

# ENGAGE-TB

Integrating community-based tuberculosis activities into the work of nongovernmental and other civil society organizations

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**Operational guidance**

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## Abbreviations

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<b>AIDS</b>	acquired immunodeficiency syndrome
<b>BMU</b>	basic management unit
<b>CBO</b>	community-based organization
<b>CSO</b>	civil society organization
<b>FBO</b>	faith-based organization
<b>HIV</b>	human immunodeficiency virus
<b>NCB</b>	NGO coordinating body
<b>NGO</b>	nongovernmental organization
<b>NTP</b>	national tuberculosis control programme or equivalent
<b>TB</b>	tuberculosis
<b>TB/HIV</b>	the intersecting epidemics of TB and HIV
<b>WHO</b>	World Health Organization

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## 1. Background

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Tuberculosis (TB) affected an estimated 8.7 million people and caused 1.4 million deaths globally in 2011, including 0.5 million women and at least 64 000 children. About 13% of TB occurs among people living with HIV, and TB causes almost a quarter of AIDS deaths. There is evidence of links between TB and noncommunicable diseases such as diabetes mellitus and with determinants of ill-health like tobacco and drug use, alcoholism and malnutrition. TB mostly affects the productive segment of society in their prime.

One third of people estimated to have TB are either not reached for diagnosis and treatment by the current health systems or are not being reported. Even in patients who are identified, TB is often diagnosed and treated late. In order to reach the unreached and to find TB patients early in the course of their illness, a wider range of stakeholders already involved in community-based activities needs to be engaged. These include the nongovernmental organizations (NGOs) and other civil society organizations (CSOs) that are active in community-based development, particularly in primary health care, HIV infection and maternal and child health, but have not yet included TB in their priorities and activities (1).

NGOs and other CSOs are non-profit organizations that operate independently from the state and from the private for-profit sector. They include a broad spectrum of entities such as international, national and local NGOs, community-based organizations (CBOs), faith-based organizations (FBOs), patient-based organizations and professional associations. CBOs are membership-based non-profit organizations that are usually self-organized in specific local areas (such as a village) to increase solidarity and mutual support to address specific issues. For example, these include HIV support groups, women's groups, parent-teacher associations and micro-credit village associations. CBO membership is comprised entirely of community members themselves, so these organizations can be considered to represent the community most directly. NGOs and other CSOs engage in activities that range from community mobilization, service delivery, and technical assistance to research and advocacy (1).

The strengths of NGOs and other CSOs active in health care and other development interventions at the community level include their reach and spread and their ability to engage marginalized or remote groups. These organizations have a comparative advantage because of their understanding of the local context. Greater collaboration between NGOs and other CSOs and local and national governments could greatly enhance development outcomes (2). A more decentralized approach that formally recognizes the critical role of NGOs and other CSOs as partners addressing gaps through support to community-based actions will expand TB prevention, diagnosis, treatment and care activities.

Community-based TB activities cover a wide range of activities contributing to prevention, diagnosis, improved treatment adherence and care that positively influence the outcomes of drug-sensitive, drug-resistant and HIV-associated TB. The activities also include community mobilization to promote effective communication and participation among community members to generate demand for TB prevention, diagnosis, treatment and care services. While diagnostic tests for TB continue to be performed in clinical settings, for lack of simpler diagnostic methods, community-based TB activities are conducted outside the premises of formal health facilities (e.g. hospitals, health centres and clinics) in community-based structures (e.g. schools, places of worship, congregations) and homesteads. Such community-based TB activities could and should be integrated with other community-based activities supporting primary health care services, including those for HIV infection, maternal and child health and noncommunicable diseases to improve synergy and impact. Community-based TB activities utilize community structures and mechanisms through which community members, CBOs and groups interact, coordinate and deliver their responses to the challenges and needs affecting their communities (3).



### Examples of community-based TB activities

- awareness-raising, behaviour change communication and community mobilization
- reducing stigma and discrimination
- screening and testing for TB and TB-related morbidity (e.g. HIV counselling and testing; diabetes screening) including through home visits
- facilitating access to diagnostic services (e.g. sputum or specimen collection and transport)
- initiation and provision of TB prevention measures (e.g. Isoniazid preventive therapy, TB infection control)
- referral of community members for diagnosis of TB and related diseases
- treatment initiation, provision and observation for TB and co-morbidities
- treatment adherence support through peer support and education and individual follow-up
- social and livelihood support (e.g. food supplementation, income-generation activities)
- home-based palliative care for TB and related diseases
- community-led local advocacy activities

Community health workers and community volunteers carry out community-based TB activities, depending on national and local contexts. Community health workers are people with some formal education who are given training to contribute to community-based health services, including TB prevention and patient care and support. Their profile, roles and responsibilities vary greatly among countries, and their time is often compensated by incentives in kind or in cash. Community volunteers are community members who have been systematically sensitized about TB prevention and care, either through a short, specific training scheme or through repeated, regular contact sessions with professional health workers.

Empowering people with TB and their communities through partnerships, effective social mobilization, including through advocacy and communication strategies, the expansion of community-based TB activities and promoting the implementation of the Patients' Charter have been key components of the Stop TB Strategy (4). On the basis of a previous document (5), WHO developed guiding principles and recommendations on community involvement in tuberculosis care and prevention in 2008 (6) which urge national TB programmes (NTPs) to form collaborative partnerships with NGOs and other CSOs in implementing community-based TB activities. The involvement of NGOs is also promoted as part of the public-private mix (7, 8), another important component of the Stop TB Strategy. Professional associations have been important in preparing and implementing the International Standards for TB Care (9). There is also increased evidence and interest to enhance community-based initiatives (e.g. campaigns) that identify unrecognized TB patients along with related co-morbidities (e.g. HIV infection, diabetes mellitus) and improve the impact of TB prevention and care activities. There is also a need to integrate TB prevention and care services with noncommunicable diseases, maternal and child health services, and development and poverty alleviation initiatives via community-based structures and mechanisms.

