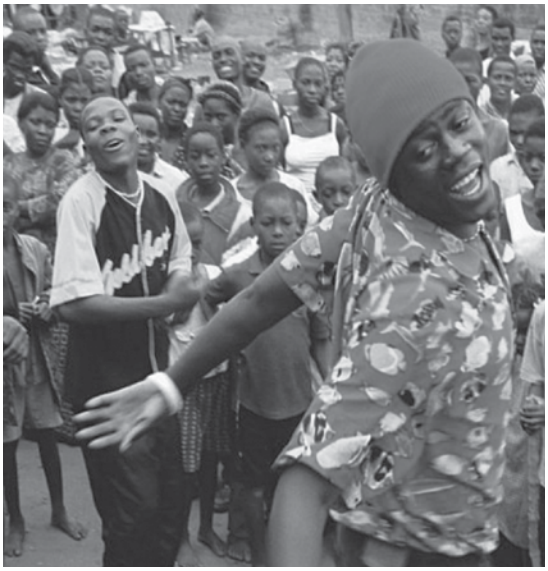
International HIV/AIDS Alliance

PATH

Supporting community action on HIV, health and rights to end AIDS

Community-based TB and HIV integration



GOOD PRACTICE GUIDE

How was this guide developed?

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Good practice guide series

This guide is one in a series of good practice guides produced by the International HIV/AIDS Alliance (the Alliance). This series brings together expertise from our global community-level HIV programming to define and guide good practice in a range of technical areas, including:

- Human rights and GIPA
- HIV prevention
- Sexual and reproductive health and rights and HIV integration
- TB and HIV integration
- HIV programming for children
- HIV and drug use

Alliance good practice guides are:

- user-friendly 'how to' guides
- targeting HIV programmers working in community settings in developing and transitional countries
- helping to define what is good practice for community-level HIV programmes.

To download Alliance publications, please visit **www.aidsalliance.org/publications**.

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Alliance good practice HIV programming standards – TB and HIV integration

This good practice guide is accompanied by the Alliance good practice standards. Implementing these standards is one of the ways that the Alliance, our partners and other organisations can define and promote a unified and quality-driven approach to HIV-related programming. The Alliance uses an assessment of whether an organisation meets these programming standards in its accreditation process. It then uses the results of the assessment to develop an action plan to strengthen integrated programming. You can also use the standards to perform a self-assessment of how your organisation is doing.

The standards below represent the important components of good practice for TB/HIV integration that all community organisations should strive to reach. They are based on scientific evidence and our experiences in HIV programming. In reality, few organisations working in TB or HIV have the opportunity or resources to design and implement a comprehensive programme of all the services that these standards cover. To begin, pay particular attention to the standards that are relevant for the work you are doing now, and plan to meet the other standards as your organisation has the opportunity and means to do so. An alternative is to partner with other groups that can complement the services you provide to build a more comprehensive package.

Throughout this guide, we will alert you to content that will help you meet these good practice standards.

KEY RESOURCE

The full Alliance good practice HIV programming standards for a range of technical areas can be found at:

English version
www.aidsalliance.org/Publicationsdetails.aspx?Id=451

French version
www.aidsalliance.org/Publicationsdetails.aspx?Id=452

Spanish version
www.aidsalliance.org/Publicationsdetails.aspx?Id=453

ALLIANCE GOOD PRACTICE HIV PROGRAMMING STANDARDS FOR TB AND HIV INTEGRATION	
Good practice standard 1	Our organisation implements an organisational strategy that supports the integration of TB/HIV activities.
Good practice standard 2	Our organisation collaborates with other TB and HIV organisations working in our country and our TB/HIV work is aligned with the strategies and objectives of the national AIDS and TB programmes.
Good practice standard 3	Our organisation actively engages TB- and HIV-infected and affected community members in planning, implementing, and evaluating our TB/HIV activities.
Good practice standard 4	Our organisation ensures that all people living with HIV have access to TB screening, co-trimoxazole preventive therapy, and either isoniazid preventive therapy or full TB treatment as appropriate.
Good practice standard 5	Our organisation ensures that all people offered HIV testing also receive understandable information about the risks of TB infection and TB disease.
Good practice standard 6	Our organisation provides people with TB symptoms, TB infection, or confirmed TB disease with information on HIV and refers them for HIV counselling and testing.
Good practice standard 7	Our organisation implements infection control guidelines that reduce the risk of TB transmission to people living with HIV, including those who work or volunteer for our organisation.
Good practice standard 8	Our organisation implements strategies to address both TB- and HIV-related stigma.

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ABBREVIATIONS

ACSM	Advocacy, communication, and social mobilisation
AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
CBO	Community-based organisation
CCM	Country coordinating mechanism
CPT	Co-trimoxazole preventive therapy
CSO	Civil society organisation
DFID	Department for International Development (UK)
DOT	Directly observed therapy
FDCs	Fixed-dose combination drugs
HCT	HIV counselling and testing
HIV	Human immunodeficiency virus
IEC	Information, education, and communication
IPT	Isoniazid preventive therapy
MDR-TB	Multidrug-resistant tuberculosis
MOU	Memorandum of understanding
NGO	Non-governmental organisation
NTP	National tuberculosis programme
PATH	Program for Appropriate Technology in Health
STI	Sexually transmitted infection
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
XDR-TB	Extensively drug-resistant tuberculosis

Foreword

Conquering TB is everybody's business. An airborne infectious disease, it afflicts almost nine million people a year and kills more than one million, sparing no one – young, old, rich, poor, male or female. The burden of this age-old killer falls disproportionately on the people who have the fewest resources to cope with it. The poor, the very young, the elderly, people living with HIV, drug users, prisoners, and other groups who are marginalised by society represent the populations most affected. TB kills more women of reproductive age each year than all pregnancy-related conditions combined, and it is the fourth leading cause of death in girls and young women between the ages of 10 and 19 in low-income countries. Despite the need to combat TB, most governments and their national TB programmes often lack the political will and the human and financial resources to do so effectively.

The global community has set an ambitious vision for itself: a TB-free world. Getting there will require a massive, coordinated, and urgent mobilisation of all available resources – human, financial, and technical. We need new drugs that can treat TB more quickly and effectively. We need to speed up the uptake of new, rapid diagnostic tests. We must redouble our efforts to find an effective vaccine to prevent TB. And we must strengthen our health systems to be able to deliver these new products efficiently to the people who need them most.

In this context, there is an urgent need to engage actively with the community-based organisations that are already so important in strengthening and supporting our formal health systems. Our community partners represent a vastly under-utilised resource that can help take the fight against TB to the next level. While their participation is critical, and has been recognised in many recent documents and initiatives, community groups have often been on the sidelines of the TB response. Many national TB programmes do not have experience of working effectively with community groups and want guidance on how to do so. In addition, many community-based organisations do not know how to start TB programming.

We welcome this initiative by the International HIV/AIDS Alliance and PATH to provide guiding principles and practical steps for community-based organisations intending to start TB programming. It offers easy-to-understand explanations of TB and TB/HIV co-infection, and provides sensible advice on how community-based organisations can work collaboratively with the national TB programmes in their countries. These community-based groups are already making a positive contribution towards improving health outcomes in their countries and this guide will be useful in adding TB to their health agenda.

We want to end TB in our lifetimes. We know it's possible if we all work together towards this common goal. We hope all of you will make full use of the information in this guide to join us in the fight to stop TB.

With best wishes for your success,

Dr Lucica Ditiu
Executive Secretary, Stop TB Partnership, Geneva, Switzerland

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Programme Manager, National Tuberculosis Control Programme, Ghana

Ms Carol Nawina Nyirenda
Executive Director, Community Initiative for Tuberculosis, HIV/AIDS and Malaria, Zambia

Background

What is this guide about?

Tuberculosis (TB) is one of the greatest threats to the health of people living with HIV in resource-poor settings. There is an urgent need to engage communities and build the capacity of community-based organisations (CBOs) to respond to the burden of TB on people living with HIV and to mobilise more global, national, and local resources to fight TB. This guide responds to requests by CBOs for information and guidance on TB integration in HIV programming. It is based on direct experiences in working with HIV service organisations in the field on TB advocacy, communication, and community/social mobilisation activity planning. It is meant to be a practical, hands-on tool you can use in your organisation to plan and implement realistic and effective TB activities in the communities where you work.

What information does it contain?

This guide will provide you with the practical information and tools you need to get started working on TB. It provides you with easy-to-understand information on TB/HIV. It also includes an accompanying workbook to guide you through a step-by-step process to plan and implement effective activities in your area, whether you work in one district of your province or in the whole country.

Specifically, this guide does the following:

- describes the International HIV/AIDS Alliance (the Alliance) good practice standards for TB/HIV integration
- provides basic TB and TB/HIV facts
- describes international policies and guidelines on TB
- highlights the kinds of TB/HIV activities community organisations can support
- discusses how to engage effectively with your national TB programme and how to create strong partnerships for TB
- explains how to analyse and interpret TB data to better understand the TB challenges of your country, province, or district
- identifies the steps you can take to select, plan, and monitor your TB activities
- suggests approaches you can use to help fund these activities.

This is *not* a clinical guide to TB/HIV that details all the necessary medical knowledge, clinical presentations, treatment protocols, programmatic guidance, or ***monitoring and evaluation*** (M&E), but it will give you a solid basis from which to start. Throughout the guide, we list additional reference materials that do contain these details should you want to gain in-depth knowledge of any of these areas.

Who should use this guide?

This guide is intended for use by CBOs, other civil society organisations (CSOs), and additional groups that work in HIV or other areas of health and want to incorporate TB activities into their programming. It is useful for organisations that are just starting to work in TB as well as those with more experience.

How should it be used?

Use this guide as a reference and a tool to plan your activities. Depending on your level of experience with TB, you may need to read all the background information on TB, or you may be able to review that information quickly. In either case, understanding the background sections will make the rest of the guide easier to follow. Once you are acquainted with the TB basics, you can go on to Chapter 3, the "how-to" part of the guide, which will lead you through steps in a process to plan the integration of effective TB activities into your HIV programming.

The "how-to" parts of the guide are accompanied by a workbook with templates that allow you to complete each step in the process for your own organisation. The workbook is available electronically so that you can modify the templates as needed to fit your situation. It is available, along with an electronic version of this guide, at: **http://www.aidsalliance.org/Publicationsdetails.aspx?Id=90632**

We recommend that you read through one "how-to" step in the guide, and then try to complete the accompanying section of the workbook so that you build your TB integration plan as you go along. By the time you are finished with the guide and the workbook, you should have all of the elements of your TB/HIV integration plan completed!

Throughout this guide, you will notice icons that highlight different types of information:

- key resources highlight additional resources for those who want to learn more
- case studies highlight examples from the field that illustrate practical points and lessons learnt from integrating certain aspects of TB activities
- workbook activities correspond to accompanying tools in the workbook
- Alliance good practice standards that apply to your TB/HIV programming
- key messages summarise the important messages.

About the terms used in this guide

The Alliance is committed to a rights-based approach that values dignity, equality and diversity. As such, we understand the importance of words in setting the tone for how people with TB or both TB and HIV are treated. We support a person-centred approach to addressing both TB and HIV, and we support the use of terms that do not have negative associations. Therefore, in this guide, we have largely replaced the older commonly used terms such as "TB suspect," "TB patient," and "defaulter" with terms that respect each person's self-esteem and autonomy and do not add to the burden of stigma for those who are infected or affected by these diseases. In this guide, we use the newer international guidance on terminology, such as "person with presumptive TB," "person with TB," or "person lost to follow-up" to support the rights and dignity of people living with TB or HIV. We encourage you to do the same in your organisation's work. However, we also recognize that much of the data that you will use in your work are recorded using the previous terms because they have a specific epidemiological meaning. So when we discuss data and its analysis, we will continue to refer to the old terms to avoid confusion when you are reviewing your country's data.

This guide is meant to support the work of CBOs and other civil society groups. When we refer to these groups, we will use the umbrella term "civil society organisations," or CSOs, to cover all of the groups that would fall under that heading – community-based, faith-based, or otherwise.

Throughout the guide, words that appear in ***bold–italic*** are defined in the glossary.

ICONS USED IN THIS GUIDE

Key resources

Case study

Workbook activity

Good practice standard

Key message

WORKBOOKS

The "how-to" parts of the guide are accompanied by a workbook with templates that allow you to complete each step in the process for your own organisation.

These are available with this good practice guide at: **http://www.aidsalliance.org/Publicationsdetails.aspx?Id=90632**

Introduction to TB and HIV integration

In this chapter:

- Facts about TB/HIV co-infection
- Why integrate TB and HIV activities?
- What does integration really mean?

The global HIV and TB epidemics fuel each other. The rapid increases in the burden of TB that the world experienced during the 1980s, particularly in sub-Saharan Africa, happened as a result of the HIV epidemic. At that time, large numbers of people with HIV were made more vulnerable to TB because of their weakened immune systems. TB spread rapidly in those countries hardest hit by HIV, and in some countries the number of people with TB increased ten-fold compared to the years before the HIV epidemic. TB also led to the deaths of many HIV-infected people in the early years of the epidemic, before antiretroviral therapy (ART) was widely available. Although the situation is vastly improved today, **TB is still the most common opportunistic infection and cause of death among people living with HIV.** While TB is a curable disease and HIV is treatable, too often people do not access services quickly enough, or do not have access to prevention, or are in other ways unable to get the help they need to stay healthy and live long, productive, happy lives. More has to be done to fight these two diseases, and community organisations have an important role to play. The rest of this guide will help you understand how your organisation can contribute to this effort.

Facts about TB/HIV co-infection

TB and HIV are "double trouble" for people living with both diseases: TB can thrive in people whose immune systems have been weakened by HIV, and HIV can replicate faster in people who are ill with TB. People who are ***co-infected*** with TB/HIV face a higher risk of severe illness and death as a result of the interaction between the two diseases.

They are also subjected to double stigma, that is, both TB- and HIV-related stigma. In some cases, this is often layered on top of other stigma related to specific behaviours or social circumstances that expose people to HIV or TB, for instance, drug use or frequent imprisonment. The good news is that TB can be cured in people living with HIV just as it can in other people. The key to a TB cure for people living with HIV is to be aware of TB symptoms, to seek health care early if symptoms appear, and to take a full course of TB treatment. In addition, ART is powerful in preventing TB disease in those who take it, particularly in combination with isoniazid preventive therapy (IPT).

Why integrate TB and HIV activities?

In most countries, national TB and HIV programmes are separate entities with varying degrees of collaboration. As a result, TB and HIV services are often delivered separately, sometimes at different levels of the health system. This not only increases the burden and inconvenience to the clients who have to access these services, but also increases the cost to the health system. With integration of TB and HIV services, the goal is to make it easier for the person who has both TB and HIV to access all of the services he or she needs as efficiently as possible.

What does integration really mean?

There are different degrees of integration of TB and HIV services, and different models may work better in certain settings, so there is no one right answer about how services are best integrated. An important consideration is what model the clients of these services prefer. It is essential to involve them in discussions about this issue before an approach is decided. Community organisations can play a big role in ensuring the voices of the infected and affected communities are included in discussions about health service structuring for TB/HIV integration, considering the advantages and disadvantages of each model from the client perspective.

