a) What are the project's objectives and expected outcomes? What questions should be asked?
- What elements of the project worked?
- What elements did not work?
- What were some successes?
- What were some failures?
- What still remains to be done?
- What is the vision for the future?
- How has capacity been strengthened during the intervention?
- Which results obtained during the intervention are likely to be sustained or improved upon?

b) What information is needed to answer the above questions and how will the information be collected?
List the instruments and methods that will be used to collect the information, such as:

- repeated surveys (baseline and follow-up);
- stories (peak moments, peak achievements);
- drawings (e.g., of project history);
- role plays to present important milestones or events;
- in-depth interviews with project participants and observers;
- group discussions;
- picture-card pile sorts (sort interventions that worked or did not);
- rankings (rank initiatives or interventions, from those that worked best to least); and
- review of the project proposal, reports and documents.

c) Who will collect the information?
It is more cost-effective to use existing human resources and platforms, if possible, to collect information. Ideally, staff should not collect information that directly measures the success or failure of their own efforts.

d) What resources/materials will be needed?
List who needs support in collecting the information from different sources and what support they need.

e) When will this information be collected?
Create a timeline for data collection.

2.5 Selecting the monitoring and evaluation methods

For the broadest view of areas where the ACSM programme has been most effective and those where improvement may be needed, use quantitative and qualitative research methods to collect evaluation data.

- Qualitative methods may include in-depth interviews, focus groups or anecdotal feedback mechanisms such as diaries and observational studies (watching people in a natural setting without their awareness and observing their behaviour).
- Quantitative methods may include sales data, service statistics or surveys.

Select a method that allows the programme to best answer evaluation questions based on access to the intended population and resources. Consider using participatory methods that make people living with, and affected by, TB part of the research process. Participatory research allows those affected by TB to help in defining the issues and working out solutions rather than being just sources from which information is extracted. Participatory methods provide ample opportunity for personal exchange so allow adequate time for people to go at their own pace.

The more complex the evaluation design is, the more expert assistance is needed to conduct the evaluation and interpret the results. An evaluation expert can be hired or assigned to help write questions that produce objective results. (It is easy to draw up questions that inadvertently produce overly positive results.) If an evaluator is not on staff, seek help to decide what type of evaluation will best serve the effort. Sources of expertise include university faculty and graduate students (for data collection and analysis), local businesses (for staff and computer time), health agencies, consultants and organizations with evaluation expertise.

2.6 Developing and pre-testing data collection instruments

Most outcome evaluation methods involve collecting data on participants through observation, questionnaires or participatory methods.
To develop data collection instruments– or to select and adapt existing ones – ask the questions below.

Which data?
The data collected should be directly related to the evaluation questions. For example, if members of the intended group need to know more about a topic before behaviour change can take place, ask knowledge-related questions in the evaluation.

From whom?
Evaluators should decide how many members of each group are required in the evaluation to measure change. There should be adequate resources to collect information from the number of people required. Different data-collection instruments and methods for different groups may be necessary.

How?
Assess available resources before deciding how to collect data. Are skilled interviewers accessible or can staff members be trained? Will self-reports from participants be used? If so, do any confidentiality issues need to be addressed?

Consider also whether participants will be comfortable with the data collection-methods.
- Will they be willing and able to fill out forms?
- Will they share personal information with interviewers?
- Will the interviews and responses need to be translated?

Methods of gathering information and interpreting results may vary depending on the culture and experience of the respondents. For example, some people may not speak out in a group, such as a focus group; some may be unwilling to provide answers they think will displease the interviewer; others may be reluctant to provide information to a person from a different culture or social status over the telephone; and many may lack familiarity with printed questionnaires or have a limited ability to read the language on the questionnaire.

In addition, the evaluator's social status (if it is different from that of the respondent) or demeanour could inadvertently affect the objectivity of the evaluation. When possible, try to use evaluators who will make the respondents feel comfortable.

2.7 Writing an evaluation report

To prepare an evaluation report, have staff with appropriate expertise analyse the outcome evaluation data and work closely with the evaluators to interpret the data and develop recommendations.

An evaluation report should:

- present the lessons learnt in a clear format that can be easily digested by others who may be planning future ACSM activities;
- demonstrate accountability to employers, partners and funding agencies;
- provide evidence of the effectiveness of the ACSM interventions and activities; and
- create a formal record to serve as an institutional memory of what has been tried, which partners had strong skills or experience in specific areas, what problems were encountered and what successes were achieved.

"Select a method that allows the programme to best answer evaluation questions based on access to the intended population and resources. Consider using participatory methods that make people living with, and affected by, TB part of the research process."

SECTION 3: Implementation and evaluation

CASE STUDY no. 7

Monitoring TB programme effectiveness in Ukraine

In Ukraine, the NTP collaborated with the World Health Organization, regional and national health authorities, the World Bank and Royal Netherlands Tuberculosis Association (KNCV) to develop a standardized TB management information system (TBeMIS) based on the WHO-recommended approach. Registration and case-management of all TB cases in pilot sites are tracked electronically using the TBeMIS. This monitoring system is being used successfully to identify programme interventions that need improvement, as described below.

Data collected by the TBeMIS were used as part of the evaluation of a model that involved the Ukrainian Red Cross Society (URCS) Visiting Nurses Service in Kyiv city and Donetska oblast (Mariupol', Yenakievo, and Horlivka) in implementing DOTS for people with TB during the continuation (or maintenance) phase. The main goals of this study were to determine the needs of TB patients during ambulatory care and to develop effective collaboration methods between local NGOs and medical facilities involved in TB care and support.

The selected indicators measured patient satisfaction with care and overall programme progress, as well as the number of patients who were supported and cured by the Red Cross visiting nurses. The primary indicator to evaluate the effectiveness of this care model was the comparison of the treatment default rates between pilot cities and other regions of Donetska oblast.

In the three pilot cities where this programme has been active for more than one and a half years, preliminary results suggest that the likelihood of treatment default is substantially lower in these cities than in the rest of the oblast. The data are encouraging, although they are based on rather small sample sizes.

Chapter 10:
Documenting results and providing feedback

By the end of Chapter 10, the reader will understand how to:
1) extract lessons learnt from ACSM activities;
2) identify people and organizations that should be aware of these findings; and
3) disseminate lessons learnt and other findings.

Knowledge and expertise related to ACSM activities can be disseminated to others involved in TB control in various ways. The wealth of experience and knowledge created and generated within affected countries and communities often remains known to only a few practitioners.

By documenting and sharing ACSM lessons, NTPs and partners can review experiences and provide strategic input for future activities. ACSM challenges, activities and lessons are similar across regions. Sharing ideas between countries therefore enables "cross pollination" of experiences and prevents "reinventing the wheel". Sharing results may also prompt partners to reciprocate with similar experiences, lessons they have learnt, new ideas or potential resources.

1. Extract "lessons learnt" from ACSM activities

It is difficult to decide which experiences are worth sharing with others. Communities and organizations often undervalue their rich experience, believing that what they have learnt may be obvious or uninteresting. Consequently, information about many effective community-based activities never spreads beyond the local area. Some people believe that, if they do not achieve everything planned, their efforts have failed and are not worth sharing. Nothing could be further from the truth!

First, not all ACSM interventions achieve positive results. Disappointing results may occur for many reasons. Sometimes events or poor decisions beyond the control of planners and implementers may be the cause. It is valuable to learn about successes and failures in TB control. "Failures" sometimes provide the most useful information for future planning.

ACSM planners should always review what happened and why. The following questions are to guide the review process in understanding lessons.

- To what extent has the project achieved its objectives?
- How much did the activity/activities cost?
- What worked? What did not work?
- What should have been done differently? What will be done differently in the future?
- What assumptions were made that were not true when evaluated?
- Did areas/communities/people not reached by the ACSM interventions fare better or worse than the target populations? Why?
- What questions remain to be answered?
- What new questions have emerged?
- What would an outsider want to know about this activity?
- What is the value of the ACSM activities in comparison to other NTP programme components?

A helpful tool that can be used to extract "lessons learnt" is an **after-action review** (AAR). The AAR is a knowledge-sharing tool that has been increasingly used by the United States Agency for International Development (USAID) and its partner community to better understand important events, activities and/or programmes. Overall, an AAR is a discussion of an event (or activity), led by people who are closest to the activity. It focuses on performance standards and enables planners to discover for themselves what happened, why it happened, and how to sustain strengths and improve on weaknesses.

Feedback compares the actual output of a process with the intended outcome. By focusing on the desired outcome and by describing specific observations, planners can identify strengths and weaknesses and together decide how to improve performance. Moreover, this shared learning process promotes bonding, collegiality and group cohesion.

Because AAR participants actively discover what has happened and why, they can learn and remember more than they would from a critique or more formal evaluation. A critique only gives one viewpoint and frequently provides little opportunity for participants to discuss what has happened. The climate of a critique – focusing on what is wrong – often prevents candid discussion and stifles opportunities for learning and team building.

All AARs follow the same general format, involve the exchange of ideas and observations, and focus on improving training proficiency. AAR organizers decide whether the review will be formal or informal.

- **Formal AARs** require more resources and involve more detailed planning, coordination, logistical support, supplies and time for facilitation and report preparation. A facilitator guides the review discussion and, with the help of

a note-taker, records comments on a flip chart. Following the AAR session itself, a formal report is prepared. Later, recommendations and actionable items are brought to the attention of whoever is managing the effort.