The implementation and scaling up of community-based TB activities remains weak, despite the clear need, the documented cost-effectiveness of community-based TB activities (10) and the tremendous efforts that have been expended in recent years. Lack of effective collaboration between NTPs and NGOs and other CSOs and the absence of joint strategic planning, monitoring and evaluation are more the norm than the exception. Difficulties in measuring the impact of community-based TB activities and the lack of standard indicators have also been noted. The absence of operational guidance on engaging NGOs and other CSOs in TB prevention, diagnosis, treatment and care, including community-based TB activities, has been mentioned as a barrier (11). NTP managers and representatives of NGOs and other CSOs requested WHO to develop an operational guidance based on existing WHO norms and guidelines (12).

## 2. Purpose of the operational guidance

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The purpose of this document is to provide operational guidance to NGOs and other CSOs and NTPs or their equivalents in implementing and scaling-up integrated community-based TB prevention, diagnosis, treatment and care using the ENGAGE-TB approach described later in the document. It describes the basic operational principles for effective collaboration between NTPs and NGOs and other CSOs. The principles are aligned with the Stop TB Strategy and are complementary to existing guidelines for engaging all health care providers (including NGOs) in TB prevention and care as part of a public–private mix. This guidance emphasizes that NGOs or other CSOs (such as FBOs) providing facility-based TB services (e.g. hospitals, health centres and clinics) should also implement community-based TB activities using the ENGAGE-TB approach.

## 3. Target audience

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This guidance is intended for NGOs and other CSOs working on health and other development initiatives (e.g. education, agriculture and income-generation schemes) that intend to integrate TB prevention and care services into their field work. Within government, this guidance is intended for NTPs or their equivalents in ministries of health and other line ministries (e.g. ministries of justice for prison health services and ministries of mining or labour for workplace health services) providing TB services.

Patients and communities affected by TB and related co-morbidities (e.g. HIV infection, noncommunicable diseases) could use this guidance to generate demand for TB services. Funding agencies and researchers (especially involved in operational and implementation research) could also benefit from this guidance to support community-based TB activities.

## 4. Integrating tuberculosis activities

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NGOs and other CSOs could integrate TB into their community-based work in many ways, without trained medical staff. It is particularly important for them to do so when they are working with high-risk populations (such as people living with HIV and the very poor), people living in congested environments (urban slums and prisons), people who use drugs, sex workers and migrant workers.

Examples of TB activities that can be integrated:

- **Assisting early case finding:** *Encouraging people who present with symptoms of TB such as chronic cough, weight loss, night sweats and fever to contact a health worker or visit a health facility. Sputum examination is the mainstay of TB investigation in many settings. In community meetings (e.g. women's groups, health clubs, farmers' groups), the main symptoms of TB could be explained. People with symptoms could be helped to have their sputum examined by transporting either the person or the sputum sample to the nearest health facility.*
- **Providing treatment support:** *Patients being treated for TB may require support to take their drugs and finish their treatment. Family members and community-based volunteers and workers can be trained as treatment supporters by NGOs and other CSOs. Patients can also be provided with nutritional and psychosocial support, if needed.*
- **Preventing the transmission of TB:** *Covering the mouth and nose when coughing and sneezing is a simple behaviour change that can help to limit the spread of infected sputum particles and so reduce the risk to others of being infected. NGOs and other CSOs could spread this message using their various social communication media.*
- **HIV programmes and projects:** *Encouraging every person living with HIV to be screened for TB and, depending on the result, helping them receive TB prevention treatment (isoniazid preventive therapy) or further examination for TB disease.*

- **Maternal and child health programmes and projects:** Encouraging all pregnant women to test for HIV and to be screened for TB symptoms at the nearest facility. Children under five are particularly vulnerable to TB infection if an adult in the home has TB. Health workers should be made aware of this and keep watch for any symptoms and signs of TB in households with young children.
- **Education programmes and projects:** Incorporating messages of TB prevention and care into curricula and classroom learning. Schoolchildren should be able to recognize TB symptoms and the importance of sputum examination so that they can encourage those at home who might have TB to get tested.
- **Agriculture and income-generation programmes and projects:** Raising awareness about TB symptoms and signs among organized groups (such as farmers' groups and savings and credit groups). Members with symptoms of TB could be encouraged to get their sputum examined. Those being treated for TB could be supported to complete their course of treatment. Nutritional and psychosocial support will improve the outcome of TB treatment.

## 5. Principles

The operational guidance emphasizes three core principles in order to improve collaboration and foster effective partnership between NGOs and other CSOs and the NTPs or their equivalents. Respect for these principles will help to remove barriers and bottlenecks affecting implementation of integrated community-based TB activities. Their importance should be recognized and efforts made to ensure their integration into the six components of the ENGAGE-TB approach described later. The principles are:

1. *Mutual understanding and respect recognizing differences and similarities in background, functions and working culture.*
2. *Due consideration and respect for local contexts and values while establishing collaborative mechanisms and scaling-up integrated community-based TB activities.*
3. *A single national system for monitoring implementation of activities by all actors with standardized indicators.*

Efforts must be inclusive rather than exclusive so that more and more NGOs and other CSOs can become engaged TB stakeholders through closer collaboration and partnership with NTPs and their equivalents based on these principles.

## 6. Adaptation of the operational guidance

This guidance was prepared as a global guiding framework. It is expected that NTPs or their equivalents together with NGOs and other CSOs will create similar guidance for use at national level by adapting the contents of this document to suit their circumstances. Consultative workshops to finalize such national-level guidance will ensure that it is locally appropriate; such workshops could be convened by NTPs or by an NGO or other CSO network. National adaptation could include consideration of the epidemiology of TB and related diseases, risk factors (e.g. HIV infection, diabetes, drug and tobacco use), social determinants of ill health and the legal, political and programme considerations relevant for the involvement of NGOs and CSOs in community-based TB activities. The goal of adaptation should be nationwide scaling-up of community-based TB activities through effective engagement of NGOs and other CSOs, with strong links to the NTPs or their equivalents.