> "Every day, a thousand people living with HIV die of TB. Their deaths just aren't acceptable when TB is preventable and curable with inexpensive drugs. We need to intensify the integration of HIV and TB services at every level of the health system. We need a stronger focus on preventing, diagnosing and treating TB in children living with HIV, who are particularly vulnerable to TB infection. All TB patients living with HIV must be put on antiretroviral therapy as soon as possible. For patients, integrating HIV and TB services means a better quality of life. They spend less time going from clinic to clinic and waste less money on visits to multiple care providers. It can also mean the difference between life and death.
>
> MICHEL SIDIBE, EXECUTIVE DIRECTOR OF UNAIDS, FROM HIS SPEECH ABOUT HIV AND TB INTEGRATION FOR WORLD TB DAY 2012

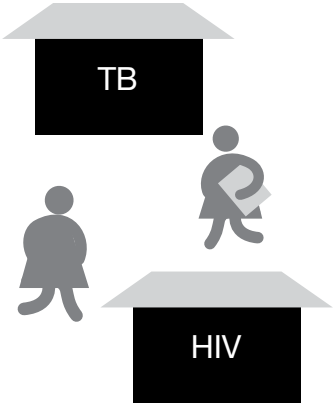
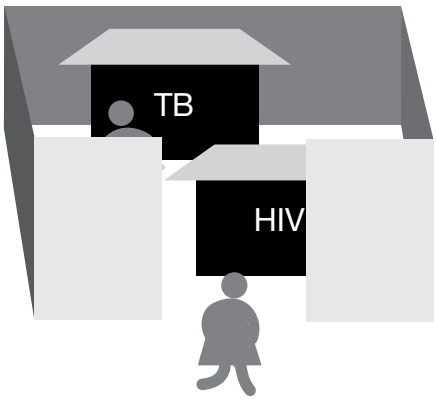
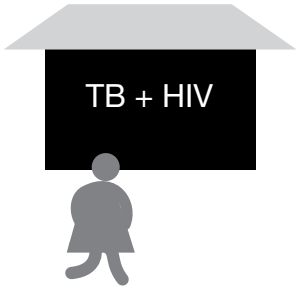
When we talk about TB/HIV integration for CSOs, we refer not only to how you can support a movement toward more health system integration of TB and HIV services, but also how your organisation can add TB activities into your ongoing HIV work in the community to increase the impact of both activities and provide more comprehensive services to your clients. As we go through the "how-to" steps in this guide, you will list your current HIV activities and then consider what TB-related activities could be added most easily. For example, if you are providing home-based care for people living with HIV, you may be able to perform TB symptom screening and referral or TB treatment support for members of those households without much additional training or expense.

Below are three possible models of TB/HIV integration within the health system, from least to most integrated.

There are advantages and disadvantages to each of these models of integration. In the first model, with separate services, the advantage is mostly that these services already exist and little change is needed in the health system to provide the services. The disadvantages include the time, effort, and expense required for clients to access the services they need, which in turn increase the likelihood of not getting those services. From the health provider perspective, it also means that information may not be shared as efficiently and clients may not get the most appropriate care as a result.

In the second model where all services are provided at the same facility, it makes it easier for clients to access services, but it may still be confusing and time-consuming for them to do so. This is especially true where facilities are large or

Figure 1: Models of TB/HIV integration in the health system

MODEL 1	MODEL 2	MODEL 3
CROSS REFERRALS BETWEEN TB AND HIV SERVICE POINTS (THE LEAST INTEGRATED)	**PARTIAL INTEGRATION AT THE SAME SERVICE LOCATION**	**FULLY INTEGRATED TB AND HIV SERVICES UNDER ONE ROOF/ BY THE SAME STAFF (THE MOST INTEGRATED)**
		
TB and HIV services are separate. People must seek HIV testing services, HIV care and treatment support at a different location than the TB clinic. TB/HIV services are linked by a referral system. This is currently the most common model.	Partial integration is achieved through deliberate efforts by health providers and facilities to ensure that services can be delivered on the same day, within the same facility, but not by the same staff or in the same clinic.	TB and HIV services (counselling and testing for HIV, ART, TB screening and treatment) are provided in the same place by the same staff (under one roof).

Adapted from Chifundo, K. et al (2010). What is the best model of TB/HIV service delivery? Experience from Malawi. XVIII International AIDS Conference, Abstract no. MOPE0858.

the queues to access services are long. And information may still not be shared very efficiently.

In the most integrated model, clients need to access only one location and information is readily available about both TB and HIV status and treatment. However, the possibility of TB transmission from one person to another increases, and infection control precautions must be in place to ensure the safety of clients who are not infected with TB.

The choice of how the health system will integrate services depends on many factors, such as the availability of human resources, location of existing facilities, government policies, and infection control considerations. CSOs can play an important role in advocating for an integration model that makes the most sense for the clients they serve.

The Alliance good practice standards for TB/HIV integration listed at the beginning of this guide describe the elements of integration that are most relevant to CSOs.

TB AND HIV FACTS AT A GLANCE

- At least one-third of the 34 million people living with HIV worldwide are infected with latent TB. People co-infected with TB/HIV are 21–34 times more likely to develop active TB disease than people without HIV.
- TB is the most common reason that people living with HIV seek health care, including those who are taking ART. There were an estimated 1.1 million people with HIV diagnosed with TB disease globally in 2011. Around 79% of these people live in sub-Saharan Africa.
- TB is the leading cause of death among people living with HIV, accounting for one in four HIV-related deaths. In 2011 some 430,000 people died of HIV-associated TB. Although globally the numbers of HIV-associated TB deaths were similar among men and women, in the African region more deaths are estimated to have occurred among women than men, whilst in other regions more deaths are estimated to occur in men.
- People living with HIV are facing emerging threats of drug-resistant TB such as multi-drug resistant (MDR-TB) and extensively drug resistant TB (XDR-TB). Worldwide, there were an estimated 310,000 people with MDR-TB among all notified people with pulmonary TB in 2011.
- HIV counselling and testing should be offered to all people with TB symptoms or with diagnosed TB. Globally in 2011, 40% of people with TB (2.5 million) were tested for HIV and accessed HIV prevention, treatment and care services, up from 33% (2.1 million in 2010). We are still far from our goal of 100%.
- Antiretroviral therapy (ART) and co-trimoxazole preventive therapy (CPT) should be given to all people co-infected with TB/HIV, regardless of their CD4 counts. Of the people who were known to be co-infected with TB/HIV in 2011, 48% (over 258,000) were enrolled on ART and 79% (410,000) were enrolled on CPT. We still have much work to do to reach our target of 100% on both ART and CPT.
- ***The Three I's*** for TB/HIV (intensified case finding for TB, isoniazid preventive therapy (IPT), and infection control) will reduce the burden of TB among people living with HIV and therefore must be urgently implemented by all HIV services.
  - > The number of people living with HIV who were screened for active TB (an element of "intensified case finding") increased from 2.3 million in 2010 to 3.2 million in 2011, representing less than 10% of the 34 million people estimated to be living with HIV. Our target is 100%.
  - > Once active TB is ruled out, people living with HIV should receive IPT. Among the 29 countries that reported data for 2011, IPT was provided to 446,000 people living with HIV more than double the 201,000 receiving it in 2010.
  - > TB infection control measures are still not implemented in many HIV service settings.
- People living with HIV need early diagnosis and treatment of active TB disease. The GeneXpert MTB/RIF rapid test is recommended as the initial diagnostic test for people living with HIV who have symptoms of TB.

SOURCE: Adapted from WHO TB/HIV Facts 2012–2013. Available at: **www.who.int/tb/publications/factsheet_tbhiv.pdf**

THE ROLE OF COMMUNITY ORGANISATIONS IN TB/HIV INTEGRATION ACCORDING TO THE WHO POLICY ON COLLABORATIVE TB/HIV ACTIVITIES

A.3.3 Involving non-governmental and other civil society organisations and communities

Expanding collaborative TB/HIV activities beyond the health sector through meaningful involvement with communities, non-governmental and civil society organisations and individuals in the planning, implementation and monitoring of TB/HIV activities at all levels is crucially important. People at risk of or affected by TB and HIV as well as community-based organisations working on advocacy, treatment literacy and community mobilisation are key actors in generating the required demand for integrated services at all levels of care. Their recognition and support, including financial support, is therefore critical. Advocacy targeted at influencing policy and sustaining political commitment, programme implementation and resource mobilisation is very important to accelerate the implementation of collaborative TB/HIV activities.

Services for TB prevention, diagnosis, treatment and care can be integrated with those for HIV, and vice versa, through community-based organisations such as community-based TB care or HIV home-based care. Trained home-based care and community health-care workers as well as non-governmental organisations have been successful in providing TB and HIV services in various countries. Community-based TB and HIV care services are cost effective. While implementing collaborative TB/HIV activities, it is imperative that civil society organisations including non-governmental and community-based organisations advocate, promote and follow national TB and HIV guidelines, including monitoring and evaluation of TB/HIV activities using nationally recommended indicators. The strengths of NGOs and other CSOs, include their reach and spread, and their ability to engage marginalised, remote and vulnerable groups.

SOURCE: World Health Organization (2012). 'WHO policy on collaborative TB/HIV activities: guidelines for national programmes and other stakeholders' (p.19). Available at: **www.who.int/tb/publications/2012/tb_hiv_policy_9789241503006/en/index.html**

- TB is the most common opportunistic infection and the leading cause of death among people living with HIV.
- Integrating TB and HIV services is an important action to improve the accessibility of these critical health services to the clients who need them.
- There are different models for integrating services. Client preferences, along with the realities of the existing health system, should be taken into account when deciding what model is most appropriate in your setting.
- The International HIV/AIDS Alliance has developed a set of eight Good Practice Standards to help guide CSOs in their work on TB/HIV.

2 TB and HIV integration activities for community organisations

In this chapter:

- What can CSOs do to support TB/HIV integration?
- Case study: Giving back: community support for TB/HIV treatment in Zanzibar

HUMAN RIGHTS AND TB

There are many issues related to TB and human rights that cannot be thoroughly covered in this guide. For a good summary of these issues and a list of important resources, please see the Stop TB Partnership TB and Human Rights Task Force's *Working Document on TB and Human Rights*.

Available at: **www.stoptb.org/assets/documents/global/hrtf/Briefing%20note%20on%20TB%20and%20Human%20Rights.pdf**

This chapter summarises the activities CSOs can undertake in TB/HIV integration. It will give you an understanding of the wide range from which you can choose and why they are important. Many of you are already familiar with these activities, so they are not described in great detail. However, before you decide on which activities to do, you will need to know much more about the specific situation in your country and how your organisation can best support the goals and objectives of the national AIDS and TB programmes. Those topics will be covered in Chapter 3 of this guide.

In general, activities that CSOs are involved in aim to:

- advocate for policy changes or additional resources
- educate the community about TB/HIV
- support the human rights and dignity of people with TB and HIV
- mobilise communities to participate actively in TB and HIV prevention, care, and treatment
- deliver health services to community members who need them.

Regardless of what sort of activities your organisation chooses to do, a planning framework can be useful in helping you to develop, plan, implement, and evaluate your activities. Such a framework will be introduced in Chapter 3.

In addition, it is important for you to know and understand the global targets for TB and HIV. These targets continue to change and evolve as new strategies are developed and new tools become available. To become familiar with the latest global targets for TB/HIV, you can visit the Stop TB Partnership's website at **www.stoptb.org** to download the current Stop TB Strategy with TB-related targets, or the Joint United Nations Programme on HIV/AIDS (UNAIDS) website at **www.unaids.org/en/targetsandcommitments/avoidingtbdeaths** to download information about TB-related HIV targets.

What can CSOs do to support TB/HIV integration?

As we all know, CSOs working in HIV have many existing strengths that can be built on to help in the fight against TB. In general, CSOs working in HIV have strong links with the community – their members are often part of the infected and affected communities served by their activities. They have systems in place for training staff and volunteers, providing outreach, treatment literacy education, and treatment support to the community, and working with local health facilities. They also provide low-cost, culturally appropriate and often highly effective support to the communities they serve. In addition, they often have strong ties to the national AIDS programme and may participate in local or national working groups. All of the lessons CSOs have learned in doing this work will be very useful in expanding activities to include TB.

Unlike HIV, however, TB is an area of health in which civil society participation has not been an integral part of the strategy from the beginning. When TB control began, it focused on a very medical model of infectious disease control that was based within health facilities and run by medical personnel. No specific role was envisioned for the community. It continued that way for many years, and even today, with the community's role affirmed in the Stop TB Strategy, CSOs often struggle to claim their rightful place in decision-making and action on TB. At the same time, NTPs remain unsure of the value-added that CSOs can provide to their efforts. As a CSO, your job is to establish your organisation as a credible partner with clear benefits to offer to the programme in your country. This guide will help you do so.

INTRODUCTION TO THE WHO POLICY ON COLLABORATIVE TB AND HIV ACTIVITIES

One very important document for all organisations working in TB/HIV integration to read is the *2012 WHO policy on collaborative TB/HIV activities* (available at: **www.who.int/tb/publications/2012/tb_hiv_policy_9789241503006/en/index.html**). We recommend that your organisation download this document and print at least one copy to use as a reference. If your country has developed its own policy on integration, it is also essential for you to be familiar with its guidance, so that your activities are aligned with national and international standards.

The policy describes the recommended activities for countries to implement to ensure universal access to TB and HIV prevention, care, and treatment. This will be an important guide for you as you think about what activities your organisation can undertake to support TB/HIV integration. The list below summarises the WHO-recommended activities. It is also important for you to read the details in the full document to understand clearly how your organisation can use its strengths to contribute to these activities.

WHO-recommended collaborative TB/HIV activities

A. Establish and strengthen the mechanisms for delivering integrated TB and HIV services
   - A.1. Set up and strengthen a coordinating body for collaborative TB/HIV activities functional at all levels
   - A.2. Determine HIV prevalence among people with TB and TB prevalence among people living with HIV
   - A.3. Carry out joint TB/HIV planning to integrate the delivery of TB and HIV services
   - A.4. Monitor and evaluate collaborative TB/HIV activities

B. Reduce the burden of TB in people living with HIV and initiate early antiretroviral therapy (the Three I's for HIV/TB)
   - B.1. Intensify TB case-finding and ensure high quality anti-tuberculosis treatment
   - B.2. Initiate TB prevention with isoniazid preventive therapy and early antiretroviral therapy
   - B.3. Ensure control of TB infection in health-care facilities and congregate settings

C. Reduce the burden of HIV in people with presumptive and diagnosed TB
   - C.1. Provide HIV testing and counselling to people with presumptive and diagnosed TB
   - C.2. Provide HIV prevention interventions for people with presumptive and diagnosed TB
   - C.3. Provide co-trimoxazole preventive therapy for people with TB/HIV
   - C.4. Ensure HIV prevention interventions, treatment and care for people with TB/HIV
   - C.5. Provide antiretroviral therapy for people with TB/HIV

KEY RESOURCE

2012 WHO policy on collaborative TB/HIV activities.

Available at: **www.who.int/tb/publications/2012/tb_hiv_policy_9789241503006/en/index.html**

THE THREE I'S

Not only does HIV increase the risk for TB, but TB disease also increases the replication of the HIV virus in the body, speeding up the progression of the HIV infection. Conversely, treating TB will slow down HIV replication. For all of these reasons, it is very important for countries to implement the Three I's for people living with HIV:

- **intensified TB case finding;**
- **isoniazid preventive therapy; and**
- **infection control**.

The Three I's are an important component of the global strategy to reduce the burden of TB in people living with HIV. You can read more about the Three I's at: **www.who.int/hiv/topics/tb/3is/en/index.html.** There you will find links to key technical documents to support implementation of Three I's activities.

KEY RESOURCE

Patients Charter for Tuberculosis Care.

Available at: **www.who.int/tb/publications/2006/istc_charter.pdf**

World Health Organization (2012). ENGAGE-TB. 'Integrating community-based tuberculosis activities into the work of nongovernmental and other civil society organizations. Operational guidance.'

Available at http://www.who.int/tb/people_and_communities/en/index.html

The list below summarises the major types of CSO activities for TB/HIV, all of which support the international guidance on TB/HIV integration. This is not a complete list of all the things CSOs can do. Do not feel limited if there are other important activities your organisation would like to implement.