• **Informal AARs** are usually conducted on-site immediately following an event, activity or programme. Frequently, an informal AAR is carried out by those who have conducted the activity. If necessary, the discussion leader or facilitator can either be identified beforehand or chosen from within the implementing group itself.

Again the guiding questions are used to generate discussion. Team or project leaders may use informal AARs as on-the-spot coaching tools while reviewing overall group or individual performance.

For example, the team could:

• quickly evaluate performance against a desired standard or established performance objective;
• identify strengths and weaknesses; and
• decide how to improve performance.

In addition, informal AARs provide instant feedback: ideas and solutions can be immediately put to use and the team can learn from them for a future or similar application. Providing direct feedback, "just in time", is a key strength of the informal AAR.

The date and time of the AAR should be identified as part of the planning schedule for the event. The AAR should be considered as an integral part of the entire planning process. For more information, USAID has published a guide on how to conduct an AAR, *After-action review. Technical guidance*[4].

2. Identify people and organizations that should be aware of the findings

Many people will be interested in what has been learnt from the ACSM activities. Consult the lists of stakeholders or potential partners that have already been compiled. These organizations may include, but are not limited to, the following:

• other NTPs;
• NTP project staff;
• community-based organizations;
• faith-based organizations;
• international and national-level NGOs;
• health professional groups, medical centres, clinic administrators;
• law and policy-makers;
• members of television, radio and printed media;
• other public health programme administrators;
• evaluators, epidemiologists and researchers;
• funding agencies;
• partner organizations; and
• the public.

More than likely, many of these groups will want the information presented in different ways. For each type of audience, consider the questions below.

• How much information will they want – a complete written report, an executive summary or selected sections of an evaluation?
• How will the information be used – to refine a programme or policy, to evaluate the programme's performance, to inform others, to support advocacy efforts or to plan future ACSM initiatives?
• In what format will they want the information – concise, with hard-hitting findings and recommendations; general, with an overview written for the public at a low reading-level; scientific, including a methodology section, a detailed discussion and references; visual, including more charts and graphics than words; or case studies, including other story-telling methods?
• What elements should be included – general intervention results/findings, evaluation methods, a chronology of activities, history of the NTP, a theoretical basis for programme and ACSM activities; implications; recommendations; barriers or reasons for unmet objectives?

[4] *After-action review, Technical Guidance* can be downloaded from the Internet at *http://pdf.usaid.gov/pdf_docs/PNADF360.pdf*

3. Disseminate lessons learnt and other findings

How information is disseminated will depend on who is getting what type of information.

With new information technologies – including the World Wide Web's programme web sites, blogs, message boards and list servers), it is easier to share information within a community, district and country, as well as more broadly with peers all over the world. A few examples of this are the Communication Initiative's web site (*www.comminit.com*) and e-magazines such as Health Communication Exchange (*http://www.healthcomms.org*) and HDNet (*http://www.hdnet.org*).

Written reports, articles and other ACSM updates can be shared through community newsletters, newspaper or journal articles and presentations at community or national-level meetings. Other creative ways to share results and encourage more dialogue and learning include a **"gallery walk"** where people view results presented as pictures. Small groups stop at each picture posted on the wall and describe what they see. This way a facilitator can explain the results in more detail and answer questions. A blank sheet placed next to each picture can be used to record comments and questions.

Another example is an **information-sharing forum**, where a facilitator discusses the results with a small group of five or six people and asks open-ended questions to learn about their reactions to the results. The group is encouraged to ask questions and offer opinions.

Role plays can present results in entertaining ways. For example, someone can portray a reporter giving a newscast – interviewing other members of the planning or implementation team then interviewing the "audience" for its reactions.

Participants' observations should be incorporated into the NTP's analysis of the ACSM activity.

It is also critical to share results with social/community mobilizers who work with people affected by TB. This is a way to get feedback on results and keep them engaged in the process – from planning activities to sharing them. Such activities with partners reinforce the idea of collective work, a defining factor of true partnership.

"Written reports, articles and other ACSM updates can be shared through community newsletters, newspaper or journal articles and presentations at community or national-level meetings."

CASE STUDY no. 8

Sharing lessons learnt in Ukraine

While implementing Ukraine's national TB plan, several developments have emerged that illustrate the change in the country:

• new national and oblast legislation and policy documents supporting modern TB control standards have been created;

• a central coordinating unit for the NTP has been established; and

• an increased commitment and interest from officials involved local organizations, such as the Ukrainian Red Cross Society, and increased the demand for DOTS training from other oblasts.

Working at the oblast level to build support and demonstrate the effectiveness of a DOTS-based strategy was instrumental in overcoming national-level resistance to changing TB control practices. A few key best practices and lessons learnt include the following.

• Working to change policy and political will is an extremely time-consuming and labour-intensive process that should be factored into project planning.

• The close coordination of all donors and partners has been instrumental in increasing political commitment by crafting a consistent message on TB and using different players to exert pressure on officials or mobilize stakeholders for advocacy.

• Starting with efforts at the oblast and rayon levels to circumvent strong national opposition to DOTS has created useful allies and supported the changes seen at the national level.

• Using a few high-level consultants at key points in the project has had two very positive effects: a) it has increased staff knowledge and confidence, and b) it has strengthened recommendations to national and oblast officials.

• Targeted, well-planned exchange visits to other countries and other oblasts – using the "seeing is believing" strategy – has convinced many sceptics not only that DOTS can work in the European region, but also that it is a particularly useful strategy for supporting changes in practice throughout the region.

• Working through existing structures (such as the Ukrainian Red Cross Society and medical institutions) to institutionalize DOTS, promotes the sustainability of project activities.

The best practices and lessons learnt are being shared widely in different ways. Presentations at meetings and symposia (e.g. board meetings of the city health administration, TB and family health departments of the national medical university, and the National Congress of Family Doctors) have reached Ukrainian stakeholders. The annual meetings of the Global Health Council and the International Union against Tuberculosis and Lung Disease have shared Ukraine's results with international players.

Collaborative meetings of the WHO Regional Office for Europe and the European Regional Meeting of the International Union Against Tuberculosis and Lung Disease have informed key European stakeholders. In these ways, ACSM activities in Ukraine are providing strategic direction to efforts in support of national TB programme implementation worldwide.

References

Advocates for Youth. *Advocating for Adolescent Reproductive Health in Sub-Saharan Africa*. Washington, DC, 1998.

AMC Cancer Research Center. *Beyond the Brochure: Alternative Approaches to Effective Health Communication – A Guidebook*. Denver, CO, 1994.

CARE International. *Advocacy Tools and Guidelines: Promoting Policy Change*. Atlanta, GA, 2001.

Family Health International. *Strategic Behavioral Communication for HIV and AIDS: A Framework*. Research Triangle Park, NC, September 2005.

Government of India, Ministry of Health and Family Welfare, Directorate General of Health Services, Central TB Division. *A Health Communication Strategy for RNTCP*. November 2005.

Health Communication Partnership. *Health Communication Insights: The Role of Health Communication in Viet Nam's Fight Against Tuberculosis*. Johns Hopkins Bloomberg School of Public Health/Center for Communication Programs, Baltimore, MD, 2004.

Health Communication Partnership. *Health Communication Insights: The Role of Health Communication in Achieving Global TB Control Goals – Lessons from Peru, Viet Nam and Beyond*. Johns Hopkins Bloomberg School of Public Health/Center for Communication Programs, Baltimore, MD, 2004.

Health Communication Partnership. *How to Mobilize Communities for Health and Social Change*. Johns Hopkins Bloomberg School of Public Health/Center for Communication Programs, Baltimore, MD.

International Union Against Tuberculosis and Lung Disease. *Best Practice for the Care of Patients with Tuberculosis: A Guide for Low-Income Countries*. Paris, 2007.

Kline N. *Hands-On Social Marketing. A Step-by-Step Guide*. Sage Publications, Thousand Oaks, California: 1999.

Open Society Institute of the Panos Institute. *Civil Society Perspectives on TB/HIV Policy*. New York, NY, 2006.

Panos Institute. *Time for Action on TB Communication: A briefing for policy-makers, programmers and health communicators on contemporary communication opportunities and challenges*. New York, NY, 2005.

Panos Institute. *What the papers aren't saying. How can we enhance media coverage of TB?* New York, NY, 2007.

Pan American Health Organization. *Planning Social Mobilization and Communication for Dengue Fever Prevention and Control: A Step-by-Step Guide*. Washington, DC, 2004.

U.S. Agency for International Development, Bureau for Africa, Office of Sustainable Development, Support for Analysis and Research in Africa (SARA). *An Introduction to Advocacy: Training Guide*. Washington, DC, 1997.

U.S. Department of Health and Human Services, National Institutes of Health, National Cancer Institute. *Making Health Communication Programs Work*. Bethesda, MD, 2001.

U.S. Agency for International Development, Bureau for Africa, Office of Sustainable Development. *Tuberculosis and Gender: A pilot study in Tanzania*. Washington, DC, 2004.

WHO, Global Polio Eradication Initiative. *Advocacy – A Practical Guide with Polio Eradication as a Case Study*. Geneva, World Health Organization, 1999.

WHO, Global Tuberculosis Programme. *TB Advocacy: A Practical Guide*. Geneva, World Health Organization, 1999.

