ENGAGE-TB

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

ONE LIFE
TWO DISEASES
Let's work together
ZERO TB/HIV DEATHS
H.I.V. positive
STOP TB

Implementation manual

World Health Organization

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Acknowledgements

Declarations of interests

All the contributors completed a Declaration of interests for WHO experts form. The declarations were analysed by the TB/HIV and Community Engagement unit of the WHO Global TB Programme, which found that no significant interest had been declared.

The following interests were declared:

Samson Agbo declared having been employed and consulted for an organization on community-based programming.

Liz Corbett declared that her academic institution, the London School of Hygiene and Tropical Medicine, received two Wellcome Trust grants for research into the public health impact of active case finding, for which she is the Principal Investigator. Her academic institution also received a grant from WHO to conduct a systematic review; the grant ended in 2012.

Carolyn Green declared that she had previously worked as a consultant in community-based health programming.

Lee-Nah Hsu declared that he works for the International Labour Organisation (ILO), where TB is listed in the international classification of occupational diseases. He therefore sometimes represents ILO to speak about TB as an occupational disease and to promote occupational safety and health protection of all workers, including health workers. He and his organization promote the International Conventions and Labour Standards on occupational safety and health of workers, including protection from TB.

Meshack Ndirangu declared that his employer, AMREF, advocated for greater involvement of communities and their structures (including civil society organizations) in health care programming. During his seven years at AMREF, he advocated for the same, especially with the Government of Kenya, and helped construct programmes that adequately involve communities in health care.

Contents

Acronyms and abbreviations

AIDS	acquired immunodeficiency syndrome
ART	antiretroviral therapy
ARV	antiretroviral
BCC	behaviour change communication
BCG	bacillus Calmette-Guérin (vaccine)
BMU	basic management unit
CBO	community-based organization
CHW	community health worker
CSO	civil society organization
CV	community volunteer
DOT	directly observed treatment
DOTS	directly observed treatment, short-course
FBO	faith-based organization
HIV	human immunodeficiency virus
IEC	information, education and communication
IPT	isoniazid preventive therapy
MDR-TB	multidrug-resistant tuberculosis
MNCH	maternal, newborn and child health
NCB	NGO coordinating body
NGO	nongovernmental organization
NTP	national tuberculosis programme
PHC	primary health care
SWOT	strengths, weaknesses, opportunities, threats
TB	tuberculosis
TB/HIV	the intersecting epidemics of TB and HIV infection
WASH	water, sanitation and hygiene
WHO	World Health Organization
XDR-TB	extensively drug-resistant tuberculosis

Introduction

In 2012, an estimated 8.6 million people around the world became ill with tuberculosis (TB), and 1.3 million died from it. This included an estimated 410 000 women and 74 000 children.[1]

However, an estimated **one third of cases of TB are still either not diagnosed or not reported**. Even when people with suspected TB are identified, the disease is often diagnosed and treated late. This means that it causes more damage and can be more difficult to treat. If a person has active pulmonary (lung) TB, this means also that more people will be infected if the person does not get treatment.

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> Even though **TB can be cured and prevented**, it is still one of the world's top infectious killers—second to HIV.

TB is the **main cause of illness and death for people living with HIV**. About one quarter of deaths of people with AIDS are linked with TB. In 2012, in countries with high levels of HIV, up to 80% of people with TB tested positive for HIV. At least one third of people with HIV infection also have latent TB, and they have a much higher risk of developing active TB disease.

In addition, TB is linked with chronic diseases such as diabetes and factors that lead to ill health, such as tobacco and drug use, alcoholism and malnutrition. These are often associated with poverty, crowded living conditions and poor access to basic hygiene measures. Pregnant women and young children are also very vulnerable to TB.

What is ENGAGE-TB?

The World Health Organization (WHO) developed the ENGAGE-TB approach when national TB programme (NTP) managers and civil society organization (CSO) representatives requested guidance on how to involve nongovernmental organizations (NGOs) and other CSOs (NGOs/CSOs) in TB prevention, diagnosis and care. *ENGAGE-TB: Integrating community-based TB activities into the work of NGOs and other CSOs—operational guidance* was published in 2012.[2]

The operational guidance explains the policies and programmes that are needed to support NGOs/CSOs to integrate TB into their community-based work in sectors such as maternal, newborn and child health (MNCH), HIV care, primary health care (PHC), education, agriculture and livelihoods development programmes. It also outlines how NTPs, NGOs/CSOs can collaborate on community-based approaches that support four main areas of TB work:

- **early TB case finding**: identifying people who might have TB or are especially vulnerable to TB and referring them for diagnosis;

- **TB treatment support**: making sure that people who need treatment receive it, complete the full course of treatment and get regular check-ups;

- **TB prevention**: educating people on how to stop infectious TB from passing from one person to another and on how to reduce the risk factors that assist the spread of the disease; and

- **addressing social determinants that contribute to TB**: poverty, poor living conditions, poor nutrition, hygiene and sanitation, and crowding.

The ENGAGE-TB approach defines six components to support the engagement of NGOs/CSOs in community-based TB activities.

Both NTPs and the NGOs/CSOs have a role in reviewing and implementing these components. Collaboration and mutual respect among all involved are essential for implementing the ENGAGE-TB approach.

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1   Global Tuberculosis Report 2012. Geneva, WHO, 2012 (http://www.who.int/tb/publications/global_report/en/index.html, accessed 15 August 2013).

2   ENGAGE-TB: Integrating Community-based TB activities into the work of NGOs and other CSOs—operational guidance. Geneva, WHO, 2012 (http://www.who.int/tb/people_and_communities/en, accessed 15 August 2013).
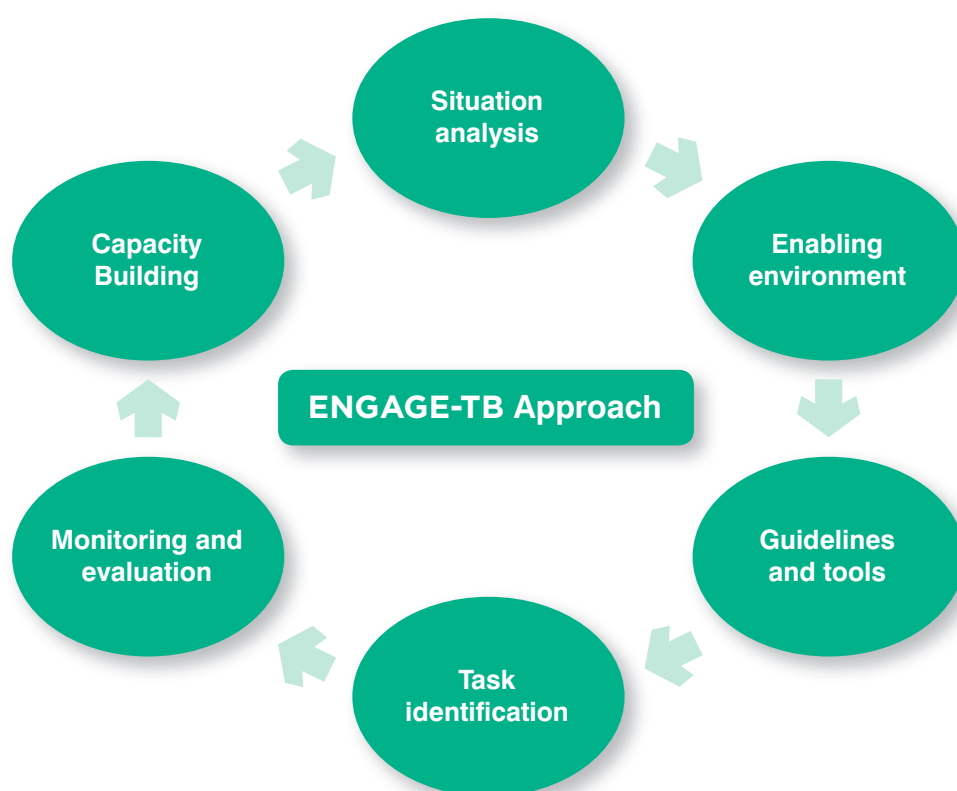
Purpose of the manual

The **ENGAGE-TB implementation manual** has been developed to explain in more detail how the actions outlined in the Operational guidance can be implemented.

The manual has three objectives:

- to explain simply **how the *ENGAGE-TB operational guidance* can be implemented** by NGOs/CSOs and by NTPs;

- to explain simply **how community-based TB activities can be integrated** into sectors such as PHC, HIV care, MNCH, water and sanitation, agriculture, livelihoods and education; and

- to explain the importance of **the two community engagement indicators** and the need to record community contributions within NTP monitoring systems. The manual also explains how the progress of community-based TB activities may be **periodically evaluated**.

The approach was piloted in five African countries: the Democratic Republic of the Congo, Ethiopia, Kenya, South Africa and the United Republic of Tanzania. The experience from these pilots contributed to developing the contents of this manual. An informal meeting of experienced NGO leaders in March 2013 also contributed valuable ideas on integrating TB into community-based health and development programmes.

Who is this manual for?

The implementation manual is intended for:

- **NGOs and other CSOs** working on health and other development initiatives (e.g. MNCH, HIV care, water and sanitation, education, agriculture and livelihoods) that intend to integrate TB prevention and care services into their field work;

- **NTPs or their equivalents** in ministries of health and other ministries providing TB services, including, for example, ministries of justice for prison health services and ministries of mining or labour for workplace health services;

- **people and communities** affected by TB and other conditions such as HIV infection or diabetes to generate demand for TB services and advocate for their inclusion in local decision-making processes; and

- **funding agencies** and **researchers** to help them target their work on community-based TB activities.

How can this manual be used?

The implementation manual is designed to help put the ENGAGE-TB approach into practice and can be used in tandem with the ENGAGE-TB operational guidance. Links are also provided to further resources that explain particular tasks in greater detail.

The manual is not a detailed instruction manual of procedures and protocols for activities. It is expected that the NTP and the NGOs/CSOs involved in each country will work together and develop their own procedures, protocols and resources, based on the local context and the guidance in this manual.

How is the manual organized?

Following this introduction, the manual is organized into four main sections and three annexes:

Section 1. TB—the basics: contains basic information about TB, including how it is transmitted, who is particularly vulnerable to it, how it can be prevented, how it affects people and how it can be treated.

Section 2. Collaboration between government and CSOs: discusses how NTPs can reach out to NGOs to collaborate with them in community-based TB activities, the potential roles of NGOs/CSOs and how formal and informal partnerships can support the ENGAGE-TB approach.

Section 3. Integrating TB into community health and development programmes: provides an overview of the types of community-based activities promoted by the ENGAGE-TB approach and outlines how these can be put into action in a range of sectors, including HIV care, PHC, MNCH, education, water and sanitation, agriculture and livelihoods.

Section 4. Implementing the WHO ENGAGE-TB approach is divided into six parts, each describing one **component** of the approach. It explains why each component is important, what activities are required to put the component into place and how those activities can be implemented. There is also a list of resources to support implementation of each component.

Annexes

Annex 1 contains a full description of the two WHO-recommended community engagement monitoring indicators.

Annex 2 describes the periodic evaluation process.

Annex 3 is a list of all the resources listed in the different sections of the manual.

Section 1. TB—the basics

What is TB?

TB is caused by a bacterium called Mycobacterium tuberculosis. TB usually affects the lungs, but it can spread to any part of the body.

Not all people infected with TB will become sick. If a person is in good health at the time of infection, the body's defences—**the immune system**—should be strong enough to keep the TB under control, and that person can stay healthy for a long time. This is called **latent TB infection**. One third of the world's population is estimated to be infected with latent TB.

> **i**
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> TB is curable and preventable!

However, if a person is in poor health at the time of infection, he or she is more likely to develop **TB disease**. This is called **active TB**. Latent TB can become active TB if the person's body's defences become weak through illness, inadequate nutrition or practices that stress the body such as smoking. Active TB disease can cause death if it is not treated successfully.

Active TB in the lungs is called **pulmonary TB**. It is most commonly **infectious** until it is treated. If TB is not treated, a person with active pulmonary TB disease can infect 10 to 15 other people per year.

Active TB outside the lungs is called **extrapulmonary TB**. A person with extrapulmonary TB cannot transmit TB to other people unless there is also untreated TB infection in the lungs.

How is TB transmitted?

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> TB is **not** transmitted by shaking someone's hand, sharing food or drink, touching bed linen or toilet seats.

TB bacteria are released into the air in the form of tiny droplets when a person with **active pulmonary TB** coughs, sneezes or spits without covering his or her mouth or nose. These droplets only survive where there is no ventilation and sunlight; they thrive in dark, poorly ventilated places. People nearby may breathe in these bacteria and become infected.

What are some of the signs and symptoms of TB?

As we have seen above, TB bacteria become active if the immune system cannot stop them from multiplying in the body. When this happens, there are changes in the body, which can be observed by the patient and by other people. These changes are called signs and symptoms.

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> **Sputum** is a thick, sticky liquid coughed up from the lungs
>
> It is different from **spit** or **saliva**

Common symptoms of **active pulmonary TB** include persistent coughing (for more than two weeks) with sputum and blood at times, chest pains, fever, weight loss, night sweats, weakness and tiredness. Sputum is a thick, sticky liquid that is coughed up from the lungs; it is different from saliva or spit.

Common symptoms of active TB:

coughing for more than two weeks

coughing up sputum, sometimes with blood in it

chest pains

fever

weight loss

night sweats

Weakness and tiredness

Weakness, tiredness, weight loss and fevers can also be symptoms of active extrapulmonary TB. Other symptoms depend on which part of the body is affected. For example, someone with active TB in the lymph nodes may have a swollen neck or armpit. Active TB in the bones can cause aches and pains in the joints. TB meningitis can cause severe headaches and mental confusion.

Symptoms of **TB in children** include persistent cough, persistent fever, loss of weight or failure to thrive during the past 3 months, and tiredness or lack of playfulness. Pulmonary TB in children is difficult to diagnose.

For **TB diagnosis**, many countries still rely on a long-used method called **sputum smear microscopy**. Sputum samples are collected in a health facility or in the community and sent to a laboratory. Trained laboratory technicians check the samples under a microscope to see if TB bacteria are present; if they are, the person has pulmonary TB. However, this test cannot detect latent TB or non-infectious TB. Diagnosis of extrapulmonary TB is more difficult, although the treatment is the same as for pulmonary TB. If good health care facilities are available, chest X-rays and sputum culture can also be used.

TB in children is:

a family illness, usually transmitted from someone in the same household

most common in young children below the age of 5

difficult to diagnose because children cannot easily cough up sputum to test

A new rapid TB test known as Xpert MTB/RIF is a fully automated diagnostic molecular test. It has the potential to revolutionize and transform TB care and control. The test:

- simultaneously detects TB and rifampicin drug resistance and

- provides accurate results in less than two hours so that patients can be offered proper treatment on the same day.

The Xpert MTB/RIF tests are not yet widely available, primarily because of their relatively high cost. As costs come down and more and more countries acquire and use the tests, TB testing will become increasingly responsive to patients' needs for quick diagnosis and immediate treatment.

What makes people more vulnerable to TB?

Anyone can get TB, but certain factors can increase the risk of developing active TB disease:

- **A weakened immune system**: The immune system is the body's defence against infection and illness. If a person is in good health at the time of TB infection, he or she can stay healthy for a long time. However, some conditions make the immune system weak, and this increases the risk of active TB disease. These include HIV infection, diabetes, certain cancers, malnutrition, smoking, use of illicit drugs and alcohol abuse.

- **Factors associated with poverty**: These include overcrowded housing with poor ventilation and little fresh air, malnutrition, and limited access to or use of medical services.

- **Congregate settings**: These are places where many people are together in the same space for long periods of time. They include factories, mills, mines, bars, prisons, hospitals and clinics, urban slums and refugee camps.

Other factors that affect TB are:

- **Stigma**: Ignorance, myths and misconceptions about how TB is transmitted have led to a lot of fears around TB. People may think it is "incurable", "a disease of the poor", "linked to promiscuous behaviour" or "a punishment from god". This has stopped people from accessing TB services and getting the treatment they need.

- **Gender**: TB affects men and women in different ways in different settings. This should be explored in each setting so that everybody can be reached by TB services. In any setting, TB should be given special attention during pregnancy (particularly in women with HIV infection) to keep both mother and baby healthy.

- **Legal restrictions** on certain activities: These can stop people from accessing TB services. For example, migrants, people who use drugs and sex workers may stay away from TB and other health services because they are afraid of being identified to the authorities and arrested or punished.

How can we prevent TB?

A **weakened immune system** enables latent TB to become active TB disease. The risk of acquiring TB can be reduced by staying healthy, eating adequate food, avoiding smoking, illicit drugs or too much alcohol, and getting prompt treatment for any health problems.

There are also some specific ways to prevent TB from spreading:

- **Infection control**: This includes covering the mouth and nose when coughing or sneezing, raising awareness of how TB is transmitted and ensuring that houses, clinics, workplaces and other "congregate settings" are well ventilated. This is particularly important for rooms where people with infectious TB spend a lot of time. Natural ventilation, by opening doors and windows, and sunlight in living spaces are very helpful.

- **Early diagnosis and case finding**: Diagnosing and treating active TB early stops it from being passed on to others. "TB case finding" refers to identifying people with signs and symptoms of active TB, and supporting them to get diagnosed and treated. With sufficient training and the right tools, community-based activities and outreach work can help to increase TB case finding. When active TB is diagnosed in a person, the people with whom he or she spends most time should also be screened for TB symptoms, particularly if they are children.

- **BCG (bacillus Calmette-Guérin) vaccine**: This was first used in 1921 and continues to be the only vaccine for TB. It is useful in protecting children under five from TB meningitis and other severe forms.

- **Prevention with medicines**: People with latent TB who are at increased risk of developing active TB, such as people living with HIV and children younger than five years who are in contact with a TB patient, could be given a course of the anti-TB drug isoniazid to prevent the development of TB. This prevention treatment is often called isoniazid preventive therapy (IPT). In addition people living with HIV are given the drug cotrimoxazole as preventive therapy (known as CPT). This helps to prevent them from getting sick with pneumonia, malaria and other infections until antiretroviral therapy (ART) helps the immune system to recover.

How is TB treated?

Active TB disease is treated with a standard six-month course of four anti-TB drugs. Because the treatment has to be taken exactly as prescribed and every day over such a long period of time, support from health workers or trained volunteers is needed. Health workers or trained volunteers observe the person taking the treatment. This is called directly observed treatment (DOT).

The reason why it is so important to take the treatment correctly for the right amount of time is to ensure that all the TB bacteria are killed off. If they are not, then the bacteria can become resistant to the drugs, and standard treatment becomes less effective or not effective at all.

When drugs do not work as they should against infections, this is called drug resistance. Resistance can be determined in a laboratory with special tests. If standard TB drugs do not work, other options are limited and will require much longer treatment.

The two main forms of drug-resistant TB are:

- **Multidrug-resistant TB** (MDR-TB) is resistant to at least the two most powerful standard anti-TB drugs (isoniazid and rifampicin). Treatment can take up to two years with more expensive second-line drugs, which also have more side-effect.

- **Extensively drug-resistant TB** (XDR-TB) is a form of TB that is resistant even to the drugs used to treat MDR-TB.[3] XDR-TB can develop when the second-line drugs are also misused or mismanaged and therefore also become ineffective. Because XDR-TB is resistant to first- and second-line drugs, treatment options are seriously limited.

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> **Types of drug resistance**
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> Acquired drug resistance: If treatment is stopped early or not taken regularly, resistant bacteria grow and active TB symptoms return.
>
> Primary drug resistance: Drug-resistant TB can be passed to others by someone with drug-resistant active TB.

How do TB and HIV affect each other?

HIV infection has seriously worsened the global TB epidemic. In some areas, up to 80% of TB patients are HIV positive. TB is the most common opportunistic infection for people with HIV and causes one in four of HIV-related deaths.

HIV infection means you are more likely to get TB: People with HIV infection are 21–34 times more likely to have active TB than those who do not have HIV. TB infection often rapidly causes serious TB disease in people with HIV infection, including children under five.

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> **All TB patients with HIV should get antiretroviral treatment (ART)**
> *(WHO Consolidated ARV guidelines 2013)*

- **Active TB makes HIV infection worse**: The development of active TB speeds up progression of HIV infection.

- **Diagnosing TB can be more difficult**: Diagnosis of TB in sputum with a microscope is difficult in people with HIV infection. Also, extrapulmonary TB is more common among those who are HIV positive. HIV infection makes diagnosis and management of TB in adults and children more difficult.

- **HIV-associated TB increases the risk of mother-to-child transmission of both HIV and TB**: HIV-associated TB is most common in women aged 15–29 years, the main child-bearing age in many countries. It is very important to treat TB in HIV-positive pregnant women; if TB is untreated, the risk of transmission of HIV to the unborn baby is much higher.

- **Treating TB in people with HIV is effective**: Joint treatment with anti-TB drugs as well as ARVs for HIV infection can help save lives and reduce the transmission of both diseases.

- **TB/HIV collaborative activities are essential** since the two diseases are so often linked. All TB patients should be offered HIV testing and, if positive, should be placed on ART. Similarly, all people with HIV should be screened for TB. The WHO policy on collaborative TB/HIV activities provides detailed guidance to national programmes and other stakeholders.