Develop organisational skills in TB/HIV integration

- Plan and implement TB/HIV programme activities.
- Recruit and manage volunteers and community health workers
- Train and supervise volunteers and community health workers to deliver information and care to the community.
- Create strong linkages with the local TB programme staff and work with them set up a standardised referral and communication system.

Raise community awareness on TB/HIV

- Provide understandable written information on TB/HIV to community members.
- Hold community meetings, perform street theatre, develop radio shows, and so on to communicate messages about TB/HIV.
- Increase demand for integrated TB/HIV services through education and outreach.
- Introduce the *Patients Charter for Tuberculosis Care* (translated into your local languages) to inform people with TB/HIV about their rights and responsibilities. (You can find the charter at **www.who.int/tb/publications/2006/istc_charter.pdf**).

Reduce stigma and support the human rights of people with TB and HIV

- Address fear and misconceptions through effective communications.
- Monitor and fight against stigma and discrimination.
- Normalise public discussions of these illnesses and mobilise different segments of society to fight against stigma.
- Advocate for the rights of people with TB and HIV to treatment and compassionate care.
- Offer community treatment support as an alternative to forced hospitalisation or detention for people with drug-resistant TB.

Support intensified case-finding

- Screen people living with HIV for TB symptoms and refer them for examination at their nearest health facility.
- Collect and transport ***sputum*** for laboratory analysis to reduce the travel burden for people with TB symptoms, especially those who are very weak.
- Trace ***close contacts*** of people with TB and encourage them to go for examination at a health facility if they have symptoms of TB or if they are in a high-risk group for TB (e.g. people living with HIV, children less than five years of age).
- Provide education and counselling to people with TB and refer them for HIV testing.
- Monitor access to care for marginalised groups and ensure referral systems are working.

GOOD PRACTICE STANDARD 2 (COLLABORATING WITH OTHER TB AND HIV ORGANISATIONS TO ACHIEVE THE OBJECTIVES OF THE NATIONAL HIV AND TB PROGRAMMES) AND STANDARD 4 (TB SCREENING AND REFERRAL).

CASE STUDY: GIVING BACK: COMMUNITY SUPPORT FOR TB/HIV TREATMENT IN ZANZIBAR

Mohammed Sultan used to be a client of the Detroit Recovery Project, but now he's a member of Tupambane na Kifua Kikuu na UKIMWI, (TUKIKIZA) a community-based organisation where he works to create community awareness on TB and TB/HIV and contribute to TB case finding in Zanzibar. Mohammed has worked at Detroit Sober House, a recovery centre for people with substance abuse problems, for three years. He used cocaine for many years before he joined the Sober House. Now he supports newcomers to Sober House as well as other projects.

In 2011, Mohammed and 19 others from TUKIKIZA participated in training on TB and TB/HIV organised by PATH with USAID support. He learnt how to screen and refer people who may have TB for proper diagnosis and treatment, support clients on TB treatment, and provide referral for drug addiction recovery. Mohammed has referred more than 100 people for TB examination, out of whom 25 people were diagnosed with TB. All of them have now gained access to treatment for their illnesses. Mohammed knows that his clients are also at risk for other diseases, and refers them for testing as needed. In just a few months, he helped find two people with TB/HIV co-infection who can now access life-saving ART in addition to their TB treatment.

In addition to TB case-finding, Mohammed received training on community-based DOT for TB and now helps others get treated in line with national guidelines. As a treatment supporter, he is responsible for storing TB medications and making sure people with TB staying at Sober House receive their daily treatment.

Mohammed says: *"I am very happy to volunteer because I wasted my time taking drugs. I feel honoured to help other people and be useful to the community. I am giving back to the ones who have helped me and I think it's only by raising awareness and helping each other that we can solve our problems, and change behaviour."*

Mohammed Sultan in front of one of the CBOs where he volunteers his time.

Through Mohammed's efforts, clients who may otherwise have been overlooked are now able to be linked with and receive health care at the Mnazi Mmoja Referral Hospital in Zanzibar. With the support from the Ministry of Health and Social Welfare and USAID, the hospital's TB/HIV programme now provides counselling, health education outreach, and psychological support for clients in addition to DOT services. This is a good example of how all TB partners can work together to improve client-centred care for people with TB/HIV.

SOURCE: Case study courtesy of PATH and USAID. This work was funded by USAID.

Support treatment adherence

- Provide client-centred treatment support to people with TB/HIV, including home-based care, ***directly observed therapy*** (DOT) for TB, and livelihood and nutritional support.
- Support people with TB/HIV in adherence to IPT and CPT, and/or any other treatment they need to take such as ART.
- Find those who have stopped coming to the clinic before they finish their treatment (people lost to follow-up) and encourage them to return to care.
- Monitor drug supplies and report stockouts that may prevent people from accessing needed medications.

Prevent the spread of TB

- Help protect people living with HIV from getting TB by providing them with IPT.
- Find people with TB symptoms early, ensure they are examined promptly and start treatment as soon as possible if needed.
- Teach people with TB about covering their coughs.
- Develop educational materials on reducing the spread of TB for the community.
- Develop infection control guidelines for your organisation.
- Train your volunteers on how to protect themselves from TB.

Provide laboratory and clinical services

- Run health facilities that provide TB and HIV services.
- Recruit and train health care staff according to national standards.

Support enabling policies and mobilise resources for TB/HIV

- Participate in local, provincial, or national coordinating bodies to represent affected communities.
- Advocate for policy change at local or national levels to support TB/HIV integration.
- Advocate for the rights of people with TB and promote alternatives to forced detention of those who do not adhere to treatment.
- Advocate at local, national, or global levels for additional human, financial, and material resources for TB/HIV to meet the needs of affected communities.

- Community organisations have an important role to play in TB/HIV service integration.
- WHO has published guidelines on TB/HIV integration that include a list of specific activities that CSOs can undertake in support of TB/HIV.
- Activities that CSOs can implement include the following:
  - > develop organisational skills in TB/HIV integration
  - > raise community awareness on TB/HIV
  - > reduce the stigma associated with TB and HIV
  - > support intensified case-finding
  - > support treatment adherence
  - > prevent the spread of TB
  - > provide laboratory and clinical services
  - > support enabling policies and mobilise resources for TB/HIV.

How to integrate TB activities into your HIV work

In this chapter:

- Getting started
- Actions for successful integration
- How to use the workbook to help you go through the actions
- Action 1: Understand TB, TB/HIV, and the global context
- Action 2: Know the TB situation in your country
- Action 3: Choose activities appropriate for your organisation
- Action 4: Create or strengthen appropriate partnerships
- Action 5: Plan, implement, and measure the success of your activities
- Action 6: Fund your activities
- Case study: Peer support for TB cure in the Democratic Republic of Congo

Getting started

As community organisations in daily contact with infected and affected communities, you already know a lot about the challenges your clients face in accessing health services. You probably also have many ideas about which activities from the list in the previous chapter will be useful to address those challenges (see pages 13–15). But that is only part of the many pieces that go into making work in TB/HIV integration successful. In talking with HIV service organisations starting or already doing TB work, they mentioned that some of the biggest challenges they face are related to the following issues:

- not having enough knowledge of TB
- not understanding how the national TB programme (NTP) operates and how to work with the programme effectively
- not knowing how to create effective partnerships to work on TB/HIV
- not knowing how to understand and interpret TB data
- not knowing how to analyse and prioritise programme gaps they can fill
- not knowing how to develop a solid plan with appropriate activities and targets to address gaps
- not knowing how to measure their results and receive recognition for their contributions to TB prevention and care from the NTP, Global Fund, other donors, and partners
- not having adequate funding to carry out their TB/HIV activities properly.

In other words, for many organisations, their greatest difficulties in doing TB/HIV work are not related to *what* to do, but *how* to go about doing it. This chapter addresses the challenges listed above to help you overcome barriers to successful community work in TB/HIV integration. You can also consider the following strategies to set up your organisation for success:

- Work collaboratively with another organisation that has more experience in TB/HIV to help improve your understanding of key concepts, successful approaches, and activities;
- Participate in a TB or TB/HIV training course offered by your NTP or one of its technical partners;
- Participate in national meetings or working groups related to TB and HIV to help you understand the political environment, key stakeholders, and opportunities for community organisations;
- Download and read information or complete TB/HIV training modules available on the internet (such as the resources listed throughout this guide).

Actions for successful integration

This "how-to" chapter is organised according to practical actions you can take to choose, plan, fund, implement, and monitor your TB/HIV activities. The actions are written in a logical order, but it is not necessary to follow them in this sequence. For instance, you might group some of them together, such as choosing your activities and developing your partnerships: ideally, your partners will work with you to identify activities and plan them. You can rearrange the actions as you like for your organisation – it is not so important what order you follow as it is that you go through all of them.

TABLE 1: ESSENTIAL ACTIONS

ACTION	WHY
1. Understand TB, TB/HIV, and the global context	An understanding of what TB is provides a basis for how to explain TB to community members, how to develop useful stigma reduction approaches, and how to provide support in line with international standards.
2. Know the TB situation in your country (or your area)	To plan effective activities, you have to understand what TB challenges your country or area faces, how the NTP functions and organises TB services, and what the national priorities are for achieving TB targets. This will give your organisation credibility with the national programme and allow you to participate in decision-making, access resources, and contribute in meaningful ways.
3. Choose activities suitable for your organisation	Because financial resources are always limited, it is important to choose activities that have a good chance of success, fit well with your current activities, and will yield the best results possible for the smallest amount of funding.
4. Create or strengthen appropriate partnerships	Very few organisations can do all the work of TB/HIV integration on their own. To ensure there is no duplication of effort and that clients are getting as complete a package of services as possible, it is important to identify the key partnerships with other organisations to accomplish this.
5. Plan, implement and measure the success of your activities	This action is the bulk of what your organisation will do and where most time will be spent. Doing sufficient planning in the beginning will help you ensure you are using resources efficiently, you can implement the activities as quickly and smoothly as possible, and you are collecting the information you will need to prove your work has been successful.
6. Fund your activities	This action will likely happen throughout your cycle of steps. To give you the greatest opportunity to implement high-quality TB/HIV activities, being able to find adequate financial resources is critical.

How to use the workbook to help you go through the actions

To help you understand how to put this information into practice for your own organisation, we have developed a workbook with tools that have detailed instructions, examples, and templates for you to fill out to complete each step in the process for your own organisation. Below is a table showing which section of the workbook goes with each section of text. We also include reminders in each text section about which workbook sections accompany the text.

TABLE 2: USING THIS GUIDE WITH THE WORKBOOK

TEXT SECTION	WORKBOOK SECTION
None	**Workbook section 1:** How to use this workbook
Action 1: Understand TB, TB/HIV, and the global context	None
Action 2: Know the TB situation in your country or region	**Workbook section 2** Tool 2.1: Organisation of TB service delivery Tool 2.2: Epidemiology of TB Tool 2.3: National policies and guidelines Tool 2.4: National TB objectives, targets, and activities Tool 2.5: Successes and challenges Tool 2.6: The Cough-to-Cure Pathway Tool 2.7: Logical linkages between challenges and activities Tool 2.8: Advocacy planning Tool 2.9: Communication planning Tool 2.10: Social mobilisation planning Tool 2.11: Service delivery planning
Action 3: Choose activities appropriate for your organisation	**Workbook section 3** Tool 3.1: Situation analysis Tool 3.2: Organisational analysis Tool 3.3: Activity prioritisation matrix
Action 4: Create or strengthen appropriate partnerships	**Workbook section 4** Tool 4.1: Partner identification and selection Tool 4.2: Partnership plan checklist and sample memorandum of understanding (MOU)
Action 5: Plan, implement, and measure the success of your activities	**Workbook section 5** Tool 5.1: Planning and M&E checklist Tool 5.2: Work plan template Tool 5.3: Sample TB screening tools Tool 5.4: Sample referral slips Tool 5.5: Monitoring template Tool 5.6: Evaluation plan template Tool 5.7: Sample results reporting forms
Action 6: Fund your activities	**Workbook section 6** Tool 6.1: Existing and potential donors Tool 6.2: Funding plan and timeline Tool 6.3: Funding application checklist

Action 1: Understand TB, TB/HIV, and the global context

In this section:

- What is TB?
- What are the symptoms of TB disease?
- What is the difference between TB infection and TB disease?
- How is TB spread?
- Who is at risk of getting TB?
- What are multidrug-resistant TB and extensively drug-resistant TB?
- How is TB diagnosed?
- How is TB treated?
- How can TB be prevented?
- Where is TB found in the world?
- What are we doing to stop TB globally?

Knowing the information in this section will help you understand some of the challenges with TB and what roles your organisation may be able to play in addressing the TB epidemic. This is only an introduction to these topics. Throughout the section, there are boxes that list resources to help you learn more.

What is TB?

Tuberculosis (TB) is an ***infectious*** airborne disease caused by ***bacteria*** (germs) known as *Mycobacterium tuberculosis*. **TB is a curable disease, with effective, low-cost antibiotic treatment available worldwide.**

TB most often affects the lungs but can also attack other parts of the body, especially in people living with HIV. ***Pulmonary TB*** is TB of the lungs. Most people with TB worldwide (70–80%) have pulmonary TB. ***Extrapulmonary TB*** is TB that occurs outside the lungs – in any other part of the body. It is more common to find extrapulmonary TB in people living with HIV, although not everyone with extrapulmonary TB is HIV-positive. Extrapulmonary TB can be found in the lymph nodes, the lining around the lungs, kidneys, bones, spine, brain, the reproductive organs, or other parts of the body. Extrapulmonary TB does not spread easily to other people since the bacteria are not expelled from the lungs into the air.

What are the symptoms of TB disease?

The most frequent symptoms of TB disease include the following:

- cough of two weeks or more
- coughing up blood
- weight loss
- night sweats or fever
- pain when breathing
- fatigue or lack of energy
- loss of appetite

People with TB may have one symptom or a combination of symptoms. The difficulty with symptoms of TB disease is that most of them are common to a variety of illnesses, so people may not suspect that they have TB and then they may wait a long time before going to a health centre for care. This is why community awareness-raising and education about TB can help improve the chances that people with TB symptoms will go to a health centre soon after the symptoms appear. Being diagnosed with TB early will give the person a better chance of recovery, and it will also help prevent the spread of TB in the community.

What is the difference between TB infection and TB disease?

Using the correct TB terms is very important because similar words can mean very different things. One important difference is between TB infection and TB disease.

TB infection or ***latent TB infection*** means that someone has breathed in TB bacteria and they are in that person's body. However, the body's immune system has stopped the bacteria from growing and they are not causing any disease – they are latent or dormant (asleep). A person with TB infection does not feel sick, does not have symptoms of TB, and cannot spread TB to anyone else. Most people who are infected with TB never develop TB disease. Their bodies are able to keep the TB dormant for their entire lives.

TB disease or ***active TB*** means that someone has been infected and instead of the bacteria being contained by the body's immune system, they are multiplying in the body and causing illness. Some people develop TB soon after becoming infected (within weeks or months) because their bodies cannot fight the bacteria

effectively, while other people may get sick many years later when their immune system becomes weak for some other reason. Someone with active TB feels sick and can spread the bacteria to others if the disease occurs in the lungs or throat.

When we say "TB" in this guide and in most other documents and reports (for example, when we look at national data on TB), we are speaking about ***TB disease***.

TABLE 3: THE DIFFERENCE BETWEEN TB INFECTION AND DISEASE

LATENT TB INFECTION	ACTIVE TB DISEASE
■ Bacteria present in body but are not multiplying ■ No symptoms ■ Does not feel sick ■ Cannot spread TB to others ■ Has a negative sputum smear ■ Has a normal chest x-ray ■ May have a positive TB skin test (called Mantoux or TST) ■ Has a negative culture	■ TB bacteria are multiplying in the body and causing illness ■ Has symptoms that may include: > a cough for 2 weeks or longer > coughing up blood or sputum > pain in the chest > weight loss > fever and chills > sweating at night > weakness or fatigue > no appetite ■ Feels sick ■ Can spread TB to others ■ May have a positive sputum smear ■ May have an abnormal chest x-ray ■ Will usually have a positive culture

How is TB spread?