WHO, Global Tuberculosis Programme. *Guidelines for Social Mobilization – Planning World TB Day*. Geneva, World Health Organization, 2000.

WHO, Stop TB Partnership. *Guidelines for Social Mobilization – A Human Rights Approach to Tuberculosis*. Geneva, World Health Organization, 2001 (WHO/CDS/STB/2001.9).

WHO, Stop TB Initiative. *TB Advocacy Report*, 2003. Geneva, World Health Organization, 2003 (WHO/CDS/TB/2003.321).

WHO, Stop TB Partnership. *Advocacy, Communication and Social Mobilization to Fight TB – a 10-Year Framework for Action (2006–2007)*. Geneva, World Health Organization, 2006.

WHO, Stop TB Partnership. *Advocacy, Communication and Social Mobilization for TB Control: A guide to developing KAP surveys*. Geneva, World Health Organization, 2007 (Draft).

Annex A

Selected strategic assessment and planning tools

The description of tools in Annex A is an excerpt from *Advocacy, Communication and Social Mobilization to Fight TB – a 10-Year Framework for Action (2006–2007)*[5].

The P Process

The P Process is a framework that enables the user to develop a strategic health communication programme. The P Process lays out a logical framework for a communication intervention—analysis, strategic design, development and testing, implementation and monitoring, and evaluation and replanning. Community participation and capacity-building are embedded in each step of the process. The P Process has been applied to a wide range of health issues.

At every stage of the P Process, there are basic principles for strategic communication programmes.

• **Strategic thinking:** Identify communication – not as posters and brochures or even television spots and radio dramas, but as a continuous, direct, and major influence on behaviour and policy. Mobilize and deploy the power of communication at all levels to promote and support good health practices.

• **Leadership support:** Build support among national and local leaders continuously, from the initial assessment to the sharing of evaluation results. Enable political, religious, and community leaders to share credit for programme accomplishments.

• **Audience participation:** Encourage your audience to be actively involved at every stage – assessing their needs, planning the strategy, carrying out local activities, assisting in monitoring and evaluation and engaging in advocacy. Develop key messages around the needs of, and the benefits for, the audience.

• **Interdisciplinary approach:** Work with people from different disciplines and backgrounds, including nurses, marketing professionals, social scientists, auxiliary health personnel, physicians, pharmacists, epidemiologists, anthropologists, and communication specialists throughout the life of the programme to secure the diverse skills and technical expertise needed.

• **Coordination with service providers:** Design communication programmes to identify and reinforce service facilities and to promote access and quality. Encourage and train health-care providers to use or refer to appropriate materials and messages in dealing with clients. Encourage communication experts to highlight the role of good providers.

• **Public–private partnerships:** Build partnerships among government agencies, NGOs, and the commercial sector to reinforce communication programmes and to share materials, messages, training, and other resources. Learn from one another.

• **Multiple channels:** Establish a lead agency and a lead channel to carry the message and reinforce it with other appropriate media – mass, community and interpersonal. Use media that reach the intended audiences best to achieve the most cost-effective programme.

• **Enter-educate approaches:** Never underestimate the power of entertainment to reach and persuade audiences, especially young people and those who are not health professionals. Develop and adapt entertaining materials for mass media and community distribution.

• **Training and capacity-building:** At every step, train individuals and build institutional capabilities to carry out effective programmes. Use educational sessions and on-the-job training to create a critical mass of communication experts.

• **Monitoring and evaluation:** Plan for evaluation from the start to measure changes in the intended audiences and to know whether objectives are achieved. Monitor project outputs regularly and make necessary adjustments. Share findings widely to improve future programmes.

• **Continuity and sustainability:** Plan for continuity from the start, with activities that can become sustainable over time. Expand programmes, services, activities, and coalitions as appropriate to build a larger base for advocacy and community support.

Over 15 years of experience, the P Process has been revised to better reflect the needs of the field and improvements in knowledge. The revised P Process adds the following new elements to the original formulation:

• emphasis on national communication strategies and positioning of products, practices, and services;

• more effective message development using the Seven Cs of Communication (command attention, cater to the heart and head, clarify the message, communicate a benefit, create trust, convey a consistent message, call for action);

• management of results;

• building a positive organizational climate;

• theory-based impact evaluation with multiple data sources; and

• early planning for resource generation and sustainability.

Communication for Behavioural Impact (COMBI)

Since 2001, the WHO Social Mobilization and Training Team (SMT) has been applying an approach known as COMBI (Communication for Behavioural Impact) in the design and implementation of social mobilization and communication plans for the adoption of healthy behaviours. COMBI is social mobilization directed at the task of mobilizing all societal and personal influences on an individual and family to prompt individual and family action. It is a process that strategically blends a variety of communication interventions intended to engage individuals and groups in considering recommended healthy behaviours and to encourage the adoption and maintenance of those behaviours.

[5] WHO. Stop TB Partnership. *Advocacy, Communication and Social Mobilization to Fight TB – a 10-Year Framework for Action (2006–2007)*. Geneva, World Health Organization, 2006.

COMBI incorporates the many lessons of the past 50 years of health education and communication in a behaviour-focused, people-centred strategy. COMBI also draws substantially from the experience of the private sector in consumer communication. COMBI is an integrated programme made up of five components.

• **Public relations/advocacy/administrative mobilization:** for putting the particular healthy behaviour on the business sector and administrative/programme management agenda via the mass media – news coverage, talk shows, soap operas, celebrity spokespersons, discussion programmes; meetings/discussions with various categories of government and community leadership, service providers, administrators, business managers; official memoranda; partnership meetings.

• **Community mobilization:** including use of participatory research, group meetings, partnership sessions, school activities, traditional media, music, song and dance, road shows, community drama, leaflets, posters, pamphlets, videos, home visits.

• **Sustained appropriate advertising and promotion:** in m-rip fashion – massive, repetitive, intense, persistent – via radio, television, newspapers and other available media, engaging people in reviewing the merits of the recommended behaviour vis-à-vis "cost" of carrying it out.

• **Personal selling/interpersonal communication/counselling:** involving volunteers, school children, social development workers and other field staff at the community level in homes and particularly at service points, with appropriate informational literature and additional incentives, and allowing for careful listening to people's concerns and addressing them.

• **Point-of-service promotion:** emphasizing easily accessible and readily available TB diagnosis and treatment.

The COMBI approach assumes a series of steps in how people change their behaviour in response to a message. First, people hear about TB, its cause and its solution (presenting for a sputum test and taking the drug treatment); then, they become informed about the disease, its cause and solution.

Later, they become convinced that the solution is worth while adopting and decide to do something about their conviction, and take action on the new behaviour. They then await reconfirmation that their action was a good one and, if all is well, they maintain the behaviour (returning for another sputum test if the same TB-like symptoms appear again).
The COMBI approach has already been piloted in several countries, including India and Kenya, and a review has been commissioned by the Stop TB Partnership Secretariat to assess the impact and lessons learnt from this experience. A very detailed explanation of the COMBI process, and the thinking it rests on, has been produced by the Stop TB Partnership.

Communication for Social Change (CFSC) Approach

CFSC is a process of public and private dialogue through which people define who they are, what they need and how to get what they need in order to improve their own lives. It utilizes dialogue that leads to collective problem identification, decision-making and community-based implementation of solutions to development issues. It is communication that supports decision-making by those most affected by the decisions being made. CFSC's focus is on the dialogue process through which people are able to remove obstacles and build structures/methods to help them achieve the goals they have outlined and defined. Rather than focusing on persuasion and information dissemination, CFSC promotes dialogue, debate and negotiation from within communities.

CFSC practitioners use a "bottom-up" approach by placing ownership, access, and control of communication directly in the hands of affected communities. This shifts control of media, messages, tools and content of communication from the powerful to the traditionally powerless. Ultimately, using such skills, previously powerless communities can become "self-renewing" – able to manage their own communication processes for their own good.

Similar to other participatory communication approaches, the process of CFSC is often more important than the products. CFSC does not attempt to anticipate which media, messages or techniques are better. The participation of social actors, who are in turn communicators, takes place within a process of collective growth that precedes the creation of messages and products such as a radio programme, a video documentary or a pamphlet. Messages and their dissemination are just additional elements of the communication process.

The driving forces of CFSC can be synthesized as described below.

• The societies in which TB has the greatest impact are changing rapidly. The way in which people receive, interpret and act on information, the way in which they communicate with each other, the way in which they make their voices heard within their own communities and nationally – all these have undergone a profound transformation over the past decade or so. In most high-burden countries, the media has undergone a revolution – formerly monolithic media structures (capable of disseminating simple messages to much of the population) have given way to much more fragmented media landscapes.

Radio, often the most important source of information for poor people, has been particularly transformed, in both its structure and its character. People listen more to talk shows, phone-ins and conversations; radio is arguably catalysing a renewal of the oral character and richness of many developing country societies. Information and communication technologies, although extremely restricted in their reach, are also contributing to a more horizontal, noisy, and discussion-oriented communication environment. Such an environment makes the simple conveyance of messages through mass media more difficult (because there are more channels and people have a greater choice in what they pay attention to) but also provides important new opportunities for health communication programmes. CFSC programmes have particularly sought to adapt communication strategies to these new environments.