- **Three essential activities can reduce the burden of TB among people with HIV infection—the "three i's"**-
  - intensified case finding for early diagnosis and treatment of TB in people with HIV infection;
  - isoniazid preventive therapy (IPT) for people with HIV infection who are at risk for TB or with latent TB; this very much reduces the risk of developing active TB; and
  - infection control to prevent TB from spreading to vulnerable people with HIV infection, care workers and the community

WHEN A VIRUS (HIV) AND A BACTERIA (TB) CAN WORK SO WELL TOGETHER - WHY CAN'T WE? DOUBLE TROUBLE

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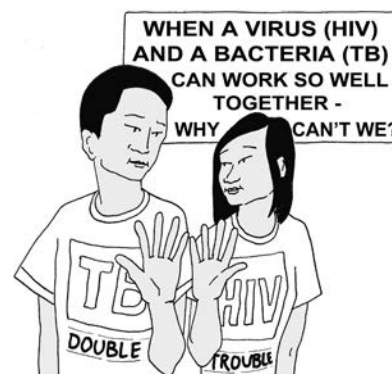
3   XDR-TB is resistant to at least four of the core anti-TB drugs. XDR-TB involves resistance to the two most powerful anti-TB drugs, isoniazid and rifampicin, also known as MDR-TB, and resistance to any of the fluoroquinolones (such as ofloxacin or moxifloxacin) and to at least one of three injectable second-line drugs (amikacin, capreomycin or kanamycin).

Estimated TB incidence rates, 2012

Estimated new TB cases (all forms) per 100 000 population per year

	0–9.9
	10–19
	20–49
	50–124
	125–299
	300–499
	≥500
	No data
	Not applicable
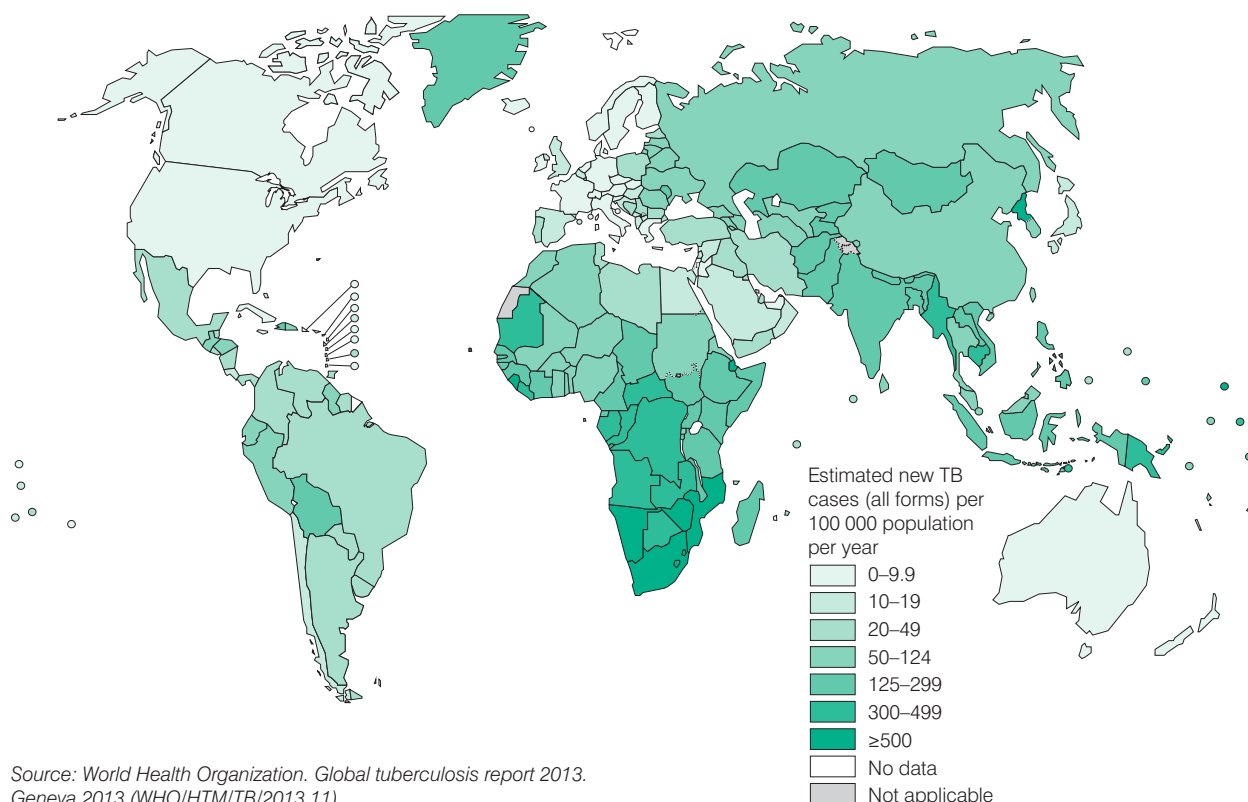
Source: World Health Organization. Global tuberculosis report 2013.
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Resources

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Section 2: Collaboration on TB between government and civil society

We know that TB is one of the major infectious causes of death in the world. We also know that up to one third of cases of TB are still either not diagnosed or not reported. A lot of progress has been made, but it is clear that greater efforts are needed to reach into communities to find, screen and treat the missing one third of people. Many of these people are in communities that existing TB services do not easily reach.

At the same time, nongovernmental health and development programmes are active in these same communities. Often, they are implementing activities that address social and economic factors that affect health. For example, they work on health care, water and sanitation, food and nutrition, poverty reduction and education. If these NGOs/CSOs integrate TB into their community-based activities, it should be possible to reach many more people with TB services.

What are CSOs?

"**CSO**" refers broadly to the organizations and institutions that operate outside the state and the private sector. They include:

- **NGOs** that are usually registered and have legal status;

- **community-based organizations (CBOs)** that are usually local and run by community members; they may not be registered unless the country's laws require it;

- **faith-based organizations (FBOs)** that are connected with and supported by a religious group; larger ones may be registered as NGOs but smaller ones are often similar to CBOs;

- **networks and associations** of people or organizations working on particular issues such as TB, HIV infection or diabetes are membership organizations. They provide support to members and engage in advocacy and education on the issues they are concerned with. Some take the form of coalitions or consortia. Larger ones may be registered as NGOs.

In this manual, the term used to include all the organizations and groups in the above list is "**NGOs and other CSOs**", or "**NGOs/CSOs**".

> **ⓘ**
>
> **Civil society organizations**
>
> are not part of government or the private sector
>
> aim to serve the interests of communities
>
> are not run for profit

How do NGOs and other CSOs work on health in communities, including TB?

NGOs/CSOs working in communities are in a unique position to contribute to community health. They are familiar with the community's culture and language, they can communicate with others about the community's needs, and they can mobilize people in the community to influence decisions made about the community. They are especially important for reaching people in isolated or neglected parts of the community when the formal health system cannot reach them. NGOs/CSOs are also able to reach vulnerable and marginalized groups such as migrants, refugees, sex workers, people who use drugs and the very poor who are often unable or unwilling to access health services from the formal health system.

NGO/CSO community projects and programmes can use community systems to contribute to health through three main types of activity. On TB, for example, they can be engaged in:

- **providing health services in the community**, including awareness and prevention, home-based care, TB screening, sputum collection and transport, treatment support including DOT and health education. They can also monitor and document the way in which communities are able to use the health system.

- **providing support for people needing or using health services**, including reducing TB stigmatization in families and health facilities, helping people to access services, providing transport and psychological, economic and legal support; and

- **acting to create and improve the enabling environment for TB activities** by:
  - mobilizing communities to act on stigma, basic rights and access to health services and basic standards of housing, nutrition, water, sanitation and hygiene;
  - linking community services with the formal health system and its personnel and institutions; and
  - engaging in local level advocacy to ensure responsiveness to needs such as for laboratory equipment or drugs and medicines at health facilities.

Community health workers (CHWs) and community volunteers (CVs) carry out community-based TB activities, depending on national and local contexts. CHWs 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. They are sometimes called "health extension workers", "village health workers" or similar names. CVs 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.

CHWs and CVs can serve as important links between the health system and the communities they serve. NGOs/CSOs working on community-related TB activities should have an active, cooperative working relationship with them.

What do NGOs/CSOs need in order to work effectively on TB?

Reaching more people with community-based TB activities requires NGOs/CSOs to identify and provide a set of TB services and to collaborate with the NTP and the health system.

Larger NGOs may already have sufficient funding and other support that enables them to integrate community-based TB activities into their existing portfolio of work. Some smaller organizations may not have enough resources or capacity to do this. However, they may have potential to develop their capacity if they are strengthened. The resources and support especially needed are:

funding to ensure their stability as organizations (core funding) while they implement their activities;

technical support, mentoring and resources to assist them in delivering services, documenting activities and engaging in advocacy;

training and capacity-building for running their organization or group and for implementing their TB activities, including mentorship and technical support;

linkages and partnerships to support their contributions to community health, including with other NGOs, national programmes such as the NTP and providers of funding, training and mentoring and technical resources.

How can NTPs and NGOs/CSOs collaborate?

NTPs operate at national, regional/provincial, district and health facility levels.

At national level, the NTP is responsible for TB strategy, policy and overall programme management. Depending on the country context, TB service delivery may be managed by a regional or provincial TB coordinator.

The NTP basic management unit (BMU) is at district or equivalent level. It is responsible for all TB public health programmes in its area, including training, supervision, drug supply and monitoring. Services are usually provided by hospitals and clinics.

At local level, TB services are usually provided through health centres, health clinics and health posts. These are usually part of the public health system. Services may also be provided by not-for-profit NGOs or FBOs and private practitioners.

A typical national TB programme (NTP) has:

a central unit: NTP manager, technical officers and support staff, national TB laboratory;

regional/provincial: TB control coordinators, including regional TB laboratory;

district (basic management unit [BMU]): coordinators for TB control; including TB laboratory services; and

TB services, including X-ray and laboratory, integrated into general health services at health facilities.

In general, NGOs/CSOs could link with the NTP at any of these levels. However, NGOs and other CSOs vary a lot in their size, resources and the type of work they do. Sometimes they are linked with other organizations and/or government systems, but sometimes they do not have linkages and are purely independent local groups. The NTP and the NGOs/CSOs therefore need a mechanism that will help them to engage with each other and bring in other organizations and groups that are not already engaged.

One of the best ways for government programmes to link with NGOs/CSOs for specific health approaches is through an **NGO coordinating body (NCB) that brings NGOs together as a coalition or network**. This should be set up and independently managed by the NGOs/CSOs, who can then more systematically engage in partnership with government but also act as advocates. In some countries there may already be an NGO/CSO body that can act as the ENGAGE-TB NCB. In other countries it will be necessary to set up a new NCB.

The NCB can act as an "umbrella" body for NGOs/CSOs to develop a working relationship and engage with the NTP, health providers and each other. It can provide the NTP with a clear contact point for active and systematic collaboration and for hearing about the needs, constraints and lessons learnt by NGOs/CSOs in planning, resourcing and implementing community-based TB activities.

The NCB is also a structure that can serve to attract more and more NGOs and CSOs that have not been aware of or involved in TB activities on a continuing basis. This has the potential to extend TB activities to more communities and to neglected parts of the population.

The NTP has a critical role in supporting the start-up and development of the NCB. With NTP support and encouragement for the NCB, the NGOs/CSOs can work together to monitor progress, address bottlenecks and highlight new ideas and approaches. Their partnership can also be used to establish the basic ENGAGE-TB components to support their activities, discussed in detail in Section 4 of this manual. The diagram on the following page illustrates how the NCB can be the main linkage point between NGOs/CSOs at national, provincial or district level and the various levels of the NTP.

The NCB links NGOs/CSOs with the NTP to enable coordination, collaboration and shared support.

NTP support and facilitation of the NCB will be helpful for the following reasons:

- to ensure that the NCB can function at national, subnational and local levels to support NGO/CSO engagement in TB;

- to ensure linkages with and acceptance as partners by TB health providers;

- to ensure that NGOs/CSOs have access to the systems, resources and support they require, including through their own partnerships and through government sources; and

- to ensure that community-based TB activities are recorded, monitored and evaluated as part of the NTP.
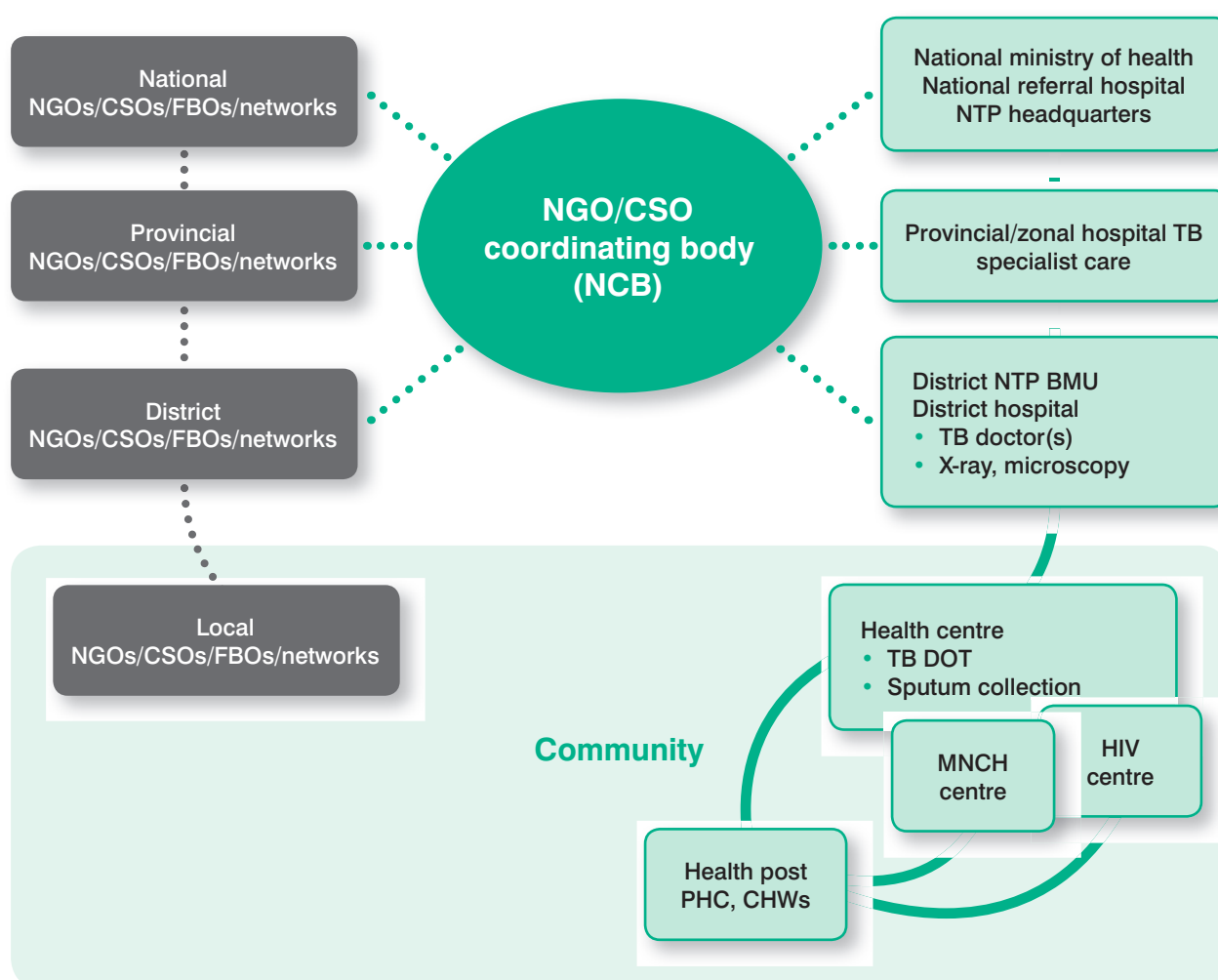
Community-based TB activities: civil society, NCB and health system linkages

━━━ Health system linkages

•••• Linkages between NGOs/CSOs, FBOs, networks and CBOs

•••• Linkages between NCB, NTP and NGOs/CSOs/FBOs/networks

Dotted lines indicate linkages that may or may not exist and may vary in strength, quality and their ability to support coordination and/or collaboration. Sustained effort will be required to build and maintain these linkages.

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Section 3. Integrating TB into community health and other development programmes

WHO recognizes the potential for integrating community-based TB activities into the work of NGO/CSO health and other development programmes. This is at the heart of the ENGAGE-TB approach. Almost any health or development programme could integrate one or more of the activities listed below into their on-going community-based work.

Integration means bringing together different activities, programmes or partners to achieve a goal, such as reaching more people with TB services.

Theme	Possible activities
Prevention	Awareness-raising, information, education, communication (IEC), behaviour change communication (BCC), infection control, training providers
Detection	Screening, contact tracing, sputum collection, sputum transport, training providers
Referral	Linking with clinics, transport support and facilitation, accompaniment, referral forms, training providers
Treatment adherence support	Home-based DOT support, adherence counselling, stigma reduction, pill counting, training providers, home-based care and support
Social and livelihood support	Cash transfers, insurance schemes, nutrition support and supplementation, voluntary savings and loans, inclusive markets, training providers, income generation
Advocacy	Ensure availability of supplies, equipment and services, training providers, governance and policy issues, working with community leaders
Stigma reduction	Community theatre/drama groups, testimonials, patient/peer support groups, community champions, sensitizing and training facility and CHWs and leaders

Although **advocacy and stigma reduction** are included as specific themes in the list above, it is important to realize that these are also **cross-cutting** issues. This means that activities on stigma reduction or advocacy can often be included in activities that address the other themes.

Stigmatization can affect people who need TB services in many ways. For example, it might prevent people going to a clinic to get TB services or affect their family and social lives so that they do not get the support that they need. Children who are thought to have TB, or who have a family member with TB, can find themselves excluded from games and activities at school.

TB stigmatization often combines stigma about HIV, poverty or other issues. A high level of **trust** and **respect for confidentiality** is needed to protect people from actual or feared stigmatization and discrimination. Stigma reduction should target all types of stigma affecting individuals and communities using or needing TB services.

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Advocacy means working to encourage improvements or changes in policies and activities. Advocacy can be needed in more than one area. For example, it might be needed to ensure that all people requiring TB care have access to it. It might also be needed to help people on TB treatment to have food and clean water to support their return to good health.

BRAC Bangladesh – an example of integrated community-based TB activities

In Bangladesh each year, around 76 000 people die because of TB. BRAC, a Bangladesh-based large international NGO, signed a memorandum of understanding with the Government of Bangladesh in 1994 to expand DOT short-course (DOTS) services nationwide.

BRAC's TB programme is part of its integrated poverty alleviation programme, which delivers microfinance, health, education, agriculture and livestock services in marginalized and ultra-poor communities.

Community stakeholders are engaged in efforts to identify TB patients, support treatment adherence and reduce stigmatization. Stakeholders include: cured TB patients, local opinion formers and religious leaders, girl guides and scouts, other NGOs, village doctors, pharmacists and private practitioners.

Frontline CHWs connect individuals with TB control services during household visits and health forums. They carry out a range of tasks such as:

- disseminating TB messages,
- identifying people who might have TB,
- referring identified people for sputum examination to the local health complex or BRAC laboratory services,
- ensuring daily intake of TB medicine through DOT for identified patients and
- making referrals for management of side-effects during TB treatment.

Integrating TB into MNCH

NGOs/CSOs can integrate TB into MNCH by linking TB tasks with CHWs, community midwives and CVs, and with community or village health committees. It is important to identify clearly which people CHWs and community volunteers (CVs) should work with, both in the community and in the health system, in order to integrate TB into the **MNCH continuum of care**.

The continuum of MNCH care includes the period before conception through pregnancy, childbirth and infancy. It includes care at home, in the community, and in the health system, at the health centre and, when needed, at the hospital.

Community-based TB activities can be integrated into different stages of the MNCH continuum of care. This can include the routine activities of community midwives and MNCH outreach workers, CHWs or CVs before and during pregnancy and after the baby is born. TB activities can take place during household visits, health promotion at community level, maternity outreach services and when linking pregnant women, mothers and their children to health facilities.

It is important to identify pregnant women and children less than five years of age as priorities for MNCH TB activities. In some countries, community mother-to-mother peer supporters are trained to support women through pregnancy, childbirth and early motherhood. They can play a key role in identifying and supporting those who also need or use TB services.

TB prevention in MNCH settings

1. **TB awareness-raising, infection control (including cough hygiene), stigma reduction, IEC and BCC**

   - Train community health workers, community midwives, NGO/CSO staff, mother-to-mother peer supporters and community leaders on the importance of TB screening and early treatment for pregnant women.

   - Target households to increase awareness, especially those with a person who has pulmonary TB.

2. **Provide IEC materials and job aids on TB prevention for use by CHWs, CVs and midwives.**

   - Develop and provide culturally appropriate materials for use at household and community levels and in MNCH health facilities.

   - NGOs/CBOs should take a lead on developing materials, supported by larger NGOs/CSOs and the NTP. All materials should be tested or pilot tested with the target audience to ensure they are easy to understand and are culturally acceptable.

3. **Engage in specific BCC campaigns and stigma reduction aimed at informing women and families and dispelling myths about TB and HIV.**

   - Train grassroots NGOs/CSOs, and mother-to-mother peer supporters to take a lead on BCC and stigma reduction at local level in local languages.

   - Hold events such as street theatre in public settings where women and families gather, e.g. markets, places of worship, antenatal clinics, mother and child support groups.

4. **Improve vaccination coverage, including BCG for infants.**

   - Engage grassroots NGOs/CSOs and mother-to-mother peer supporters to work with CHWs and MNCH community outreach and vaccination campaigns, and ensure that all children needing vaccination are identified and able to access it.

   - Use regular community health outreach visits and child health days to reach the largest numbers.

TB case detection, referral and surveillance in MNCH settings

1. **Screen, identify and refer mothers, their partners and child contacts to the health facility for TB and HIV diagnosis and management.**

2. **Provide education on the importance of TB testing and linking to HIV testing and counselling for all mothers and family members who may benefit from it.**

   - Train CHWs and CVs, NGOs/CSOs and mother-to-mother peer supporters to inform and support households and family groups (including male family members) and antenatal support groups on TB screening and HIV testing and counselling.

3. **TB contact tracing, sputum collection, sputum transport**

   - Train CHWs, CVs and community midwives on screening methods, TB contact tracing and sputum collection, safe storage and transport.

   - Ensure that under-fives and newborns, who are vulnerable to TB, are identified during contact tracing as well as adults and older children.