TB is spread (transmitted) from one person to another. TB is spread through the air when a person with active TB disease of the lungs or throat releases droplets containing TB bacteria into the air by coughing, sneezing, singing, or shouting. Then another person nearby breathes those bacteria into his or her lungs and becomes infected (see Figure 2). People with active TB disease are most likely to spread it to people they spend a lot of time with every day, especially if they are inside where it is dark and air circulation is poor. When a person breathes in TB bacteria, the bacteria may settle in the lungs and begin to grow. From there, the bacteria can move through the blood and attack other parts of the body.

A person with TB disease is most ***infectious*** before he or she begins treatment with TB medicines – that is the time when it is most likely to transmit TB from one person to another. The people who are most likely to transmit TB are those who are diagnosed with ***sputum smear-positive*** TB (see page 24, How is TB diagnosed?). Once a person is on effective TB treatment, the risk of transmitting TB quickly becomes much lower. There are also certain places where TB is more likely to spread. These include buildings where a lot of people crowd together and share the same air in poorly ventilated spaces, such as small houses with closed windows, bars and clubs, or prison and jail cells. Other places include health facilities where more people with TB are likely to visit and have contact with other clients and care providers.

KEY RESOURCES

World Health Organization (2012). 'WHO policy on collaborative TB/HIV activities: guidelines for national programmes and other stakeholders'.

Available at: **www.who.int/tb/publications/2012/tb_hiv_policy_9789241503006/en/index.html**

Stop TB Partnership TB/HIV Working Group website, a website with news and up-to-date information on policies and guidance on TB/HIV co-infection.

www.stoptb.org/wg/tb_hiv/

Carter, M. (2008). 'HIV and TB', NAM. An excellent resource for community education.

Available at: **www.aidsmap.com/HIV-amp-TB/page/1060273/**

It is also important to understand how TB is not spread, so you can help clear up any misinformation or fears that community members may have about being around someone with TB. This can help reduce the stigma and social isolation that many people with TB experience. TB is *not* spread by:

- shaking hands
- kissing
- sexual contact
- touching objects handled by someone with TB
- sharing clothing, food or utensils.

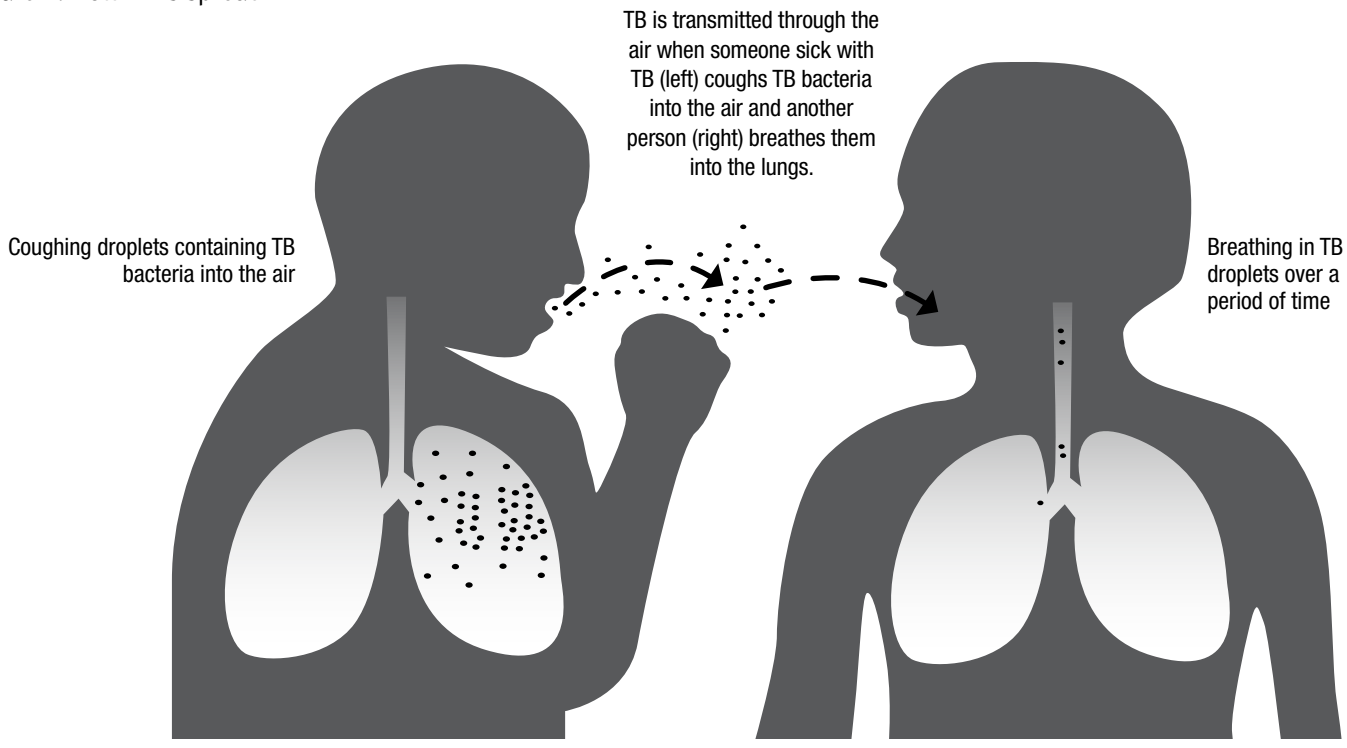
It is also very difficult for TB to survive outside in the open air, because the ultraviolet rays found in sunlight will kill TB bacteria quickly. So if community members are interacting with a person who has TB outside in the open air, for example in the market or in front of their home, there is very little chance that TB will be transmitted. All these facts are important to know when thinking about infection control for TB.

Who is at risk of getting TB?

Anyone can get TB. Because TB is transmitted through the air, anyone breathing near a person with infectious TB is at risk. However, there are certain groups for whom the risk of becoming sick after getting infected is higher.

The greatest risk factor for developing TB disease is HIV. People living with HIV are much more likely to develop TB disease than people without HIV. That is because their immune systems are weakened, and so they have a hard time keeping the TB bacteria from multiplying in their bodies and causing illness. While an HIV-negative person infected by TB has a 5–15% chance of developing TB disease *over a whole lifetime*, an HIV-positive person infected with TB has a 5–15% chance of becoming sick with TB disease *per year*, which translates into a 21 to 34 times greater risk of getting TB during his or her lifetime.

Figure 2: How TB is spread



There are other groups of people who also have a higher risk for TB disease. As we have seen, the immune system plays a big role in protecting people who have been infected with TB from becoming sick with TB disease. Many of the groups who are at a higher risk of TB disease also have conditions that weaken their immune systems. For example, young children under the age of five have immune systems that are still developing, and so they are also at high risk of becoming sick with TB after infection. Older people have immune systems that are weakening with age, and may no longer be able to fight off illness. People with diabetes, malnutrition, and certain kinds of cancer also have a higher risk. Those who smoke, drink large amounts of alcohol, or use drugs have behavioural risks that weaken their immunity. In addition, some people have occupational (work-related) risks for disease – for example, miners who develop a lung condition called silicosis are less able to fight off TB disease, and health care workers in hospitals and clinics have a higher risk of coming into contact with TB in the facilities where they work. In addition, clients attending health care facilities, either as in-patients or out-patients, have a greater risk of exposure to TB. Understanding who is at risk is important as it can help you and your organisation to focus on reducing the probability that vulnerable people will acquire TB infection and develop TB disease. For instance you could teach people with TB disease how to cover their mouths when they cough

GOOD PRACTICE STANDARD 7 (IMPLEMENTING INFECTION CONTROL MEASURES TO REDUCE RISK OF TB TRANSMISSION AND DISEASE)

What are multidrug-resistant TB and extensively drug-resistant TB?

Drug resistance means that the medicines (***antibiotics***) used to treat TB are no longer effective in killing the TB. ***Multidrug-resistant TB (MDR-TB)*** is resistant to the two most powerful TB drugs – isoniazid and rifampicin. ***Extensively drug-resistant TB (XDR-TB)***, is resistant to isoniazid and rifampicin, and has resistance to additional drugs as well. Drug resistance develops when treatment is inadequate. This occurs when the ***treatment regimen*** (the kind of antibiotics, their dosages, and the length of treatment) prescribed is inadequate, or the medication is of poor quality, or the person with TB does not take the medication regularly as prescribed. Any of these problems may allow some of the TB bacteria to survive and become resistant to the drugs used to treat TB. While it is still possible to treat MDR-TB and XDR-TB, it is much more difficult and expensive than treating TB that is not resistant (***pan-sensitive*** or ***pan-susceptible TB***).

MDR- and XDR-TB present some major challenges to the people suffering with them, the community, and the health system. For the individual, the treatment is very long (up to two years) and the medications have many side effects, making it difficult to continue treatment until completion. In addition, depending on the laws in their country, they may face required isolation from the community while they are infectious. That means they may be separated from their families for long periods of time while they are hospitalised, unable to work, and unable to support their families. For the community, people are often afraid to interact with anyone who has MDR- or XDR-TB because they fear becoming infected. For the health system, the drugs and the time from health care workers needed to treat people with MDR- and XDR-TB are very expensive and place a large burden on a system that is often very fragile already.

There are many activities CSOs can undertake to address MDR- and XDR-TB. The first is to help prevent it from happening by supporting people with TB to complete their treatment. CSOs can also provide community-based treatment support for people with MDR- and XDR-TB, educate the community to reduce the stigma and fear that surrounds these conditions, and work with local health facilities to promote good community infection control practices that prevent further spread of drug-resistant TB.

THE SPECIAL CHALLENGE OF TB IN CHILDREN

Although TB affects children just as it does other groups, and is especially dangerous for young children, TB in children (pediatric TB) has received very little attention until recently. CSOs can play several important roles in addressing the challenge of pediatric TB. They can advocate for NTP attention to this issue, include children as a key group in their TB-related activities, and integrate TB care for children in any of their activities for women and children. The facts below and the suggested actions that follow are taken from the *Call to Action for Childhood TB* made at a global meeting in 2011.

Facts on childhood TB

- Worldwide, at least 1 million cases of TB occur each year in children under 15 years of age.
- The true global burden of TB in children is unknown because of the lack of child-friendly diagnostic tools and inadequate surveillance and reporting of TB in children.
- Children with TB infection today represent potential TB disease tomorrow.
- Children are more likely to develop more serious forms of TB, resulting in higher rates of serious illness and death .
- Despite existing policy guidelines, the use of methods to find TB in children through contact tracing and delivery of IPT to young and HIV-infected children is often neglected by public health programmes.
- Most public health programmes have limited capacity to meet the demand for care and high-quality services for childhood TB.
- TB care for children is not consistently integrated into HIV care and maternal and child health programmes.
- The only licensed TB vaccine (BCG), has limited effectiveness against the most common forms of childhood TB and its effect is for a limited time.
- A large number of children suffering from TB are not appropriately treated because they have not been diagnosed. This problem is made worse by drug stock outs and the lack of child-friendly anti-TB drugs.
- Children are rarely included in clinical trials to evaluate new TB drugs, diagnostics or preventive strategies.

Suggested actions in the *Call to Action for Childhood TB*

- National TB programmes should include and prioritise childhood TB in their national strategic plans.
- All health care providers should integrate childhood TB into their services.
- The scientific community should include children – of all ages – in clinical and operational studies.
- TB drug and diagnostic product developers should include children in development plans and implementation of research at an early stage.
- Donors should encourage collaboration with researchers, local communities, TB and HIV programmes and other stakeholders to address the growing problem of childhood TB concentrating on:
  - > innovative research to develop child-friendly TB diagnostics, drugs, biomarkers and vaccines
  - > strengthening public health facilities and services so that mothers and children with and without HIV can receive appropriate TB care
- Providers of technical assistance should invest in building local capacity to prevent, diagnose and treat TB in children in all age groups.
- WHO should accelerate in-country adoption and use of childhood TB guidelines and coordinate global efforts to collect and generate data to improve estimates of the childhood disease burden
- Policymakers should adopt the existing and new WHO recommendations for childhood TB, evaluate implementation, scale-up and assess the impact of implementation strategies.
- Civil society should demand equitable prevention, diagnostics, treatment and care services for childhood TB and monitor the scale- up of these services.

SOURCE: Adapted from the Stop TB Partnership website: **www.stoptb.org/getinvolved/ctb_cta.asp**

How is TB diagnosed?

It is important to diagnose TB disease early and treat it properly to prevent serious illness or death, especially in people who are vulnerable such as young children and people living with HIV. Even though it is fully curable, it remains the most common cause of death among people living with HIV because they do not get diagnosed early enough.

There are a number of different ways TB disease can be diagnosed. The problem with TB diagnosis is that up until recently, the kinds of diagnostic tests most countries use have not been very good at making a rapid and definite diagnosis. New tests are becoming available now, and methods for diagnosis are expected to change rapidly, so it's important to keep up to date on developments.) One of the things community organisations can do is advocate for national availability of the improved and more rapid diagnostic tests for TB.

The following methods are now in use to diagnose TB disease:

Sputum smear microscopy is the most common and lowest cost method of diagnosing pulmonary TB in most countries. It is often used to test people for TB at the health centre level. Someone with TB symptoms is asked to cough up at least two and sometimes three ***sputum specimens*** from deep in the lungs into small containers called sputum cups. The specimens are then smeared on a glass slide, dried, stained with dye, processed, and looked at under a microscope. If TB bacteria are present, they will show up as rod-shaped forms (***bacilli***) on the slide, indicating that the specimen is ***smear-positive*** and that the person has TB. If the slides do not show any TB bacilli, the person is said to be ***smear-negative***. Someone's sputum can be smear-negative but that person may still have TB. Being smear-negative only means that no TB bacilli were seen in the sputum. More tests need to be done to confirm or rule out TB disease for someone who is smear-negative. Unfortunately, people living with HIV are more likely to be smear-negative, so their diagnosis takes longer, meaning that it also takes longer for them to start treatment. Challenges with sputum smear microscopy include the fact that the person who is sick has to return to the health centre two or more times to deliver specimens and get the results, and the specimens must be of good quality to get accurate results.

A ***chest x-ray*** is often the next test done if someone is smear-negative. A chest x-ray will show abnormalities in the lungs or around the lungs that may indicate TB. However, a chest x-ray alone is not enough to make a diagnosis since many different conditions can cause abnormal chest x-rays. Chest x-rays may look very different in people living with HIV, and cannot confirm that the problem is TB.

Solid culture is a definite test that can confirm TB, and the one that most countries have available to them at the reference laboratory level – either in the district, province or at national level. A sputum sample is processed and put into a test tube with food to help any bacteria present to grow. The laboratory technician will check the tube to see if TB bacteria are growing. The difficulty with a solid culture is the time it takes to get a result. Since TB grows very slowly, it may take several weeks or up to two months to get a result, during which time the sick person may be waiting for a diagnosis and treatment.

Liquid culture methods are becoming more common in many countries, and may be available at the provincial or national reference laboratory. A common machine used for liquid culture is known as the Mycobacterial Growth Indicator Tube (MGIT). This method is similar to the solid culture described above, but the specimen is grown in liquid food and the results are available much more quickly (in about seven to ten days). The challenge with liquid culture is that it is relatively

KEY RESOURCES

For more information on TB diagnosis

Stop TB Partnership New Diagnostics Working Group.

Available at: **www.stoptb.org/wg/new_diagnostics**

Stop TB Partnership Global Laboratory Initiative.