• During several decades the same models, messages, formats and techniques were utilized – and still are today – in distinct cultural contexts. The communication process cannot ignore or deny the specificity of each culture and language; rather, it should support them to acquire legitimacy and thereby support "cultural renewal." Cultural interaction, or the exchanges between languages and cultures, is healthy when it happens within a framework of equity and respect, through critical dialogue, debate of ideas and solidarity.

• Vertical models of communication for development take it for granted that poor communities in developing nations lack "knowledge". Access to information generated in industrialized countries is sometimes seen as a "magic bullet". CFSC is cautious of the linear model of transmission of information from a central sender to an individual receiver, and promotes instead a cyclic process of interaction focused on shared knowledge and collective action. CFSC strengthens local knowledge and promotes exchanges in equal terms, learning through dialogue, in a process of mutual growth. CFSC should be empowering, horizontal versus top-down, give a voice to previously unheard members and be biased towards local content and ownership. In short, CFSC is concerned with culture and tradition, respect towards local knowledge, and dialogue between development specialists and communities. CFSC is about engaging people to want to change, to define the change and required action, and to carry them out. The goal of CFSC is self-renewing societies.

ANNEX A

There are comparatively few examples of CFSC applied to TB control. An NGO in Bangladesh, Building resources across communities (BRAC), is pioneering a new process called Participation, Interaction and Mobilization (the PIM Process). It is aimed at providing a comprehensive approach that locates social empowerment as the critical engine of behavioural change and argues that social empowerment means active community participation by civil societies in disease management, providing help to formal health-service providers as well as community health agents. BRAC uses Shastho shebikas – key health agents – who have emerged from the community.

Through a process catalysed by these health agents, community members participate in creating awareness, mobilization, household level visits and stigma reduction through social interaction, disabling stigma generation and creating a sense of a common goal. It does not replace any agency or approach but utilizes the meaning of partnership. It is good, argues BRAC, for monitoring, social auditing and message delivery. Ultimately the approach is aimed at broadening ownership and agency of TB disease management from a smaller group of health managers at various levels to include civil society as a whole, including various social groups like youths, household leaders, women, clubs, religious groups, etc.

CFSC has many similarities and complementarities to a community DOTS approach and is particularly appropriate in tackling issues of stigma and community inclusion in DOTS. Any CFSC approach does focus essentially on the communication process, whether through media or at an interpersonal level. Many of the best examples of CFSC practice are created and driven at a local level. It has been recommended that the Stop TB Partnership have a facility for tracking good practice in all forms of communication so that it can be shared among practitioners and NTPs. This applies particularly to highlighting examples – at the community as well as the national level – which are often poorly detected.

JHU Outcome Map to strengthen DOTS

Johns Hopkins University has developed an Outcome Map to strengthen the DOTS strategy to Stop TB. This is recommended as a potentially highly effective planning tool for matching communication responses to programme needs, and for outlining key planning and measurement indicators.

The Outcome Map retrofits communication interventions on to the well-established but medically-oriented DOTS strategy for TB control. The model includes suggested activities and performance indicators. It does not replace or complicate the DOTS strategy; rather it enhances it to include demand generation for high-quality DOTS services and suggests strategies for encouraging treatment adherence and completion. The model introduces the idea of a "TB-free community," which allows for ownership of the entire strategy at the community level by community members and health-care providers.

The Cough to Cure Pathway

Understanding patients' behaviour is fundamental in designing interventions to strengthen NTPs, including communication interventions. Communication interventions need to identify key challenges to control TB among intended populations. To assist in identifying these barriers it is useful to map them out along a preferred behavioural continuum from the first sign of symptoms (cough) to treatment completion (cure). The Academy for Educational Development has developed a diagnostic and planning tool: the Cough to Cure Pathway.

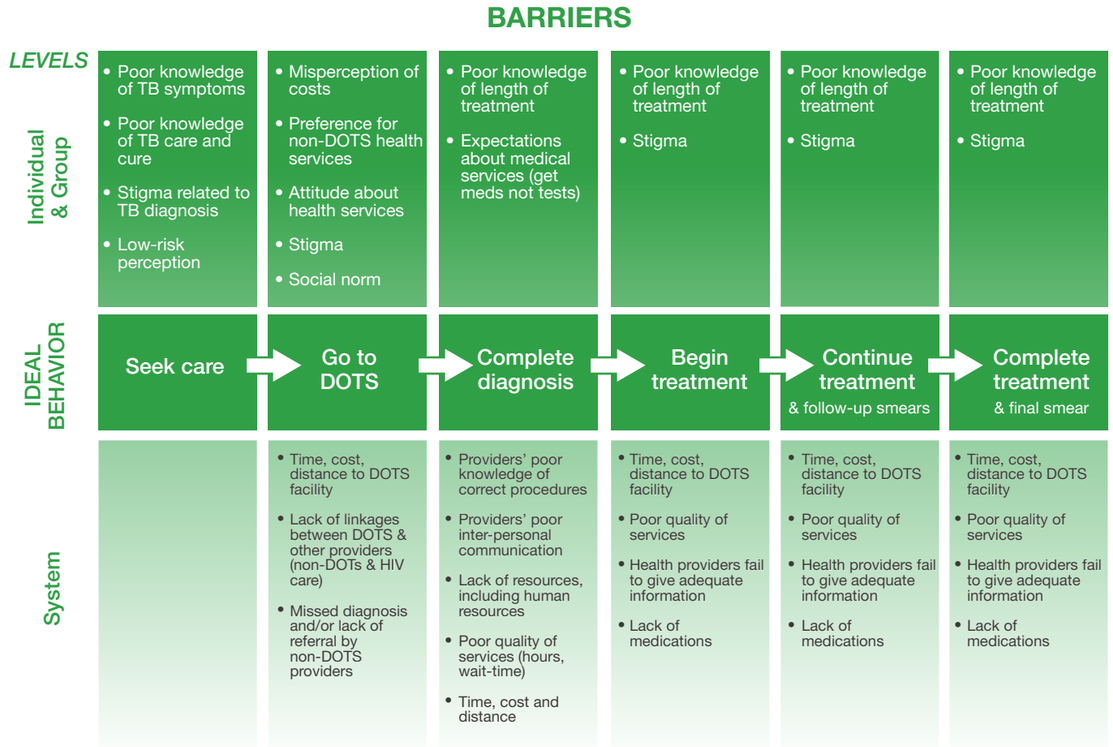
The pathway is designed to help NTPs identify where TB drop-outs are occurring, and for each step of the pathway it lists the most common barriers at the individual, group and systems levels. It outlines six steps and identifies the behavioural barriers to people taking these steps at each stage.

- First, to seek timely care.
- Second, to go a DOTS facility.
- Third, to get an accurate diagnosis.
- Fourth, to begin treatment.
- Fifth, to persist in getting treatment.
- Sixth, to complete treatment.

Baseline studies need to be conducted to identify key barriers to completing ideal behaviours. Then, programmes need to weigh the relevance of different barriers in order to prioritize courses of action and the focus of communication interventions.

See an illustration of the pathway below.

From Cough to Cure: A path of ideal behaviors in tuberculosis control



Annex B

Assessment of advocacy, communication and social mobilization in national tuberculosis programmes

Checklist

Programme funding and strategy

• What is your total budget for ACSM and the sources of funding?

Budget	Dates	Total, $m	ACSM, $m	%
NTP				
Funding				
National government				
Global Fund				
Other sources				
GAP				

• Is there a national ACSM strategy/plan? Who was involved in developing it?
• What is the overall timeline and spending plan?
• How are ACSM plans and goals articulated within the national/technical plan and goals?

Implementation resources

• Who are the key stakeholders and implementers involved in ACSM activities?

• What initiatives to involve communities in TB care are implemented?

• How do communities participate in different phases/activities/in what capacity?

• How do they get involved?

• What training do the different implementers have in ACSM and TB?

• What ACSM human resources exist in the national TB programme (NTP)?

• What ACSM human capacity exists at different levels (national, state, district)?

• Are all human resource needs met? If not, what are the gaps?

Strategy design

• What type of data, for example from a KAP survey, focus group or other quantitative/qualitative sources, is used as input to design ACSM plans?

• How are ACSM goals articulated within the overall goals of the NTP?

Priority populations (Who?)

• Who are the priority populations for ACSM activities?

• How were they selected/identified?

• Does the programme have specific ACSM activities for populations such as alcohol abusers, cross-border populations, ethnic minorities, immigrants, migrant workers, injecting drug users, people living in prisons, refugees, slum dwellers and the orphaned or homeless? If so, please list the activities.

Behavioural goals (What?)

• What are the key behaviours identified in ACSM activities to be promoted among different populations?

• What are the key barriers to successful TB control among those populations?

• What methods are used to address people and motivate them to engage in ideal TB control practices?

Communication activities (How)

• What activities have been planned and actually rolled-out?

• What channels/networks/institutional resources are used? What criteria were used to select them?

• What materials have been produced?

How are ACSM activities monitored and evaluated?

• What indicators and data are used for monitoring and evaluation?

• What is the frequency of data reporting? Is it often enough (e.g. daily/weekly/monthly) to give timely feedback on activities?

• What is the process for reporting? Who does what (who prepares reports, who are they sent to) and how are decisions influenced by report results?

• What data can you share?

• How are different activities evaluated in terms of reach, efficacy and other indicators?

• What are the three most important ACSM needs?