   - Ensure that sputum collection and transport follow national policy and protocols; this will also depend on the availability of laboratory facilities.

4. **Referrals to link health facilities for women and children with presumptive TB**

- Ensure that systems are in place for referring patients from the point of contact in the community through to the health facility and re-referring them back to the community for ongoing adherence and other forms of support.
- Ensure close linkages between community and health facilities, with agreed referral forms and recording systems.
- Provide transport support (such as bus fares or lifts) where needed.
- Provide accompaniment by peer supporters to assist mothers and young children in completing referral journeys and accessing TB care.

TB treatment adherence support in MNCH settings

1. **Home-based TB DOT and adherence counselling**

- NGOs/CSOs and NTPs can work together to ensure that CHWs and CVs have the skills needed for these tasks.
- In addition to DOT adherence support, include stigma reduction, home-based care and tracing of patients who are lost to follow-up; checking TB, HIV and antenatal appointment cards; and referring mothers on TB treatment for follow-up sputum smears.

Social and livelihood support in MNCH settings

1. **Link pregnant women and mothers to local support mechanisms.**

- Ensure access, when needed, to cash transfers, insurance, nutrition, voluntary savings and loan schemes and income generation projects.

2. **Involve others in the home to create a suitable home environment for TB and other treatment.**

- Ensure that psychological and physical support is available in the home and in peer support centres for mothers and children.
- CHWs can link clients with local NGOs/CSOs for these activities.

TB Advocacy in MNCH settings

1. **Advocacy on supplies of TB and HIV drugs and laboratory tests**

- Monitor availability of essential supplies, drugs and tests, and advocate for consistent, good-quality supplies, equipment and human resources to be available at local facilities.
- Advocacy can address medicine shortages and quality problems and local availability of equipment and tests, e.g. laboratory microscope, tests for TB and HIV screening (including for newborns and infants).
- In cases of emergency, local NGOs/CSOs and community health providers can advocate with national or international providers to provide supplies as a short-term solution, where resources are available.
- CHWs, NGOs/CSOs and NTPs should work together to create effective coordination between MNCH, TB and HIV services.

2. **Advocacy on access to services**

- Bringing services closer to where people live is a priority for ensuring early access to diagnosis and treatment, particularly for pregnant women and mothers with young children who find it difficult to travel. Advocacy may be needed to ensure that TB and HIV treatment and diagnostic services are available at a local health centre.
- Local NGOs/CSOs, CHWs and local health committees can act as advocates on behalf of mothers and children to ensure MNCH, TB and HIV services.

3. **Advocacy for policy changes**

- Policy changes may be needed at community level and all levels of the NTP, MNCH services, laboratory and pharmacy services. For example, changing policy to allow CHWs to collect and transport sputum or permitting trained midwives to initiate treatment for pulmonary TB. Task shifting to allow CHWs to do more at the household level should be encouraged.
- NGOs/CSOs should work together within the NCB and with the NTP to address needs and provide guidance for the country.

4. **Advocacy for research**

   - Research is an important part of TB activities, especially in community settings where it is not yet clear what approaches are the best for community-based TB activities.

   - Operational research is a useful approach, allowing different types of evidence to be gathered and involving communities and NGOs/CSOs in asking and answering the research questions.

   - NGOs/CSOs, researchers and the NTP should work in partnership to gather evidence of what works, for adoption by the NTP and other departments.

TB stigma reduction in MNCH settings

1. **Raise community awareness on stigma experienced by pregnant women, mothers and young children with TB.**

   - Address key issues of stigmatization affecting pregnant women and mothers, specifically blame, rejection by partner, marriage breakdown and loss of financial support.

   - Use public settings such as markets or community centres for stigma reduction events, such as street theatre, public testimonials, group discussions and participatory activities.

2. **Sensitize, train and mentor community leaders and MNCH and CHWs on stigma reduction.**

   - Train NGO/CSO staff, TB/HIV patients, community leaders, mother-to-mother peer supporters and women's groups, on stigma reduction for mothers and young children with TB.

3. **Support CHWs to include stigma reduction during contact tracing.**

   - Work with NTP staff and CHW supervisors to train and support CHWs on stigma reduction among families of mothers and children with TB.

Integrating TB and HIV activities at community level

WHO has encouraged TB and HIV integration within health systems since 2004. Many HIV programmes working in communities have also started to address TB in their activities. However, it is important to target everyone at risk from TB in communities as well as everyone at risk from HIV infection.

Although TB and HIV epidemics often affect the same people, not everybody in an affected community has both diseases. Some people will need both HIV and TB care, support and treatment; others may need them only for TB or only for HIV infection. It is important that communities and health workers understand that **HIV infection and TB are separate diseases** and need different treatments and different methods of prevention. However, there are large numbers of people with undiagnosed TB and/or undiagnosed HIV infection. Increased screening, case-finding and early treatment are priorities for both diseases.

All people with a positive HIV antibody test should be screened for TB, and those without any TB symptoms should receive IPT, which can prevent latent TB from becoming active TB. TB screening and treatment should be integrated into all HIV programmes.

Similarly, HIV testing should be integrated into all TB programmes. All people who have presumptive or confirmed TB should be offered an HIV test. Anyone with TB disease who tests positive for HIV should be linked to HIV treatment and care services.

TB prevention in HIV care

1. **TB awareness-raising in HIV care settings**

   - Educate people on TB when they attend HIV care services, for example at community centres during outreach, mobile and stand-alone voluntary counselling and testing sites and sexually transmitted infection clinics.
   - Educate providers and people attending clinics on cough hygiene, including provision of face masks for health workers and patients.
   - Promote the TB Patients' Charter and International Standards for TB Care as part of HIV prevention work.
   - Educate community HIV care and support providers on TB prevention and the importance of IPT.
   - Provide integrated training to CHWs and other health care providers on TB/HIV stigma and TB/HIV literacy.

2. **Community TB/HIV awareness-raising and stigma reduction**

   - Use radio and TV, printed brochures and posters to provide IEC on TB/HIV, using peer educators and people recovering from TB, supported by NGO/CSO communications and programme teams.
   - Emphasize prevention through cough hygiene, and promote ventilation and exposure to sunlight as additional measures to reduce risk.
   - Emphasize that TB can be cured with effective TB treatment and that it is a different disease from HIV infection, which can be controlled with ART.

TB detection in HIV care

1. **Screening:**

   - Develop standardized tools and simple TB screening protocols based on international guidance to help identify people at highest risk.
   - Train CHWs, staff and volunteers at HIV voluntary counselling and testing sites, community centres and households to use the screening tools and refer people with TB symptoms for diagnosis.

2. **Sputum collection and transport**

   - Develop standardized tools and simple TB screening protocols for sputum collection in households, community centres and health posts.
   - Train CHWs, HIV outreach workers and carers to collect, store, label and transport sputum specimens to laboratories for examination.

3. **Contact tracing**

   - Train CHWs and CVs on contact tracing in households and other community settings.
   - Prioritize contacts of sputum positive patients, as they are most at risk, but also respect confidentiality to prevent the risk of stigma.

Referral between community HIV and TB services

1. **Link patients with clinics for TB diagnosis and care (clinical examination and treatment).**

   - Ensure that TB patients can connect with TB services. They may need active support and accompaniment to access services, including transport.

   - Develop referral linkages between TB services and community HIV services such as voluntary counselling and testing sites and community HIV centres, including back-referral to CHWs and peer supporters for ongoing support and follow-up.

2. **Ensure that patients are able to get transport to TB services.**

   - Engage peer supporters to provide support and accompaniment where needed.

   - Mobilize resources to pay fares or hire vehicle transport for those in need to travel from community HIV centres, voluntary counselling and testing or ART sites to TB centres.

3. **Train providers on facilitating community referrals.**

   - Work with CHW supervisors, TB and HIV clinic staff and peer supporters to develop and use a two-way referral system, with referral and back-referral forms and recording systems that are linked with national reporting mechanisms.

   - Train peer supporters and other CVs on tracing TB and HIV clients who fail to keep appointments.

TB treatment adherence support in HIV settings

1. **Provide adherence counselling and support for TB treatment and IPT.**

   - Train ART adherence counsellors, CHWs, peer support groups, peer educators, carers and family members on TB treatment and IPT.

   - Send SMS text reminders and appointment reminders, and trace patients who miss appointments. Monitor progress and side-effects, re-referring clients when needed.

   - Address stigma reduction as an important factor affecting TB and HIV treatment adherence.

2. **Home-based TB and HIV care and support including stigma reduction in family and community**

   - Engage family members, peer supporters, CSOs and CHWs to provide integrated TB and HIV treatment adherence support, including preventive treatment with isoniazid and cotrimoxazole and support for dealing with the effects of stigmatization.

   - Also consider providing TB and HIV adherence support at community centres or HIV drop-in centres as an alternative for those who do not want to disclose their status.

   - Reinforce messaging on the importance of treatment adherence during pre-ART counselling and after initiation in community outreach and in IEC materials.

Social and livelihood support for people affected by TB/HIV

1. **Nutrition support and supplementation**

   - Ensure that patients receiving treatment have access to adequate, balanced nutrition to support them in recovering from TB and opportunistic infections due to HIV infection, especially during the early stages of TB or HIV treatment. Note that this is a specific medical need apart from any longer-term food access issues.

2. **Income generation and vocational training**

   - If the organization is implementing income generation and vocational training, etc, specifically include people with, affected by or at risk of HIV infection and TB.

TB advocacy in HIV settings

1. **Monitor availability of TB supplies, equipment and services and advocate for better access.**

   - Engage CHWs, patient groups, community leaders, TB advocates and champions in monitoring activities.

   - Where available, use electronic messaging or cell phone reporting systems to communicate shortages to national level for rapid action and advocacy.

2. **Monitor policy barriers on access to TB and HIV services, especially for the most vulnerable groups.**

   • Train NGO leaders, TB and HIV advocates and champions on how to advocate, and measure its success using or adapting available tools.

   • Ensure advocacy at local and national levels, using mechanisms for partnership and collaboration, e.g. national networks such as the NCB for TB.

TB stigma reduction in HIV settings

1. **Raise public awareness on TB and HIV stigmatization.**

   • Train patient and peer support groups, TB champions and advocates in stigma reduction activities.

   • Use community theatre, public testimonials and disclosure by people living with TB and HIV, public community sensitization events in markets, sports events, places of entertainment.

2. **Training and capacity-building**

   • Provide TB and HIV stigma reduction training for community leaders, CHW supervisors, peer support groups, teachers, religious leaders, health workers, NGO staff and people in authority, such as police.

   • Support disclosure and acceptance of people living with TB and HIV infection and taking treatment in affected communities and in workplaces, e.g. health facilities, schools.

3. **Take action against discrimination.**

   • Support legal action for loss of work or property related to having TB or HIV infection, for example in law courts, employment tribunals, parliament or local councils.

   • Engage in public campaigns against specific forms of discrimination.

   • Train NGO/CSO leaders and coordinating bodies, networks of affected people and communities on how to act against discrimination and provide legal support to people affected by TB and HIV infection.

Integrating TB within PHC

PHC reaches across many different sectors, as its aim is to include everything affecting health in communities. It is "multi-sectoral", involving several different sectors. It also includes the activities of different types of health care providers, such as CHWs, mobile clinics and outreach teams from health facilities.

NGOs, CSOs and FBOs should therefore engage with PHC providers to support and increase the integration of TB activities into their work. Depending on the local context and needs, PHC programmes could, for example, work with CHWs and outreach or mobile teams to integrate TB activities into the following range of PHC activities:

• education on common community health problems and methods of preventing and controlling them;

• appropriate treatment of common diseases and injuries;

• promotion of food supply and healthy nutrition;

• adequate supply of safe water, basic sanitation and hygiene;

• MNCH care, including family planning;

• vaccination against the major infectious diseases; and

• provision of essential drugs.

TB prevention in PHC settings

Awareness-raising, infection control, stigma reduction, IEC, BCC, training of providers

- Conduct surveys related to TB.
- Develop and distribute IEC materials on TB.
- Train on counselling and effective communication with people who may have TB.
- Develop TB radio messages and jingles.
- Include TB in PHC for both children and adults.
- Engage in family and community dialogue on TB during home visits.
- Promote BCG vaccination.

TB detection in PHC settings

Screening, contact tracing, sputum collection and transport, training providers

- TB screening of children under five during child health days and nutritional surveys, school health programmes and de-worming campaigns;
- TB screening during outreach visits;
- training school health clinic staff on sputum collection and safe storage; and
- training providers at school and in the community on how to assess TB signs and symptoms and how to refer children for TB diagnosis and treatment.

Referral to TB services from PHC settings

Linking people at risk of TB with clinics, including transport support and facilitation

- Link people who might have TB to a referral or infectious disease hospital.
- Provide transport support to help patients complete referral journeys.
- Support transport of sputum specimens to the nearest health facility.
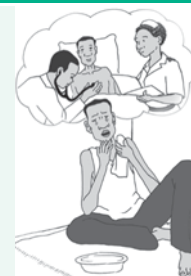
TB treatment and adherence support in PHC settings

Home-based DOT, counselling, adherence, home visits, pill counting, stigma reduction, training providers, home-based care and support

- Conduct home visits to support adherence (at least weekly).
- Provide training on counselling and effective communication skills (family and community dialogue).
- Monitor treatment adherence and adverse drug effects.
- Re-refer patients who have difficulties due to side-effects of anti-TB drugs or poor adherence.

TB surveillance in PHC settings

Record data at community level; maintain summary records and registers on referrals and transfers at health facility.

- Engage community members to form a community monitoring body.
- Train CHWs to maintain record sheets and registers.
- Train school clinics to keep registers.

Report on the contribution of communities to TB services

- Develop a mechanism for reporting to the NTP at district and national level.

Social security, food and nutrition security, livelihoods in PHC settings

Provide social safety nets to support people affected by TB, especially during the recovery phase of treatment.

- Consider food and nutrition supplementation and conditional and/or non-conditional cash transfers.
- Develop community insurance schemes, and train providers to support people's access to inclusive markets, voluntary savings and loans and income-generating activities.
- Link organizations with limited capacity with other organizations offering social, nutrition and livelihood support.

TB advocacy in PHC settings

- Monitor the availability of supplies, equipment and services at health facilities, and report any gaps and weaknesses.
- Engage community and faith-based leaders to add their voices to improve TB services.
- Train health providers on stigma and barriers to community use of services.

Social mobilization and TB stigma reduction in PHC settings

Use community theatre/drama groups, patient/peer support groups, community champions, testimonials, sensitizing/training facility and CHWs and leaders.

- Design and conduct community "docudramas" on TB.
- Identify and engage TB champions.
- Host public testimonials by people who have been cured of TB.
- Support peer-to-peer groups (e.g. school hygiene groups, women's or men's groups).
- Train social **mobilizers** on TB.

Integrating TB into agriculture programmes

Most agriculture programmes supported by NGOs use group approaches for their work. These can include "farmer field and livelihood schools" for adults and young people, farmers' clubs, associations and cooperatives. Group members meet regularly throughout an agricultural season or cycle. The groups help to improve farmers' decision-making capacity, life skills and agricultural practices by sharing their experience and knowledge.

The structured learning provided by farmer field and livelihood schools and other group approaches is adaptable to local situations and priorities. Learning about TB prevention and improving social and livelihood support for those affected can therefore be easily integrated into group activities. TB screening and referrals for TB diagnosis can also be included. It is important to have a reliable health system to receive and support such referrals and to ensure that confidentiality is protected, especially for people in small, close-knit rural communities.

TB prevention in agriculture programmes

1. **Engage farmers' groups members to promote TB prevention.**
   - Train members in TB awareness-raising among rural households (men, women and young people), including how to prevent/reduce the risk of TB and other diseases.

2. **Improve community information on TB prevention through community sensitization and awareness-raising.**
   - Use IEC materials, TB campaigns, school competitions, debates.
   - Increase capacity of community leaders through training on TB prevention.
   - Train lead farmers to be TB champions in rural communities.
   - Educate people on healthy living to reduce vulnerability to TB.
   - Link ultra-poor households with livelihood support schemes.

TB detection and referral in agriculture programmes

1. **Train group members to recognize TB symptoms and encourage community members with symptoms to be tested.**
   - Discuss TB signs and symptoms.
   - Establish an easy-to-use, reliable system for referral to CHWs or a clinic.

Note: Issues of confidentiality and trust are particularly important in small communities and groups.

Social and livelihood support for people affected by TB in agricultural settings

1. **Integrate TB into training on life skills and confidence-building within agricultural learning.**
   - Train ultra-poor caregiver and producer groups in TB screening, nutrition, production and use of nutritious foods and income generation to support affected families.
   - Develop/establish savings groups to support ultra-poor households and caregivers.
   - Establish livelihood support and cash transfer mechanisms for affected households.
   - Train selected community members on TB adherence support.

Integrating TB into a livelihoods development programme

Livelihood development programmes are aimed at improving the quality of life of people and communities who are marginalized, vulnerable or stigmatized. The objective is to create opportunities for people to move out of poverty and powerlessness.

Health is an integral part of livelihood programmes, along with food and nutrition, water and sanitation, education and shelter. Community-based TB activities should therefore fit naturally into the activities of livelihoods programmes. Livelihood programme officers work closely with their communities and community structures, such as village development committees. They can also link with CHWs and volunteers, midwives, water and sanitation and agriculture workers.

TB prevention in livelihoods development settings

1. **Use livelihoods development programme supervision mechanisms to raise awareness on**: TB basics, including transmission and prevention, signs and symptoms, stigma reduction, importance of nutrition for protection from disease, personal hygiene and living conditions.

2. **Include education on aspects of TB during visits to families by programme officers**, who generally use a checklist to monitor livelihoods and life skill development; education on TB can be included in this checklist.

3. **Integrate marginalized ultra-poor groups into the wider local community.**

   • Use an existing village committee or work with village leaders to set one up, to provide support to the target group and raise awareness about TB among the whole community.

   • Hold regular (monthly) village meetings called by the village committee to inform people about TB and other social issues; use media such as video shows to make a greater impact on the community.

   • The local manager of the livelihoods development programme can lead the task of forming the committee and facilitating the monthly meetings.

   • Organize and build the capacity of the committees so that they continue to address TB and other issues after the livelihoods development programme withdraws.

4. **Address health in livelihoods programmes: Recruit and train CVs on prevention, detection and treatment of TB along with other health services**

   • Invite the health volunteers to village committee meetings to raise awareness on TB.

   • Health volunteers can organize community health forums to discuss TB along with other health issues.

TB detection in livelihoods development settings

1. **Train the programme officer on TB signs and symptoms so that she or he can identify people with TB symptoms during home or group visits.**

   • The programme officer refers the person to a sputum collection point, or:

   • if a health volunteer is trained in sputum collection, the programme officer can ensure that she or he visits people with TB symptoms at home to collect sputum and send it to the laboratory for testing.

2. **Link health volunteers in the livelihood programme to the local TB diagnostic facility.**

3. **If there are no health volunteers, link the programme officer with the local TB programme (NTP) team** to make sure that any presumptive cases of TB are tested and diagnosed.

4. **Mobilize village development committees to support sputum transport** from remote areas (livelihood programme staff can facilitate the process).

TB referrals in livelihoods development settings

1. **Livelihoods programme staff and programme health volunteers support referrals** by identifying the nearest clinics, accompanying the patient and providing support for transport.

2. **Village development committees can also support referrals** in the same ways.

Treatment adherence support in livelihoods development settings

1. **Health volunteers associated with the livelihood programme** can encourage patients to take their medicines regularly through DOT.

2. **If there are no health volunteers, the programme officer can support DOT during home visits,** including counselling on treatment adherence and completion and the importance of adherence support by caregivers in the household.

Social and livelihood support for people with TB

1. **Provide extra support to TB patients in livelihoods programmes, including:**
   - special stipends for income support during the TB treatment period,
   - special nutrition support to support recovery from TB and
   - mobilizing additional care from village committees, e.g. child care support.

TB advocacy in livelihoods development settings

1. **Use livelihoods programme staff and events to educate people on TB and reduce social stigma around TB.**
   - Use social communication strategies such as community theatre/drama at local level.

2. **Provide feedback from the field** to meetings within or outside the organization, aimed at strengthening the TB programmes. For example, highlight issues such as supplies, quality of services, realities about transport and the challenges related to the referral services, as relevant.

3. **Contribute to policy dialogue with local and national government,** on the basis of the programme's field observations.

Integrating TB into education

The education sector has a vital role to play in supporting community efforts against TB. As we have seen, ignorance about TB contributes to myths and stigmatization and, as a result, to the spread of TB. Education on TB should therefore be included in school curricula.

Four levels of intervention can be addressed: early childhood, primary school, secondary school and non-formal education. Education on TB prevention is one contribution that the education sector can make quite easily by teaching children to cover their mouths and noses when they cough and sneeze and explaining the benefits of sunlight and ventilation. Other activities and lessons should also be included that can contribute to TB stigma reduction, screening, treatment and advocacy.
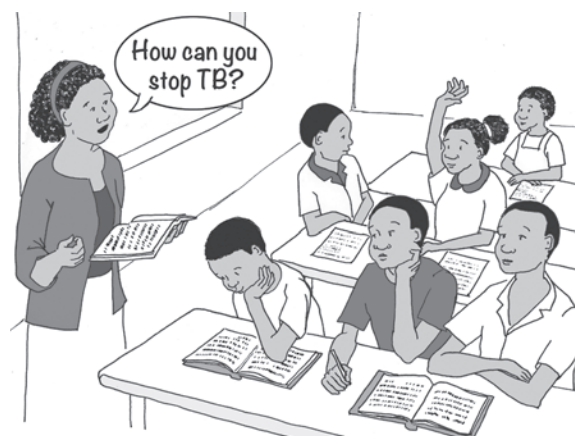
TB prevention in educational settings

1. **Early childhood development:** *"the earliest is the best":*
   - **Engage** school managers, teachers, young children and the national education service.
   - **Implement TB activities** in nurseries, early childhood development and pre-school centres.
   - **Teach young children about hygiene and sanitation**, such as cough hygiene, body and hand washing, drinking clean water and being in fresh air and sunshine.
   - **Provide TB life skills education** through play-based activities such as dramatic play, art, social games, songs and telling stories.
   - **Develop a simple TB curriculum** if not already available, and train preschool teachers to implement it.