Available at: **www.stoptb.org/wg/gli**

World Health Organization (2012). 'Tuberculosis diagnostics: Xpert MTB/RIF test'.

Available at: **www.who.int/tb/features_archive/factsheet_xpert_may2011update.pdf**

Solid culture of TB

Liquid culture using a MGIT machine

expensive, requires more training for the laboratory technician, and there is a higher chance that the specimens will be contaminated so that the results may not be correct.

The greatest advances in diagnosing TB have occurred recently with the development of ***rapid molecular tests*** (such as the GenoType MTBDRplus and Xpert MTB/RIF tests). These tests use processed sputum specimens to determine if genetic material (DNA) from TB is present, confirming a TB diagnosis. The great advantages of these methods are that they are very quick (a few hours), are relatively simple to use, and can diagnose TB in people whose specimens are smear-negative (a particular advantage for people living with HIV). They can also diagnose resistance to rifampicin at the same time, indicating the strong possibility that the person has MDR-TB and needs a different treatment regimen to be cured. **WHO currently recommends that Xpert MTB/RIF be used as the first diagnostic test for people living with HIV who have TB symptoms to increase the speed and accuracy of diagnosis**. The main challenges are the need for a reliable supply of electricity and the relatively high cost of these test.

For people who are being tested for extrapulmonary TB (remember, that means TB outside the lungs), the health care provider may take a ***biopsy*** (sample) of material from the part of the body where the TB disease is suspected. It may then be processed in a similar way to the methods described above, with a smear or culture, depending on the type of specimen.

When some of the tests above are not available or do not provide a definite answer, a health care provider may make a ***clinical diagnosis*** of TB. That means that the TB is not ***bacteriologically confirmed*** by any test, but the health care provider has carefully thought about and decided against other possible causes for the illness, so that TB is the most likely diagnosis.

How is TB treated?

In this section, you will find basic current information about treating TB. However, new drugs are under development that may change treatment significantly in the coming years. To learn more and keep up with new developments, please refer to the resources listed at the end of this section.

Most TB is treated with a standard regimen of four ***antibiotic*** drugs that is the same or very similar all over the world. Treatment requires multiple antibiotics over a long period of time because no one drug is completely effective against TB and TB bacteria take a long time to kill completely. The four drugs most commonly used are isoniazid, rifampicin, pyrazinamide, and ethambutol. (Sometimes streptomycin, an injectable drug, is used instead of ethambutol.) These are called ***first-line drugs*** because they are the best drugs to treat TB that is not resistant. Isoniazid and rifampicin are the two most effective drugs against TB. Currently, TB treatment takes a long time – a minimum of six months for someone whose TB is not resistant to any drugs (pan-sensitive or pan-susceptible TB). There are two phases of treatment for TB: the ***intensive phase*** that lasts for the first two months or so, during which time the person with TB takes all four antibiotics (usually on a daily basis), and the ***continuation phase*** for another four to six months, when the person with TB takes only isoniazid and rifampicin (usually daily or three times a week, depending on the guidelines used in your country).

Many people with TB will experience a rapid improvement in their health after they start treatment. At that point, they may feel so much better that they question the usefulness of continuing their medication because they already feel "cured," even though TB bacteria are still alive in their bodies. For this reason, ***treatment adherence support*** is recommended for every person with TB – this includes providing a treatment supporter who will encourage him/her to continue treatment

KEY RESOURCES

For TB treatment

Your country's TB treatment guidelines

World Health Organization (2009). 'Treatment of tuberculosis: guidelines for national programmes, 4th edition'.

Available at: **www.who.int/tb/publications/tb_treatmentguidelines/en/**

World Health Organization (2011). 'Guidelines for the programmatic management of drug-resistant tuberculosis – 2011 update'.

Available at: **www.who.int/tb/challenges/mdr/programmatic_guidelines_for_mdrtb/en/index.html**

World Health Organization (2010). 'Management of MDR-TB: a field guide'.

Available at: **www.who.int/tb/challenges/mdr/programmatic_guidelines_for_mdrtb/en/index.html**

Stop TB Partnership Working Group on New TB Drugs.

www.newtbdrugs.org

TB Alliance.

www.tballiance.org

GOOD PRACTICE STANDARD 5 (PROVIDING UNDERSTANDABLE INFORMATION ABOUT TB) AND STANDARD 8 (ADDRESSING TB AND HIV STIGMA)

CASE STUDY: PEER SUPPORT FOR TB CURE IN THE DEMOCRATIC REPUBLIC OF CONGO

A CAD member visits TB clients on his project bicycle.

The Democratic Republic of Congo has the third highest TB burden in Africa. Two local civil society organisations (CSOs) are working to make a difference in this very challenging environment. Their impact is being felt by people with TB and MDR-TB who have received more support and information regarding symptoms, disease and treatment.

The Club des Amis Damien (CAD) is an organisation made up of people with TB or cured of TB who work to help others with TB. One person who has been cured shared his story of how the project helped him overcome stigma and start supporting others undergoing treatment: "After receiving support from CAD members, I joined the association, which enabled me to overcome the loneliness from which I had been suffering for so long. Today I am cured and I continue to support and advise other MDR-TB patients through the Club. This is my contribution to the fight against tuberculosis in all its forms."

CAD provides critical support services to their communities, including community education on TB, challenging TB-related stigma, treatment support through home visits, follow-up of clients who have been lost to follow-up, and one-on-one support to MDR-TB clients undergoing difficult treatment regimens, and distribution of treatment support packages.

Another person with MDR-TB relied on CAD members for psychosocial support to continue her treatment regimen. *"I was screened and found positive for tuberculosis at the health centre in Kinshasa where I was receiving care. I was scared, because I had already lost one of my sisters to tuberculosis."* She was diagnosed with MDR-TB and sent to Bondeko Health Center for treatment. The side effects she was experiencing, including body aches, dizziness and difficulty walking, made her worried about being able to complete treatment. But after being connected with CAD, a CAD member accompanied her during treatment sessions, brought medications to her and checked in on a daily basis. *"I met with CAD members in Bondeko, where I had begun treatment ... I began to feel better and better, and today I'm carrying on with my treatment.*" To help people who live far from diagnostic centres, CAD and another CSO (LNAC) also trained 428 community volunteers to collect and transport samples of sputum to test for TB and 87 volunteers to educate people about TB and TB/HIV co-infection.

In two years, CAD has formed 62 new outreach groups in DRC by training 566 former and current TB clients as volunteers. With their help, CAD referred 2,916 persons with suspected TB in 22 health zones. Of those referred, more than a third (1,039) were found to be sputum smear-positive for TB and started treatment. Out of these, CAD supported 687 people with TB to complete treatment, including 292 people with MDR-TB; and 99 people originally lost to follow up returned to treatment, including 10 with MDR-TB. Case notification rates in the five supported regions increased from 92/100,000 to 106/100,000 and treatment success increased from 89% to 91%.

SOURCE: Case study courtesy of PATH and USAID. This work was funded by USAID.

until the end, watching the person take the pills (DOT), and providing other social support to enable them to complete treatment (for example, transportation money to go to the health centre to pick up pills, or food to take the pills with).

The medicines are taken by mouth. They may come in separate tablets, or they may be combined into ***fixed dose combination*** pills (FDCs) that contain three or four of the needed drugs in one pill, both for adults and children. The benefits of FDCs are that they reduce the number of pills (the pill burden) a person has to take, and they make it more difficult to take only part of the medicine, which helps prevent the development of drug resistance.

REMEMBER!

There are special considerations for treatment of people with TB/HIV because there can be ***drug interactions*** between the medicines that are used to treat TB and ARTs that can change the effectiveness of the individual drugs. These problems can be avoided, and people with TB/HIV can be safely treated with the right combinations of medicines. CSOs who participate in providing treatment or treatment support for people with TB/HIV and the clients they serve should be aware of these issues, however. The NTP and AIDS programme can provide information and guidance on these issues, and they are usually discussed in national treatment guidelines.

KEY RESOURCES

Resources for TB vaccine development

Stop TB Partnership Working Group on New TB Vaccines

Available at: **www.stoptb.org/wg/new_vaccines/**

Aeras website **www.aeras.org**

People with MDR-TB face a longer and more complicated course of treatment. The treatment currently consists of 18 to 24 months with at least five drugs that are likely to be effective against the MDR-TB, including at least one drug that must be injected for the first six months of treatment. These are called second-line drugs because they are used only when the first-line drugs are no longer effective because the TB bacteria have become resistant to them. While all the complexities of MDR-TB treatment cannot be discussed here, it is important to know several things as a community organisation working on TB:

- The best and most cost-effective way to deal with MDR-TB is to prevent it from occurring. This can be done by making sure that people with pan-sensitive TB take a full course of treatment, the treatment regimen prescribed is correct (the right medicines with the right dosages for the right amount of time), and the drugs are of good quality.
- MDR-TB is more complex to treat and more difficult to cure. It is more expensive for the health system, and requires specialised training of providers and treatment supporters.
- People with MDR-TB take much longer to complete treatment. That means they may face a prolonged loss of income, be further stigmatised by the community or family, and face more possible medication side effects. Treatment adherence support is required for the full course of treatment, which may last for up to two years.
- Having drug-resistant TB may affect the rights of people who are sick. Some countries have laws or policies that require people with drug-resistant TB to be hospitalised for treatment until they are no longer infectious. Community organisations can help advocate for the rights of people with MDR-TB and can offer alternatives such as supported treatment in the community.

How can TB be prevented?

Currently, we do not have a very effective ***vaccine*** to prevent TB. ***BCG vaccine***, which is used in many parts of the world, is useful for preventing serious TB complications in young children, but it does not completely protect anyone from TB. New vaccines are being researched, and are needed.

The best way to prevent TB at present is to find, diagnose, and treat people with existing TB at the earliest possible time, so they have less of a chance to infect other people who then may develop TB disease. Community organisations have a big role to play in this intensified case-finding effort, as described on page 28.

Where is TB found in the world?

TB occurs in every country in the world. About one-third of the entire population on Earth is infected with TB bacteria. WHO estimates that every year, from those who have the infection, 9 million people become ill with TB and more than 1.5 million people die from TB.

While TB can happen anywhere, the burden of disease is not equally distributed between countries. Countries that account for most of the people with TB globally include those with large populations (such as India, China, and Indonesia), or heavily affected by HIV (such as in sub-Saharan Africa). Together, the 22 countries that make up more than 80% of the world's total of people with TB are called the ***high-burden countries*** (HBCs). Within countries, TB is also unevenly distributed. TB occurs most commonly among the poorer population groups, among high-risk populations (people living with HIV or other immunity-affecting diseases such as diabetes and silicosis), and among prisoners and health workers because of their risk of exposure to infection, or where all these factors appear in combination. As you review your country's TB data later on in this chapter, think about what groups of people might be at highest risk for getting TB in your area.

Figure 3: The 22 high-burden countries for TB

What are we doing to stop TB globally?

The fight against TB is guided by a common global vision of a TB-free world.

The most important global document for you to understand is the Stop TB Strategy (**www.who.int/tb/strategy/en**), which outlines the objectives and approaches needed to control and eliminate TB by the year 2050. Many national TB programmes organise their own objectives and activities according to the framework of the Stop TB Strategy. Being familiar with the strategy will help you align your work with international and national objectives and standards and understand how community efforts fit into the bigger picture of TB prevention and care in your country. The six components of the strategy are listed below.

1. Pursue high-quality DOTS expansion and enhancement

- Secure political commitment, with adequate and sustained financing
- Ensure early case detection, and diagnosis through quality-assured bacteriology
- Provide standardised treatment with supervision, and client support
- Ensure effective drug supply and management
- Monitor and evaluate performance and impact

2. Address TB/HIV, MDR-TB, and the needs of poor and vulnerable populations

- Scale-up collaborative TB/HIV activities
- Scale-up prevention and management of multidrug-resistant TB (MDR-TB)
- Address the needs of TB contacts, and of poor and vulnerable populations

3. Contribute to health system strengthening based on primary health care

- Help improve health policies, human resource development, financing, supplies, service delivery and information
- Strengthen infection control in health services, other congregate settings and households
- Upgrade laboratory networks, and implement the Practical Approach to Lung Health (PAL)

KEY RESOURCES

World Health Organization. 'Global Tuberculosis Control Report'.

Available at: **www.who.int/tb/publications/global_report/en/**

This document contains summary data describing the burden of TB in each region and country of the world. It is updated annually.

World Health Organization. 'Tuberculosis > TB data'.

Available at: **www.who.int/tb/data**

Profiles for your country that summarise important TB epidemiologic data and TB funding information.

WHAT IS DOTS?

DOTS stands for **Directly Observed Treatment, Short Course**. It was the original global strategy for TB prevention and care, and now it is component 1 of the Stop TB Strategy listed here. The global community recognised that there was more to eliminating TB than the five elements of the original DOTS strategy, and so expanded the approach to include all of the components listed here.

STOP TB STRATEGY

Vision
A TB-free world

Goal
To dramatically reduce the global burden of TB by 2015 in line with the Millennium Development Goals and the Stop TB Partnership targets

Objectives
1. Achieve universal access to high-quality care for all people with TB
2. Reduce the human suffering and socioeconomic burden associated with TB
3. Protect vulnerable populations from TB, TB/HIV and multidrug-resistant TB
4. Support development of new tools and enable their timely and effective use
5. Protect and promote human rights in TB prevention, care and control

Targets
1. MDG 6, Target 8: Halt and begin to reverse the incidence of TB by 2015
2. Targets linked to the MDGs and endorsed by the Stop TB Partnership:
   a) by 2015: reduce prevalence and deaths due to TB by 50% compared with a baseline of 1990
   b) by 2050: eliminate TB as a public health problem

- Adapt successful approaches from other fields and sectors, and foster action on the social determinants of health

4. Engage all care providers

- Involve all public, voluntary, corporate and private providers through public-private mix (PPM) approaches
- Promote use of the International Standards for Tuberculosis Care (ISTC)

5. Empower people with TB, and communities through partnership

- Pursue advocacy, communication and social mobilization
- Foster community participation in TB care, prevention and health promotion
- Promote use of the Patients' Charter for Tuberculosis Care

6. Enable and promote research

- Conduct programme-based operational research
- Advocate for and participate in research to develop new diagnostics, drugs and vaccines

As you can see, component 5 of the Stop TB Strategy talks specifically about the need to work with communities and people with TB, so that many of your activities will be part of this component. However, if you look more closely and think about the activities that you might do to support TB/HIV integration, you will see that community organisations have something to contribute to all six components of the Stop TB Strategy! For example, if your organisation is providing treatment support to people with TB/HIV, you are engaging the community in TB prevention and care through your volunteers but you are also supporting components 1 and 2 – you are providing standardised treatment with supervision, client support, *and* you are helping to address TB/HIV at the same time. Community organisations clearly have much to contribute to TB care, prevention and health promotion. We will show you how to talk about and document your contributions under Action 5.

CHECK!