Annex C

Examples of ACSM goals/indicators

The examples in this annex are excerpted and adapted from *The Global Plan to Stop TB, 2006–2015*[6].

Knowledge indicators

- Knowing what TB is and the difference between TB, MDR-TB and XDR-TB.
- Knowing how a person can get TB.
- Knowing what kind of people are more likely to get TB or are most susceptible to TB.
- Knowing how a person can prevent getting TB.
- Knowing if and how a person with TB can be cured.
- Knowing what a person could do to reduce his or her chances of a cure.
- Knowing the cost of TB diagnosis and treatment in the country.
- Knowing how long TB treatment lasts.

Attitude indicators

- How serious TB is considered to be as a disease. (When checking this, ask the question in relation to other diseases or provide a scale.)
- How serious a problem TB is considered to be in the country/region.
- What a person would think if he/she were diagnosed with TB.
- What a person would do first (or how would they react) upon receiving a TB diagnosis.
- What a person thinks about the effectiveness of TB treatment.
- What a person thinks about the side effects or other problems related to TB treatment.

Health-seeking behaviour indicators

- Where people usually go if they are sick, or to treat a general health problem.
- How often people generally seek health care at a clinic or hospital.
- What a person would do if they thought they had symptoms of TB.
- What help a person would seek if they thought they had symptoms of TB.
- If a person had a cough for more than three weeks, or if they were coughing up blood in their sputum, what they would do.
- If a person had symptoms of TB, at what point they would seek medical help.
- If a person had symptoms of TB, how long they would wait before seeking treatment.
- Who a person would talk to about TB if they were diagnosed.

Exposure to communication and mass media indicators

- Where people usually hear about TB and what sources of information can most effectively reach people with information on TB.
- Sources from which people currently get their health information and which ones they trust most.
- How often people watch television/listen to radio/read newspapers; which they listen to/watch/read, and how often.

Stigma indicators

- The feelings people have toward others they know who have TB or have had TB.
- If a person's close friend had TB, whether the relationship would change and how.
- In the community, how a person who has TB is regarded/treated.
- Whether HIV-positive people should be concerned about TB and why.
- Why some people are more likely to become infected with TB than others.
- Whether having TB carries the same stigma as having AIDS – or less, or more.
- If there was only one bed in a hospital for a TB patient or an AIDS patient, who should get the bed and why.

Gender indicators

- Women usually go to a health-care facility alone.
- Men usually accompany their wives to visit a health-care facility.
- Men – or women – are considered to be more likely to get TB, or men and women have the same risk.
- What a man in the community would do if his wife got TB.
- The reaction in a family if a family member/prospective daughter-in-law/prospective son-in-law had TB.

Health-care worker-specific indicators

- Education on TB or HIV is provided. If yes, how often.
- The type of materials used to guide education sessions.
- The source of the materials used for TB and HIV education.
- What would help families discuss TB more openly.
- What would help people with TB discuss the disease more openly.
- What would make it easier for communities to have more open dialogue on health topics.
- The best communication channel likely to be effective in reaching people with TB in the community.
- The communication channels that health workers should use to encourage TB or HIV prevention practices in the community.
- The stage in their illness when people with TB usually begin seeking health care at the facility.
- How people react once they find out that they have TB.
- Who people generally tell about their illness.
- How a person who has TB is usually regarded/treated.

[6] WHO, Stop TB Partnership. *The Global Plan to Stop TB, 2006–2015.* Geneva, World Health Organization, 2006.

Annex D

Planning a World TB Day event

Annex D is excerpted from Guidelines for Social Mobilization: Planning World TB Day[7].
World TB Day is a valuable opportunity to raise awareness of the prevalence and impact of TB – as well as the state of TB prevention and control efforts – at the national, regional and local levels.

Reasons for holding an event

- To highlight achievements of the NTP.
- To obtain additional political commitment.
- To mobilize new partners to address TB in their work.
- To increase the demand for TB services (diagnosis and treatment).
- To attract media attention (television, radio, newspaper) to increase understanding of TB in the general public, and increase commitment from local leaders and politicians to support TB control activities.

Planning steps

1) Set up a World TB Day planning committee that includes partners, organizations and other motivated people (e.g., NGOs, student groups, religious groups, media, medical associations, networks of people living with TB, politicians, women's groups, HIV/AIDS organizations and programmes). Hold regular meetings of the committee, keep minutes of the proceedings and distribute them widely after each session.

2) Consider mobilizing external resources by involving private industry or businesses.

3) Determine interesting and relevant activities.

4) Determine what each member of the planning committee can contribute and assign tasks and responsibilities.

5) Set deadlines for accomplishing the various tasks.

6) Make provisions to assess the impact of the event.

7) Collect information to build a case for supporting TB control.

8) Transform statistics into key messages and stories to state the extent and effects of the problem; share success stories about what can be done to address the problem; and provide human interest examples that document the impact of TB on the individual.

9) Design activities and events that will mobilize partners for action (forums, seminars, courses, parades, competitions, street events and other "infotainment" events).

10) Organize media events to make news (such as a press conference with politicians or other leaders to highlight the opening of a new DOTS centre).

[7] Larson H, Mahanty B. *Guidelines for Social Mobilization: Planning World TB Day.* Geneva, World Health Organization, 2000 (WHO/CDS/STB/2000.1).

11) Prepare speeches, fact sheets, video, and other visual materials with statistics and key messages.

12) Assess the event afterwards and compile the lessons learnt.

13) Organize a "thank you" event for members of the planning committee to build on successes and nurture partnerships for the future.

Examples of World TB Day events

The **Philippine Coalition against Tuberculosis (PHILCAT)** organized awareness-raising events to promote DOTS on World TB Day. The theme was "the critical role of the private sector in DOTS". PHILCAT, whose members include pharmaceutical companies, announced its support for a local foundation called the "Centre for TB in Children". PHILCAT also sponsored a motorcade and an entertainment event on the day. Hundreds of people participated and the media highlighted this as an example of private sector involvement with children affected by TB. In addition, banners with the sponsors' names were flown on the streets and appeared on local television.

In **Nigeria**, a private organization in collaboration with the University Teaching Hospital organized a national convention coinciding with World TB Day called "TB—a re-emerging infectious disease; HIV/AIDS and the health worker". The objective was to improve the knowledge and understanding of the health-care staff about TB to enhance TB services and health worker–patient relations. The event updated the staff on the importance of each element of the DOTS strategy and reinforced their commitment to TB control.

In Jijiga, **Ethiopia**, children learnt the main messages about TB management and prevention by playing the "snakes and ladders" game. Teams of five children, representing the five elements of DOTS, took part in bicycle relay races. Participants as well as spectators had fun while learning about the importance of everyone's involvement in making TB control effective.

In the **Philippines**, the "dating game" was played on World TB Day. Four potential candidates went out on a date with a young woman and responded to her questions from behind a screen. The young woman chose her date for the evening, not having seen the candidate, based on his answers. In this version of the game, one of her questions was: "How would you treat me if I had TB?" By picking the candidate who gave the most caring response, the young woman brought attention to the importance of a non-stigmatized attitude towards people with TB.

In **Nepal**, World TB Day served as the launch of "Kathmandu Valley DOTS" and the official opening of 17 new DOTS centres. In addition, the "Dixa Daxa" award was inaugurated to honour people who made important contributions to TB control. The event created widespread media attention and the awards ceremony generated news about who would be honoured for their contribution to fighting TB.

On World TB Day the governor of a province in **Pakistan** called for the start of an "adopt-a-patient" programme to fund treatment for people who could not otherwise afford it. The governor funded the treatment of 10 people with TB and called on the medical community to "provide more ideas to improve the health situation of the population". At the same event the importance of implementing the DOTS strategy was highlighted, and the governor's participation received widespread media coverage in the province.

Beyond World TB Day

The list below includes other international commemorative days and events to use as a foundation for ACSM activities.