NGOs already implementing TB prevention and care services in health facilities such as hospitals and clinics (e.g. through formal arrangements with the NTP) should make all possible efforts to integrate community-based TB activities into their programmes. This will involve reviewing their programme activities and consulting with the NTP and their constituencies to find ways of doing this without disrupting existing arrangements and activities. The adaptation of these guidelines should also include national and subnational consultations among NTP structures, NGOs and other CSOs, patients, other clients and

community members. A nationally or subnationally tailored training manual for the effective engagement of government health workers and NGOs and other CSOs which describes how to implement the principles of this operational guidance will be useful.

## 7. Process of development

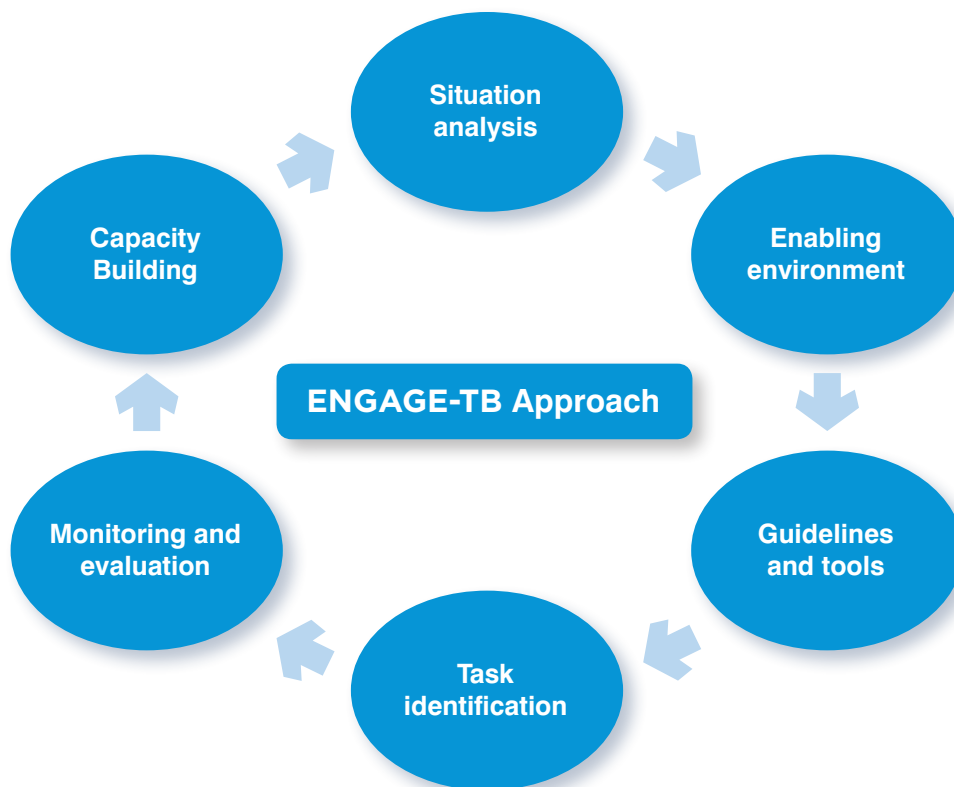
This document builds on the strengths and limitations of the 2008 WHO document on guiding principles and recommendations on community involvement in tuberculosis care and prevention (6). Relevant content has also been drawn from the WHO guidance (7) and toolkit (8) on the public–private mix, and the International Standards for TB Care (9). The first draft was written by staff of the Stop TB Department of WHO using as a template the structure of the WHO TB/HIV policy written in 2004 (13) and updated in 2012 (14).

An initial draft was discussed and revised by participants in an expert consultation held on 20–21 September 2011 in Geneva, Switzerland. The participants included national TB programme managers, national HIV programme managers, representatives of international and national NGOs and other CSOs, including professional associations involved in TB prevention, diagnosis and treatment and also in other development and community-based health services, including maternal and child health, prison health and health initiatives for populations at greatest risk. The next consultation was held in conjunction with the 42nd Union World Conference on Lung Health in Lille, France, on 29 October 2011 and the third in conjunction with the 16th International Conference on AIDS and Sexually Transmitted Infections in Addis Ababa, Ethiopia, on 6 December 2011. Views and opinions were sought from teams at WHO, the Stop TB Partnership secretariat and the senior management of Stop TB to ensure alignment of the approaches. A writing committee that included representatives of NGOs and other CSOs, community activists, national TB programmes and WHO met in Geneva on 3–4 May 2012 to produce a further draft of the guidance, which was sent to numerous individuals and institutions for peer review. The document was further revised on the basis of the feedback received.

## 8. The ENGAGE-TB approach

Components
• situation analysis
• enabling environment
• guidelines and tools
• task identification
• monitoring and evaluation
• capacity-building

The ENGAGE-TB approach seeks to shift the global perspective of TB from only a medical illness to a more comprehensive socioeconomic and community problem. ENGAGE-TB is a brand that proposes six areas to facilitate the engagement of NGOs and other CSOs in community-based TB activities. These are a situation analysis; an enabling legal and policy environment; guidelines and tools; assessing the relevant TB tasks needed to be undertaken and included in action plans; monitoring and evaluation to enable learning and continuous improvement; and enhancing the capacity of organizations to scale up their work sustainably. The ENGAGE-TB approach emphasizes the value of collaboration and partnership between NGOs and other CSOs and the NTPs or equivalents. ENGAGE-TB emphasizes close alignment of systems, especially in TB monitoring and reporting, to ensure that national data adequately capture the contributions of community-based TB activities. Each component of ENGAGE-TB is independent, and all six components are not always required to implement community-based TB activities.



## 8.1 Situation analysis

A situation analysis helps to identify the specific needs and tasks for integrated community-based TB activities. It involves information-gathering at all levels to analyse and understand the existing situation. It is useful to involve and engage multiple stakeholders, including the NTP, NGOs and other CSOs, and community members, including patients and their families. NGOs and other CSOs and/or the NTP should take the lead in conducting situational analyses at the national and subnational levels. An NGO or CSO should take the lead for the situational analysis of its own operational area.