CSOs should be aware that, as of the publication of this guide, WHO and the Stop TB Partnership are engaged in a consultative process to develop a new global TB strategy with new targets for the years beyond 2015. Please check the post-2015 strategy website for news about the new strategy and ways to participate in the strategy development process: **www.who.int/tb/post2015_strategy/en/index.html**

KEY MESSAGES

- TB is a global epidemic that caused approximately 8.7 million people to become ill and 1.4 million people to die in 2011. An estimated 13% of the people with TB were co-infected with HIV.
- TB is an infectious disease caused by bacteria. It is passed from person to person through the air. Anyone can get TB, but people who have a weakened immune system are at higher risk of getting sick.
- TB most commonly affects the lungs, but can affect many other parts of the body as well. TB outside the lungs is more common in people living with HIV.
- TB is a serious but curable disease. A combination of antibiotics taken for six to eight months will cure most TB, including TB in people living with HIV.
- Drug-resistant TB is caused when the TB bacteria become immune to the drugs used to treat TB. Drug resistance occurs when the treatment prescribed is not correct, when the person with TB does not complete the entire course of treatment, or when the drugs received are of poor quality. Drug-resistant TB is much more difficult to treat and takes up to two years to treat. The drugs required have more side effects and are much more expensive.
- TB is diagnosed using sputum smear microscopy and culture in a laboratory. New diagnostic tools are now available that can diagnose disease more quickly and reliably. These include the Xpert MTB/RIF test, which is an important new tool for diagnosing TB in people living with HIV and TB that is drug-resistant.
- WHO and the Stop TB Partnership have developed a plan and strategy to stop TB that has been adopted as the global approach to eliminating TB as a public health problem by the year 2050. Most NTPs follow the components of this strategy in creating their national TB programmes.
- It is important for CSOs to understand the technical aspects of TB prevention and care and the global strategy so that their activities can support local, national, and global efforts to stop TB.

Action 2: Know the TB situation in your country

In this section:

- National TB programme structures and organisation
- TB epidemiology
- National TB guidance, objectives, targets, activities and indicators
- Identify successes, challenges, barriers and solutions
- Link potential activities with objectives and challenges
- Case study: A photography project in Tanzania allows people with TB/HIV to use their voices for change

GOOD PRACTICE STANDARD 7 (COLLABORATING WITH OTHER TB AND HIV ORGANISATIONS TO ACHIEVE THE OBJECTIVES OF THE NATIONAL HIV AND TB PROGRAMMES)

In doing TB/HIV work in your country, it is essential for you to work in close collaboration with your national AIDS and TB programmes. These structures within the ministry of health are responsible for developing policies and protocols; setting national programme priorities, goals, objectives, and activities; ensuring programme quality; coordinating partners; managing recording and reporting; and requesting and properly allocating sufficient resources for programme operations. You should work cooperatively with the national programmes toward a common set of objectives and targets to make the best use of resources, avoid duplications or confusion, deliver quality services, and do the most possible to help people with TB/HIV.

In order to do meaningful and effective work on TB/HIV it is also crucial to understand the overall situation in your country or region and how your work will contribute to the national response. This is a step that is sometimes missed by CSOs, but it is very important so that you can work effectively with the national AIDS and TB programmes and establish your credibility with them.

All of this sounds reasonable, but community organisations often encounter a number of challenges in trying to work with NTPs on TB/HIV integration. Some of the barriers to doing so are related to difficulties in understanding how the NTP functions, how to access national and local level data, what the TB data mean, and how to talk about these issues using language that demonstrates your understanding of TB prevention and care. This section, along with Workbook Section 2, will help you gain a better understanding of TB in your country so you can overcome these challenges and work effectively with the NTP.

National TB programme structures and organisation

How are TB services delivered?

The first thing to understand is how your NTP is structured and organised. This will help you build effective relationships with key people in the NTP or other relevant structures, such as the National Stop TB Partnership, Global Fund Country Coordinating Mechanism, or national TB working groups on specific topics. It will also help you understand where TB services are delivered and who is responsible for managing those services at the national, provincial, and district levels of the health system. If you are going to help people with TB/HIV access care more efficiently, you need to know where they can go for the services they need, what the potential challenges are in doing so, and how you might be able to help improve the coordination between the two services for the good of your clients.

In most countries, there will be a central management unit for the NTP consisting of the NTP manager, several technical staff, and support staff. There will also be a national TB reference laboratory responsible for organising and assuring the quality of the national TB laboratory network. The reference laboratory may or may not fall under the direction of the NTP. You often will have similar structures at the provincial and district levels, with most TB services (smear microscopy and treatment) provided in health centres at the district level or below.

WORKBOOK ACTIVITY

To gather information on the organisation of the NTP in your country, go to Workbook Tool 2.1.

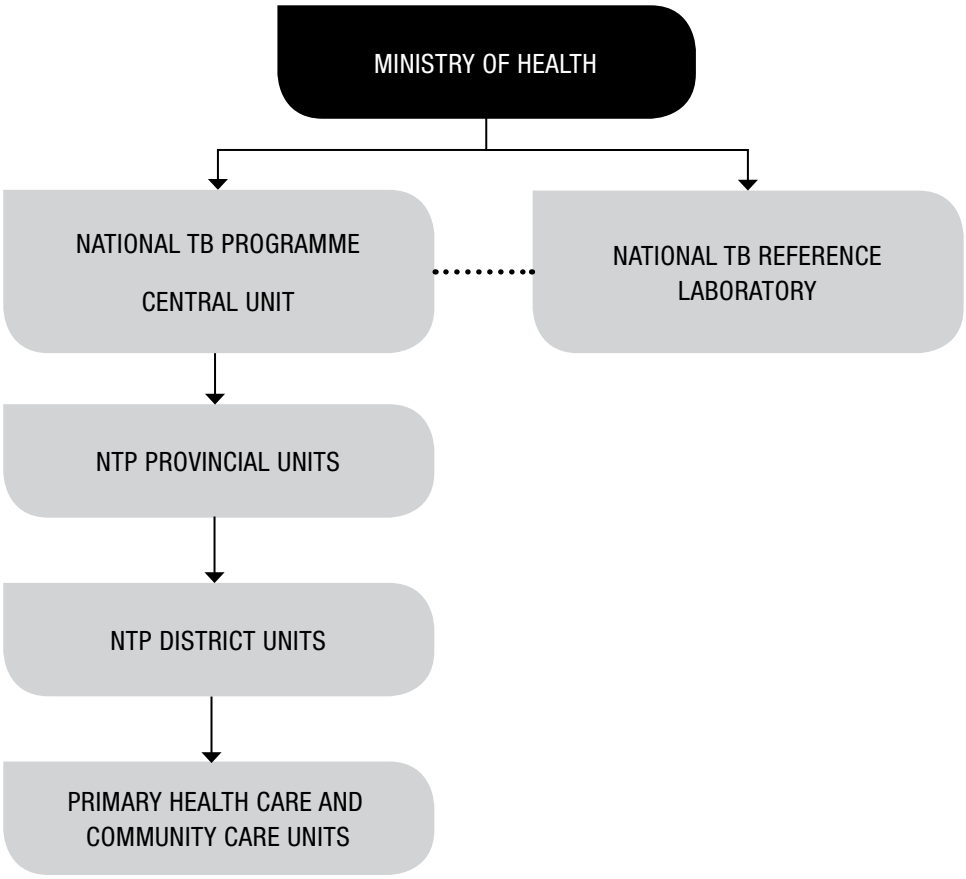


Figure 4: Typical structure of a national TB programme

TIPS FOR WORKING WITH NATIONAL TB PROGRAMMES

- **Be well-informed:** Review and understand the national strategy, NTP objectives and activities, NTP planning cycles, and TB data before you talk with the NTP.
- **Speak their language:** Use standard TB terms in your discussions and clearly describe how your activities can support the NTP objectives and activities.
- **Be patient and open to dialogue:** Remember that NTPs often are not used to working with community activists and organisers, and it may take effort from both sides to learn to work together productively.
- **Have one voice:** Work as a group of organisations and relate to the NTP through one representative or a small group of representatives for all CSOs working on TB. This means the NTP saves valuable time by not having to communicate with each group separately and that your messages are more powerful because they come from a whole group of ogranisations.
- **Decide on key messages:** When you want to meet with the NTP, know beforehand what three to four key points you want to communicate, and bring data, stories, pictures, or other materials to back up your points.
- **Know what you want:** Develop an agenda for discussions with the NTP and define clearly what outcomes or decisions you would like to reach as a result of each meeting.
- **Follow up:** Document the key points of meetings in written notes that are shared with all CSOs in the constituency (represented groups) and with the NTP. Thank the NTP for their time, and make sure to follow up on the action items you agreed to during the meeting.
- **Communicate regularly:** Provide regular updates to your NTP contact(s) on the work you are doing and the results you are seeing. Alert them to any challenges on the ground, and submit your data through the national reporting system.
- **Participate actively:** Know what events your NTP is planning and participate in them. For example, World TB Day is often a time when community organisations can advocate for more resources, educate communities, and mobilise people to take an active role in ending TB.

TB epidemiology

Where is TB in our country, how much is there, and who is at risk?

(Note: You will see in this section that when we are talking about ***epidemiological*** data, we use terms such as "TB case" that we mentioned earlier we would like to avoid. However, your NTP data is currently reported using these epidemiological terms, so we will also use these terms here to avoid confusion as to what numbers we are discussing.)

Once you know how services are organised, you need to understand the epidemiology of TB in your country. Epidemiology is the science that describes how disease is distributed – among different geographic areas (for example, urban and rural or one province versus another), different ages and genders (such as children and adults, men and women), different risk groups (such as

drug users, prisoners, migrants, slum dwellers, or health care workers), and over time (for example, in the last five years). Epidemiologic data are useful for several reasons:

- understanding what areas or populations in your country should be given highest priority when implementing activities – usually in places where there are large populations or high population density and in populations with a high risk of TB
- understanding the ***trends*** in TB prevention and care (whether there are increases or decreases in disease over a certain period of time)
- pointing to potential TB programme performance gaps that can be addressed to strengthen the programme.

Every quarter, the TB programme at all levels (from the health facility to the national level) gathers and reports data on TB and its performance in controlling TB, including how many people with TB ("TB cases") have been diagnosed and reported; how many received HIV counselling and testing; how many people are on TB treatment; and what the treatment outcomes have been for people who should have completed treatment during the quarter, for example. These are the types of data you will need to understand, collect, analyse, and report for your work in TB/HIV.

Every year your country reports its national-level data to WHO, which is then compiled into country profiles. You can access your latest country profile at **www.who.int/tb/data** to review some of the key data for your country. For your organisation, the national-level data will give you information about the overall situation in the country, but if you are working in a specific geographic area (for example, one district, or one province), you will pay most attention to the same kind of data for your specific area. In general, those data may be accessed through the local NTP staff, in published reports, and sometimes online at the NTP's website.

Table 4 provides definitions for the key indicators that you will be reviewing as a community organisation. The definitions here have been simplified – some of the calculations of these numbers are complicated, but these definitions give you a working understanding of the terms.

There are three specific areas of the data described in the table that are most important for you to know well as a CSO working on TB/HIV:

- **Case notification data:** gives you information about how many people with TB are being diagnosed and reported to the TB programme in your area. The case notifications are influenced by many factors, such as the prevalence of TB in your area, the accessibility of the TB services (easy to reach, client-friendly services at an affordable cost), and the ability of the TB programme to record and report people with TB correctly.
- **Treatment outcome data:** gives you information about how well the TB programme is performing in making sure that people with TB complete their treatment. You will work with cohort analysis to evaluate performance (see Workbook Tool 2.2).
- **TB/HIV co-infection data:** gives you information about how well the programmes are doing in providing TB/HIV screening and testing, how many people with TB are co-infected with HIV, and how many of them are provided with treatment and prevention services.

Understanding these three areas of data will help you identify potential gaps or weaknesses that can be strengthened. It will also help you in reporting your own results in a way that is consistent with national recording and reporting.

WORKBOOK ACTIVITY

Go to Workbook Tool 2.2 to review an example of what the data in the country profile mean and what questions to think about in looking at your own data.

KEY RESOURCES

World Health Organization. 'Definitions and Reporting Framework for Tuberculosis – 2013 revision'.

Available at: **http://apps.who.int/iris/bitstream/10665/79199/1/9789241505345_eng.pdf**

TABLE 4: DEFINITIONS OF KEY TB TERMS

TERM	MEANING	COMMENT
Incidence	The estimated number of all new and re-treatment cases of TB that occur during a one-year period.	Incidence estimates are based on mathematical models and interpretation of TB prevalence survey data.. Incidence is therefore not a measure of actual cases, it is a best guess. It is very difficult to measure this directly because it is not currently possible to detect every single case of TB that occurs in a country.
Incidence rate	Incidence expressed as the number of persons with TB per 100,000 people living in the country. WHO publishes the estimated incidence rate each year in its Global Tuberculosis Report.	Prevalence can be estimated more accurately by conducting a countrywide prevalence survey, during which a representative sample of the population is examined for TB disease. When measured in a survey done every 5 or 10 years, prevalence is a good indicator for the trend of the TB epidemic in a country.
Prevalence	The estimated number of persons with TB that exist at any point in time. This number includes the people diagnosed with TB during the current year, as discussed above, PLUS people with TB who were diagnosed in previous years, are still alive, but have not completed treatment.	In country profiles, this number does NOT include deaths from TB in people living with HIV – those deaths are recorded as HIV deaths. This means the actual number of deaths related to TB may be higher than the mortality estimate.
Mortality	The estimated number of deaths due to TB that occur during a one-year period.	
Case notification	The actual number of persons with TB diagnosed and reported to the national programme during a one-year period.	
Case notification rate	This is the actual number of persons with TB reported and recorded to the national TB programme per 100,000 population during a one-year period.	The trend of the TB notification rate over the years gives an indication of whether the TB epidemic in a country, province, or district is getting better or worse It is influenced by the actual occurrence of TB (whether the number of people with TB is decreasing or increasing over time) and by the performance of the TB programme (whether the programme is doing a better or worse job finding and recording people with TB). over time.
New case	A person diagnosed with TB who has no previous history of TB or has been treated for TB in the past, but for less than one month.	
Re-treatment case	A person diagnosed with TB who has been diagnosed with TB in the past and has been treated with anti-TB drugs, but who needs to be treated again. A re-treatment case can be further categorised into relapse, failure, or default (see below for a comment about “default”).	

TABLE 4: DEFINITIONS OF KEY TB TERMS

TERM	MEANING	COMMENT
Relapse	A person who successfully completed treatment in the past, but has now been diagnosed with TB again and reported to the TB programme again.	
Treatment after failure	A person with TB who did not improve after five or more months of TB treatment (remained smear-positive or culture-positive) and was restarted on a different (and usually more powerful) re-treatment regimen.	
Treatment after loss to follow-up	A person with TB who started TB treatment but stopped for any reason and did not take TB medicines at all for two or more consecutive months, but who has restarted treatment.	"Loss to follow-up" was previously known as "treatment after default". It is likely that term "treatment after default" will remain in many forms and databases for some time.
Pulmonary TB	TB in the lungs.	
Smear-positive TB	Pulmonary TB in which at least one sputum smear shows TB bacteria when examined under a microscope.	
Smear-negative TB	Pulmonary TB in which a sputum smear does not show TB bacteria when examined under a microscope.	People living with HIV are more likely to have smear-negative TB. Smear-negative TB takes a longer time to diagnose because more tests are needed to confirm the diagnosis.
Extrapulmonary TB	TB outside the lungs. (This can be in any other part of the body).	
Bacteriologically confirmed	TB diagnosed with a positive laboratory test confirming the presence of TB bacteria	
Treatment outcome	The final result of treatment for a person with TB.	All treatment outcome results are reported by the TB programme in total numbers every quarter of the year and at the end of the year. Treatment outcome data are important in evaluating how well the TB programme is performing. Performance is evaluated by looking at the percentage in each outcome category, compared to the total number of persons started on treatment in a particular quarterly period. This is called ***cohort analysis***. Please refer to Workbook Tool 2.2, Epidemiology of TB, for an example of cohort analysis.
Cured	A person with TB who completed treatment and had a negative sputum smear or culture result at the end of treatment.	This is the most desirable outcome for a person with TB.
Treatment completed	A person with TB who finished treatment but did not have a final sputum smear or culture result reported.	This is a good outcome, but the effectiveness of the treatment was not confirmed by the laboratory.
Treatment success	The total number of people with TB who were reported as cured plus those reported as treatment completed.	