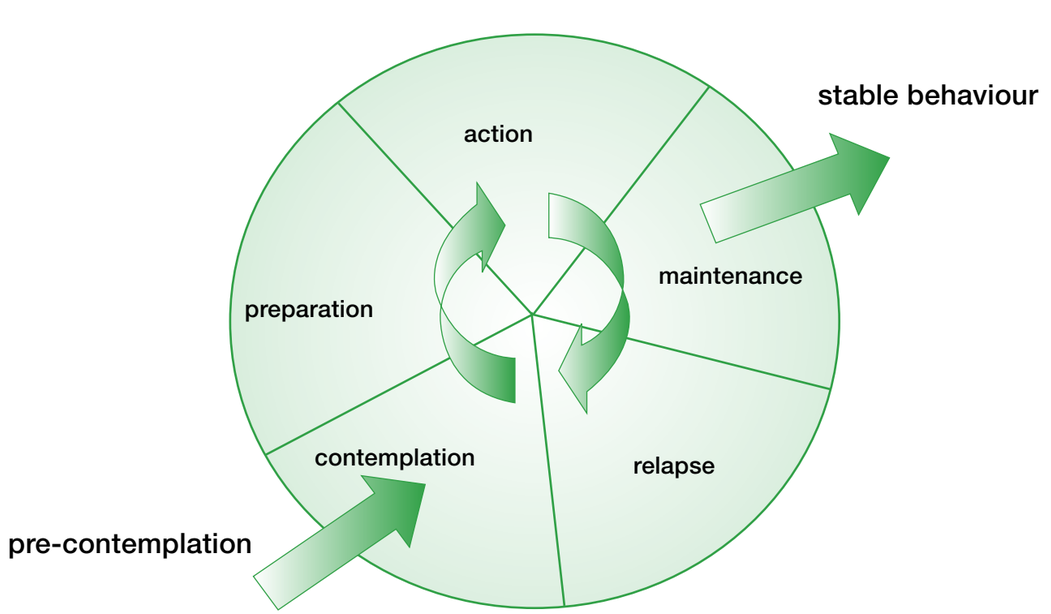
- **8 March**: UN Day for Women's Rights and International Peace (focus on gender, human rights, access to TB services).
- **7 April**: World Health Day (DOTS is an effective treatment strategy to cure TB).
- **15 May**: International Day of Families (TB affects families, puts children out of school, decreases family income).
- **31 May**: World No-Tobacco Day (smoking weakens the immune system and can further the progression from TB infection to disease).
- **11 July**: World Population Day (TB impacts on life expectancy and quality of life).
- **1 October**: International Day of Older Persons (TB is a disease that affects older people; DOTS can cure TB and increase the quality of life).
- **17 October**: International Day for the Eradication of Poverty (TB puts many families into poverty; TB disproportionately affects those already living in poverty).
- **16 November**: International Day for Tolerance (de-stigmatise people with TB).
- **20 November**: Universal Children's Day (many children are orphaned or otherwise affected by TB).
- **1 December**: World AIDS Day (the dual epidemic of TB and HIV; TB is the leading killer of people with HIV).
- **10 December**: Human Rights Day (access to treatment and information is a human right; discriminating against people with TB is a violation of their human rights).

Annex E

The stages-of-change model

Annex E is adapted from: *Changing for Good: A Revolutionary Six-Stage Programme for Overcoming Bad Habits and Moving Your Life Positively Forward*[8].

The stages-of-change are:
- pre-contemplation (not yet acknowledging that there is a problem behaviour that needs to be changed);
- contemplation (acknowledging that there is a problem but not yet ready or sure of wanting to make a change);
- preparation/determination (getting ready to change);
- action/will power (changing behaviour);
- maintenance (maintaining the behaviour change); and
- relapse (returning to former behaviour and abandoning the new changes).



Stages-of-Change Model

[8] Prochaska JO, Norcross J, DiClemente C. *Changing for Good: A Revolutionary Six-Stage Programme for Overcoming Bad Habits and Moving Your Life Positively Forward.* New York, Avon Books, 1994.

Stage one: Pre-contemplation

In the pre-contemplation stage, people are not thinking seriously about changing and are not interested in any kind of help. People in this stage tend to defend their current bad habit(s) or dangerous situation(s) and do not feel it is a problem. They may be defensive in the face of other people's efforts to pressure them to take action, to go for diagnosis for example.

Stage two: Contemplation

In the contemplation stage people are more aware of the personal consequences of their negative situation and they spend time thinking about their problem. Although they are able to consider the possibility of changing, they tend to be ambivalent about it.

In this stage, people weigh the benefits and the negative aspects of modifying their behaviour. Although they think about the negatives of their bad habit or situation and the positives associated with doing something about it, they may doubt that the long-term benefits associated with taking action will outweigh the short-term costs.

It might take as little as a few weeks or as long as a lifetime to get through the contemplation stage. (In fact, some people think and think and think about giving up their bad habit or changing their situation, and may die never having moved beyond this stage). On the positive side, people are more open to receiving information about their bad habit or dangerous situation, and more likely to actually use educational interventions and reflect on their own feelings and thoughts concerning their bad habit or situation.

Stage three: Preparation/determination

In the preparation/determination stage, people have made a commitment to make a change. Their motivation for changing is reflected by statements such as: "I've got to do something about this– this is serious. Something has to change. What can I do?" During this phase people are taking small steps toward changing their situation. They are trying to gather information about what they will need to do to change their behaviour.

For example, they may talk to a health-care provider or a friend, trying to find out what resources are available to help them. Too often, people skip this stage; they try to move directly from contemplation to action and fail because they have not adequately researched or accepted what it is going to take to make a behaviour change.

Stage four: Action/will power

This is the stage where people believe they have the ability to change and are actively involved in taking steps to change their bad behaviour or dangerous situation by using a variety of different techniques.

This is the shortest of all the stages. The amount of time people spend in action varies. It generally lasts about six months, but it can be as short as one hour! This is a stage when people depend most on their own will power. They are making overt efforts to change their behaviour and are at greatest risk of moving back to their previous, negative behaviour or situation.

Mentally, they review their commitment to themselves and develop plans to deal with both personal and external pressures that may lead to slipping back to their former situation. They may use short-term rewards to sustain their motivation, and analyse their behaviour change efforts in a way that enhances their self-confidence. People in this stage also tend to be open to receiving help and are also likely to seek support from others (a very important element).

Stage five: Maintenance

Maintenance involves being able to successfully avoid any temptations to return to the bad habit or dangerous situation. The goal of the maintenance stage is to maintain the new status quo. People in this stage tend to remind themselves of how much progress they have made.

People in maintenance constantly reformulate the rules of their lives and are acquiring new skills to deal with life and avoid returning to their previous behaviour or situation. They are able to anticipate the situations in which this could occur and prepare coping strategies in advance. They remain aware that what they are striving for is personally important. They are patient with themselves and recognize that it often takes a while to change old behaviour patterns and practice new ones until they become "normal" to them. Even though they may have thoughts of returning to their old habits or situations, they resist the temptation.

Stage six: Relapse

Along the way to the stable reduction of a bad habit or removal from a dangerous situation, most people experience relapse, a return to the previous behaviour or situation. In fact, it is much more common to have at least one relapse than not. Relapse is often accompanied by feelings of discouragement and seeing oneself as a failure.

While a relapse can be discouraging, the majority of people who successfully change do not follow a straight path to a lifetime free of negative behaviour or situations. Rather, they cycle through the five stages several times before achieving a stable behaviour change. Consequently, the stages-of-change model considers relapse to be normal.

Annex F

Worksheet for a creative/strategic brief

Annex F has been excerpted and adapted from *Making Health Communication Programmes Work*[9].

Intended audiences What types of people do you want to reach?	
Objectives What do you want your intended audiences to do after they hear, watch, or experience the message?	
Obstacles What beliefs, cultural practices, peer pressure, misinformation, etc. stand between your audience and the desired objective?	
Key promise Select one single promise/ benefit that the audience will experience upon seeing, hearing, or reading the objectives that you have set.	

[9] U.S. Department of Health and Human Services, National Cancer Institute. *Making Health Communication Programmes Work*, Bethesda, MD, 2001.

Support statement/the reason Include the reasons the key promise/benefit outweighs the obstacles and the reasons that what you are promising or promoting is beneficial. These often become the messages.	
Tone What feeling or personality should your message have? Should it be authoritative, light, emotional? Choose a tone.	
Media What channels will the message use, or what form will the message take? Television? Radio? Newspaper? Internet? Poster? Flyer? All of the above?	
Openings What opportunities (times and places) exist for reaching your audience?	
Creative considerations Is there anything else the creative staff should know? Will it be in more than one language? Should they make sure that all nationalities are represented?	

Note: All briefs should be accompanied by a page summarizing the background situation of the work/activity.

Annex G

Sample recruitment document for a focus-group discussion

Annex G is adapted from an internal recruitment screener, developed in 2006 and used by the Academy for Educational Development in Viet Nam to recruit individuals among heads of households to participate in a focus group on information-gathering and media habits, and to pre-test television spots.

SCREENING QUESTIONNAIRE

Project Name

Respondent's name _____

Address _____

Occupation _____ Telephone _____

Interview date | Started at | Ended at | Length

Office use only | *Observed by* | *Quality control by* | *Validated by*

Location		**Quota**	**Group no.**	**Gender**	
Name	1	Rural commune	1	Male	1
		District town	2		
Name	2	Rural commune	3	Female	2
		District town	4		
Name	3	Rural commune	5		
		District town	6		
Name	4	Rural commune	7		
		District town	8		

Interviewer _____ I.D. _____

I declare that the respondent, whose name and address appear above, was unknown to me until the interview. I confirm that, before returning this questionnaire, I have checked that it complies with – and was carried out in accordance with – the instructions supplied to me for this study. I understand that the information given to me during the interview must be kept confidential.

Signed _____ Date _____

Hello, I am …… [insert interviewer name], an interviewer from [insert organization name]. We are currently having discussions with people who live in this area on their lives. Could I speak to the head of the household please?

Speak to contact person

1. Do you or any member in your household, relatives or close friends work for any of the following businesses?

Public relations, media (television station, radio, newspaper)	1	TERMINATE
Advertising	2	TERMINATE
Marketing/market research/new-product development	3	TERMINATE
None of the above	6	**CONTINUE**

2. In the past six months, have you, yourself, ever participated in any market survey or group discussions?

Yes	1	TERMINATE
No	2	**CONTINUE**

3. Could you please tell us your year of birth? [Record year of birth and assign a code based on age.]

Under 20 years old	1	TERMINATE
21–29 years old	2	**CONTINUE**
30–39 years old	3	**CONTINUE**
Over 39 years old	4	**CONTINUE**

4. Which of the following best describes your marital status?

Single	1	TERMINATE
Married with child/children	2	**CONTINUE**
Married without children	3	TERMINATE
Refused	4	TERMINATE

5. How often do you watch television?

Three or more times a week	1	**CONTINUE**
Two or fewer times a week	2	TERMINATE

6. Now I am going to read out some statements. Please let me know if you agree with any of them.

	Agree	Disagree
a) I like watching television commercials.	1	2
b) I love watching television and do not mind television commercials interrupting my programme.	1	2
c) I like watching television but would prefer to not have television commercials interrupting my programme.	1	2
d) I immediately switch to another channel any time I see an advertising break.	1	2

--> TERMINATE IF RESPONDENT CHOSE CODE 1 FOR STATEMENT D.