2. **Primary school**
   - **Engage** teachers, children and academic authorities.
   - **Implement TB activities** in primary schools, villages and other places where children of this age group gather.
   - **Continue training on TB life skills** with more detailed focus on identifying signs of TB and what one should do if signs persist. Include basic information about HIV and other infections and drug abuse:
     - **Include TB in the basic science curriculum**.
     - **Train children using the child-to-child approach** so that they can train each other on TB awareness and prevention.
     - **Train teachers on the child-to-child approach**, BCC and active methods in order to facilitate implementation of TB activities.
     - **Include TB in school activities**, e.g. competitions, social games, trips of discovery.
     - **Emphasize TB messages with materials** such as booklets, flyers, T-shirts, pens and posters to help children and adults remember key information.

*Note: More information about the child-to-child approach can be found at **http://www.child-to-child.org/action/index.html**.*

3. **Secondary school**
   - **Focus in more depth on scientific explanations of TB and its links with HIV infection**, building on the TB learning in primary school.
   - **Include information on prevention of HIV, sexually transmitted infections, drug abuse and tobacco use.**
   - **Engage** teachers, adolescents and young people in **implementing TB screening activities** in junior schools and high schools.

4. **Non-formal education**
   - **Engage** community facilitators, NTP and NGO staff and supervisors to work on community TB education.
   - **Train adult men and women on TB prevention** through behaviour change, including cough/sneezing hygiene and safe disposal of sputum.
   - **Include TB in literacy activities**, focusing on how to prevent TB.

Detection

1. **Train teachers in TB screening** of their pupils and fellow teachers.
2. **Include TB prevention in adult literacy curricula.**
3. **Train literacy group members to screen fellow students for TB** based on their growing knowledge and awareness.

Referral

1. **Teachers and adult literacy class facilitators should refer** those with TB signs and symptoms to CHWs or directly to health facilities, depending on their age.

Treatment adherence support

1. **Teachers can support children taking TB medication** to ensure adherence.

2. **Use parent–teacher association meetings** as a forum for discussing adherence and improving TB treatment literacy.

Advocacy

1. **Engage parent–teacher associations** to increase awareness of TB and advocate for TB messages to be included in school curricula by school boards and government education departments.

Stigma

1. **Increase knowledge and discussion about TB at all levels of schooling**. Increased awareness and understanding are powerful ways to reduce stigma.

2. **Engage in specific anti-stigmatization activities** using approaches such as the *Understanding and challenging TB stigma toolkit* (see resources list below).

3. **Educate teachers and parents** to recognize the signs and to act if children are being stigmatized when they or members of their family are known or thought to have TB or HIV infection.

Integrating TB into water, sanitation and hygiene (WASH) programmes

Water, sanitation and hygiene (WASH) are essential for maintaining health and preventing disease. Sputum is body waste that can infect other people and must be safely disposed of, just like urine or faeces. WASH programmes can therefore integrate TB into disease prevention by promoting better hygiene.

- **Water**: All people need to have equal access to the necessary amount of good-quality water. Good water storage and management, including treatment of water, are also vital.

- **Sanitation**: Excreta (faeces, urine) must be handled safely, and waste and vectors (such as mosquitoes or ticks that carry diseases from one host to another) need to be managed. Consistent and proper use of latrine facilities is also vital and requires availability and accessibility for all, as well as cleanliness and management.

- **Hygiene**: This includes the proper use of water and sanitation. Personal and body hygiene involves hand-washing with soap at critical times (after toilet use, after changing nappies, before preparing food and eating, before breastfeeding), washing body and clothes, and cleaning and drying eating and cooking utensils.

NGOs/CSOs can work on this approach with health surveillance assistants, CHWs, extension workers and CV groups, clubs and CBOs. The community water management committee can be a strong entry point for TB integration. Lessons can also be adapted from work on HIV integration into WASH in communities.

Prevention

1. **Public awareness meetings and door-to-door hygiene and sanitation promotion**
   - Include TB messages as part of the overall promotion.

2. **Develop IEC and BCC materials to link TB prevention with improved hygiene.**
   - Promote ventilation, good cough hygiene and hand-washing with soap.
   - Use health surveillance assistants, CHWs and CVs to communicate messages.

3. **Train health extension workers, CVs (WASH committees) and sanitation entrepreneurs** (providing hardware, soap etc) on TB basics, counselling and the linkages between TB, HIV infection and WASH.

4. **Teach the basics of TB and HIV infection to school sanitation clubs.**

5. **Promote good hygiene practices in families and communities.**

TB detection

1. **Screen family members with TB symptoms during door-to-door/household visits** to promote sanitation and hygiene.

2. **Use the volunteer water and sanitation committees to identify and follow up cases** within their membership and in the wider community, especially groups associated with WASH programmes.

3. **Deliver messages on TB and conduct screening for referrals during campaigns** (for example, vaccination, water chlorination) or when dealing with emergency outbreaks such as cholera. This could be community wide or target certain groups e.g. schoolchildren.

4. **Invest in capacity and build skills** for observation of symptoms and knowledge of health status of community members.

Referral for TB services

1. **Use volunteer committees to refer people** who may have TB to CHWs for screening and onward referral to health facilities for diagnosis and treatment.

2. **Establish partnerships/alliances**, especially with clinics and laboratories, for follow-up, with diagnosis and treatment for those referred by CVs and workers.

TB treatment adherence support

1. **Work to improve the sanitation facilities at TB treatment centres** to encourage patients to attend (patients can sometimes discontinue treatment due to poor hygiene facilities at clinics).

2. **Support community WASH volunteers to provide home-based DOT support** to community members or ensure DOT support by others.

TB advocacy

1. **Community groups should advocate** for the provision of adequate WASH services and infrastructure in health facilities.

2. **Promote improved coughing and sneezing behaviour** in the community.

Resources

Global Network of People Living with HIV. *Human rights and stigma—the stigma index* (http://www.gnpplus.net/en/resources/human-rights-and-stigma, accessed 15 July 2013).

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World Health Organization. *Integrated Management of Childhood Illness (IMCI)* website (http://www.who.int/maternal_child_adolescent/topics/child/imci/en/index.html; accessed 15 July 2013).

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Section 4. Implementing the ENGAGE-TB approach

TB is a community problem. It is diagnosed in clinics and hospitals, but it lives in the community. Action in the community is therefore essential in a country's efforts against TB. It is also important to link community action on TB with the work of the NTP so that the efforts of the health system are extended and reach as many people as possible.

NGOs/CSOs can use the ENGAGE-TB approach to support their work with communities on TB, by:

- finding more people who might have TB and linking them to TB services;
- supporting people to start and complete TB treatment;
- raising community awareness on prevention and increasing demand for TB testing, treatment and support;
- advocating for better access to TB diagnostics, treatment and care; and
- advocating for policy changes to facilitate greater access to services, e.g. task-shifting that allows nurses, CHWs or CVs to do sputum collection and provide DOT in the community.

The NTP is responsible for the whole programme, including at community level. It should form partnerships with NGOs and CSOs and help them to carry out community-based TB activities in a way that contributes to national efforts. This can help to improve national outcomes in TB case detection, notification and treatment success. The NTP has a key role in encouraging NGOs/CSOs that do not work on TB to integrate TB into their activities, by providing resources, facilitating support and responding to their needs.

The **six ENGAGE-TB components** provide a systematic framework for establishing partnerships between the NTP and NGOs/CSOs for NGOs/CSOs to integrate TB activities. Not all components of the framework have to be addressed by every NGO if there are capacity constraints. The most important priorities are to find a way to select the TB tasks that will be implemented and to ensure that the outcomes are monitored and reported. The other components support these two main priorities.

Each of the six components is described in this section. Collaboration between different partners will help in addressing each component.
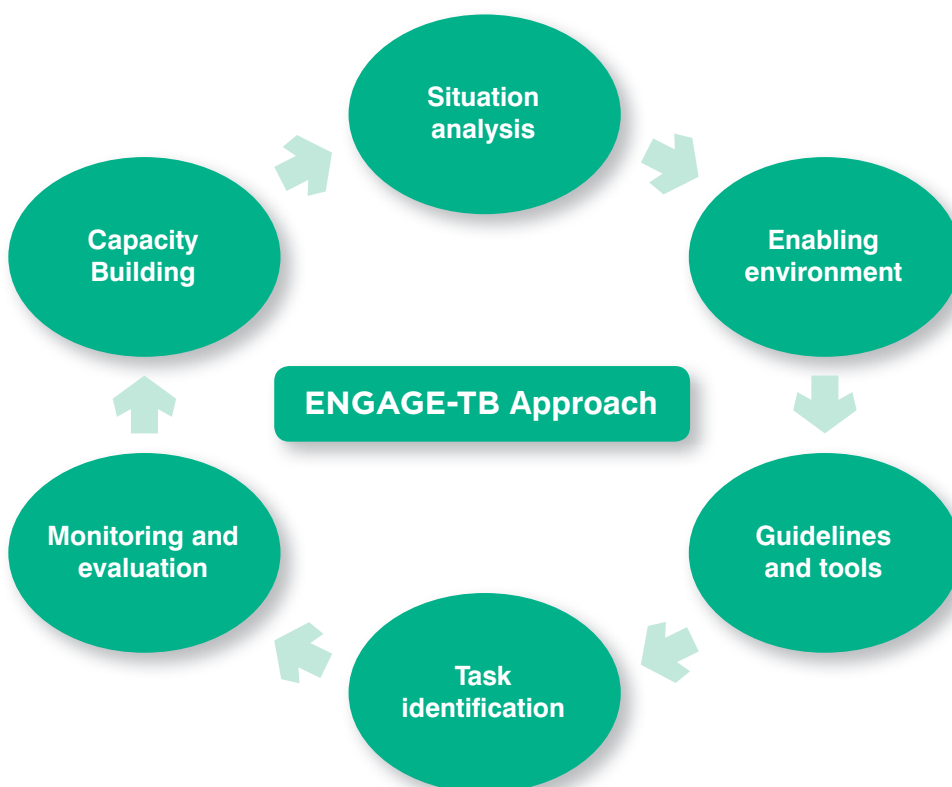
Component 1: Situation analysis

Some tasks and methods for a situation analysis by NGOs/CSOs and NTPs are suggested below. The methods used depend on the information required and how many people will be consulted.

Different methods are described for use by NGOs/CSOs and for NTPs; however, any of the methods described can be used or adapted by either the NTP or an NGO/CSO. Each organization should choose the methods appropriate for its context.

It is not possible to explain in this manual how to use all of the possible methods. Some of the most useful ones are described below. The resources listed at the end of this section describe these and additional methods for situation analysis in more detail.

Quantitative information is used to answer questions such as "how many" and "how often". This can come from surveys, reports and research statistics. **Qualitative** information reflects what people think or experience. This can be obtained by careful questioning and discussion. Some methods provide **both** types of information, for example an interview with stakeholders or a group discussion of the strengths, weaknesses, opportunities and threats (SWOT) faced by an organization or project.

Participatory methods can be extremely useful at community level; use them whenever possible. For example, a community group can rank its preferences for health providers and explain why some people are not using the available TB services. The group might also have ideas about community support for TB activities such as sputum collection or treatment adherence.

An "actor–factor analysis" is a simple analytical tool for understanding the situation in an area, with methods such as focus group discussions and key informant interviews. A list of the main **actors** (stakeholders) is prepared, for example the key people and organizations that will be implementing community-based activities. The impact of various relevant factors on these actors is then listed and analysed.

Guidance for NGOs/CSOs

The main information that an NGO/CSO will need from a situation analysis will be about the TB services and health infrastructure currently available to their community. This will help to understand **where** the services are and how people can use them. It will show whether there are any gaps or barriers that prevent people from accessing TB services. It should also make clear where and how people can be referred from the community to TB services.

It is important to find out how community members view the existing TB services: Do they know about them and are they willing to use them? Are there other people ("stakeholders") who have a direct interest in community-based TB activities? It will be important to know who they are and how they can work with NGOs/CSOs and the NTP.

The situation analysis should include all the places in which community-based TB activities can happen and where the health system provides TB services, for example in:

- the community (CHWs and CVs, community meeting places),
- local dispensaries or health posts,
- health centres used by the community

Situation analysis

Important basic principles for situation analysis:

Choose carefully what information will really be useful; don't drown in information!

Make a practical plan for collecting the information.

When the analysis is complete, share a summary with those who need to know.

NGO
CBO Network
FBO

Asking about community experiences of TB services can help to:

identify gaps in services

plan how to help people overcome any barriers

advocate with health workers and managers to improve access to services.

- health facilities with TB laboratory and X-ray services,

- TB clinics with diagnosis and treatment facilities (for example, in the district hospital) and

- referral centres for specialist TB care, such as for MDR-TB and XDR-TB (usually at regional, zonal or national level).

TB services, including:

- those available to the community from government, NGO, workplace or private health services; they could include separate, "stand-alone" services and TB services integrated with other services, such as MNCH, HIV or diabetes care; and

- existing community-based TB activities, e.g. sputum collection or treatment support, including who is doing them and how they can link with the NGO/CSO.

In each facility that offers TB services, are there:

- TB diagnosis facilities, such as microscopes, chest X-rays, skin tests;

- referral systems from community to the facility, onward referrals to specialist care and referrals back to the community for ongoing support; and

- TB outreach from facility to community, such as visits by CHWs or nurses, mobile TB screening or sputum collection services?

Community experience with available TB services:

- knowledge, attitudes, behaviour and practices on TB;

- knowledge of TB prevention, testing and treatment services;

- perceptions on access to TB services, access barriers and quality of services.

Stakeholders concerned with TB at community level:

- organizations, groups, networks, leaders that could be involved in TB activities;

- for each stakeholder, which TB activities it could be involved in; and

- links between NGOs/CSOs and other stakeholders that will help in planning and implementing ENGAGE-TB.

Make a plan for the situation analysis:

- Choose carefully what information you will try to obtain. Make a list of the most important information that you need, and stay focused on getting it.

- Decide which health facilities to visit and which health care workers to talk to.

- Identify which people and groups in the community could help you understand more about their experience with TB and the health system.

- Decide who to involve in collecting information, and train them if needed.

- Decide what resources you will need, such as transport, Internet, money; make sure they will be available when needed.

- Make a timetable for gathering and analysing information, and plan how to share it.
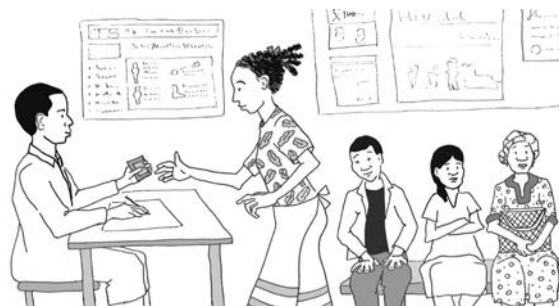
Don't drown in information!

Choose who to talk to; they could include:

- district health officials, local health workers in charge of TB and other services;

- CHWs and local development or health committees, which are important links between the health system and the community;

- other NGOs/CSOs, community leaders and support groups who know the community experience with existing TB facilities; and

- other individuals and organizations in the education, water and sanitation, agriculture or development sector that could be involved in community-based TB activities.

Collect the information you need.

Use a range of methods for collecting information from different people, which will depend on their situation and their role in community-based TB activities and on what resources are available for the analysis.

The following methods are useful for situation assessment in community settings. They are particularly suitable for NGOs/CSOs. Some are best for gaining information from individuals or small groups; others are better for working with larger groups.

Semi-structured interviews with individuals or a small group

Suitable for one to five people and if there is limited time available. The interviewer guides the interviewees through the main topics:

- Use a list of topics and questions (an "interview guide") to guide the conversation.

- Other topics can be discussed if they arise and the interviewer feels they are appropriate.

- Write notes to help remember what was said. This can be easier if there is one person to lead the discussion and another to write the notes.

Participatory approaches and visual methods

Suitable for: groups of 5–25 people. Many of these methods have been used for years in community development; they can easily be adapted for assessing community health needs, resources and experience, including those related to TB.

Working with mixed groups can be very helpful; for example, bringing together community representatives, health workers and community leaders to share their experiences and ideas for developing activities.

Smaller groups (5–12 people) can be run as "focus groups": a facilitator uses a list of questions to guide people to talk about their knowledge and experience of a particular topic.

Group facilitators will have to be trained to adapt participatory methods and use them successfully for community-based TB activities. They need good listening skills, openness and creativity to get good results. They also need basic knowledge on TB and health, so that participants can receive information as well as providing it.

Participatory methods provide rich information on community needs and priorities. This can help to:

plan how to overcome barriers,

identify gaps in services,

discuss how to improve services with health workers and managers and

advocate for policy changes.

Review of reports and other information sources (literature review)

Suitable for project staff. This involves reading reports, case studies and evaluations in print or online. A literature review can provide information that helps to understand what is happening with TB in the area and country. It can also help to identify what community-based TB activities are already being implemented and whether they have been successful.

Surveys

Suitable for obtaining a limited amount of information from a lot of people. Surveys can provide quantitative information (numbers, percentages) and qualitative information (opinions, beliefs, attitudes). They should be carefully planned to provide accurate information with guidance by someone who is trained and experienced, for example an experienced health researcher.

Examples include:

- knowledge, attitude and practices surveys to find out what people know, believe and do about TB in a community;

- exit surveys (e.g. of people leaving TB clinics) to find out people's opinions about a service or activity they have been involved in. The survey could focus on community TB efforts, local health services or another key topic.

Analyse the information you have gathered:

When you have all the information you want, bring it together. Determine the most important themes and issues you have found. Look at:

- what is happening on TB in the target communities;

- gaps in services and NGOs/CSOs that are not active on TB but could be engaged;

- important barriers that prevent people from using TB services or completing their TB treatment and any ideas for removing those barriers; and

- the SWOT facing your organization as you seek to integrate TB into your work.

Share the analysis with key stakeholders, especially the NTP and local health providers. Present the information in a format that will help them to understand the analysis.

NTP   Guidance for NTPs

The NTP or its equivalent will want to find out which NGOs/CSOs in each area could integrate the ENGAGE-TB approach into their work. They will also want to know about the capacity of the NGOs/CSOs to use the approach and to be part of an NCB that could work with the NTP to expand TB services. The NTP should include its own knowledge of the general health, economic and social context of the communities they wish to involve in the ENGAGE-TB approach.

NTP managers should identify:

- NGOs and other CSOs working in health and other areas of development that could integrate community-based TB activities into their work;

- the existing capacity of the NGOs/CSOs to engage in community-based TB activities and to be active members of an NCB;

- existing structures for coordinating NGO/CSO activities related to health and/or TB, and how they might be adapted to act as an NCB;

- gaps and barriers for scaling-up community-based TB activities, including policy and regulatory barriers, health system capacity barriers, NGO/CSO capacity barriers;

- health, social and economic contexts of target communities and how they affect TB; and

- past experience and evaluations of community action on TB.

Making a plan for the situation analysis

- Identify which member(s) of the NTP staff should be involved in the situation analysis, including staff with knowledge of the local situation.

- Identify who can provide information on which NGOs/CSOs are currently assisting people with TB or could potentially integrate TB activities into their work.

- Prepare a list of questions to ask about TB services and community-based TB activities

- Make a timetable or work plan for gathering, analysing and summarizing information.

- Decide how you will share the information and with whom.

Choose who to talk to, for example:

- district health officials and local health workers in charge of TB and other services, such as HIV care, MNCH, sexual health, diabetes, environmental health;

- NGOs/CSOs, community leaders and support groups, who know the community experience with existing TB facilities and the changes they would like to see; and

- other individuals and organizations that are or could be integrating TB into their community activities in the health and development sectors.

"This is what we want for our community!"

Collect the information you need.

The NTP will wish to know which NGOs or other CSOs could integrate the ENGAGE-TB approach into their work. It should also assess the capacity of NGOs/CSOs to use the approach and be part of the NCB. Resources, gaps and potential blocks for ENGAGE-TB should be assessed.

The methods used for the ENGAGE-TB situation analysis will depend on the local context and the roles of the different stakeholders. They also depend on the resources available to the NTP for the analysis. Methods that could be used include:

Review of reports and other information sources (literature review)

A literature review by the NTP should bring together relevant information from policy documents, reports, surveys and evaluations on TB and other health, social and economic factors that affect the target communities. It should identify:

- what TB services are available for the target communities,

- what community-based TB activities are already being implemented and whether they are integrated into other health and development programmes and

- whether CHWs (or similar) in those areas can play a role in community-based TB activities.

Surveys

If information for the ENGAGE-TB approach is not readily available, one or more surveys may be required for the NTP situation analysis. These might include:

- knowledge, attitude and practices surveys to find out what people know, believe and do about TB in a community;

- exit surveys (e.g. of people leaving TB clinics) to find out people's opinions about existing TB services, stigmatization and health workers' attitudes to people with TB, TB/HIV etc; and

- a vulnerable populations survey to identify groups in target communities that are most vulnerable to TB and/or have the most difficulty in accessing TB services.

Semi-structured interviews or meetings with an individual or a small group

Suitable for one to five people and when limited time is available. This type of meeting could also be held with other health service colleagues or with representatives of NGOs/CBOs who have good knowledge of what is happening on TB in the target communities.

- Use a list of topics and questions (an "interview guide") to guide the discussion.
- Have two people interviewing: one person to lead the discussion and another to write notes; this also helps after the meeting in analysing what was said.