### Examples of key areas for situation analysis

- What is the overall situation with regard to TB in the country or the operational area?
- Who are the most at risk populations for TB in the operational area?
- Is there adequate and good-quality TB diagnosis and treatment capacity (e.g. laboratory and drugs) in the area? If not, what are the options to address the gap? What government facilities and services are available in the area?
- Are there any other key players in community-based TB activities in the area?
- Who are the main NGO and CSO stakeholders in the area? Which are already involved in TB? Which others could integrate TB into their work?
- What are the best existing community-based structures for community-based TB activities?
- What is the capacity of the NGO/CSO to use the structures for community-based TB activities?
- What are the strengths, weaknesses, opportunities and threats to TB activities?
- What are the main barriers to better delivery of TB services?
- Can community-based TB activities address the barriers identified?
- In which areas is collaboration between NGOs and other CSOs and the NTP necessary?

The situation analysis should identify and prioritize problems situations and needs in TB prevention and care, especially those of vulnerable groups such as prisoners, migrants, sex workers and injecting drug users who might face stigma and have difficulty in using the services of the formal health system. Opportunities and stakeholders in TB activities (including community-based TB activities) should be identified in order to forge synergies, use resources efficiently and prevent duplication of effort. The community structures that are best positioned to address the problems and gaps should be identified. Information on the available TB diagnostic and treatment facilities helps in understanding how the system will work in terms of activities such as referral, sputum collection, diagnosis, treatment and follow-up. Where capacity is limited, alternative mechanisms should be found to ensure high-quality service delivery, including an adequate supply of anti-TB drugs and diagnostics in accordance with national policies and guidelines. The situation analysis should also examine other critical areas such as the incentives that could be offered to improve the performance of community-based TB activities. Both qualitative and quantitative methods can be used to gather information and improve understanding of the situation. The situation analysis helps greatly in identifying the specific TB tasks that can be undertaken.

**Points for consideration:**

- *Basic data should be collected on the TB prevalence in the country or operational area. In many countries, such data are already available and NGOs and other CSOs should secure these from the NTP.*
- *The facilities providing general health care and TB diagnosis, treatment and drugs should be mapped to analyse potential access for TB patients and people with presumptive TB.*
- *The need for sputum collection centres and sites and the implications for sputum transport should be analysed.*
- *Qualitative information should be gathered by participatory methods such as 'participatory rural appraisal', 'participatory learning and action', 'participatory action research' (15) and 'focus group discussions'. For example, patients and other community members could provide a preference ranking of various health providers and services and thus contribute directly to the situation analysis while themselves benefiting from it.*
- *Knowledge, attitude and practices surveys (16) can also be conducted to understand the existing situation with respect to TB.*
- *A 'stakeholder analysis' should be part of the overall review to gain a better understanding of all the actors and their possible contribution and influence.*
- *The 'strengths, weaknesses, opportunities, threats' analysis tool (17) is a practical framework to apply to the situation analysis. It can also be used to assess the readiness of NGOs and other CSOs to integrate TB prevention, diagnosis, treatment and care services, including community-based TB activities.*

## 8.2 Enabling environment

A mutually enabling legal and policy environment based on the principles of equity, equality and mutual respect will increase the engagement of NGOs and other CSOs in TB activities, particularly those who are newly engaged in TB prevention and care. A facilitated registration process of NGOs and other CSOs in accordance with local norms and needs and ensuring greater integration of processes and requirements between different government departments could be key areas for government to support the operations of NGO and other CSOs. Reducing the complexity of transactions and increasing the speed of facilitation are key factors that improve the operating environment for NGOs and other CSOs. NTPs or their equivalents have the responsibility of creating enabling national or local legal, policy and administrative environments to support the effective engagement of NGOs and other CSOs in TB activities. This should be done in close consultation with the relevant government and legislative structures (e.g. parliament, ministry of justice or other regulatory bodies) depending on the local context and aligned with the national health strategy, if necessary.



NGOs and other CSOs should also stimulate and support the development of an enabling legal and policy environment through constructive dialogue and engagement with the NTPs or relevant legislative structures, with the participation of the segments of society they represent. This can be best done on a sustained, continuing basis if NGOs and other CSOs form an umbrella NGO coordinating body (NCB) to represent their best interests and to allow systematic sharing and dissemination of lessons learnt by individual organizations. NTPs should support the formation of such NGO coalitions and make time to meet with them in order to understand their needs, constraints and the lessons learnt.

Existing structures can also be used for the functions of the NCB, if they are acceptable to the NGOs and other CSOs concerned, particularly in satisfying their desire for independence from both the government and the private for-profit sector. In some countries, national Stop TB partnerships already exist. A national stop TB partnership is a voluntary alliance between organizations drawn from the public, civil society and private sectors who commit to work collaboratively towards TB prevention, care and control, in which all partners contribute from their core competences, share risks and responsibilities and benefit by achieving their own, each others' and the overall goal (18). Depending on the local context and the need of the NGOs and other CSOs, linkages can be sought with effective and vibrant national Stop TB partnerships, especially as previously unengaged NGOs and other CSOs take up TB prevention and care activities.

At the community level, NGOs and FBOs should support the growth and development of CBOs that include TB prevention, care and support in their mission. Existing CBOs, such as HIV support groups, could be approached to integrate TB into their work (and TB groups should be encouraged to integrate HIV support). It will be important for NGOs and other CSOs to create mechanisms to interact regularly with these CBOs, listen and respond to their concerns and promote their continuing growth and empowerment.