7. Could you please let us know whether you agree or disagree with the following statement.

READ OUT EACH STATEMENT AND RECORD THE ANSWERS BELOW.

	Agree	Disagree
I do not have trouble expressing my opinion.	1	2
Getting together, talking to others is a good way to know more.	1	2
I like sharing my opinions with others.	1	2

CONTINUE ONLY IF THE RESPONDENT AGREES TO EACH OF THE THREE STATEMENTS ABOVE.

THEN READ ALOUD:

We

estimated to last about two hours. Whatever information you provide will be kept confidential and will not be shared with anyone else. You will not receive any payment for participating but your answers may help to improve health in your community. You do not have to answer any questions that you do not want to answer. Would you like to participate?

Agree to participate	1	**INVITE**
Refuse to participate	2	Thank and terminate

Annex H

Sample guide for a focus-group discussion

This sample guide was prepared by PATH in 2004 for people living with HIV in Ukraine to talk about their knowledge of TB and their experiences with it.

The instructions in italics address the facilitator.

Date (day/month/year) _____

Time focus-group discussion began _____

Name of facilitator _____

Time focus-group discussion ended _____

Name of recorder _____

Age of group participants: __ >30 __<30 _____

Introduction

Read the introduction; it explains the purpose of the group.

Ask participants to complete the background information form. This should be done individually.

Tell participants that if they participate in the focus-group discussion, they will be asked not to repeat any information discussed in the group. While the study staff expect all participants to follow this instruction, they cannot guarantee that what a participant says in the group will not be repeated outside the group by one of the other participants.

Anyone who participates in a focus-group discussion is free to use a name other than their own during the discussion.

Tell participants that, if at any time they do not feel comfortable with a topic, they are not required to speak and they are completely free to end their participation in the meeting at any time. There are no wrong or right answers.

Attitudes towards health services

Begin the discussion by saying:

Today we will be discussing health care, how we seek and receive health care, and how we learn information about health topics. These issues are important to men and women in Donetsk, Kyiv and across Ukraine. We will talk about TB in particular.
Let us first talk about your experiences when you have needed medical care.

Ask each participant to answer in turn. Follow up with questions then open up the discussion to the group. Explore feelings about where participants go for medical care, and their reasons for seeking medical care. Discuss how people feel about seeking health care and how they are treated when they go to medical facilities.

Ask the following questions.

What do you think about the situation of health care in Ukraine right now?
Tell me about your experiences when you have gone to a medical facility to seek health care.

Probe:
- Where do you go for health care? Who provides health care to you?
- How long do you wait to be seen by a trained medical provider?
- What is the medical provider's attitude to you? What do they say and do? What are your feelings about this?
- In general, what do you like when you go to see a medical provider?
- In general, what do you dislike when you go to see a medical provider?
- Describe a particular experience you had when you sought health-care at a medical facility.

Health-seeking practices

- Do you usually get medical care when you feel a need of it?

Probe:
- If not, why not? (Do not read this list – just take notes of responses or give an example if necessary.)

Possible reasons include:
- cost
- transportation
- not sure where to go
- stigma
- privacy and confidentiality issues
- do not like to wait
- have to care for children
- attitude of health providers
- cannot leave work
- afraid to find out that something is really wrong
- will probably be told that nothing is wrong
- other

- How often in a year do you get medical care?

Probe:
- For what types of medical problems?
- Where do you go for medical care?
- How long do you normally wait before you go get medical care?

Probe:
- When you realize something is wrong, what symptoms tell you this?
- What else? What other signs tell you when your health needs attention?
- Take coughing, for example, when do you know that the cough is not normal?

ANNEX H

Knowledge of TB

• Have you ever heard of TB?

Probe:

- What have you heard about TB?
- How did you first hear of TB?
- What are the symptoms or signs of TB?

• In your opinion, how is TB transmitted (passed from one person to another)?

Probe:

- In what ways are you sure that TB cannot be transmitted?
- How is TB treated? What can happen if it is not treated?
- Can TB be cured?
- In your opinion, is TB a major health problem in Ukraine?
- Who is at particular risk of getting TB?

Attitudes toward people with TB

• Have you ever know someone who has TB?

Probe:

- How did you learn they had TB?
- What was your reaction? What did you think/feel at that time?
- Did anything change in the way you relate to that person?

• How would you feel if a member of your family had TB?

Probe:

- How would you treat them? What would you do for them?
- Would anything change in the way you relate to them? If yes, what?
- Would you give your family member any advice? If so, what advice would you give them?
- What do you feel about the TB medical facilities?

Probe:

- Would you feel comfortable visiting such facilities in case of TB symptoms?
- Do you think you would get appropriate care, diagnosis and treatment?
- Do you fear that you will get infected?
- Do you feel stigmatized?
- Are you sure that confidentiality would be assured in these facilities?

Opinions & preferences regarding effective media

• Where do you get information about health topics?

Probe:

• If from a person, from whom? (Do not read the list; take note of responses.)

- friends or co-workers
- family members or spouse
- medical provider
- school teacher
- other.

Probe:

• If from the media, what source? (Do not read the list; take note of responses.)

- television
- radio
- billboards
- magazines
- newspapers
- brochures or other printed matter
- other.

• What source of information do you trust the most and why?

• From what source would you like to learn more about TB?

Probe:

- If media, what kind of media?
- If people, what people?
- If printed materials, what kind? (Describe.)
- Why do you prefer this source of information? What makes this source trustworthy?

• If you were to read a brochure or poster about TB, what would make it interesting to you?

- colourful
- celebrity/famous person
- simple, easy-to-read
- good content and information
- other.

• If you were to see a television spot informing you about TB, what would make it interesting to you?

Probe:

- What should a good television spot on TB be like?
- What style should it be?
- How long should it take?
- What information should it include?
- At what time of day should this television spot be shown?

• How about the radio – what would make a radio spot interesting to listen to?

Probe:

- What should a good radio spot on TB be like?
- What style should it be?
- How long should it take?
- What information should it include?
- At what time of day should this radio spot be broadcast?

• If you saw a spot about TB on television, or heard one on the radio, what would make you act or take the information seriously?

• What messages about TB are most important to pass to the public?

Conclusion

We will close today's meeting with some final thoughts.

Read the following text to the participant(s).

Some of the topics we have discussed are very personal for people to talk about. We want to thank you for sharing your honest thoughts and personal opinions today. Think for a moment about what we have talked about.

Ask each person if there is anything else she/he would like to add. Conclude by saying:

We are now finished. How do you feel about our discussion? Do you have any suggestions for improving the group process?

Here are our business cards. If you have any more questions or comments you wish to share after the interview, do not hesitate to contact us. We have refreshments – coffee and cookies – here for you.

Thank the participants and tell them that their contribution has been very valuable. Emphasize that this information will be used to improve health education campaigns according to their realities and preferences.

After the focus group

Immediately after the discussion, note-taker and/or facilitator:

- debrief together;
- look over the forms with the participants' background information;
- make a note of suggested changes in the way the group or interview should be conducted or in the technical aspects of the logistics;
- revise, edit and complete notes.

DO NOT DELAY THE FOLLOWING STEPS

That afternoon or evening, note-taker and/or facilitator:

- review the recording; make clarification notes as necessary;
- complete and correct the notes in accordance with the recording;
- summarize important themes or points made in the summary section of the interview;
- send the tape and the clarification notes to be transcribed;
- meet with the other project staff to discuss how the focus groups and interviews are going;
- share suggestions for changes to the guide, the interviews or the focus-group discussions.

Annex I

Sample questions for pre-testing materials

Annex I is adapted from *Developing Health and Family Planning Print Materials for Low-Literate Audiences: A Guide*.[10]

Sample questions for pre-testing printed materials

Ask these questions about each page of the material being tested:

1) What information is this page trying to convey?

2) In your own words, what does the text mean?

3) What does the illustration show?

4) Do the words match the picture on the page? Why, or why not?

5) Are there any words in the text you do not understand? Which ones? (If any, explain the meaning to respondents and ask them to suggest other words that can be used to convey that meaning.)

6) Are there any words that you think others might have trouble reading or understanding? (Again, ask for alternatives.)

7) Are there sentences or ideas that are not clear? (If so, have respondents show you what they are. After explaining the intended message, ask the group to discuss better ways to convey it.)

8) Is there anything on this page that you like? What?

9) Is there anything on this page that you do not like? What?

10) Is there anything on this page that is confusing? What?

11) Is there anything about the pictures or the writing that might offend or embarrass some people? What? (Ask for alternatives.)

Ask these questions about the entire material:

12) Do you think the material is asking you to do anything in particular? What?

13) What do you think this material is saying overall?

14) Do you think the material is meant for people like yourself? Why?