Focus groups

Suitable for five to eight people. This consists of planned discussion, led by a moderator, that includes people who have experience and knowledge on a particular topic. A focus group of community and/or NGO leaders, for example, can share and discuss how TB affects the local community and what can be done to bring people and TB services closer together. A group of health care providers may be able to provide a different perspective on the same issues.
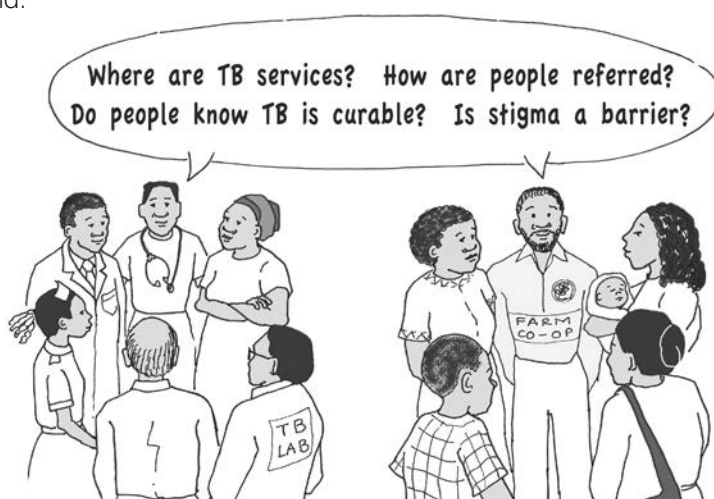
Meetings with larger groups

Suitable for 8–25 people. Such meetings could, for example, bring together representatives of a number of NGOs/CSOs, TB service providers and NTP staff members. Bringing them together in this way can be very valuable to start building the relationships and linkages that will be essential for implementing ENGAGE-TB. The meetings could be:

- a "lecture-format" meeting, for example to provide information about the ENGAGE-TB approach and introduce plans to involve NGOs/CSOs in rolling it out; or
- participatory group work, for example to get input from different stakeholders (preferably working together) for tasks such as mapping local TB facilities and vulnerable groups, which would include:
  - what services are available (e.g. sputum collection, laboratory tests, X-ray, TB treatment);
  - how people are currently referred for TB care (the "referral pathway");
  - where vulnerable populations live;
  - which NGOs/CSOs are currently active in relation to TB;
  - where gaps exist and where new community-based activities should be started or expanded;
  - which other NGOs/CSOs could collaborate in ENGAGE-TB; and
  - where capacity-building and extra resources will be needed.

Field visits

These could include visits to community-based groups, health providers working in communities (CHWs and similar) and key non-health areas for community-based TB activities, such as schools, farmers' groups and community drop-in centres.

Field visits will help NTP staff involved in the situation analysis to see how TB services are currently delivered. They can also hear directly from local health service and NGO/CSO staff. Community leaders and representatives, such as peer support groups and local health or development committees, can help to identify, for example, what is preventing people from using TB services or adhering to their TB treatment.

Analyse the information you have gathered.

In the final stage of the assessment, bring together all the information you have gathered, and determine the most important themes and issues. Share the analysis with key stakeholders, especially NGOs and other CSOs. It will be important to present the analysis in a way that helps other stakeholders to understand the NTP analysis and to use it along with the NGO/CSO situation analysis.
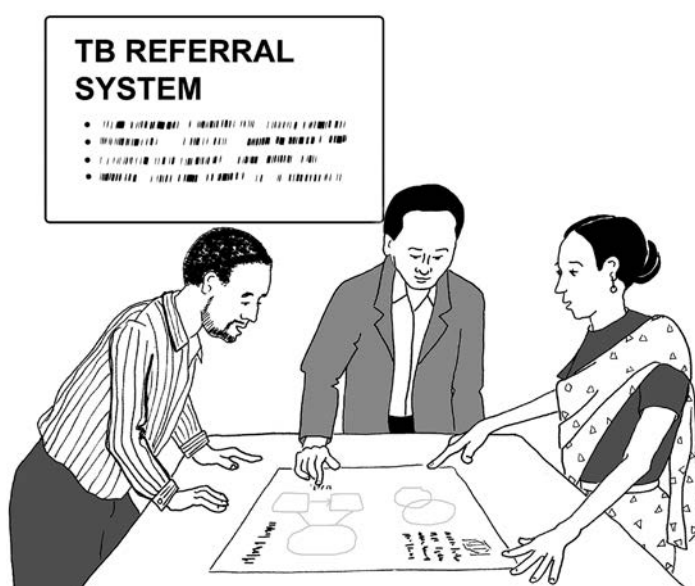
Resources

American Society for Advancement of Project Management and World Bank Institute. *Analyzing the project context: actors and factors*. Colorado Springs, Colorado, 1998 (http://www.asapm.org/asapmag/a_af.html; accessed 15 July 2013).

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Component 2: Enabling environment

Enabling environment

A mutually enabling environment should be established for community-based TB activities so that activities can take place in a favourable setting that supports everyone involved to plan, implement and coordinate their work.

The NTP and the NGOs/CSOs should address the following areas in order to establish an enabling environment for community-based activities:

- Ensure that **laws** and **policies** support and do not hinder community-based TB activities. National TB strategies and policies and laws should enable TB services to be delivered to all who need them without discrimination.

- Establish an **NCB**, an **independent coalition of NGOs/CSOs** that will enable them to work together and collaborate with the NTP and other stakeholders. It should also include **representatives of TB patients and affected communities**, especially women and other target groups. The NTP should facilitate the start-up of the NCB, but **the NCB is an NGO/CSO structure and should be led and managed by its members**. Independence from government and the private for-profit sector will enable the NCB to advocate for affected communities and the quality of TB services.

> **ℹ**
>
> **Basic principles** for an enabling environment:
>
> equity
>
> equality,
>
> mutual respect

- Establish a **code of conduct**, agreed between the NCB members and including the NTP. This should establish professional relationships among all involved, make roles and responsibilities clear and establish **basic principles** for working together on community-based TB activities. It should be made available in local languages if necessary, especially for CBOs and other small groups.

- **Support small organizations** such as CBOs, networks and groups of patients and affected communities to participate in the NCB, and build their capacity for community-based TB activities.

NGOs/CSOs and the NTP should include a **review of the enabling environment** as part of their overall situation analysis for ENGAGE-TB. This will help to identify gaps and barriers and any specific actions required to improve the environment for community-based TB activities.

NGO
CBO Network
FBO
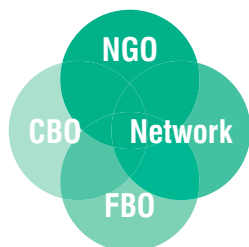
Guidance for NGOs

NGOs/CSOs should make **establishment of an NCB** and a **code of conduct** early priorities. These structures will support the planning and start-up of activities and facilitate the inclusion of new organizations in the coalition. The structure of the NCB and the content of the code of conduct should be reviewed regularly to ensure that they continue to meet the needs of the NCB members.

NGOs/CSOs will be expected to support the **growth and development of CBOs, FBOs and other small organizations** for engaging in community-based TB activities and taking part in the NCB. NGOs/CSOs might have to build their own capacity to do this and assist smaller organizations to:

- find and use sources of support for funding, training and mentoring, organizational development, and technical assistance;

- develop skills for managing people, money and other resources; and

- collaborate in activities with other organizations

Addressing the legal and policy environment

Legal and policy issues can affect the status of an NGO/CSO, such as the communities they are allowed to work with and the health activities they are allowed to do. NGOs/CSOs should be aware of how national laws and policies affect their work, for example:

- What are the registration requirements for NGOs and other CSOs to allow them to organize community-based TB activities and to take part in an NCB?

- Will unregistered groups, such as small CBOs, FBOs, community action groups and support groups, be allowed to take part in community-based TB activities, and what restrictions are there on what they can do?

- What are the legal or policy restrictions on working with certain groups, for example unregistered migrants, slum dwellers, sex workers or people who use drugs?

- Are certain TB-related activities, such as sputum collection and provision of DOT, restricted to certain types of health worker?

Registration of NGOs/CSOs is required in many countries before they are allowed to set up a bank account or receive grants. This can be lengthy and complex. Larger NGOs/CSOs may have sufficient capacity for this, but smaller organizations may require guidance and support. NGOs and CSOs should:

- ensure that their own organization is registered;

- support smaller organizations in completing registration procedures;

- identify any registration difficulties, such as slow processes, complex forms or unaffordable fees; and

- advocate for simpler, faster, more affordable registration procedures.

Restrictions on health activities: Changes in policies and regulations might be required to allow NGOs/CSOs to implement a wider range of community-based TB activities. For example, the rules on who may perform **TB screening**, who may **collect and transport sputum** samples to laboratories and who may observe and support **treatment adherence** might have to be changed. NGOs/CSOs should check what the existing regulations are, and evaluate whether they are a barrier for access to TB services. If so, advocacy may be needed to bring about changes that will allow improved access for communities. Such advocacy can be well supported by an NCB for TB that meets regularly with the NTP.

Establishing the NCB in cooperation with the NTP

It is important that the NGOs/CSOs lead the establishment of the NCB, but they should collaborate closely with the NTP to ensure that the NCB will function well. The chosen approach will depend on the local context and needs. NGOs/CSOs should:

- Schedule a start-up meeting, bringing together a few NGOs to establish a nucleus around which the coalition could form.

- Establish a structure for the NCB, e.g. how often it will meet; how it will be organized and managed; monitoring and reporting systems; and a code of conduct.

- Agree who will host the secretariat and for how long.

- Meet with the NTP to discuss collaboration and agree a schedule of meetings (quarterly meetings are recommended, although monthly meetings might be useful in the initial stages).

- Identify what linkages and cooperation are needed with government, such as national and district contacts in the NTP, TB health facility managers, employers and employee representatives.

- Prepare a work plan to ensure:

  - regular quarterly NCB coordination meetings with the national and district NTP;

  - regular reporting to NCB members and to the NTP on key indicators and emerging successes and challenges and using data to take action on any challenges;

  - building the capacity of NCB members for collaborative activities, advocacy, monitoring and evaluation, and accountability;

- supporting skills-building, development and mentoring of NGOs/CSOs and of smaller CBOs involved in TB prevention, care and support; and

- working collaboratively to secure funding for TB integration from donors such as the Global Fund.

Establishing a code of conduct

NGOs/CSOs in collaboration with the NTP should support the development of a code of conduct. The code should provide clear guidance on the basic principles and standards of behaviour for members of the NCB. It should define the roles and responsibilities of each NCB member and also the NTP. A code of conduct will also help to show other people that the NCB sets a high standard of behaviour and expects its members to be accountable for their actions.

The code of conduct should also explain:

- the decision-making processes of the NCB;

- what should be done if members behave in unacceptable ways;

- what the standards (benchmarks) are for data reporting and evaluation by members; and

- the NTP's obligations to support NGOs/CBOs in implementing community-based TB activities, for example with supplies, services, mentoring and establishing linkages for sources of technical and financial support.

The paper *Developing a code of conduct for NGOs* (see list of resources below) describes what is involved and gives some examples. When the code has been agreed, NCB members should work together to prepare simplified versions in local languages if necessary. These will help CBOs and other small organizations to understand how they fit into the NCB and their rights and responsibilities when they are involved in community-based TB activities.

The code of conduct could be presented in the following sections:

- a section outlining the basic principles and ideals that member NGOs/CSOs should agree to;

- a section stating the standards and rules of conduct or behaviour to which each NGO/CSO will be expected to adhere;

- a section outlining the responsibilities of the NTP, the NGOs/CSOs, the smaller CBOs and other CBOs and groups;

- a section outlining how the code will be enforced, in order to ensure adherence to the provisions of the code; and

- a section stating how and when the code will be revised to keep it up to date.

Inclusion of smaller CBOs, FBOs and other groups in community-based TB activities

Smaller CBOs and similar groups are generally self-organized, work on local issues and provide each other with solidarity and mutual support. They include, for example: peer support and home-based care groups, micro-credit schemes and parent-teacher associations. With training and support, many CBOs could integrate TB activities into their other work. CBOs are important representatives of their communities because they are **run by community members and serve community needs**. They should therefore be fully engaged in planning, delivering and evaluating community-based TB activities.

However, CBOs vary greatly as organizations. Some are well organized and have a formal structure. Others may be informal, such as a group of neighbours working together. As we have already seen, many do not have official registration and have limited or no direct access to funding.

CBOs may therefore need support from larger NGOs/CSOs to help them develop their community-based TB activities and contribute their unique insights to the NCB. As they are small organizations, they should not be overloaded with bureaucratic procedures, but their organization and skills should be strengthened so that they become sustainable and effective in their work.

To support CBOs, members of the NCB should:

- find ways to include CBOs and enable them to access funding for their TB activities;

- help them to develop their skills so that they can obtain and manage grants, collect data and report on their activities; and

- provide mentoring and supervision for implementation of TB activities.

NTP — Guidance for NTPs

The NTP has responsibility for ensuring that national policies, laws and requirements contribute to the enabling environment for NGOs and other CSOs engaged in community-based TB activities. NTP leaders should therefore determine whether the policies, laws and requirements are in operation at national, district and local levels and whether any improvements and changes are required.

The NTP should address any issues at national level that prevent NGOs from implementing community-based TB activities. This may require collaboration with the health ministry and other ministries, such as finance, justice and social welfare. At subnational, district and local levels, the NTP should prepare health system TB care providers to collaborate with NGOs/CSOs in providing TB services. The NTP will also be required to initiate NCB formation by reaching out to unengaged NGOs and encouraging them to consider integrating TB into their work.

Addressing the legal and policy environment

The NTP should ensure that national laws and policies fully enable NGOs/CSOs, including smaller CBOs, to engage in community-based TB activities, by:

- developing a national policy on effective engagement of NGOs/CSOs in TB prevention, diagnosis, treatment, care, support and research. The NGOs/CSOs should be full involved in policy development, with active engagement in initiating and leading the process alongside the NTP. This is best done by engaging the NCB in a deliberate consultative process to agree a national policy.

- addressing any gender, disability or other rights issues that restrict access to TB prevention, diagnosis, care and treatment;

- engaging with other government departments to bring about any changes required in the legal or policy environment; for example, access to health care including TB care for prisoners or people engaged in illegal activities such as sex work or drug use; and

- ensuring that, as far as possible, integrated services are available for groups vulnerable to TB and other major diseases such as HIV infection and diabetes, and for women and children using MNCH services. This should include groups that cannot easily access services, such as people in remote areas, refugees and migrants and sexual minorities.

Our mother is always sick, and the clinic is so far away.
What can we do?

Initiating establishment of an NCB

The NTP can help to encourage NGOs/CSOs to integrate TB into their work. The NTP should approach NGOs individually, speak to their leadership, explain why community-based TB activities are effective in saving lives and preventing loss of livelihoods and invite the NGO to attend a national consultation meeting. If necessary, the NTP should solicit the support of local WHO staff to meet with NGO leaders to initiate these discussions. At the national stakeholder meeting, which should be hosted by the NTP or the local WHO office, the concept and purpose of an NCB should be introduced and agreement reached on what the NCB will do. The NTP should support the creation of an NCB steering group to start the process of NCB formation. Establishing the NCB and making it effective for coordinating NGO/CSO TB work, along with a code of conduct (discussed above), will result in a formal relationship between the NTP and the NGOs/CBOs, which should facilitate their collaboration.

Supporting the NCB and ensuring regular meetings with it will be an important task for the NTP. The NCB will be the main coordinating structure for NGO/CSO engagement in TB and requires active support from the NTP. The NCB will also be the main channel for collaboration between the NTP and the NGOs/CSOs, especially for working towards measurable improvements in TB prevention, care and treatment at community level. In collaboration with the NGOs/CSOs, the NTP can help to ensure that the NCB is inclusive, with representatives of people with TB and affected communities, including women and other vulnerable groups.

Organizational development and support for NGOs/CSOs are important areas for the NTP to address, especially for small community organizations. The NTP should focus on building their capacity and enabling them to remain viable and sustainable. They may need support with funding, building skills and knowledge, and developing linkages within their communities and with health care providers. The NTP can also help NGOs/CSOs to develop links with national or international agencies for assistance with capacity-building and resources.

The NTP has a key role in establishing a favourable **legal and policy environment**. This includes policies that relate to TB and other health services and policies linked to social and economic development, including agriculture, education, environmental health and social security. An enabling environment in these other sectors will be needed to support integration of TB activities and reduction of TB risks for the communities concerned.

The NTP can facilitate the **registration of NGOs/CSOs** by liaising with government departments to ensure rapid, simple registration procedures. This will enable NGOs/CSOs to set up bank accounts and engage in fund-raising from public, NGO or private agencies.

The NTP should also consider how **unregistered local groups** representing patients and affected communities can be engaged, including small CBOs, neighbourhood action groups and peer support groups. This might be achieved best by linking them with registered NGOs/CSOs. The NTP can encourage NCB members to prioritize inclusion of smaller CBOs and patient representatives. The NTP could also specifically request input from them at regular NCB meetings and during periodic reviews and evaluations.

There may be **legal and policy restrictions on tasks** that NGOs/CSOs and smaller CSOs are permitted to carry out as part of community TB activities, such as TB screening, sputum collection and transfer, and community-based DOT. The NTP may advocate for changes to regulations or policies so that certain NGO/CSO staff or volunteers can be trained to carry out tasks previously done only by qualified health workers. This is known as "task-shifting".

There may also be **legal and policy restrictions on certain groups** in terms of access to public services and criminalized behaviour. For example, sex workers or people who use drugs are often vulnerable to TB, but they may be excluded from community-based TB activities because their activities are illegal. The NTP may have to advocate for changes to laws and policies to enable community-based TB activities to reach these groups. Similar considerations may apply to prisoners and undocumented migrants.

The NTP's initial **situation analysis** should include an **assessment of the enabling environment** at local and national level. This should include not only the legal and policy environment but also the current involvement of the NGO/CSO sector in community-based TB activities and the potential for existing and new NGOs and other CSOs to

become part of the ENGAGE-TB approach in the country. The NGOs/CSOs should include those engaged in other health activities and in other development sectors.

Establishing a code of conduct

A voluntary code of conduct is intended to:

- provide clear guidance on the **basic principles and standards** of behaviour for all stakeholders and
- define the **roles and responsibilities** of NCB members and of the NTP.

The NTP should engage actively with the NGOs/CSOs to establish the code and assist them, where feasible, with resources to ensure that it is published and available to all the organizations and stakeholders involved. The code of conduct will explain decision-making processes within the NCB and define the obligations of members for reporting and evaluation. It will also include the NTP's obligations to support NGOs/CBOs in implementing community-based TB activities, by ensuring that health facilities are equipped and services are available when demand is generated.

Including CBOs in community-based TB activities

The NTP should actively encourage the inclusion of smaller groups and organizations, since these have close, regular contact with vulnerable communities.

Actively requesting community representatives to attend meetings with the NTP will help to establish the importance of their experience and knowledge of their communities to the development and implementation of ENGAGE-TB.

The NTP should also encourage larger NGOs and their coordinating bodies to offer support to smaller groups. The NTP can offer practical support, such as training and supportive supervision. It can also help to link the CBOs with technical support providers such as the international NGOs that are skilled in these areas.

"Today, we CBOs can share experiences and plan training with the NGOs and NTP."

Resources

International Council of AIDS Service Organizations, African Council of AIDS Service Organizations, International HIV/AIDS Alliance. *Coordinating with communities, Part A: Background to involving communities*. Toronto, 2007 (http://www.icaso.org/files/coordinating-with-communities-book-a, accessed 15 July 2013).

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Stop TB Partnership. *Good practice: Stop TB Partnership challenge facility for civil society—financial support to community initiatives for positive change*. Geneva, 2011 (http://www.stoptb.org/assets/documents/global/awards/cfcs/goodPractice_FINAL_LO_111011.pdf, accessed 15 July 2013).

The Global Fund. *The Global Fund community systems strengthening framework,* 2011 (http://www.theglobalfund.org/en/civilsociety/reports; accessed 25 August 2013).

The NGO HIV/AIDS Code of Practice Project. *Renewing our voice: code of good practice for NGOs responding to HIV/AIDS*. Geneva, 2004 (http://www.gnpplus.net/images/stories/Empowerment/NGO_Code/code-of-good-practice_EN.pdf; accessed 15 July 2013).

Transparency International. *Developing a code of conduct for NGOs*. Berlin, 2009 (http://www.u4.no/publications/developing-a-code-of-conduct-for-ngos/; accessed 15 July 2013).

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World Health Organization. *Public–private mix for TB care and control: a toolkit*. Geneva, 2010 (WHO/HTM/TB/2010.12) (http://whqlibdoc.who.int/publications/2010/9789241500487_eng.pdf; accessed 19 July 2013).

Component 3: Guidelines and tools

The NTP and the NGOs/CSOs should collaborate to prepare **guidelines** and **standard tools** for community-based TB activities. Existing guidelines and tools should be used when possible, adapted to the needs of NGOs/CSOs. New tools and guidelines may also be needed, especially for any new community-based TB activities that involve NGOs/CSOs.

A memorandum of understanding is a useful tool for establishing good cooperation between the NTP and the NGOs and other CSOs involved in community-based TB activities. It is a formal written agreement between organizations, for example an NGO or the NCB and the NTP. It is not legally binding but it sets out simply what people have agreed to do. The contents of the document should include:

- what the agreement is about;

- who is making the agreement;

- what each organization or group will do, including tasks, meeting requirements for reporting and monitoring, and commitment to observe the code of conduct; and

- signatures of representatives of each organization or group involved.

The situation analysis (component 1) should include an **assessment of existing guidelines and tools**, what they cover and who they are aimed at. This will help to identify where adaptations are required and where new guidelines or tools are needed.

The NTP and the NCB should work closely together to make sure that:

- National guidelines and tools are based on international, evidence-based policies and guidelines.

- Health care staff are involved, with the NTP and the NGOs/CSOs, in developing new or modified guidelines and tools.

- Local guidelines and tools are in line with national guidance and with guidelines and tools used locally by the health system.