TABLE 4: DEFINITIONS OF KEY TB TERMS

TERM	MEANING	COMMENT
Treatment failed	A person with TB who did not improve after five or more months of TB treatment (they continue to have positive sputum smears or cultures).,	
Lost to follow-up	A person with TB who did not start treatment or stopped it for any reason and did not take TB medicines at all for two or more consecutive months, and therefore did not complete treatment.	This was previously known as "default". It is likely that the term "default" will remain in many forms and databases for some time.
Transferred out	A person with TB who moved from one reporting location to another during treatment.	In the latest WHO TB outcome definitions (2013), "transferred out" is not included. Transferred out is no longer considered an acceptable final outcome for someone with TB, because we don't know what happened with this person. The location where the person with TB was originally diagnosed is responsible for communicating with the place the person went and for finding out and reporting what the final result of treatment was. In practice, however, this is very difficult because of weak referral systems.
Died	A person with TB who died for any reason after diagnosis and before completing treatment.	
Not evaluated	A person with TB for whom no outcome information was reported.	

GOOD PRACTICE STANDARD 2 (COLLABORATING WITH OTHER TB AND HIV ORGANISATIONS TO ACHIEVE THE OBJECTIVES OF THE NATIONAL HIV AND TB PROGRAMMES)

WORKBOOK ACTIVITY

Use the checklist in Workbook Tool 2.3 to review your country's key TB documents and Workbook Tool 2.4 to summarise your country's TB objectives, targets, and key activities.

National TB guidance, objectives, targets, activities and indicators

What are we trying to achieve and how?

Now that you understand the epidemiological context and the organisation of TB services, you can start to become familiar with the key strategy and policy documents that guide the NTP's work. Your goal is to fit your activities into the existing framework for TB in your country and align your objectives and targets to contribute to the overall objectives and targets of the national programme.

Most countries have several key documents that are important to review. The first is the NTP's TB strategy document, which usually covers a five-year period. The strategy document will provide you with background information on the TB situation in the country and how it has changed over time, will describe the NTP's priority areas during the current five-year period (for example, laboratory strengthening, MDR-TB control, or TB/HIV), and will often provide objectives with targets that the NTP would like to achieve by the end of the five years.

The second document to review, when available, is the NTP's work plan or action plan. This plan usually covers a one-year period and lays out in detail what activities the NTP will undertake in the current year to help it reach its five-year targets.

Other NTP documents that will be useful to you include any TB and TB/HIV policies, guidelines, protocols for diagnosis and treatment, reporting instructions, or other tools that can help you align your work with NTP standards.

Identify successes, challenges, barriers, and solutions

Analyse the data and use the Cough-to-Cure Pathway

Knowing all of the background information discussed in the previous section will set you up for success in choosing and implementing your TB/HIV activities. It allows you to understand the system through which you must work. In addition, you can identify where some of the challenges may lie by analysing the TB programme data.

Once you have identified performance areas where there may be challenges, you will combine this information with your own knowledge of the community and the challenges people face in getting care for TB/HIV to come up with the activities that will be most useful to making improvements. The project planning, implementation and evaluation cycle below is the cycle you will go through in doing this type of analysis, using the NTP's goals and objectives as your starting point.

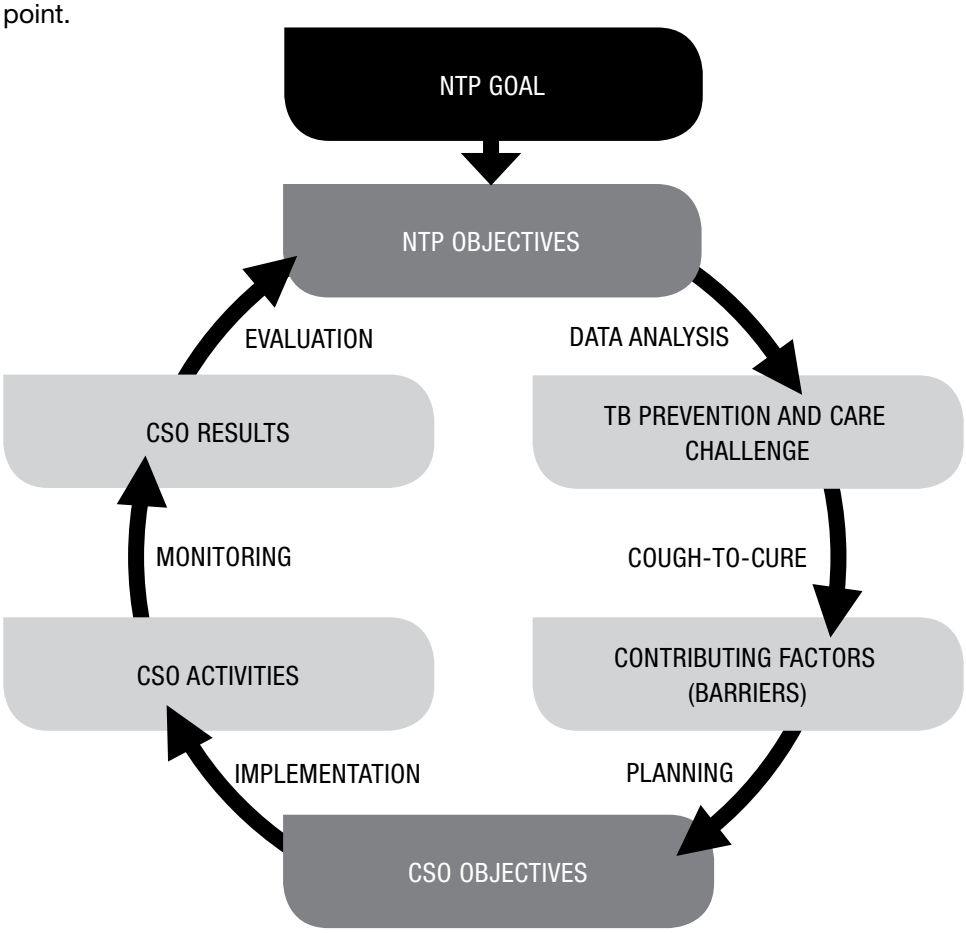


Figure 5: The project planning, implementation and evaluation cycle

WORKBOOK ACTIVITY

Go to Workbook Tool 2.5 to practise identifying possible programme gaps using your local data.

To start this process, look at your national TB programme's objectives and targets. Now compare the data from the area where you work with the targets the country is trying to achieve. Has your area reached the target for that objective, or is there still room for improvement? If you haven't quite gotten to the target, you will then go through the rest of the cycle to understand what is causing the gap in performance, and how to correct it.

Another tool that has proven extremely useful in going through this process of analysis is the ***Cough-to-Cure Pathway***. This pathway describes the ideal journey of a person with TB from the point at which symptoms first appear until the person is cured of disease. There are many factors that go into making this journey successful or unsuccessful. These include individual factors (such as ability to pay for transport or willingness to take medications), community or group factors (such as traditional beliefs or stigma), health system factors (such as the hours the TB clinic is open, the location of TB services, or policies such as public health acts and laws that prescribe harsh punishment or detention for people who are unable to consistently take their TB medications). By looking at your data and relating the information to each step of the Cough-to-Cure Pathway, you can identify at which step(s) there may be problems that prevent people from having a successful outcome. Then you can investigate why these problems exist and develop activities to help address them.

The Cough-to-Cure Pathway (see Table 5) shows you all the things that would happen to a person with TB from the beginning to the end of their disease if everything were working perfectly. When the data show that everything isn't perfect, we can use this pathway to identify where things are breaking down and develop activities to prevent the breakdowns. The key question to ask in going through an analysis using the pathway is "Why?" Continue to ask "Why?" until you get to the root cause of your problem, and then you will know how to fix it.

WORKBOOK ACTIVITY

Try using the Cough-to-Cure Pathway to analyse some of the challenges your clients may face at each step of the Pathway by turning to Workbook Tool 2.6.

For example, let's say our data show us that of a total of 150 people were diagnosed with TB in our district during a one-year period. However, only half of them (50%) were counselled and tested for HIV, when the national target is to have every person with TB counselled and tested (100%). So, we are a long way from reaching our target in our district. In this example, there is a problem somewhere in the "complete diagnosis" step of the Cough-to-Cure Pathway, since HIV counselling and testing should be an integral part of TB diagnosis and treatment initiation. We then ask "Why aren't all the people diagnosed with TB getting HIV counselling and testing?" We do some further investigation – we talk to clients and providers – and we discover that many people are refusing to be tested. We ask "Why?" again, and this time we discover that people are refusing to be tested because of the stigma associated with TB/HIV, both self-stigma and community stigma. Now we have something specific we can address – as a CSO, we can create activities that help reduce stigma in the community and educate people with TB about the importance of knowing their HIV status so they can receive the appropriate treatment and have the best chance of becoming healthy again.

WORKBOOK ACTIVITY

Use Workbook Tool 2.7 to practise developing activities that address identified TB challenges. To plan specific activities in the areas of advocacy, communication, community/social mobilisation, or service delivery, you can use Workbook Tools 2.8–2.11. Come up with a list of activities that your organisation will consider doing.

You can use this same step-by-step process for any of the issues you find when looking at the data to come up with practical, appropriate solutions. You can also create and use a similar pathway for any health issue, including HIV. A key point to remember is that you should not assume you know why a problem exists – back up your idea with solid information. That way you will know you are using your resources to solve the right problem.

Link potential activities with objectives and challenges

Now that you have a good understanding of what the TB programme is trying to accomplish, where the challenges lie, and what the root cause of the problem is, you can put all of this information together to develop activities that can help overcome the challenges. You will use all of the information from Workbook Tools 2.4, 2.5 and 2.6 to develop your own logical chain as shown in the cycle diagram in Figure 5. This will form the basis of your work in the next action, when you decide which activities are the most important ones for your organisation to implement.

TABLE 5: THE COUGH-TO-CURE PATHWAY

Ideal	■ Community members have knowledge of TB symptoms ■ Community members know when, where and how to seek care ■ The community supports care-seeking behaviour for people with TB symptoms ■ Health facilities provide the community with information about TB symptoms and where to seek care for free	■ Community members know the facility to visit for TB evaluation ■ Community members trust the facility to provide quality services ■ The community encourages care-seeking behaviour ■ Health facility is available nearby with trained staff and client-friendly services	■ People with TB symptoms have the correct information about where to go for evaluation and how to produce sputum ■ People with TB symptoms trust the facility to give them an accurate diagnosis ■ Laboratory equipment and supplies are available to diagnose TB and test for HIV ■ Staff are trained to diagnose TB ■ Staff are trained to provide HIV counselling and testing ■ Services are provided in a timely manner for free	■ People with TB receive thorough client education and understand the importance of treatment ■ A treatment supporter is identified for each person with TB ■ Quality drugs are available for treatment ■ Treatment support is provided and DOT is done at a place and time convenient for the person with TB ■ People with TB do not face stigma or discrimination	■ People with TB receive ongoing encouragement and education from health care staff and community volunteers ■ Regular monitoring of treatment is done including a final sputum ■ Side effects are identified quickly and addressed ■ Treatment supporters help people with TB cope with ongoing treatment ■ Quality drugs are available
COUGH-TO-CURE PATHWAY	**Recognise illness and the need to seek care →**	**Seek care at a health facility that can diagnose TB →**	**Complete diagnosis for TB, including HIV counselling and testing →**	**Begin treatment for TB →**	**Continue and complete treatment**
Individual barriers: Examples	■ Lack of knowledge about TB symptoms ■ Lack of knowledge about when, where and how to seek care ■ Health not a priority ■ Self-stigma	■ Lack of knowledge about where to go ■ Lack of time to attend health facility ■ Lack of money for transport ■ Mistrust of the health system ■ Misinformation about costs associated with TB diagnosis ■ Self-stigma	■ Lack of knowledge about where to go ■ Lack of knowledge about how to produce sputum ■ Lack of time to attend health facility ■ Lack of money for transport ■ Self-stigma	■ Misinformation or misconception about the cost of treatment ■ Concern about potential side effects of medication ■ Other pressing personal priorities ■ Fear of losing job ■ Self-stigma	■ Lack of understanding of the need to continue treatment for the full course ■ Feel better ■ Self-stigma
Community barriers: Examples	■ Stigma ■ Lack of community priority	■ Stigma	■ Stigma	■ Stigma	■ Stigma ■ Lack of community support for people on TB treatment
System barriers: Examples	■ Lack of educational services and materials on TB for the community	■ Lack of health facilities in the community ■ Operating hours that do not match needs ■ Fees for services ■ Discrimination on the part of health workers ■ Forced hospitalisation policy for people with TB	■ Lack of well-trained health care workers ■ Lack of lab equipment and supplies ■ Overcrowded in health facilities ■ Discrimination by health workers	■ Poor client education ■ Drug stock-outs	■ Poor client education ■ Lack of treatment support ■ Drug stock-outs ■ Inconvenient DOT location, timing

SOURCE: Adapted from the original Cough-to-Cure Pathway developed by the Academy for Educational Development in conjunction with the Stop TB Partnership.

GOOD PRACTICE STANDARD 8

STIGMA

Stigma is one of the most widespread and difficult challenges in the fight against TB. In many places, people with TB or suspected of having TB are discriminated against by providers in the health system, family members, community members, employers, and others. This discrimination comes from ignorance or misinformation, usually because people associate TB with behaviours or conditions they perceive as negative, like poverty, poor hygiene, drug use, or HIV infection. Overcoming stigma is an important and challenging role for CSOs. Through education, open dialogue, and advocating for the rights of people with TB just as they do for people living with HIV, CSOs can help overcome this major barrier to stopping TB. It is important to also address HIV stigma as it can occur alongside TB stigma.

KEY RESOURCE

International HIV/AIDS Alliance's (2009). 'Understanding and challenging TB stigma: toolkit for action'.

Available at: **www.aidsalliance.org/includes/Publication/TB_and_Stigma_May09.pdf**

An important tool in combating TB-related stigma.

GOOD PRACTICE STANDARD 3 (MEANINGFULLY ENGAGING PEOPLE WITH TB AND HIV IN PLANNING, IMPLEMENTING AND EVALUATING TB AND HIV ACTIVITIES) AND STANDARD 8 (ADDRESSING TB AND HIV STIGMA)

CASE STUDY: A PHOTOGRAPHY PROJECT IN TANZANIA ALLOWS PEOPLE WITH TB AND HIV TO USE THEIR VOICES FOR CHANGE

In Tanzania, about half of people diagnosed with TB are infected with HIV. To address stigma, educate the community, and improve health services in response to this crisis, PATH enlisted the help of people being treated for TB and HIV. Together, they worked on a photography project based on the PhotoVoice model originally created by Romel Lacson, a man who lost his wife and daughter to TB. Tanzanians with TB and HIV and the health care providers who treated them took photographs of their daily lives and experiences with TB/HIV treatment, and then talked about what these pictures meant to them. Far from being gloomy, the photographers' subjects often told inspiring stories of how integrated care had changed their lives. They went on to support change in their communities by using these experiences.

"I was referred to the AIDS clinic where I met other patients and exchanged ideas and learnt more about HIV/AIDS. This gave me more hope and comfort. I was started on ARVs, and since then I have been feeling better and better."

ATHUMANI

Some of the photographs and quotes were made into posters and flyers and distributed in the community to educate the public and encourage them to get tested. They were also used to discuss the issue of stigma and reduce its impact on people living with TB and HIV. The people who took the photographs presented them to local Community Health Management Teams and talked about the benefits of integrated services. They used the opportunity to become advocates for more financial resources and ask for improvements in the way services were delivered.

As a result of this project, stigma in the community and among health care providers was reduced, and more people went to the clinic for TB and HIV testing. People with TB also felt empowered to become change agents in their own community. This type of project is an important way to engage people infected and affected by TB and HIV in addressing the difficult issue of stigma, which continues to be one of the key barriers to effective diagnosis and treatment worldwide.