**Points for consideration:**

- *NGOs and other CSOs should come together to create a NCB that is functional at all administrative levels (national, subnational and local) to facilitate the effective engagement of NGOs and other CSOs in community-based TB prevention, diagnosis, treatment and care services. Such a coordinating body could be an existing NGO network or an umbrella body that expands its membership and functions or a new body that is established specifically to support community-based TB activities.*
- *The NCB should also include representatives of patients and affected communities including women and young people or other target groups or beneficiaries of the NGOs. The NCB should meet regularly and have mechanisms for sharing information and for discussing issues of common interest related to community-based TB activities and the relations with NTPs or its equivalents at all levels.*
- *Nominated representatives of the NCB should meet regularly (preferably quarterly) with the NTP or its equivalents to improve contributions to national TB strategies and plans, discuss challenges and opportunities and secure support. If needed, a bilateral or multilateral organization could help to initiate and facilitate the linkage and partnership between the NCB and the NTP and host its meetings.*
- *The NCB representatives should ensure that all NCB members are fully involved in discussions and negotiations and have opportunities to provide input and receive feedback regularly.*
- *The NTP, with inputs from the NCB and other stakeholders, should prepare a national policy to facilitate the effective engagement of NGOs and other CSOs in TB prevention, diagnosis, treatment and patient care and support and in research activities aligned with the national health strategy. In countries with decentralized political authority, the policy could be prepared at appropriate administrative levels (e.g. provincial or state authorities). NGOs and other CSOs must always be involved in policy preparation as partners or even as initiators and leaders of the process.*
- *NGOs and other CSOs and NTPs and equivalents should support the growth and development of CBOs involved in TB prevention, care and support. They should receive the information and training they need as well as financial support. Their links to formal health care facilities should be strengthened and their access to diagnostic and treatment facilities improved. Their efforts to reach out to members of their own communities should be supported.*

- The NCB and NTP or its equivalent should agree on a code of conduct with clear roles, responsibilities and decision-making processes, defining acceptable professional behaviour, and providing benchmarks for evaluation and reporting (19). The code of conduct could define the responsibilities of NGOs and other CSOs for reporting, for example, on nationally agreed monitoring indicators. It could also define the responsibility of the NTP or its equivalent to support NGOs and other CSOs to implement community-based TB activities, including supplies and services.

### 8.3 Guidelines and tools

#### Examples of tools

- national operational guidelines for community-based TB prevention and care
- national curriculum for training health workers, including community health workers and community volunteers
- implementation manual or primer
- templates to formalize the relationship between NGOs and other CSOs and NTPs and their equivalents, such as memoranda of understanding

The NTPs or their equivalents should work with NGOs and other CSOs in the NCB to prepare national operational guidelines and standard tools based on internationally recommended, evidence-based policies and guidelines. They should be adaptable to the mission, mandate, resources and activities of the NGOs and other CSOs. If necessary, NTPs or their equivalents should facilitate clearances and approvals of these instruments. Existing tools and instruments should be used when feasible and adapted to the needs of NGOs and other CSOs

#### Points for consideration:

- The NTP in collaboration with the NCB should finalize national operational guidelines to increase the engagement of NGOs and other CSOs in community-based TB activities. The ENGAGE-TB approach could be used as a template.
- The NTP in collaboration with the NCB should prepare standardized and aligned implementation tools (e.g. referral-for-screening, diagnosis or treatment form, feedback or back-referral form, transfer form, laboratory register, TB register and the TB treatment card) for use by NGOs and other CSOs. These can then be used as developed or adapted by NGOs and other CSOs to suit their circumstances.
- The NTP and/or the NCB should prepare a manual based on international guidance that helps NGOs and other CSOs to undertake specific community-based activities successfully (e.g. sputum collection and transport, patient referral, treatment adherence and care).
- The NCB and the NTP should design a curriculum for training health workers, including community health workers and volunteers, in community-based TB activities. The curriculum should define activities to be implemented by each type of health worker and provide technical advice on each activity.
- When necessary, the NTP in collaboration with the NCB should prepare templates for a memorandum of understanding or other arrangement to formalize the collaboration and to specify the arrangements that will govern the relations between the NTP or their equivalents and NGOs and other CSOs. The memorandum of understanding should also specify the protocols to be used to comply with the code of conduct.



## 8.4 Task identification

The current WHO Stop TB Strategy and its components provide the framework for the tasks involved in the prevention, diagnosis, treatment and care of drug-sensitive, drug-resistant and HIV-associated TB (2). To increase synergy and effectiveness, all the parties involved (NGOs and other CSOs, NTPs or equivalents) must determine which tasks are to be carried out.

TB is linked to HIV infection and also to social determinants of health and noncommunicable diseases such as poverty, crowding, malnutrition, drug and alcohol use and diabetes mellitus. Therefore, the opportunities, capacities and comparative advantages of the NGOs and other CSOs working in such areas should be considered in determining how best to address TB. Consideration must also be given to the availability of resources and expertise and ensuring synergy.

### Examples of tasks for NGO and other CSO engagement in TB activities

- awareness-raising to generate demand for services
- behaviour change communication for community mobilization
- stigma reduction
- advocacy at all levels (e.g. for improved availability of resources, services and drugs)
- early community-based TB case-finding (e.g. through campaigns or house-to-house visits)
- sputum collection and transport
- tracing contacts of persons with infectious TB in their families and communities
- TB treatment adherence support
- social and livelihood support (e.g. food supplementation, income-generation activities)
- promoting use of the Patient's Charter for TB Care
- screening, prophylaxis and treatment of TB for people living with HIV
- HIV testing and counselling for TB patients and persons with presumptive TB
- management of patients with multi-drug-resistant and extensively drug-resistant TB
- information-sharing and networking to address social determinants of health and social protection
- support to improve the health care delivery system (e.g. human resources, infrastructure, supply)
- conducting programme-based operational research
- financing and resource mobilization

The NTPs or their equivalents should include the implementation and scaling up of community-based TB activities through the engagement of NGOs and other CSOs in their medium- and long-term national TB strategic plans and budgets as well as in annual national and subnational operational plans. The action plan may address only TB or be integrated into broader action plans (e.g. HIV, maternal and child health or micro-credit plans). NGOs and other CSOs implementing TB prevention and care services should include community-based TB activities in their strategic plans. NGOs and other CSOs working on health issues that are linked to TB (e.g. HIV infection, maternal and child health, noncommunicable diseases such as diabetes mellitus, tobacco, drug use and alcoholism) should integrate TB prevention, diagnosis, treatment and care into their activities.