- Standard forms, registers and tools are used by all NGOs/CSOs involved in community-based TB activities.

National TB policy documents should reflect the priorities set by WHO in *Implementing the WHO Stop TB Strategy: a handbook for national tuberculosis control programmes* (2008) and any recent guidance on specific topics, such as: *Systematic screening for active tuberculosis: principles and recommendations* (2013). The documents should provide explicit guidance for community-based TB activities as well as health facility-based activities. The guidance should include:

- how community-based TB prevention and care can be delivered;

- how national TB programme management will include collaboration with NGOs/CSOs in delivering community-based TB care;

- how the country's comprehensive, integrated TB control approach will support community and patient engagement in TB care and prevention; and

- what each organization or group will do, including tasks, meeting requirements for reporting and monitoring, and commitment to observe the code of conduct.

Guidelines and tools
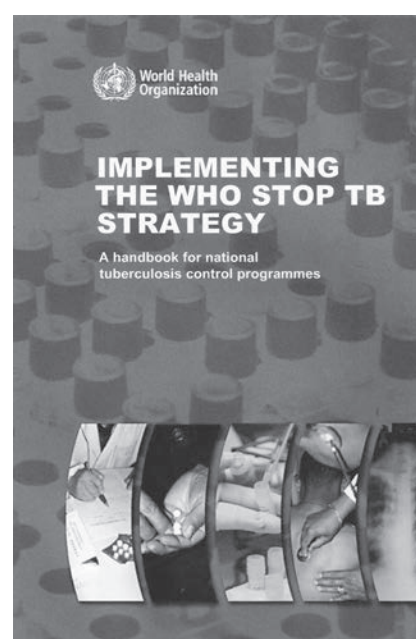
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Examples of guidelines and tools:

national guidance for community-based TB prevention and care

TB registers, treatment cards and referral forms

reporting forms and monitoring tools

training course curricula and toolkits

community TB information and awareness-raising posters, leaflets etc.

Plain language is essential when writing guidelines and tools for community-based TB activities. Most users will be people with no medical training, including NGO/CSO staff and volunteers. Any **forms** for community-based TB activities should also be easy to complete and written in plain language. Plain language makes documents:

- easier to read and understand and

- easier to translate into other languages when necessary.

Some **basic rules** for writing (and speaking) in plain language include:

- Use every-day words and short sentences as much as possible.

- Try to imagine who is reading or listening to your words. For example, people who do not have medical training might not understand the term "case-finding" the first time they hear it. Instead, you could write "finding people who have TB - this is usually called case-finding."

- Use technical language (jargon) only if you really cannot avoid it. Try first to say it in plain language. For example, SWOT analysis is a term that may not be familiar to all readers. Instead of "SWOT", use the full form, "strengths, weaknesses, opportunities and threats". This will make the guidelines easier to understand.

- Also, if you want to use abbreviations such as TB or CXR, use the whole word or words the first time you mention them, e.g. "tuberculosis (TB)" or "chest x-ray (CXR)".

Test new guidelines and forms with a group of people who have not seen them before. This will highlight any difficulties, and the guidelines and forms can be amended before distribution to NGOs/CSOs.

Mobile phone technology is cheap and widely available in most parts of the world, even in low-resource settings.[4] Mobile phone technology can serve to link CHWs and CVs with people with TB. It can also link CHWs and CVs with health facilities and other institutions. It can be used to provide information to caregivers and patients. Short message service (SMS) alerts can be used to remind patients about taking their anti-TB medicines and also provide reminders for appointments at the clinic. The database on patients kept by CHWs and CVs can be shared with health facilities to validate and verify monitoring data, such as community referrals and treatment support. Mobile phones can also be used to provide information to CHWs and CVs and can assist with their on-going training.
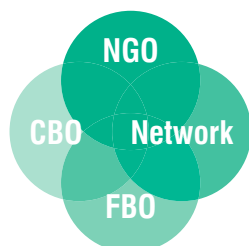
Guidance for NGOs

NGOs/CSOs can use NCB meetings to **review existing guidelines and tools** and decide whether to adapt them or develop new ones for community-based TB activities. An **NCB working group** should be set up to work closely with the NTP to make sure that all guidelines and tools are in line with national TB policy and health system protocols. They should also make sure that existing, adapted or new tools will be suitable for NGO/CSO staff and CVs to use at community level.

NGOs/CSOs should collaborate with the NTP in preparing guidelines based on national policies and procedures (protocols) for TB detection, diagnosis and treatment. The NGOs/CSOs will make sure that the experiences and needs of people and communities living with and affected by TB inform the content of the guidelines. Particular attention should be paid to developing appropriate **tools and guidance for CVs and CHWs**. Tools and manuals should be user-friendly and written in language that people at community level can easily understand. Ask a trained TB health worker to make sure that all the technical information on TB and other health matters is accurate and up to date.

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4   Braun R et al. (2013). *Community health workers and mobile technology: a systematic review of the literature.* (http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0065772, accessed 29 August 2013).

Implementation manuals and tools should be very clear on **when to consult a trained health worker** for decisions on what to do about symptoms, treatment or drug toxicity. Guidance and training for NGO/CSO managers on **supportive supervision** and **mentoring** may be needed. NGO/CBO staff and volunteers must gain enough knowledge about TB to carry out their community-based TB activities. They should also learn to be open about what they do not know and to link community members to trained health workers for anything they are not competent to do.

Training and **mentoring** will be required to make NGO/CSO staff familiar with guidelines and follow procedures correctly, such as making referrals and reporting on their work. The NCB should work with the NTP to agree on a set of training courses—a **national curriculum**—that can be used with CVs, CHWs and local health facility staff.

Training and **implementation guides** and **job aids** will also be needed. These should explain how to do the different tasks that NGO/CSO staff and volunteers will perform.

A job aid can be a poster, leaflet or booklet with instructions and pictures that show what to do and how to do it. An example is this job aid for sputum collection. It includes pictures and words and shows what has to be done in stages. Another example could be a small card for CVs to use in identifying people who might have TB. It includes four basic questions for TB case-finding:

- Do you have night sweats?
- Do you have weight loss?
- Do you have a cough that has lasted more than 2 weeks?
- Do you have a fever?

Supportive supervision:

checking that people understand how to do their work and have what they need to do it

solving problems that prevent the work from being done well

Mentoring:

sharing knowledge and guiding a person who is learning new skills

TUBERCULOSIS (TB)
SPUTUM COLLECTION PROCEDURE

1 CLEAR YOUR MOUTH
Rinse with water
Empty your mouth

2 BREATHE IN AND OUT 3 TIMES

3 GIVE A SPUTUM SAMPLE
No saliva

Examples of **training courses** that can be adapted for community-based TB activities are included in the list of resources below. Different approaches may be needed, depending on who is being trained and what tasks they will do as part of community-based TB activities. Participatory methods should be used, and trainees should learn by doing, whenever practical.

Training courses could include:

- TB basic knowledge, including how to inform communities about transmission, prevention and the necessity of seeking and completing treatment;

- case-finding: identifying vulnerable communities and individuals who might have TB;

- sputum collection, storage and transport to a laboratory;

- referring individuals for TB diagnosis and care, including assistance in gaining access to services;

- TB treatment: what it is, how it works, the importance of completing it and how to provide support for adherence, including DOT;

- how to use participatory methods for working with communities; and

- how to do a situation analysis, plan activities and manage resources.

Community information and education leaflets and posters will be needed for patients, families and community members. They must contain accurate information about TB and help people to make the best use of services.

The *Patients' charter for tuberculosis care* (World Care Council, 2006) will help TB patients to understand their rights and responsibilities. The charter should be adapted into plain language for use at community level. The following summary was adapted for use at community level in Project Axshya in India (http://www.axshya-theunion.org/). It shows how the charter can be adapted to fit the context of the country and communities that wish to make use of it.
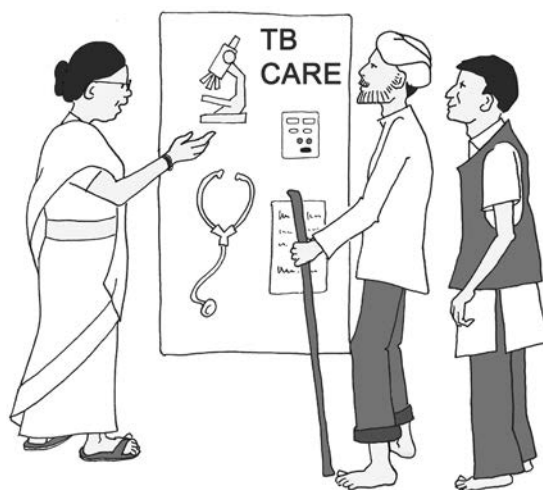
Patients' rights – you have the right to:	
Care	• free and equitable care for tuberculosis (TB) • quality care meeting the international standards (ISTC) • benefit from community care programmes
Dignity	• be treated with respect and dignity • social support of family, community and national programmes
Information	• information about available care services • be informed about condition and treatment • know drug names, dosage and side-effects • access your medical records in the local language • have peer support and voluntary counselling
Choice	• a second medical opinion, with access to medical records • refuse surgery if drug treatment is at all possible • refuse to participate in research studies
Confidence	• have your privacy, culture, religious beliefs respected • keep your health conditions confidential • care in facilities that practise effective infection control
Justice	• file a complaint about care, and have a response • appeal unjust decisions to a higher authority • vote for accountable local and national patient representatives
Organization	• join or organize peer support groups, clubs and NGOs • participate in policy-making in TB programmes
Security	• job security, from diagnosis through to cure • food coupons or supplements if required • access to quality-assured drugs and diagnostics

Patients' responsibilities: You have the responsibility to:	
Share information	• inform health care staff all about your condition • tell staff about your contacts with family, friends etc. • inform family and friends and share your TB knowledge
Contribute to community health	• encourage others to be tested for TB if they show symptoms • be considerate of care providers and other patients • assist family and neighbours to complete treatment
Follow treatment	• follow the prescribed plan of treatment • tell staff of any difficulties with treatment
Show solidarity	• show solidarity with all other patients • empower yourself and your community • join the fight against TB in your country

Well-designed **referral forms and registers** are important for NGO/CSO community health activities. The establishment receiving a referral (such as a health centre) should receive information about the person referred. NGOs/CSOs should also receive information about people when they return to their communities, and there should be a "back-referral" from the health facility to the community for further support. Confidentiality must be protected as well as making sure that people are linked with comprehensive care and support in both health facilities and the community.

NGOs/CSOs should ensure that referral forms and registers support a two-way referral system and encourage health providers to collaborate in it. Referral tools that can easily be adapted for community-based TB care can be found in: Tools for establishing referral networks for comprehensive HIV care in low-resource settings (see below). They include a two-way referral form, a referral register, a patient tracking form and a directory of all the services that patients can be referred to for care, support and other types of assistance. It is important that referral forms and registers be kept as simple as possible so that they can be easily completed. This supports accurate, prompt record-keeping, which is essential for monitoring activities and outputs.

The image below is an example of a simple two-way referral form used by ART adherence support workers in Zambia and other countries. This could be adapted for use in a community TB referral system.

REFERRAL FORM

Name of client: _____   Referral No:_____

Client's Age/Sex:_____/_____   Date:_____/_____/_____

Time of referral: _____

Organization/health facility client is referred to: _____

Organization/health facility referring the client: _____

Reason(s) for referral:

Name of person referring the client: _____

- -

FEEDBACK ON SERVICES BY PROVIDER

Client Referral No: _____

Date client was received by the organization: _____/_____/_____

Service(s) offered to client: _____

Comments on service(s) provided to the client:

Name of person who attended to the client: _____

Designation: _____   Date: _____/_____/_____

NTP　**Guidance for NTPs**

NTP national managers should take the lead in **finalizing national operational guidelines** for community-based TB activities. They should work closely with the NCB to ensure that the role of NGOs/CSOs in TB care and prevention is stated clearly in the relevant sections of guidelines, in order to support their collaboration with health workers in facilities and in the community.

The NTP and the NCB should also collaborate to prepare the **forms and tools** that NGOs/CSOs require to implement their activities. Existing forms, such as those for referrals, may have to be adapted for use at community-level. **Training and implementation manuals** will also be required. Examples of tools, forms and manuals include:

- **TB treatment cards** that include community-level adherence and other support provided;

- **referral forms and registers and protocols** appropriate for making and recording referrals from various community points, e.g. CHWs, CBOs, support groups;

- **implementation manuals** to assist CSOs in doing specific tasks such as sputum collection, making referrals, providing treatment adherence support;

- **training manuals and courses** on community-based TB activities, aimed at facility and CHWs and CVs; and

- **a template for a memorandum of understanding** or similar formal agreement to support collaboration between the NTP and the NGOs/CSOs.

As mentioned at the beginning of this section, **national guidelines** should be based on internationally recommended, evidence-based policies and guidelines. These can be accessed through the WHO TB website. **Guidance documents** that are likely to be relevant to planning and implementing community-based TB activities can be accessed on the following web pages:

> **ⓘ**
>
> **Development process for all guidelines and tools:**
>
> must embrace participatory methods and
>
> must engage all the main stakeholders meaningfully.

- Pursue high-quality DOTS expansion and enhancement, Element 3: Standardized treatment, with supervision and patient support: http://www.who.int/tb/dots/treatment/en/index.html.

- Pursue high-quality DOTS expansion and enhancement. Element 5: Monitoring and evaluation system, and impact measurement. Monitoring and evaluation guidance: http://www.who.int/tb/dots/monitoring_evaluation/en/index.html.

- The revised TB recording and reporting forms 2006: http://www.who.int/tb/dots/r_and_r_forms/en/index.html.

- Practical approach to lung health (PAL): http://www.who.int/tb/health_systems/pal/en/index.html.

The NTP should take the lead and collaborate closely with the NGOs/CBOs to ensure that national guidance and procedures are **adapted to include the roles of NGOs/CSOs** in integrating TB into their work and collaborating with the health system.

The NTP should take particular care to ensure that facility-based **TB health providers and managers** understand their role in supporting the work of the NGOs/CSOs.

Existing NTP tools may have be adapted to allow for new tasks that will be implemented by NGOs/CSOs. For example, tools used by facility-based staff may require further adaptation for use by CHWs. An existing CHW **referral form** for TB or other care may

have to be simplified and have additional sections for back-referral from clinic to community and onward referral to non-medical support.

Simple protocols for **TB screening by CVs and CHWs** should be prepared, with clear instructions on how someone thought to have TB can be referred to a health facility. Where **sputum collection, storage and transport** are to be done by community organizations and CVs, simple protocols should be established, including active supervision to ensure that sputum samples are always received in acceptable condition by the laboratory.

The NTP should also collaborate with NGOs/CSOs in preparing **TB treatment adherence support guidance**. The NGOs/CSOs should take the lead on this, but should have good linkages with TB services and advice to ensure that the correct technical approaches are used. Particular emphasis should be paid to:

- establishing and sustaining community-based DOT,
- determining when and how to refer patients for management of drug side-effects,
- determining when and how to refer patients for repeat sputum checks,
- ensuring family and community education on TB control and
- reducing stigmatization.

Resources

Arkangelo Ali Association. T*B HIV training manual for community health workers, trainers' manual.* Nairobi, 2009 (http://www.hciproject.org/chw-central/resources/tb-hiv-training-manual-community-health-workers; accessed 15 July 2013).

Braun R et al. (2013) *Community health workers and mobile technology: a systematic review of the literature.* http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0065772 (accessed 29 August 2013).

Family Health International. *Establishing referral networks for comprehensive HIV care in low-resource settings.* Arlington, Virginia, 2005 (http://pdf.usaid.gov/pdf_docs/PNADF677.pdf, accessed 15 July 2013).

Family Health International. *Tools for establishing referral networks for comprehensive HIV care in low-resource settings*. Arlington, Virginia, 2005 (http://pdf.usaid.gov/pdf_docs/PNADI858.pdf, accessed 15 July 2013).

Family Health International. *Simplified checklist for TB infection control*. Arlington, Virginia, 2011 (FHI 360). (http://www.tbcare1.org/publications/toolbox/tools/ic/TB_Infection_Control_Simplified_Checklist.pdf, accessed 15 July 2013).

Family Health International. *TB infection control at the community level: a training handbook.* Arlington, Virginia, 2011 (FHI 360). (http://www.tbcare1.org/publications/toolbox/recent/TB_IC_at_Community_Level_Training_Handbook.pdf, accessed 15 July 2013).

Plain English Campaign. *How to write medical information in plain English*. New Mills, 2001 (http://www.plainenglish.co.uk/files/medicalguide.pdf, accessed 15 July 2013).

Plain English Campaign. *The plain English guide to forms*. New Mills, 2002 (http://www.plainenglish.co.uk/files/formsguide.pdf, accessed 15 July 2013).

Project AXSHYA and the World Care Council. *Patients' charter for tuberculosis care*. New Delhi, 2010 (http://www.axshya-theunion.org/documents/Patient%20Charter%20poster%20English.pdf, accessed 15 July 2013).

Tuberculosis Coalition for Technical Assistance. *Implementing the WHO policy on TB infection control in health-care facilities, congregate settings and households*. The Hague, 2010 (See part 6, Congregate settings, and part 7, Households) (http://www.stoptb.org/wg/tb_hiv/assets/documents/TBICImplementationFramework1288971813.pdf, accessed 15 July 2013).

World Health Organization. *Monitoring and evaluation guidance* (http://www.who.int/tb/dots/monitoring_evaluation/en/index.html, accessed 10 September 2013).

World Health Organization. *Practical approach to lung health (PAL)* (http://www.who.int/tb/health_systems/pal/en/index.html, accessed 10 September 2013).

World Health Organization. *Pursue high-quality DOTS expansion and enhancement, Element 3: Standardized treatment, with supervision and patient support, and Element 5: Monitoring and evaluation system, and impact measurement*. (http://www.who.int/tb/dots/treatment/en/index.html, accessed 10 September 2013).

World Health Organization. *Systematic screening for active tuberculosis: principles and recommendations*. Geneva, 2013 (WHO/HTM/TB/2013.04) (http://apps.who.int/iris/bitstream/10665/84971/1/9789241548601_eng.pdf, accessed 30 August 2013).

World Health Organization. *The revised TB recording and reporting forms 2006* (http://www.who.int/tb/dots/r_and_r_forms/en/index.html, accessed 10 September 2013).

World Health Organization. *WHO policy on collaborative TB/HIV activities: Guidelines for national programmes and other stakeholders*. Geneva, 2012 (WHO/HTM/TB/2012.1) (http://whqlibdoc.who.int/publications/2012/9789241503006_eng.pdf, accessed 19 July 2013).

Component 4: Task identification

This section is about **identifying the specific tasks** that can support implementation of community-based TB activities by NGOs/CSOs. It will vary for each organization, as it will depend on their particular capacity and the skills required to carry out the different tasks. It will be necessary to assess **what resources and expertise** are available and **how to build synergies**, i.e. increasing impact as a result of cooperation among organizations.

It is vital to involve and engage the NTP as NGOs/CSOs decide what tasks they should undertake in a particular country and within particular communities. The document *Implementing the WHO Stop TB Strategy*[5] is an important guide to the tasks involved in TB care and control. This and other helpful guidance are included in the resources list at the end of this section.

Section 3 of this implementation manual describes the activities that could be implemented in the different sectors, as summarized in the table below:

Theme	Possible activities
Prevention	Awareness-raising, IEC, BCC, infection control, stigma reduction, training providers
Detection	Screening, contact tracing, sputum collection, sputum transport, training providers
Referral	Linking with clinics, transport support and facilitation, accompaniment, referral forms, training providers
Treatment adherence support	Home-based DOT support, patient education, adherence counselling, stigma reduction, pill counting, training providers, home-based care and support
Social and livelihood support	Cash transfers, insurance schemes, nutrition support and supplementation, voluntary savings and loans, inclusive markets, training providers, income generation
Advocacy	Ensuring the availability of supplies, equipment and services, training providers, governance and policy issues, working with community leaders
Stigma reduction	Community theatre or drama groups, testimonials, patient and peer support groups, community champions, sensitizing and training facility and CHWs and leaders

These represent the broad range of activities that could be considered in task identification as outlined in this section.

The ENGAGE-TB approach is particularly concerned with integrating TB activities into the work of NGOs/CSOs. The community-based TB tasks involved will be integrated into

- **health programmes**, especially HIV, MNCH and PHC; and
- **other development programmes**, including education, agriculture, livelihoods and water and sanitation.

Some tasks will be directly connected to **TB prevention and care**; others will be related to the wider context of TB, such as

- **other diseases and conditions**, especially the connections between TB, HIV infection, noncommunicable diseases such as diabetes, and other health challenges such as excessive smoking or drug or alcohol abuse; and
- **social factors or determinants** that affect health, such as poverty, overcrowding, malnutrition and lack of access to education, clean water or hygiene facilities.

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5 *Implementing the WHO Stop TB Strategy*. Geneva, World Health Organization, 2008 (WHO/HTM/TB/2008.401).

NGOs/CSOs may also have to undertake activities that support increased **financing and resource mobilization** and participation in **programme-based operational research**. The first would increase their capacity to engage in TB activities, while in the second they would use their field experience to add to knowledge and understanding about community-based TB services.
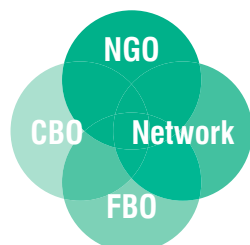
Guidance for NGOs

Each organization could assess the particular SWOT it faces in order to determine what community-based TB activities it can successfully undertake. The assessment tool is called a SWOT analysis.

A SWOT analysis can be completed quite quickly and is not too complex. It requires some or all members of staff to meet to discuss and review each of the four elements in the matrix. They should work on the best information they have, rather than trying to gather new information. The results should be listed after analysis and agreement. This will provide insight and assist in determining which tasks can be introduced into the programme of work. The SWOT analysis should be compared with the situation analysis in order to review the main possible TB tasks that could be undertaken.