15) What can be done to make this material better?

Ask the above questions for each version of the material, and then ask:

16) Which version of the material do you prefer? Why?

[10] PATH. *Developing Health and Family Planning Print Materials for Low-Literate Audiences: A Guide.* Seattle, 1996.

Sample questions for pre-testing radio and video

The following sample questions have been excerpted and adapted from *How to Conduct Effective Pre-tests*.[11]

1) In your own words, what do you think is the message of this programme?

2) Are there any words in the programme whose meanings you did not understand? If yes, identify the word(s) then ask: What do you think [mention the word] might mean? Which word do you think should be used instead?

3) Can you hear and understand what they are saying in the programme? If not, what can you not hear or understand?

4) Are there any scenes in the programme that you did not understand? If yes, explain.

5) Are the music, sound effects, visuals and dialogue appropriate for this programme?

6) Is there anything in the programme that you think is not true? If yes, what? What about it seems untrue?

7) Does the programme say anything that might offend anyone in your community? What?

8) What did you like most about the programme?

9) Is there anything about the programme that you do not like? If yes, what? How would you say it so that you would like it?

10) What do you think this programme is asking you to do?

11) Are you willing to follow the advice given to you? What would cause you to be willing to follow the advice? What would discourage you?

12) To whom do you think this programme is directed? What about it makes you think that?

13) Who are the people in the programme? What are they doing?

14) Where do you think they are?

15) What do you think you will remember most about this programme?

16) Do the people in the programme talk the way people from here talk? Do they look like people from here? If not, what would you change?

17) In your opinion, what could be done to improve this programme?

Two or more versions being pre-tested

If you have multiple versions of your spot or programme, ask the above questions for each version, and then ask the following comparison questions:

1) Which of the two programmes do you like best? Why?

2) If you had to prepare a programme containing the best parts of each version, which parts would you choose from each?

[11] Family Health International. *How to Conduct Effective Pre-tests.* Research Triangle Park, NC.

Annex J

Sample questions for evaluating an advocacy initiative

Adapted from *Advocacy Tools and Guidelines: Promoting Policy Change*. Atlanta, GA, CARE, 2001.

Evaluating impact

- Have policy changes resulted in improvements in TB treatment or access to treatment? Why/why not? Can data be provided to support these findings?

- Have policy changes contributed to protecting, promoting or expanding people's rights and mitigating discrimination based on stigma?

Evaluating effects

- Has the intended policy change occurred or are the prospects better than they were before?

- Have new policies been approved or have outdated/adverse polices been changed? Are policies enacted at the national, regional and/or local levels? Why/why not?

- What factors enabled/hindered the success of the policy change (in other words, the creation, revision or enactment of policies)?

- Were bills or proposals formally introduced in the legislature or other government body or were informal decisions made?

- Who made final decisions that enabled/hindered the policy change?

Evaluating the strategy

- Were the appropriate primary and secondary populations selected? Did the targets of advocacy have to be changed along the way? Why/why not?

- Did the advocacy messages change opinions or knowledge on the policy issue? Which messages were most successful and which failed to convey the main point(s)?

- Were appropriate roles chosen for the advocacy initiative? Could other roles have been more effective?

- Was advocacy conducted within a larger partnership or coalition? What were the benefits/drawbacks of the arrangement?

- Has the advocacy initiative increased the ability of community groups and/or local organizations to represent their own interests?

- Did the advocacy initiative raise public awareness and interest in the policy issue?

- What were the major obstacles faced by the advocacy initiative? What was done to overcome those obstacles?

- What can be learnt from the strategy implementation for future advocacy initiatives?

Annex K

The Patients' Charter for Tuberculosis Care

The Patients' Charter for Tuberculosis Care (the Charter)[12] outlines the rights and responsibilities of people with tuberculosis (TB). It empowers people with the disease and their communities through knowledge of the disease. Initiated and developed by patients from around the world, the Charter makes the relationship with health-care providers a mutually beneficial one.

The Charter sets out the ways in which patients, communities, health-care providers – both private and public – and governments can work together as partners in a positive and open relationship to improve standards of TB care and enhance the effectiveness of the health-care process. It allows all parties to be held more accountable to each other, fostering mutual interaction and a "positive partnership".

Developed in tandem with the International Standards for Tuberculosis Care[13] to promote a "patient-centred" approach, the Charter adheres to the principles on health and human rights of the United Nations, UNESCO, WHO and the Council of Europe, as well as other local and national charters and conventions.[14]

The Charter embodies the principle of greater involvement of people with TB (GIPT). This affirms that the empowerment of people with the disease is the catalyst for effective collaboration with health-care providers and authorities and is essential to victory in the fight to stop TB. The Charter, the first global "patient-powered" standard for care, is a cooperative tool, forged from a common cause, for the entire TB community.

Patients' rights

1. Care

a) The right to free and equitable access to TB care, from diagnosis to completion of treatment, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture or health status.

b) The right to receive medical advice and treatment that fully meets the new International Standards for Tuberculosis Care, centring on patient needs, including the needs of patients with MDR-TB or TB-HIV co-infection, and preventive treatment for young children and others considered to be at high risk.

c) The right to benefit from proactive health sector community outreach, education and prevention campaigns as part of comprehensive health-care programmes.

[12] *Patients; Charter for Tuberculosis Care; Patients' Rights and Responsibilities*. World Care Council, 2006 (*http://www.worldcarecouncil.org/pdf/*).

[13] International Standards for Tuberculosis Care: *http://www.worldcarecouncil.org*

[14] United Nations CESCR General Comment 14 on the right to health: *http://www.worldcarecouncil.org/pdf/*

WHO Ottawa Charter on health promotion: *http://www.worldcarecouncil.org/pdf/*

The Council of Europe Convention for the Protection of Human Rights and Dignity/ biology and medicine: *http://www.worldcarecouncil.org/pdf/*

UNESCO Universal Draft Declaration on Bioethics and Human Rights: *http://www.worldcarecouncil.org/pdf/*

2. Dignity

a) The right to be treated with respect and dignity, including the delivery of services without stigma, prejudice or discrimination by health-care providers and authorities.

b) The right to high-quality health care in a dignified environment, with moral support from family, friends and the community.

3. Information

a) The right to information about the availability of health-care services for TB, and the responsibilities, engagements and direct or indirect costs involved.

b) The right to receive a timely, concise and clear description of the medical condition, with diagnosis, prognosis (an opinion as to the likely future course of the illness) and treatment proposed, with communication of common risks and appropriate alternatives.

c) The right to know the names and dosages of any medication or intervention to be prescribed, its normal actions and potential side-effects and its possible impact on other conditions or treatments.

d) The right of access to medical information relating to the patient's condition and treatment and to a copy of the medical records if requested by the patient or a person authorized by the patient.

e) The right to meet, share experiences with peers and other patients and to voluntary counselling at any time, from diagnosis to completion of treatment.

4. Choice

a) The right to a second medical opinion, with access to past medical records.

b) The right to accept or refuse surgical interventions if chemotherapy is possible and to be informed of the likely medical and statutory consequences within the context of a communicable disease.

c) The right to choose whether or not to take part in research programmes without compromising care.

5. Confidence

a) The right to respect for personal privacy, dignity, religious beliefs and culture.

b) The right to confidentiality relating to the medical condition, with information released to other authorities contingent upon the patient's consent.

6. Justice

a) The right to make a complaint through channels provided for this purpose by the health authority and to have any complaint dealt with promptly and fairly.

b) The right to appeal to a higher authority if the above is not respected and to be informed in writing of the outcome.

7. Organization

a) The right to join, or to establish, organizations of people with or affected by TB, and to seek support for the development of these clubs and community-based associations through health-care providers, authorities and civil society.

b) The right to participate as "stakeholders" in the development, implementation, monitoring and evaluation of TB policies and programmes with local, national and international health authorities.

8. Security

a) The right to job security after diagnosis or appropriate rehabilitation upon completion of treatment.

b) The right to nutritional security or food supplements if needed to meet treatment requirements.

Patients' responsibilities

1. Share information

a) The responsibility to provide as much information as possible to health-care providers about present health, past illnesses, any allergies and any other relevant details.

b) The responsibility to provide information to health-care providers about contacts with immediate family, friends and others who may be vulnerable to TB or who may have been infected.

2. Follow treatment

a) The responsibility to follow the prescribed and agreed treatment regimen and to conscientiously comply with the instructions given to protect the patient's health and that of others.

b) The responsibility to inform health-care providers of any difficulties or problems in following treatment, or if any part of the treatment is not clearly understood.

3. Contribute to community health

a) The responsibility to contribute to community well-being by encouraging others to seek medical advice if they exhibit symptoms of TB.

b) The responsibility to show consideration for the rights of other patients and health-care providers, understanding that this is the dignified basis and respectful foundation of the TB community.

4. Solidarity

a) The moral responsibility to show solidarity with other patients, marching together towards cure.

b) The moral responsibility to share information and knowledge gained during treatment and to share this expertise with others in the community, making empowerment contagious.

c) The moral responsibility to join in efforts to make the community free of TB.
Help turn these words into realities. Support the drive towards implementation in the community. Sign online at http://www.wcc-tb.org or sign-up by SMS text at +33 679 486 024.

In common cause, with mutual respect, together we can raise the standards of TB care.

ISBN 978 92 4 159618 3

www.stoptb.org