**Points for consideration:**

- *Joint consultation between NGOs, other CSOs and NTPs or equivalents is recommended when assessing and determining the tasks for implementation.*
- *The plans should address the gaps identified in the situational analysis and include the tasks identified.*
- *Specific, measurable, achievable, realistic and time-bound objectives should be defined for the main tasks identified.*
- *TB patients and their communities should be involved in developing and implementing the plan.*
- *The planned activities must be aligned with national policies and guidelines. TB forms and registers should be standardized and linked to the national TB monitoring and evaluation system to ensure that the contribution of community-based TB activities to national TB prevention and care is recorded.*

## 8.5 Monitoring and evaluation

Regular monitoring and evaluation will help in assessing the quality, effectiveness, coverage and delivery of community-based TB activities and the engagement of NGOs and other CSOs. It promotes a learning culture and serves as a foundation to ensure continuous improvement of programme implementation. NTPs or their equivalents should ensure that there is a single national monitoring and evaluation system that recognizes the contribution and engagement of NGOs and other CSOs. Electronic systems and modern technologies should be tested, standardized and used to improve monitoring and evaluation.

### Examples of areas for learning and follow-up

- choice of target groups and ability to reach these
- appropriateness of initial targets set and need for revision
- bottlenecks in referrals, case notification, treatment, care and support
- difficulties faced by patients and their communities in securing good-quality services
- difficulties in the arrangements between the NGO or other CSO and the NTP or equivalent
- scaling-up of best practices

Quarterly reviews of progress would help to uncover issues in implementation and enable mid-stream correction to plans and budgets and to overall strategy. The NTP should help to smooth any operational difficulties that NGOs and other CSOs may face and cannot independently resolve. Quarterly meetings to discuss the review findings could be held at subnational or local levels so that there is cross-fertilization of learning between NGOs and other CSOs and with the NTP. Annual meetings at the national level should be organized by the NCB and a broad spectrum of implementing NGOs and other CSOs invited to share their findings and report progress. The resulting national report issued by the NTP should be shared widely with all stakeholders within government, NGOs and other CSOs, patients and community members, donors and the general public.

Evaluation of the results of initial implementation of the action plan is important to guide replication and scaling-up of activities. Evaluation should be an ongoing process and include evaluation of both the activities (process evaluation) and achievement of the objectives (impact evaluation) of the action plan. Qualitative methods and periodic surveys could be used to provide an understanding of how well NGOs and other CSOs are supported and how they have engaged in community-based TB activities (see annexes 1 and 2).

**Points for consideration:**

- *The NTP in consultation with the NCB should develop nationally recommended, standardized data collection and reporting tools aligned with the national TB strategies for use by NGOs and other CSOs.*
- *Indicators to measure the implementation of community-based TB activities should be agreed with NGOs and other CSOs.*
- *Enhance the standardized use of electronic systems and processes in the monitoring and evaluation of community-based TB activities.*
- *Establish mechanisms that enable patients, clients and their affected communities to contribute to the monitoring of the implementation of community-based TB activities in order to increase accountability, responsiveness and the quality of services. Tools such as citizen score cards could be used to measure community satisfaction with various service providers including NTP or equivalent and NGOs and other CSOs.*
- *The NCB should design standardized tools for supportive supervision so that its members can better monitor community-based TB activities aligned with national policies and guidelines.*
- *National surveillance and reporting systems should explicitly reflect the contribution of community-based TB activities to the overall results. The reports should be enriched by NGO perspectives on the data, as secured via meetings of the NCB.*
- *Each implementing agency should undertake a full evaluation at least once every five years. The NTP should support a national evaluation process every five years, using the results from various implementing partners, through a participatory and consultative process that includes all stakeholders, taking advantage of opportunities such as national TB programme reviews.*
- *The outcomes of periodic evaluations should be communicated widely to the NTP, NCB, patients, community members and local policy-makers to share learning and also to use findings for advocacy and improvement of programmes.*

**8.6 Capacity-building**

Capacity-building is necessary for strengthening and sustaining the engagement of NTPs, NGOs and other CSOs in implementing and scaling-up community-based TB activities. It requires joint actions by the NTPs or their equivalents and NGOs and other CSOs and will be of mutual benefit. Capacity-building needs and approaches can vary between countries and settings depending on factors such as the legal and policy environment for engagement of NGOs and other CSOs and the type of health system.

**Examples of areas for capacity-building**

- Human resources: increasing the number of employees and volunteers and their knowledge and skills in the fields in which they work
- Financial resources: increasing the ability to attract additional funding from a wide range of multilateral, bilateral, institutional and private donors
- Physical resources: ensuring the necessary investment in assets such as vehicles, computers and facilities that will allow organizations to scale-up activities
- Management and leadership: improving managerial capacity in organizations and improving governance and leadership to increase accountability and transparency
- Systems development and strengthening

Increasing financial resources is crucial for scaling-up community-based TB activities and the effective engagement of NGOs and other CSOs. Innovative resource mobilization from internal (e.g. national governments, private donors, philanthropists) and external sources (e.g. the Global Fund to Fight AIDS, TB and Malaria, bilateral donors and charitable foundations) should be undertaken by NGOs and other CSOs and the NTPs.

Operational research is another area in which NTPs and CSOs with research expertise (e.g. professional associations) should collaborate to improve the performance and implementation of the programme (20).

In some countries, NTPs may have little prior experience of engaging with NGOs and other CSOs. Their capacities should also be built to cultivate and maintain effective relationships with the nongovernmental sector. Health sector governmental staff might require training in community mobilization, including communication styles and methods. Health systems should be strengthened further to meet increased demand for services from affected communities.

Capacity-building interventions should also support sharing and transfer of knowledge, skills and resources between international CSOs and national CSOs, with both groups gaining from the process. Regular forums for sharing knowledge, experience and good practices should be established. Mutual learning and support can increase confidence and capability to scale-up activities.