When the list of possible tasks is determined, the NGO/CSO should consult the NTP to generate support and improve coordination. This could lead to the development of an **implementation plan** in collaboration with the NTP. The plan should include details of:
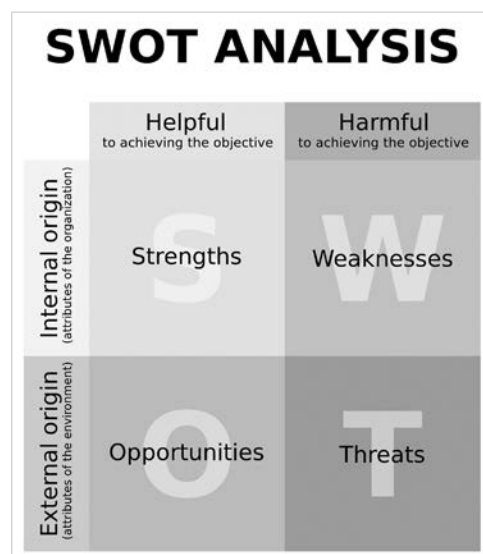
- what the "SMART" objectives will be,
- which tasks and activities will have to be undertaken to achieve the objectives,
- who will do which tasks and activities,
- who each NGO/CSO will collaborate with,
- which sections of the community their activities will focus on and
- what support will be needed from the NTP and other facilities and staff.

The NCB should periodically review the range of tasks being carried out by members with the NTP so that common concerns and issues arising are shared and resolved jointly. This will help the continuation of activities and reduce difficulties that may be experienced in implementation.

SMART objectives:

Specific

Measurable

Achievable

Realistic

Time-bound

Determination of tasks by individual NGOs/CSOs can also be assisted by broader group discussion with other NGOs/CSOs, the NTP and other stakeholders. This could also help in improving synergy and collaboration.

The following process is suggested to help multiple organizations and groups decide on tasks and agree on collaboration with each other. The participatory approach is valuable, as it will help to understand community needs and experiences. It will also support the development of cooperative relationships and shared ownership of the proposed programme of activities. The suggested steps in the process could be:

- **Step 1**. In a particular geographical area, the NCB should convene a meeting to bring together representatives from NGOs/CSOs who have decided to work on TB, selected CHWs, health facility staff involved in TB care and representatives of the NTP.

- **Step 2**. Use a participatory method to understand how people in the target communities decide what to do when they have TB-related health problems and to understand what pathways people follow to get help with those problems. This will help to clarify what TB services people are able to access and what

barriers might prevent access. An adaptation of The health journey: a community-centred methodology (referenced in the resources list below) would provide a simple approach. This participatory approach will put community experiences and needs at the centre of the planning process. It also brings together the knowledge and experience of all organizations involved.

- **Step 3**. Next, facilitate the group to prepare a map of each implementation area based on what they learned in Step 1, including information such as:

  - where people live, especially those most vulnerable to TB;

  - the location of public services such as health facilities, council offices, schools, churches, police;

  - the location of community gathering places, such as markets, community or youth centres, popular entertainment places; and

  - a list of which organizations are already involved in TB or other health-related services or in programmes that could integrate TB activities into their work, such as education, agriculture, nutrition, WASH and poverty reduction programmes.

- **Step 4**. When the mapping activities have been completed and discussed, all participants should have a good understanding of the context and needs of the communities they wish to serve. This will help participants to start to identify the activities that are needed, the people responsible for them, sources of funding and other resources, and to develop an action plan and budgets. More than one meeting may be required to finalize objectives, activities, work plans, budgets and monitoring and evaluation plans.

- **Step 5**. When plans have been prepared, NGOs/CSOs should share them with other stakeholders in community-based TB activities. These could include technical support providers, local development programme leaders, networks and community groups and local health workers. This will help to identify and establish partnerships with the various stakeholders who will be crucial to successful implementation and integration of community-based TB activities.

NTP   Guidance for NTPs

NGOs that are newly integrating TB into their activities will require guidance and support in selecting tasks and activities to implement. NTPs can provide such support effectively. NTPs should include the scaling up of community-based TB activities in national TB strategic plans and budgets and in national and subnational operational plans. This will provide a framework for NTP engagement with NGOs/CSOs and expansion of community-based TB activities. The NTP should also work with the NCB to ensure that integration of community-based TB activities into the work of NGOs/CSOs in different sectors is in line with national TB policies and guidelines.

The NTP should:

- make time to meet with NGOs/CSOs that are newly integrating TB to discuss and review their chosen tasks;

- meet regularly with the NCB to review the plans for TB integration of their members;

- maintain a list of all NGOs/CSOs working on TB with defined tasks; and

- review and promote opportunities for increased collaboration with health facilities and staff to improve delivery of tasks.

The NTP should assess **which NGOs and CSOs are available** for community-based TB activities and work with them and the NCB (when established) to list tasks and clarify which organizations can implement them. **NTP link persons** for the NCB and NGOs/CSOs should be identified and helped to build cooperative working relationships.

The NTP should also ensure that the tasks outlined in national strategic and operational plans are included in the implementation plans of the NGOs/CSOs.

The NTP should **review the planned activities** to ensure that:

• all the necessary tasks are included;

• NGO/CSO staff and volunteers work within their competences;

• activities can be implemented in a coherent, consistent way, with close cooperation among all involved;

• supervision and mentoring are regular, supportive and adequately resourced;

• meetings are held periodically to track progress, identify problems, find and implement solutions, and accelerate successful approaches; and

• reporting of activities is coordinated and consistent, and responsibility for onward reporting to the NTP is clearly designated.

Resources

CORE Group TB Working Group. *Community-based tuberculosis prevention and care: why—and how—to get involved. An international handbook for nongovernmental organizations and civil society organizations*. Washington DC, 2013 (http://www.coregroup.org/resources/342-community-based-tuberculosis-prevention-and-care, accessed 15 July 2013).

Family Health International. *Establishing referral networks for comprehensive HIV care in low-resource settings*. Arlington, Virginia, 2005 (http://pdf.usaid.gov/pdf_docs/PNADF677.pdf, accessed 15 July 2013).

International HIV/AIDS Alliance. *The health journey: understanding the dimensions of care and treatment for people with HIV*. Brighton, 2007 (http://www.aidsalliance.org/publicationsdetails.aspx?id=263, accessed 15 July 2013).

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) (http://whqlibdoc.who.int/hq/2006/WHO_HTM_TB_2006.360_eng.pdf, accessed 30 August 2013).

World Health Organization. *Implementing the WHO Stop TB Strategy: a handbook for national tuberculosis control programmes*. Geneva, 2008 (WHO/HTM/TB/2008.401) (http://whqlibdoc.who.int/publications/2008/9789241546676_eng.pdf, accessed 19 July 2013).

World Health Organization. *Public–private mix for TB care and control: a toolkit*. Geneva, 2010 (WHO/HTM/TB/2010.12) (http://whqlibdoc.who.int/publications/2010/9789241500487_eng.pdf, accessed 19 July 2013).

World Health Organization. *Public–private mix for TB care and control. A tool for national situation assessment* (WHO/HTM/TB/2007.391) (http://whqlibdoc.who.int/hq/2007/WHO_HTM_TB_2007.391_eng.pdf, accessed 30 August 2013).

World Health Organization. *The Stop TB Strategy*. Geneva, 2006 (WHO/HTM/TB/2006.368) (http://whqlibdoc.who.int/hq/2006/WHO_HTM_STB_2006.368_eng.pdf, accessed 30 August 2013).

World Health Organization. *The Stop TB Strategy one-page summary*. Geneva, 2010 (http://www.who.int/tb/publications/2010/strategy_en.pdf, accessed 30 August 2013).

World Health Organization. *Tuberculosis care with TB-HIV co-management: integrated management of adolescent and adult Illness (IMAI)*. Geneva, 2007 (WHO/HTM/TB/2007.380) (http://www.who.int/hiv/pub/imai/TB_HIVModule23.05.07.pdf, accessed 19 July 2013).

Component 5. Monitoring and evaluation

Monitoring and evaluation are aimed at measuring and collecting information on what is being done and what changes are happening over time in response to certain activities. They are important for a number of reasons:

- **providing information on progress** in implementation;
- **assessing the quality and effectiveness** of a programme or activity; and
- **reporting** to bodies such as the NTP, donors, advocacy groups and community representatives on what has been achieved, any barriers or blocks to implementation and lessons learnt.

Objectives	Inputs	Process	Outputs	Outcomes	Impact
What does the programme want to achieve? e.g. increase case detection and referrals	What is needed to implement the programme? e.g. trained people, supplies, funds	What does the programme do? e.g. home visits, school TB prevention lessons	What did the programme achieve? e.g. number of referrals, number of children informed	How has it contributed to programme objectives? e.g. increased case notification, improved treatment outcomes	What has changed? e.g. fewer TB deaths; fewer people infected with TB bacterium

As shown in the diagram above, **objectives** must first be decided for a programme of activities, as described in component 4. They should be clear, easy to understand and **SMART**. They will help in tracking how the programme is progressing with what it wants to achieve. **Baseline information** should be collected before the start of the programme so that data collected during implementation can be compared with it. This will help with review and evaluation.

Monitoring means regular tracking and reporting of priority information about a programme including:

- **inputs**: the resources used to carry out activities, which can be human, such as staff and volunteers, or physical, such as machines and equipment;
- **processes**: the activities that use the inputs to produce outputs;
- **outputs**: the products and services generated by activities, which could be the number of home visits by a CHW or the number of referrals to a clinic by a CHW;
- **outcomes**: the results achieved, which usually relate to the objectives, such as the change in TB case notification rates; and
- **impact**: the long-term changes in the quality of life that result from a set of outcomes, such as a reduced mortality rate due to TB.

SMART objectives should be:

Specific

Measurable

Achievable

Realistic

Time-bound

Review and **evaluation** are based on the information provided by monitoring. They are performed after implementation has continued for some time, often at the middle and the end of a funding period.

As it would make no sense to try to measure everything that a programme does, indicators are used. These are specific types of information that can be tested (validated) and relied upon to measure performance, progress and changes connected to an activity.

Good data are essential for monitoring and evaluation. Activities and progress can be measured only if information is consistently and accurately recorded.

Bad data will give an inaccurate picture of what is happening, for example when forms are not completed properly. This makes it difficult to know where good practice is happening and where action needs to be taken to improve implementation. This will affect resource allocation as well as the management of the programme.

The ENGAGE-TB indicators and periodic evaluation:

The NTP and NGOs/CSOs should work together to identify which data should be collected and who will take responsibility for it, especially for the core ENGAGE-TB indicators. As countries gain experience with implementing the ENGAGE-TB approach, the NTP and NGOs/CSOs may decide to add other indicators so that they can gain a greater understanding of what progress is being made.

There are two WHO-approved ENGAGE-TB core indicators and a WHO outline for periodic evaluation of the progress of community-based TB activities (with four qualitative indicators). The full texts of these are provided in annexes 1 and 2, with explanations of some of the specialist words used.

The two core indicators are essential for community-based TB activities. They are part of the national monitoring system of the NTP. They are designed to record two important results of community-based TB activities. The records will be collected by the NTP and will be included in national TB reports. The two core indicators are:

1. **the numbers of new patients** in whom TB is diagnosed and notified who were referred by CHWs or CVs as a proportion of all new TB patients notified to the same BMU; and

2. **the numbers of new TB patients successfully treated** who received treatment adherence support from CHWs or CVs as a proportion of all new TB patients receiving treatment adherence support from CHWs and CVs.

Every three to five years, the NTP will also carry out a **periodic evaluation** of the national TB programme. This will include a review of community engagement in TB services. NGOs/CSOs will be asked to participate in the evaluation. This will help to assess how they have contributed to new case notifications and treatment success. The four qualitative indicators for the periodic evaluation, which will help to answer these questions, are:

> **i**
>
> **Successfully treated** means
>
> cured or
>
> completed treatment

- **Is there an NCB** for community engagement in TB, and how well is it working?

- **How well do the NTP, NGOs/CSOs work together** at national, district or local level?

- **What have been the respective contributions of NGOs/CSOs and of the NTP** to new case finding and treatment success? How have they changed over time?

- What **are the challenges and hurdles** faced by the different community, health system and national organizations in increasing new case notifications? What successes and new opportunities are there?

The NTP is responsible for national reporting on TB indicators and for ensuring that there is a **single national TB monitoring and evaluation system** that recognizes the contribution and engagement of NGOs/CSOs. The two WHO ENGAGE-TB core indicators are central to this.

Collaboration between the NTP and NGOs/CSOs will therefore be essential in order to decide responsibilities and procedures for collecting and reporting data. As planning and implementation of community-based activities progresses, organizations may decide to include additional indicators, either for their own programme management and learning or in response to the requirements of funding partners. Any additional indicators should be aligned with the national TB monitoring and evaluation system.

Regular reviews and evaluation will highlight areas in which further learning and follow-up may be needed for ongoing implementation of community-based TB activities. They could include:

- groups vulnerable to TB and the ability of NGOs/CSOs to reach them;

- emerging good practices and the potential for scaling them up;

- bottlenecks in the processes of referral, diagnosis, case notification, treatment, care and support;

- barriers experienced by patients in accessing and using TB services; and

- obstacles to collaboration and cooperation among organizations implementing integrated community-based TB activities in different sectors.
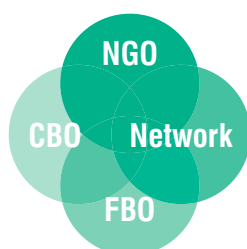
Guidance for NGOs

A monitoring and evaluation plan should be prepared by each implementing NGO, incorporating the core indicators to be reported to the NTP. The plan should be based on the **single national TB monitoring and evaluation system**. Monitoring requirements may depend on the size and capacities of the different organizations and their roles in community-based TB activities. **All organizations and groups should monitor inputs and outputs** and regularly review and evaluate the data that they collect. Only some programmes will have the capacity for monitoring and evaluating outcomes. **Impact measurement** for the ENGAGE-TB approach is likely to be an NTP responsibility, but NGOs/CSOs should cooperate in carrying this out. The NTP will also lead the periodic evaluation of community-based TB activities every three to five years in collaboration with the NGOs/CSOs.

The two core ENGAGE-TB indicators are the **minimum requirement** for reporting on community-based TB activities to the NTP, and all organizations should make a continuing contribution of good quality data for these indicators.

NGOs/CSOs may also want to understand more about the **target groups** that they refer or support. For example, they could find out if they are seeing more men, women or children with suspected TB or people from different population groups. A range of other possible monitoring needs may arise in different sectors depending on their priorities and objectives.

NGOs/CBOs should review their monitoring and evaluation plans regularly and adapt them to emerging needs. NGOs with strong monitoring and evaluation capacity should assist other NGOs and CSOs to develop their capacities for data collection, data analysis and reporting.

As implementation progresses, new information may be required about different areas of work. If new indicators are needed, they should be chosen carefully and developed and validated in cooperation with the NCB and the NTP. This will ensure that they are consistent with the national TB monitoring and evaluation plans, and that other organizations will be able to use them.

The NCB should **review progress in monitoring and evaluation** regularly. Members of the NCB should work constructively with each other and support those that are facing particular difficulties. The **NCB should keep the NTP informed** about implementation progress on a regular basis.

NGOs/CSOs should **include monitoring and evaluation in capacity-building plans** for community-based TB activities. At an early stage, all staff and volunteers should be trained in the importance of collecting, recording and reporting accurate data. They should also be made aware of how the data will be used to analyse the effectiveness of their activities. It should be emphasized that monitoring and evaluation are important for everyone involved in community-based TB activities.

It will probably be necessary to ensure **that selected NGO/CSO staff are trained on monitoring and evaluation** at a level suitable for their organization and its chosen activities. The activities that they should be familiar with should include:

- **preparing and implementing the organizational monitoring and evaluation plan**, and participating in preparation and implementation of national monitoring and evaluation plans that include community-based TB activities;

- **recording and reporting data** within the organization, to fellow NCB members, to the NTP and to funding partners;

- **analysing and using monitoring data** for programme improvement;

- **learning how to do an evaluation** and how often it should be done; for example, it is recommended that every NGO/CSO should carry out a full evaluation at least every five years; and

- **analysing and using evaluation data** for programme improvement and for sharing knowledge with stakeholders and other interested organizations.

Capacity-building for NGOs/CSOs in monitoring and evaluation might include provision of adequate **material and financial resources**, including **NTP-approved data collection forms and registers**. Wherever possible, **computers and standardized electronic tools** should be made available, and training should be provided on how to use them.

Regular supervision and mentoring should be provided to ensure that NGO/CSO staff and volunteers **maintain the quality of data recording** and alert their managers to any challenges or bottlenecks.

Finally, monitoring and evaluation outcomes should be used to **keep patients, community members, local policy-makers and stakeholders informed**. The outcomes will also provide validated evidence that is valuable for advocacy and improvement of programmes and services for people at risk of or affected by TB. The NCB should hold an **annual national review and reflection meeting** to share progress and discuss lessons learnt. The meeting should allow patient representatives and a range of NGOs and CSOs to share their experiences and demonstrate how community TB activities have affected people's lives.

NTP   ## Guidance for NTPs

The NTP has an important role in supporting high-quality monitoring and evaluation in community-based TB activities, including TB activities integrated into the work of other sectors. The NTP has national responsibility for ensuring that there is a **single national TB monitoring and evaluation system**. This should include the **ENGAGE-TB core indicators and periodic evaluation** process. The NTP should:

- **Ensure that the single national monitoring and evaluation system** recognizes the contribution and engagement of NGOs/CSOs in community-based TB activities. This includes their contribution to referral, diagnosis and notification of new TB cases and to successful treatment of new TB cases through provision of adherence support.

- Use the NCB as a forum to collaborate with NGOs/CSOs in developing **systems for data collection and monitoring** by NGOs/CSOs, including smaller CBOs and community groups. The systems should be easily understood and implemented and should not increase the workloads of organizations that have few staff and high demand for their activities.

- Ensure that **standardized data collection and reporting** tools are available and adapted to the needs and capacities of the range of NGOs/CSOs involved in community-based TB activities. Depending on resources, **electronic recording and data communication** methods and technology should be made available to NGOs/CSOs, with any necessary capacity-building. These can help to reduce data recording workloads and should result in greater accuracy and more rapid attention to potential problem areas.

- Facilitate **capacity-building and technical support** of NTP and NGO/CBO staff for high-quality monitoring and evaluation and supervision. The NTP should consider how to resource and provide the necessary technical support and capacity-building for NGOs/CSOs to monitor and evaluate community-based TB activities. National or international technical experts may be required to provide training and mentoring. This will be important for **ensuring that high-quality data are collected on the core indicators**. It will also be needed to ensure that the monitoring and evaluation of community-based TB activities in different sectors is adapted in response to implementation experience and any increased demand for community TB services and support.

- Meet with the NCB for **quarterly reviews** of progress, share results and facilitate resolution of any difficulties that have arisen.

- Prepare and disseminate an **annual report** after the annual review and reflection meeting with the NCB, in order to share experience and progress with stakeholders, national and local government, patient groups, community members and donors.

- Lead a **periodic evaluation** of all community-based TB activities every three to five years, in collaboration with the NCB and individual NGOs/CBOs.

- **Communicate periodic evaluation outcomes** widely so that the findings are available for use in advocacy for any policy change that is needed and for resource mobilization and programme improvement.

Resources

International NGO Training and Research Centre. *Tracking progress in advocacy: Why and how to monitor and evaluate advocacy projects and programmes* (INTRAC M&E Paper 4). Oxford, 2009 (http://www.stoptb.org/assets/documents/global/awards/cfcs/Tracking-Progress-in-Advocacy-Why-and-How-to-Monitor-and-Evaluate-Advocacy-Projects-and-Programmes.pdf, accessed 15 July 2013).

Joint United Nations Programme on HIV and AIDS. *Monitoring and evaluation guidelines*. Geneva, 2010 (http://www.unaids.org/en/dataanalysis/datacollectionandanalysisguidance/monitoringandevaluationguidelines/ especially the four monitoring and evaluation fundamentals documents; accessed 15 July 2013).

MEASURE-Evaluation. *M&E of tuberculosis programs*. Chapel Hill, North Carolina, 2006. (http://www.cpc.unc.edu/measure/training/materials/tb, accessed 15 July 2013).

The Global Fund to Fight AIDS, Tuberculosis and Malaria. *Monitoring and evaluation toolkit, part 3: Tuberculosis and part 5: Health and community systems strengthening*. Geneva, 2011 (http://www.theglobalfund.org/en/me/documents/toolkit/, accessed 15 July 2013).

World Health Organization. *A guide to monitoring and evaluation for collaborative TB/HIV activities*. Geneva, 2009 (WHO/HTM/TB/2009.414) (http://www.who.int/hiv/pub/tb/hiv_tb_monitoring_guide.pdf, accessed 19 July 2013).

World Health Organization. *Definitions and reporting framework for tuberculosis—2013 revision*. Geneva, 2013 (WHO/HTM/TB/2013.2) (http://apps.who.int/iris/bitstream/10665/79199/1/9789241505345_eng.pdf, accessed 19 July 2013).

World Health Organization. *Electronic recording and reporting for tuberculosis care and control*. Geneva, 2012 (WHO/HTM/TB/2011.22) (http://www.who.int/tb/publications/electronic_recording_reporting/en/index.html, accessed 4 September 2013).

World Health Organization. *Tuberculosis (TB)—Pursue high-quality DOTS expansion and enhancement, element 5: Monitoring and evaluation system, and impact measurement*. WHO web page. (http://www.who.int/tb/dots/monitoring_evaluation/en/, accessed 15 July 2013).

Component 6. Capacity-building

Capacity Building

Capacity-building aims to improve the ability of a person, group, organization or system to meet objectives or to perform better. For community-based TB activities, this means ensuring that all have the abilities, skills and resources to plan, implement and scale up their engagement.

Capacity-building includes training, supervision, mentoring and adaptation of practices based on learning from experience or new evidence on what works. This is likely to be needed in the following key areas:

Capacity-building aims to:

strengthen systems and organizations

improve skills and performance

support scaling-up of activities when demand increases

- **human resources**: ensuring that sufficient people are involved, with the skills and abilities for technical, organizational, leadership, advocacy and research tasks;

- **financial resources**: ensuring that sufficient funding is available to start up and sustain activities;

- **material resources**: ensuring that adequate infrastructure, information and commodities are available, e.g. tools and places to work;

- **systems development and strengthening**: ensuring that systems are in place to support activities, including, community support and care, TB referral, diagnosis and treatment and organizational systems; and

- **knowledge-sharing**: ensuring that data are collected, that good practices and lessons learnt are recorded, and that knowledge is shared within the programme and with others such as WHO and donor organizations.

Capacity-building is an **ongoing cycle**, as shown in the following diagram:
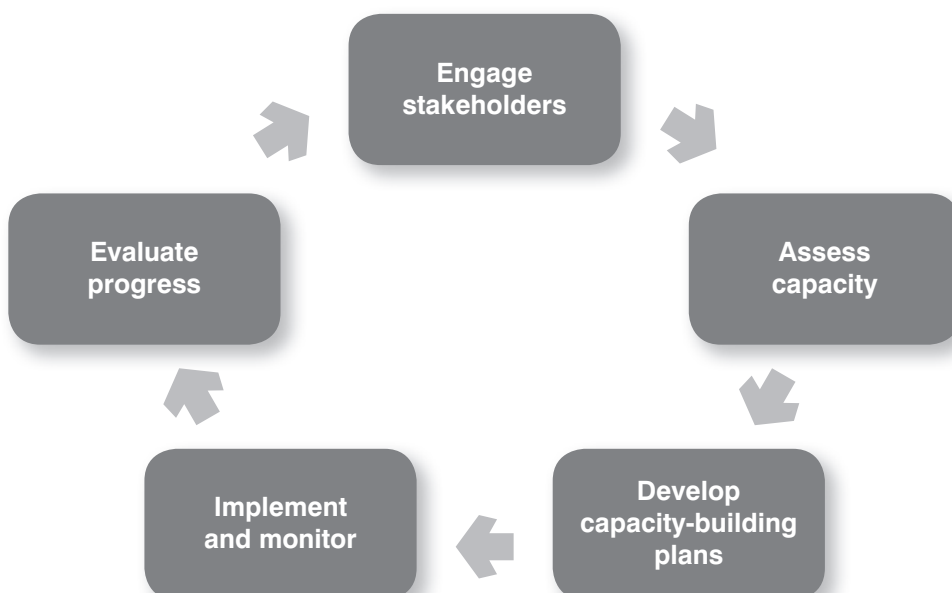
The approach to capacity-building will depend on the national and local context. The first step in the cycle involves **engaging stakeholders** on the need for capacity-building. This should include NGOs/CSOs, the NTP, funding agencies and any other stakeholders interested in TB. All stakeholders should understand and be committed to the **objectives of capacity-building** for community-based TB activities.

The next step involves **assessing the capacities** of each organization involved. This should include assessing what capacities each stakeholder already has and what capacities should be strengthened. Based on the assessment, **capacity-building plans** should be made, both for the overall national ENGAGE-TB approach and for each organization involved.

It is important to note that successful implementation of activities can lead to **increased demand**, which is likely to mean a **need for increased capacity**. For example, when communities are better informed about TB treatment, more people are likely to come forward for screening. Organizations should monitor whether demand is starting to increase and try to prepare for this as far as possible. This will help them to provide a continuous service and avoid disappointing community expectations.

Implementation of capacity-building should be based on the implementation plans but should be flexible enough to respond to changing circumstances. Organizations should review their progress regularly and share their experiences and lessons learnt at the regular NCB meetings. The NCB and the NTP can take responsibility for oversight and monitoring of overall capacity-building progress. Regular monitoring and review will facilitate **evaluation and reporting** to the NTP and other agencies that have provided technical and financial support for capacity-building.

Operational research can be a very useful capacity-building tool. Staff and volunteers engaged in research tasks often learn new skills and the importance of collecting and documenting information. It can also make programme activities better informed and help organizations to see how a programme can become more effective.
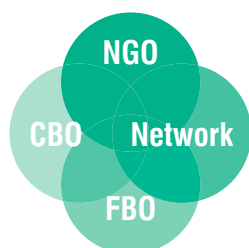
Operational research can help to:

assess the feasibility of new approaches

identify how to improve health care and prevention

highlight community experiences and support advocacy for change

Guidance for NGOs

As the ENGAGE-TB approach depends on collaboration among organizations and integration of TB into other types of activities, it is important that organizations collaborate in capacity-building. NGOs/CSOs should have a **shared understanding** of the type of capacity development that is needed for community-based TB activities. Each organization will have strengths and capacities that will be especially useful for the integrated approach; these are the **comparative advantages** of each organization. Capacity-building for all stakeholders should aim to strengthen their comparative advantages as well as address any weaknesses that are identified.

Each organization should decide its own capacity-building **objectives**, do a capacity **analysis**, and start to outline a **capacity-building plan** as a first step. This will allow the organization to join in discussions with other organizations with a clear picture of its existing capacities and needs for capacity-building. Other organizations should also share their ideas and proposals on capacity-building during a review and sharing meeting, the aim of which is to develop **shared objectives** and **build capacity for the whole programme** and not just for each organization. This allows organizations to use their comparative advantages to build each other's capacity and to assess needs for external resources and facilitation to build new skills.

For example:

- Those working in non-formal education could train others on participatory learning.

- WASH programmes could share knowledge of how to run hygiene campaigns.

- Health programmes could train non-health organizations on health issues and on how health systems work.

- HIV stigma trainers could train trainers from development and health programmes on tackling stigmatization for both TB and HIV infection.

- Disabled people's organizations could train other organizations in ensuring access to TB and HIV services.

Special attention should be given to the needs of smaller, less well-resourced organizations, focusing especially on their need to become sustainable and able to cope with increased demand when they may have to manage increased funding and take on more staff.

Different NGOs/CBOs will have **different capacity-building** needs depending on their current work and context. For example:

- All will probably need to build their **organizational, financial, technical and knowledge-sharing skills** in order to integrate community-based TB activities into their work.

- Potentially, all will also require capacity-building in **reducing stigmatization**, focused on stigma related to TB, HIV, disability, poverty and vulnerable populations.

- Organizations already working in health will have a range of health skills, and the capacity for using these skills in **community-based TB activities** should be assessed and built if needed.

- Organizations already working in other sectors will have capacities that are relevant for community-based TB activities, such as skills in community education or peer support, but they will have to acquire **specific TB knowledge and skills** in order to implement community-based TB activities.

A suggested process for planning and implementing capacity development is outlined below.

Step 1. Clarify the capacity-building objectives: It is important to be clear about what each capacity-building activity is intended to achieve. The NCB could bring NGOs/CSOs together so that shared capacity needs can be efficiently supported, e.g. via joint training programmes or through secondment of staff.

Step 2. A capacity analysis will help to clarify what capacities require attention and how this may be achieved. There are many tools for capacity assessment that could be adapted for organizations involved in community-based TB activities. These are included in the list of resources at the end of this section. The *UNDP capacity development primer and the International HIV/AIDS Alliance NGO, CBO and networks capacity analysis toolkits* are particularly recommended for use by NGOs/CSOs. Larger or more experienced organizations should assist smaller or less experienced organizations to assess their capacity.

A suggested approach to capacity analysis for an NGO/CSO would be to assess each of the areas listed below. Examples are provided, but each organization or group of organizations should prepare its own assessment checklist.

- **Organizational capacity**
  - internal governance;
  - human resources and administration;
  - material resources: infrastructure, transport, technology, information;
  - programme management, monitoring, evaluation and reporting;
  - financial management and sustainability;

- **TB technical capacity of NGO/CSO staff and community volunteers**
  - knowledge and skills;
  - access to technical resources and knowledge;

- **Capacity for partnerships, referral systems and coordination**
  - awareness and working relationships with other organizations;
  - referrals to health care and other sources of help and information;

- **Capacity for promoting participation of vulnerable communities**
  - level and range of involvement of vulnerable communities;
  - efforts to promote involvement of vulnerable communities;

- **Involvement in research and advocacy**
  - capacity to conduct operational research and analysis as a foundation for advocacy work; and
  - capacity to communicate and broadcast lessons learnt to support advocacy.

Step 3. Prepare capacity-building plans: An NGO/CSO capacity-building plan should be based on the situation analysis (component 1) and the identification of tasks (component 3). The **NCB collective capacity-building plan** would be similar and would include the main tasks for capacity-building and the organizations involved in each task. The aim should be to strengthen the comparative advantages of individual organizations and provide new skills where necessary. The NCB plan would aim to make sure that the NGOs/CSOs work together in a coordinated way and are able to implement all the TB activities that are needed in the communities they serve.

A capacity-building plan for each organization should generally include:

Capacity-building required building strengths, addressing gaps and weaknesses	What? actions needed (more than one may be required)	When? now/soon/later	Who? Who will be responsible?	Resources required technical, financial, other material resources
Identify the capacity-building area from the example checklist above, identify specific needs in that area.	Identify specific activities that are necessary to address the specific need.	Indicate the priority of this activity relative to other capacity-building needs.	Indicate which person, group or organization will ensure that this happens.	Include any external technical skills and funding or material resources required.

Step 4. Monitor and review progress: Capacity-building plans should be part of an organization's annual work plan, and managers should regularly **monitor capacity-building progress** against the stated objectives of the capacity-building plan. This will include not only **inputs**—training sessions attended, supervisory visits made, patients referred—but also **outputs**—did people who attended training retain the knowledge they gained, did supervision result in better practice, did referred patients actually complete the journey and use the service they were referred to? **Regular progress reviews** of the capacity-building plan should be included in quarterly management meetings. This will allow the plan to be revised if needed, in response to changing circumstances.

NTP   **Guidance for NTPs**

There should be agreement within the NTP on **capacity-building needs for NTP managers and health facility staff** to enable them to support community-based TB activities. There should also be a **shared understanding between the NTP and the NCB** of each other's capacity-building needs, so that each can help to facilitate and support the overall capacity-building required for the programme.

For example, it will be important for the NTP to ensure that health sector involvement in capacity-building for community-based TB activities includes both:

- technical capacity for activities such as screening or sputum collection, and

- social and communication skills for interacting with NGO/CSO staff, volunteers, representatives of patient groups and advocacy networks. These skills will greatly facilitate health worker–patient–carer interactions and will help patients to feel more confident about using TB services.

Involving NGOs/CSOs and representatives of patients and communities in NTP capacity-building makes use of their comparative advantage of knowing their communities and how they can build community engagement to increase support and use of TB services.

Achieving consensus on capacity-building will also help to **clarify the key objectives** of capacity-building by highlighting the most important capacities and skills for successful implementation of the ENGAGE-TB approach in a country or region.

The UNDP *Capacity development primer, Annex 1* (referenced below), may be helpful for NTPs in assessing their own capacity and planning and managing their collaborative work with NGOs/CSOs in the health and development sectors. The framework of the publication is based on the four core issues of capacity development:

- institutional arrangements,

- leadership,

- knowledge and

- accountability.

The NTP must also understand the capacities of NGOs/CSOs in order to engage them effectively. In the start-up phase of the ENGAGE-TB approach in a country, the NTP should identify which NGOs and CSOs are ready to participate and assess their current capacities and their potential to increase capacity. Special attention should be given to the capacity needs of smaller organizations that have limited access to resources.

The assessment will help the NTP to understand the capacity gaps of the NGOs/CSOs. It will also help the NTP to assess its own ability to respond to those gaps and needs. The plans for the NTP's own capacity-building in relation to community-based TB activities should be addressed within national strategic plans and national and subnational operational plans and budgets.

Capacity assessment will inform the development of an **NTP capacity-building plan** that should be aligned with and included in the annual national TB plan. Important areas for the NTP to analyse its own capacity-building needs may include the following areas:

- adequacy of staff and skills for effective engagement with communities;

- knowledge and skills to engage with NGOs/CBOs and collaborate with the NCB, patient groups and networks;

- capacity to provide or facilitate training, supervision or mentoring of NGOs/CBOs, including development and dissemination of appropriate training materials, job aids and other tools for use at community level;

- capacity for additional resource mobilization for community-based TB activities; and

- capacity for operational research to develop the evidence base on what works in community-based TB activities.

Capacity-building linkages and responsibilities: As the aim of the ENGAGE-TB approach is integration with other health and development programmes, there must be effective linkages and clear lines of communication between NTP managers and managers in the other sectors. In order for this to proceed smoothly, it may be necessary to negotiate who will be responsible for management, reporting, resourcing and capacity-building in NGOs/CSOs when TB activities are implemented within other programme activities.

Specific link persons might be appointed to coordinate activities between the different sectors. They must understand the importance and range of capacity-building for community-based TB activities. They may also need to improve their skills in negotiation, collaboration and resolution of differences in order to be effective in this role. Such skills will also be beneficial for NTP liaison with the NCB and with individual NGOs/CSOs.

Resources

Capacity. *Capacity.org—A gateway for capacity development*. Web-based resource portal.
(http://www.capacity.org/capacity/opencms/en/index.html, accessed 15 July 2013)

DFID and Evidence for Action Consortium. *Introduction to qualitative research methodology*. London, 2011
(http://r4d.dfid.gov.uk/PDF/Outputs/HIV_AIDS/qualitativeresearchmethodologymanual.pdf, accessed 15 July 2013).

International HIV/AIDS Alliance. *NGO/CBO capacity analysis tools: resource pack 02*. Brighton, 2010
(http://www.aidsalliance.org/publicationsdetails.aspx?id=436 (includes three toolkits); accessed 15 July 2013).

MEASURE-Evaluation. *A guide to monitoring and evaluation of capacity-building interventions in the health sector in developing countries*. Chapel Hill, North Carolina, 2007 (http://www.cpc.unc.edu/measure/publications/ms-03-07, accessed 15 July 2013).

United Nations Development Programme Global Fund Partnership. *Capacity development toolkit: strengthening the capacity of national entities to implement national responses to HIV and AIDS, tuberculosis and malaria*. UNDP online resource portal.
(http://www.undp.org/content/undp/en/home/ourwork/hiv-aids/focus_areas/focus_undp_gfp/capacity-development-toolkit/, accessed 15 July 2013).

United Nations Development Programme. *Capacity development: A UNDP primer*. New York, 2009
(http://www.undp.org/content/-undp/en/home/librarypage/capacity-building/capacity-development-a-undp-primer.html, accessed 15 July 2013).

Annex 1. Indicators for monitoring implementation

The ENGAGE-TB core indicators are essential for monitoring the contribution of community-based TB activities. They are part of the national monitoring system of the NTP. The indicators are designed to record two important results of community-based TB activities. The records are collected by the NTP and included in national TB reports. The two indicators are:

- referrals and notifications of new TB patients by community health workers and community volunteers and

- treatment success for new TB patients who received treatment adherence support from CHWs and CVs.

The two ENGAGE-TB core indicators:

What do the words mean?

Numerator: the top part of a fraction; usually the number of the action you are measuring, e.g. number of community referrals to the TB clinic

Denominator: the bottom part of a fraction, such as the total number of referrals to the TB clinic from all sources

Dividing the numerator by the denominator gives the proportion of referrals contributed by the community to the total number of referrals. Annual computations would show trends, such as whether the proportion of community contributions is increasing, decreasing or remaining the same.

Periodicity: simply, how often an indicator should be measured, such as quarterly (every 3 months) or annually (every year)

Indicator 1: Referrals and new notifications	
Definition	Number of new patients with TB (all forms) diagnosed and notified who were referred by CHWs and CVs, expressed as a percentage of all new TB patients notified in the BMU during a specified period
Numerator	Number of new patients with TB (all forms) referred by CHWs or CVs to a health facility for diagnosis and notified in the BMU(s) in a specified period
Denominator	Number of new patients with TB (all forms) notified in the BMU(s) in the same period
Purpose	To measure the level of engagement of CHWs and CVs in increasing new notifications of TB. It can also indicate the effectiveness of the referral system in ensuring the flow of people with presumptive TB from community-based structures to the BMU.
Method	A CHW is a person with some formal education who is trained to contribute to community-based health services, including TB prevention and patient care and support.
A CV is a community member who has been systematically sensitized about TB prevention and care, either through a short, 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 TB 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 CHWs and CVs" 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 CHWs and CVs to ensure that data are reported to the NTP 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 as having TB are tagged as having been referred by CHWs and CVs, supported either by an NGO/CSO or the NTP.
Responsibility	All stakeholders (NGOs/CSOs or the NTP or its equivalent) implementing community-based TB activities will ensure accurate data collection at community and facility levels.
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 TB is confirmed, they should then be recorded in the TB register as having been referred by a CHW or CV supported by either the NTP structure or NGOs/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.

Indicator 2. Treatment success

Definition	New patients with TB (all forms) successfully treated (cured plus completed treatment) who received support for treatment adherence from CHWs or CVs among all new patients with TB (all forms) provided with treatment adherence support by CHWs or CVs (number and percentage)
Numerator	Number of new patients with TB (all forms) successfully treated and provided with treatment adherence support by CHWs or CVs in the BMU(s) in a specified period
Denominator	Total number of new patients with TB (all forms) given treatment adherence support by CHWs or CVs 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 CHWs or CVs by patients with TB as treatment adherence support providers.
Method	A CHW is a person with some formal education who is trained to contribute to community-based health services, including TB prevention and patient care and support. A CV is a community member who has been systematically sensitized about TB prevention and care, either through a short, specific training scheme or through repeated contact with professional health workers. Both can be supported by NGOs/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. Treatment adherence includes all efforts and services provided by CHWs and CVs 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.
Periodicity	Quarterly and annually
Strengths and limitations	Monitors how well treatment adherence is supported by the community-based activities of NGOs/CSOs or the government.
Responsibility	All NGOs/CSOs and the NTP or its equivalent implementing community-based TB activities will ensure that data are collected at community and facility levels. NTPs 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

The NTP will organize evaluation of community-based TB activities every three to five years. NGOs/CSOs will be asked to participate in this process, with external reviewers.

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/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 the people involved, the factors in success and the overall interest and drive of the NTP in involving NGOs/CSOs in TB activities.

Indicators	• Existence of a NCB
	  - trends in membership
	  - frequency of meetings
	  - spread to subnational levels
	  - coordination between levels
	  - mechanisms for transferring knowledge, skills and resources
	• Quality of interaction with the NTP at various levels
	  - frequency of meetings
	  - quality of follow-up on agreed actions
	  - availability of TB diagnostic services and drugs
	• The relative contributions of NGOs/CSOs and of the government to new case notifications and treatment success, with trends in these variables over time
	• Challenges and hurdles faced by different actors in government and civil society as well as successes and new opportunities

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/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/CSOs at various levels.
	The emphasis should be on sharing and learning in order to understand and improve the programme, rather than fault-finding or "finger-pointing".
Periodicity	Every 3–5 years
Strengths and limitations	Provides a periodic assessment of the contributions of NGOs/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/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.

Annex 3. Useful resources and references

This annex gives a complete list of the resources and references included in the sections of this manual, in alphabetical order. Web links are also included for each resource or reference, but these may change over time. If a web link does not work, try a web search using the title of the document. It is also useful to check the WHO TB website pages from time to time, including the Community engagement/ENGAGE-TB pages, to find up-to-date information and guidance.

American Society for Advancement of Project Management and World Bank Institute. *Analyzing the project context: actors and factors*. Colorado Springs, 1998 (http://www.asapm.org/asapmag/a_af.html, accessed on 15 July 2013)

Arkangelo Ali Association. TB *HIV training manual for community health workers, trainers' manual*. Nairobi, 2009 (http://www.hciproject.org/chw-central/resources/tb-hiv-training-manual-community-health-workers, accessed 15 July 2013).

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CORE Group TB Working Group. *Community-based tuberculosis prevention and care: why—and how—to get involved. An international handbook for nongovernmental organizations and civil society organizations*. Washington DC, 2013 (http://www.coregroup.org/resources/342-community-based-tuberculosis-prevention-and-care, accessed 15 July 2013).

DFID and Evidence for Action Consortium. *Introduction to qualitative research methodology*. London, 2011 (http://r4d.dfid.gov.uk/PDF/Outputs/HIV_AIDS/qualitativeresearchmethodologymanual.pdf, accessed 15 July 2013).

Family Health International, Tuberculosis Coalition for Technical Assistance. *Engaging community-based organizations in TB/HIV collaborative activities: a case study in Nigeria*. Arlington, Virginia, 2008 (http://pdf.usaid.gov/pdf_docs/PNADO895.pdf, accessed 15 July 2013).

Family Health International. *Establishing referral networks for comprehensive HIV care in low-resource settings*. Arlington, Virginia, 2005 (http://pdf.usaid.gov/pdf_docs/PNADF677.pdf, accessed 15 July 2013).

Family Health International. *Tools for establishing referral networks for comprehensive HIV care in low-resource settings*. Arlington, Virginia, 2005 (http://pdf.usaid.gov/pdf_docs/PNADI858.pdf, accessed 15 July 2013).

Family Health International. *Simplified checklist for TB infection control*. Arlington, Virginia, 2011 (FHI 360) (http://www.tbcare1.org/publications/toolbox/tools/ic/TB_Infection_Control_Simplified_Checklist.pdf, accessed 15 July 2013).

Family Health International. *TB infection control at the community level: a training handbook*. Arlington, Virginia, 2011 (FHI 360) (http://www.tbcare1.org/publications/toolbox/recent/TB_IC_at_Community_Level_Training_Handbook.pdf, accessed 15 July 2013).

Global Network of People Living with HIV. *Human rights and stigma—the stigma index* (http://www.gnpplus.net/en/resources/human-rights-and-stigma, accessed 15 July 2013).

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