**Points for consideration:**

- *Assess capacity-building needs to implement and scale-up community-based TB activities, including capacity in health service delivery, the quality and adequacy of the health workforce (including community health workers and volunteers), monitoring and evaluation, training, advocacy, operational research and organizational development.*
- *Ensure that specific capacity-building measures, based on the assessed gaps, are included in the annual plans of each organization so that capacity is systematically improved.*
- *The NTP or equivalent in consultation with the NCB should prepare a standardized training curriculum for community-based TB activities to be used by NGOs and other CSOs, which should be adaptable to their mission, organizational structure and expertise.*
- *NGOs and other CSOs should ensure that their staff and volunteers are trained, especially on the instruments needed for monitoring and evaluation. When necessary, the NTP or equivalent should support such training.*
- *International NGOs working in partnership with national NGOs and other CSOs should transfer financial resources, knowledge and skills to fill gaps and so build local capacity to scale-up community-based TB activities. Training and support in fund-raising will be required to sustain national NGOs and CBOs after their partnership with the international NGO ends.*
- *National and local CSOs should share their understanding of local realities and their skills with international NGOs to enrich their plans and their likelihood of having a positive impact.*
- *The NCB, at all levels, should support processes that allow learning to be transferred from one member to the other and also become available to new entrants to community-based TB activities. The tools developed and lessons learnt should be widely shared and made available on the Internet.*

## 9. References

1. Getahun H, Raviglione M. Transforming the global tuberculosis response through effective engagement of civil society organizations: the role of the World Health Organization. *Bulletin of the World Health Organization*, 2011, 89:616–618.
2. Jareg P, Kaseje DC. Growth of civil society in developing countries: implications for health. *Lancet*, 1998, 351:819–822
3. The Global Fund to Fight AIDS, Tuberculosis and Malaria. *Community systems strengthening framework*. Geneva, 2010.
4. World Health Organization. *The Stop TB Strategy*. Geneva, 2006 (WHO/HTM/TB/2006.368).
5. World Health Organization. *Community contribution to TB care practice and policy*. Geneva, 2003 (WHO/HTM/TB/2003.312).
6. World Health Organization. *Community involvement in tuberculosis care and prevention. Towards partnerships for health. Guiding principles and recommendations based on a WHO review*. Geneva, 2008 (WHO/HTM/TB/2008.397).
7. World Health Organization. *Engaging all health care providers in TB control: guidance on implementing public-private mix approaches*. Geneva, 2006 (WHO/HTM/TB/2006.360)
8. World Health Organization. *Public-private mix for TB care and control: a toolkit*. Geneva, 2010 (WHO/HTM/TB/2010.12).
9. Tuberculosis Coalition for Technical Assistance. *International standards for tuberculosis care*, 2nd Ed. The Hague, 2009.
10. Sinanovic E et al. *Cost and cost-effectiveness of community-based care for tuberculosis in Cape Town, South Africa*. Cape Town, Health Economics Unit, University of Cape Town, Observatory.
11. World Health Organization. *Report of a WHO consultation on strengthening the active engagement of civil society organization in the global TB prevention, care and control efforts*. Geneva, 2010 (WHO/HTM/TB/2010.15).
12. World Health Organization. *Statement from the WHO-civil society consultation meeting, 30 September–1 October 2010*. Geneva, 2010 [http://www.who.int/entity/tb/features\\_archive/who\\_cso\\_statement.pdf](http://www.who.int/entity/tb/features_archive/who_cso_statement.pdf), last accessed 11 September 2012)
13. World Health Organization. *Interim policy on collaborative TB/HIV activities*. Geneva, 2004 (WHO/HTM/TB/2004.330).
14. World Health Organization. *WHO policy on collaborative TB/HIV activities: guidelines for national programmes and other stakeholders*. Geneva, 2012 (WHO/HTM/TB/2012.1)
15. Tones K, Green J. *Health promotion: planning and strategies*. London, SAGE, 2004.
16. World Health Organization and Stop TB Partnership. *Advocacy, communication and social mobilization for TB control: a guide to developing knowledge, attitude and practice surveys*. Geneva, 2008 (WHO/HTM/STB/2008.46).
17. McKenzie JF, Neiger BL, Smeltzer JL. *Planning, implementing, and evaluating health promotion programs: a primer*. San Francisco, Pearson/Benjamin Cummings, 2005.
18. Stop TB Partnership. *Concept note on national partnerships*. (<http://www.stoptb.org/countries/>, last accessed 11 September 2012).
19. Transparency International. *Developing a code of conduct for nongovernmental organizations*. Berlin, 2009 (<http://www.u4.no/helpdesk/helpdesk/query.cfm?id=200>, last accessed 11 September 2012).
20. World Health Organization and Stop TB Partnership. *Priorities in operational research to improve tuberculosis care and control*. Geneva, 2011.

## Annex 1. Indicators for monitoring implementation

One of the main challenges of monitoring the implementation of community-based TB activities has been the lack of standardized indicators. The following are suggested core indicators to measure the implementation of community-based activities that need to be included in the TB monitoring system of all stakeholders and linked with the national monitoring and evaluation system of the NTP or its equivalent.

<b>Indicator 1: Referrals and new notifications</b>	
Definition	Number of new TB patients (all forms) diagnosed and notified with TB who were referred by community health workers and community volunteers expressed as a percentage of all new TB patients notified in the basic management unit (BMU) during a specified period
Numerator	Number of new TB patients (all forms) referred by community health workers or community volunteers to a health facility for diagnosis and notified in the BMU(s) in a specified period
Denominator	Number of new TB patients (all forms) notified in the BMU(s) in the same period
Purpose	To measure the level of engagement of community health workers and community volunteers in increasing new notifications of TB. It can also indicate the effectiveness of the referral system in ensuring the flow of persons with presumptive TB from community-based structures to the BMU.
Method	Community health worker refers to a person with some formal education who is trained to contribute to community-based health services including TB prevention and patient care and support. Community volunteer refers to a community member who has been systematically sensitized about TB prevention and care, either through a short and specific training scheme or through repeated contact with professional health workers. Both can be supported by NGOs, other CSOs and/or the government. It is important to use the definitions in this guidance in order to standardize the documentation, monitoring and evaluation of community-based activities. This will prevent confusion about what constitutes 'community engagement' in TB prevention and care. Entries on tuberculosis treatment cards, the presumptive TB register (also known as 'TB suspects' register) kept at facilities, the BMU TB register and the laboratory register should be modified to include 'Referral by community health workers and community volunteers', to allow standardized recording of the community contribution to referral. The quarterly report on TB registration in the BMU should also be adjusted to record this contribution. These forms and registers should be adapted locally and used by community health workers and community volunteers to ensure that data are reported to the NTP's monitoring and evaluation system. Indirect sources of data include historical data analysis of overall TB notifications and comparisons of geographical areas with and without community-based activities, time trends in TB notifications and comparisons of referrals in areas with and without community-based activities.
Periodicity	Quarterly and annually
Strengths and limitations	This indicator will depend on the completeness and reliability of community-initiated referral data at clinic level, especially ensuring that referred persons with presumptive TB when confirmed with TB are tagged as having been referred by community health workers and community volunteers, supported either by an NGO, other CSO or the NTP.
Responsibility	All stakeholders (NGOs, other CSOs or the NTP or its equivalent) implementing community-based TB activities will ensure accurate data collection at community and facility levels. NTP and their equivalents will aggregate data at district, subnational and national level, depending on the local context, to ensure that the information is included in the national TB monitoring system.
Measurement tools	Presumptive TB patients should be recorded on the 'persons with presumptive TB' register (also known as 'TB suspects' register), which should specify who referred them. If confirmed with TB, they should then be recorded in the TB register as having been referred by a community health worker or community volunteer supported by either the NTP structure or NGOs and other CSOs. Data should be aggregated quarterly for the quarterly report on TB registration and for the yearly report on programme management in districts or BMUs.



<b>Indicator 2: Treatment success</b>	
Definition	New TB patients (all forms) successfully treated (cured plus completed treatment) who received support for treatment adherence from community health workers or community volunteers among all new TB patients (all forms) provided with treatment adherence support by community health workers or community volunteers (number and percentage)
Numerator	Number of new TB patients (all forms) successfully treated and provided with treatment adherence support by community health workers or community volunteers in the BMU(s) in a specified period
Denominator	Total number of new TB patients (all forms) given treatment adherence support by community health workers or community volunteers in the same period
Purpose	To measure the scope and quality of implementation of community-based TB activities particularly relating to treatment outcome of patients. It can also indicate the acceptability of community health workers or community volunteers to patients with TB as treatment adherence support providers.
Method	<p>Community health worker refers to a person with some formal education who is trained to contribute to community-based health services including TB prevention and patient care and support. Community volunteer refers to a community member who has been systematically sensitized about TB prevention and care, either through a short and specific training scheme, or through repeated contact with professional health workers. Both can be supported by NGOs, other CSOs and/or the government. It is important to use the definitions in this guidance in order to standardize the documentation, monitoring and evaluation of community-based activities. This will prevent confusion about what constitutes 'community engagement' in TB prevention and care.</p> <p>Treatment adherence includes all efforts and services provided by community health workers and volunteers to TB patients receiving treatment to help them complete their treatment successfully. These can include treatment observation, adherence counselling, pill counting and other activities to monitor both the quantity and timing of the medication taken by a patient.</p>
Periodicity	Quarterly and annually
Strengths and limitations	Monitors how well treatment adherence is supported by the community-based activities of NGOs, other CSOs or the government.
Responsibility	All NGOs, other CSOs and the NTP or its equivalent implementing community-based TB activities will ensure that data are collected at the community and facility levels. NTP and their equivalents will ensure that data are aggregated at district, subnational and national levels, depending on the local context, to ensure that the information is included in the national TB monitoring system.
Measurement tools	TB register

## Annex 2. Periodic evaluation

Purpose	Periodic evaluation provides a qualitative view of the progress of community-based TB activities. In particular, it helps to assess the contributions of NGOs and other CSOs to new case notifications and to treatment outcomes. It also indicates whether NGO contributions are increasing or decreasing and reflects the quality of the relations between NTPs and NGOs on the basis of variables such as the frequency of meetings, the quality of such meetings, the cooperation of people involved, the factors in success and the overall interest and drive of the NTP in involving NGOs and other CSOs in TB activities.
Indicators	<ul style="list-style-type: none"> <li>• Existence of a NCB             <ul style="list-style-type: none"> <li>- trends in membership</li> <li>- frequency of meetings</li> <li>- spread to subnational levels</li> <li>- coordination between levels</li> <li>- mechanisms for transferring knowledge, skills and resources</li> </ul> </li> <li>• Quality of interaction with the NTP at various levels             <ul style="list-style-type: none"> <li>- frequency of meetings</li> <li>- quality of follow-up on agreed actions</li> <li>- availability of TB diagnostic services and drugs</li> </ul> </li> <li>• The relative contributions of NGOs and other CSOs and of the government to new case notifications and treatment success, with trends in these variables over time</li> <li>• Challenges and hurdles faced by different actors in government and civil society as well as successes and new opportunities</li> </ul>
Method	Qualitative techniques should be used, including focus group discussions and key informant interviews. Appreciative inquiry techniques will help improve the quality of the feedback. NTP managers and district and clinic staff should be interviewed both singly and in groups. Similarly, representatives of NGOs and CBOs at national, district and local levels should be interviewed singly and jointly. The main issues emerging from the interviews should be identified, shared and discussed at a meeting between the staff of the NTP at various levels and representatives of NGOs and CSOs at various levels. The emphasis should be on sharing and learning in order to understand and improve the programme, rather than on fault finding or 'finger pointing'.
Periodicity	Every 3–5 years
Strengths and limitations	Provides a periodic assessment of the contributions of NGOs and other CSOs as well as the quality of the relations with the NTPs. The value of such studies depends on the professionalism and ability of the evaluators and the biases they may bring to the process.
Responsibility	All NGOs, other CSOs and the NTP or its equivalent implementing community-based TB activities must be willing to participate and share their views. The primary responsibility for organizing such evaluations is with the NTP. They could coincide with the national TB reviews generally held every 5 years in each country.











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