Often, the difficulty with this type of work is in measuring and reporting your results. We will discuss more about the importance of providing data under Action 5 (see page 55).

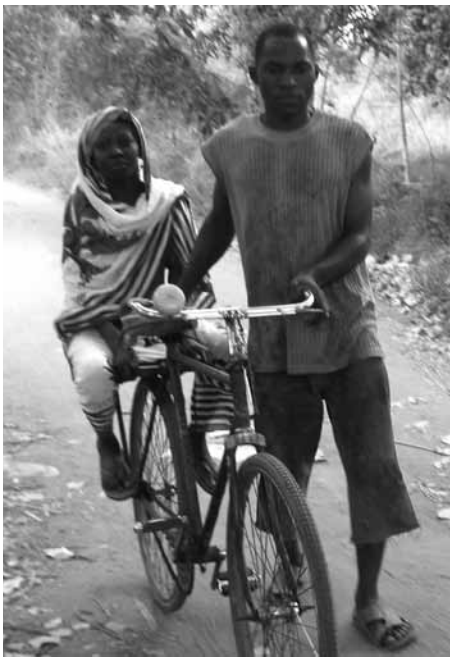
An example of one of the posters produced is provided on the next page. You can learn more about this project at **www.path.org/projects/photovoice.php.** You can learn more about the PhotoVoice model at **www.photovoice.org**.

"I'm glad that now I have counselling skills and sufficient working knowledge that makes it easy for me to convince my patients to test for HIV… more and more accepted to be tested for HIV – this was not the case before."

MARGARETH, SENIOR PUBLIC HEALTH NURSE

SAMPLE POSTER FROM THE CLIENT-LED PHOTOGRAPHY PROJECT

Do not stigmatise or discriminate against TB and HIV patients



"My name is Habiba, I have been sick for three years and have been to several hospitals without any improvement or knowing what was affecting me. I eventually decided to go to Kisarawe district hospital where I was examined and told that I had TB. The TB nurse also advised me to check my HIV status; I accepted to be tested and the results came out positive. I was very shocked, but having learnt that there were many of us who had both diseases I felt some comfort. The nurse referred me to the AIDS clinic where my immune status was checked and was after two weeks started on drugs that reduce the 'fierceness' of HIV called ARVs.

"At the beginning, as shown in this picture, I was very weak and my neighbour had to give me a lift on his bicycle as I could not walk to the clinic. After taking anti-TB and ARV drugs as instructed for about three months, my strength returned and I felt better and stronger. Since then I have been able to go to the clinic on foot by myself. I have learnt that HIV is not curable but my TB will go away and I will have to continue with ARVs. I am grateful to the nurses and doctors at the hospital; they have saved my life. I am also grateful to my neighbour who helped me when I was in most need. He was not afraid of being infected by me as the clinic nurse said that with cough hygiene and proper treatment one cannot infect others with TB. She also said that one cannot get HIV by being in casual contact with someone who has HIV."

KEY MESSAGES

To participate effectively in TB/HIV integration:

- work with your NTP
- understand how your NTP is structured
- review and analyse your national TB strategy and plans
- understand national priorities and targets for TB and HIV
- review key information for your area, including the characteristics of the population, how much TB there is, and who is most at risk for TB
- identify TB control challenges and then look for the factors that contribute to these gaps in performance
- identify activities that will contribute to the overall goals and objectives set out in national and regional plans.

Action 3: Choose activities appropriate for your organisation

In this section:

- Situation analysis
- Organisational analysis
- Prioritising activities
- Case study: The road to becoming a leading TB/HIV organisation: Alliance Ukraine's story

Situation analysis

Doing TB/HIV integration work does not happen in isolation. There are many factors to consider in deciding what your organisation can do. In the previous section, you completed an analysis of the successes, gaps, and opportunities in TB by reviewing the TB programme data. Now you will begin to place those into the larger context, so you understand what else is already planned and where your organisation might fit into the national response.

Key questions to ask in looking at the bigger picture of TB/HIV integration include:

- What are the major barriers to effective TB prevention and care in my area? Do our clients agree that these are the most important barriers they face to accessing the quality care they need? (Use your Cough-to-Cure analysis, in-depth interviews, and focus group discussions.)
- What organisations are currently involved in TB/HIV work in my area?
- What activities are they doing or planning to address any of the barriers, and with which populations?
- What funding is currently available to implement activities?

To collect this information, you may have to meet with the local NTP representative, attend meetings, hold a roundtable discussion with other CSOs, review available planning documents, review Global Fund grant documents, and have one-on-one or focus group discussions with clients. It is critically important not to make assumptions about why certain challenges exist, but to collect evidence to identify key problems. This process can also help introduce your organisation to others and begin to build the relationships that will form the basis of strong partnerships in the future.

WORKBOOK ACTIVITY

Go to Workbook Tool 3.1 to complete a situation analysis for your area.

When your organisation is just beginning TB/HIV integration activities, start small. Do something that can be accomplished relatively quickly and successfully without a huge investment in new equipment, training, or staff. This will help you learn, establish credibility, and motivate others to join in these efforts by demonstrating your success.

Organisational analysis

Very few organisations will have the capacity to implement activities to address all of the challenges identified through your analysis. The question for your organisation then becomes "Which activities should we implement if we have to choose?" The answer will be based on your organisation's strengths, what activities the NTP or other organisations could cover, and the activities that are expected to yield the greatest benefits. All of these things will fit together to develop a TB/HIV action plan.

The next step in making decisions about activities is to perform an organisational analysis. This analysis will identify the key features of your group – what activities you are doing currently, where you are doing them, what funding you have and for how long, and other factors that can help you decide which TB activities to integrate into your HIV programming.

The goal is to integrate TB activities that match well with your current HIV activities in terms of location, staffing numbers and skills, and funding levels. For example, a small community organisation that is currently working in two districts in home-based HIV care could more easily incorporate TB treatment support as an activity in those two districts. In contrast, setting up additional microscopy centres to diagnose TB in those districts might be beyond the expertise, staffing, and financial resources of that organisation at the moment.

GOOD PRACTICE STANDARD 1 (IDENTIFYING AND IMPLEMENTING AN ORGANISATIONAL STRATEGY THAT SUPPORTS TB/HIV INTEGRATION)

WORKBOOK ACTIVITY

Go to Workbook Tool 3.2 to complete an organisational analysis for your own group.

Prioritising activities

Now that you have a good sense of what needs to be done, what others are doing, and what strengths your organisation brings to this work, you are ready to list potential activities and prioritise them for implementation. In order to do so, you can ask yourselves the following questions:

WORKBOOK ACTIVITY

Go to Workbook Tool 3.3 to complete a prioritisation template for your organisation.

- What activities is our organisation best-suited to undertake?
- Of these, which activities could have the greatest benefit for the most people? Which activities does the affected community feel are most important to them?
- Which of these has the highest chance of success?
- If we are successful, what will be the specific (measurable) outcomes of these activities?
- Which of these can we accomplish with available resources, or are most likely to be able to get additional resources to implement?
- Which of these can we accomplish in a reasonable timeframe?

Answers to these questions may provide you with clear answers about the choice of activities, or there may still be uncertainty in deciding which activities are the best for your organisation. In either case, final decisions should be made in consultation with the NTP, your partners, communities, staff, and any other important stakeholders such as donors.

GOOD PRACTICE STANDARD 1 (IDENTIFYING AND IMPLEMENTING AN ORGANISATIONAL STRATEGY THAT SUPPORTS TB/HIV INTEGRATION) AND STANDARD 5 (PROVIDING UNDERSTANDABLE INFORMATION ABOUT TB)

CASE STUDY: THE ROAD TO BECOMING A LEADING TB/HIV ORGANISATION: ALLIANCE UKRAINE'S STORY

Ukraine is a high-burden country for both TB and HIV. HIV is concentrated among people who inject drugs, sex workers, and men who have sex with men. The main burden is among people who inject drugs, who account for 46.5% of all cases of HIV infection. People who use drugs are often more vulnerable to TB because of high rates of HIV and crowded living conditions, including in prisons. Since Alliance Ukraine has traditionally worked with people who use drugs, it recognised the need to respond to the TB epidemic among this population. WHO also recommends integration of TB and harm reduction services people who use drugs. This involves ensuring that people who use drugs get access to health education on TB symptoms and transmission; TB screening and diagnosis; isoniazid preventive therapy if they are HIV positive and do not have active TB; and TB treatment if they have TB disease. Conversely, all people who use drugs with TB infection should be offered provider initiated HIV testing and counselling; and all people who use drugs who are co-infected with TB/HIV need to start ART.

In concentrated HIV epidemics, which usually involve marginalised groups, it is especially important to engage civil society as key stakeholders who can play an important role facilitating access to services, for example, through outreach work and case management.

The International HIV/AIDS Alliance began work in Ukraine in 2000 and in 2001 formed Alliance Ukraine. In 2004, Alliance Ukraine rolled out a national-level response guided by a strategy to develop comprehensive package of services for people who use drugs and other target population. Multidisciplinary teams were formed consisting of medical staff and outreach workers. Alliance Ukraine and its partners started to address TB through approaches they were familiar with – producing information, education, and communication (IEC) materials and providing referral services. Between 2004 and 2007, with some technical support, Alliance Ukraine's implementing partners published educational materials on TB/HIV for teachers, people living with HIV, and prisoners.

Parallel to the IEC and referral work, Alliance Ukraine started preparing for TB/HIV integration work by raising the awareness about TB alongside HIV. Alliance Ukraine also started to engaged in advocacy and lobbying for TB, consultation with other service providers on the ground to identify gaps in TB services, and participation in the national technical working groups which develops national TB/HIV guidelines. In addition, Alliance Ukraine used their experience in procurement and supply management of ARVs to procure TB drugs and TB-related medical products. As a result of their long-term efforts and strategic focus on TB/HIV, Alliance Ukraine is now playing a key role in the country's response to TB and HIV. For instance the organisation was selected as a sub-recipient to Global Fund Round 9 TB grant to address HIV/TB co-infection and provide procurement and supply chain support.

SOURCE: Excerpted from International HIV/AIDS Alliance and Alliance Ukraine. Full case study is available at: **www.aidsalliance.org**

KEY MESSAGES

To be successful in TB/HIV integration:

- understand the current situation in the areas where you are working by doing a situation analysis. It will include what is being done in TB/HIV, which organisations are involved, and where there are gaps that your organisation might be able to fill.
- understand the strengths of your own organisation by doing an organisational analysis. This will help you choose activities that fit well with your existing projects and fill important gaps in service to your clients.
- prioritise activities that will make the biggest improvements for your clients, can be accomplished in a reasonable amount of time with a reasonable amount of funding, and contribute to national or local goals and objectives.

Action 4: Create or strengthen appropriate partnerships

In this section:

GOOD PRACTICE STANDARD 2 (COLLABORATING WITH OTHER TB AND HIV ORGANISATIONS TO ACHIEVE THE OBJECTIVES OF THE NATIONAL HIV AND TB PROGRAMMES)

- Joining existing partnerships
- Building new partnerships
- Choosing partners
- Partnering with the national TB programme
- Creating and maintaining effective partnerships
- Preparing a partnership plan
- Assessing your partnerships
- Case study: A partnership to implement intensified TB case finding among people at risk for HIV in India

Now that you understand the local context, know what others are doing, and have prioritised your own organisation's activities, you are ready to select the partnerships you will join or form to make your work as effective as possible and avoid duplicating the efforts of others. As a community organisation, you may be developing new partnerships at local level for your TB/HIV work. You may also be joining the larger partnership groups that have already been established to help coordinate the local or national response to TB. These partnerships might include a National Stop TB Partnership, a Global Fund Country Coordinating Mechanism (CCM), or a national TB/HIV coordinating body. Regardless of what form they take, developing and maintaining effective partnerships takes time and effort. You should have clear reasons for joining or creating partnerships to avoid wasting the valuable time and resources of your organisation and staff. Focus on ***strategic partnerships*** – those offering your organisation clear benefits and to which you can provide meaningful contributions.

Joining existing partnerships

To save yourself time and resources, make as much use as possible of partnerships that already exist in your country, rather than creating something new, as long as they serve your needs well. There are two ways to go about doing so: either a representative from your organisation could become a member of the partnership directly, or your organisation could belong to a ***constituency*** with one representative on the partnership who reports back on decisions and activities to all the member organisations of that constituency. There are advantages and disadvantages to each approach, and your choice will depend upon your context and on the rules of the existing partnership.

Having your own representative on a partnership allows your organisation to participate directly in decision-making and have firsthand information on partnership decisions and activities. However, it is time-consuming and may leave you in a weak position if others in the partnership do not agree with your opinions. If you belong to a constituency, one person is selected to represent the collective opinion of a whole group of organisations, which may carry greater weight in decision-making and saves staff time. However, a constituency approach requires excellent and frequent communications between groups and a commitment to resolving differences if the constituency is to be represented successfully in the partnership.

Building new partnerships

In addition to joining or strengthening existing partnerships, most organisations will create new partnerships to expand their work in TB. You may be creating new partnerships with local, national, or international stakeholders. Your approach will depend upon your reasons for creating a new partnership and the specific needs it will fill.

If you are creating new partnerships, particularly if you are partnering with large non-governmental organisations (NGOs) or international organisations in the role of a recipient of funds from them, it is especially important for you to understand their administrative processes and requirements and for them to understand yours. If you are partnering with smaller local organisations, you should understand both their strengths and their challenges so that you can support them in developing their own capacities further.

Building new partnerships is a process. We will discuss some of the key components of successful partnering after you have identified your partners.

Partnering with the national TB programme

When it comes to partnerships for TB/HIV, there are certain specific partners with whom every organisation will work at local or national level. As we discussed in Action 2: Know the TB situation in your country, the first key partner in all TB activities will be the NTP at local or national levels or both. You may also be working with the national AIDS programme or other government ministries (such as the ministry in charge of prisons).

You have already learnt how your NTP is structured and how it functions. You have identified a contact person with whom you can communicate about your activities. You know how your activities support the goals and objectives of the NTP. To solidify and maintain your partnership, it is important to formalise that relationship and establish a mechanism for ongoing coordination. As discussed above, that step may happen through your participation in existing structures, such as the National Stop TB Partnership, Global Fund Country Coordinating Mechanism, or TB/HIV coordinating body. Alternatively, it may happen through a new memorandum of understanding between your organisation or consortium of

WHAT IS PARTNERSHIP?

“Partnerships are commonly defined as voluntary and collaborative relationships between various parties, both State and non-State, in which all participants agree to work together to achieve a common purpose or undertake a specific task and to share risks, responsibilities, resources, competencies and benefits.”

REPORT OF THE UN SECRETARY GENERAL

organisations and the NTP. There is no one right way to do this, and the option you choose should take the local context into account. Whichever option you agree on, however, it is important that there is a well-defined partnership plan, as discussed later in this section.

WORKBOOK ACTIVITY

Use Workbook Tool 4.1 to identify key partners and partnerships for your TB work in your country.

Choosing partners

Your reasons for choosing partners will be many. However, all of those decisions should be based on the information you have gathered in your situation analysis and organisational analysis (see page 46). That information will provide you with some basic criteria for selecting partners. Some questions you may ask to determine what partners you would like to have include the following:

- What gaps would we most like to fill in our current expertise, available human or material resources, geographic or population coverage, or activities?
- Are there decision-makers who are important in accomplishing our work with whom we currently lack influence?
- Are there decision-making processes related to our work in which we currently cannot or do not participate?
- Are there connections we would like to make with other groups that are difficult for us to accomplish without an introduction?
- Is there overlap in the activities or geographic coverage between our organisation and that of other groups?
- Are there stakeholder groups with whom we have little contact right now?
- Are there specific populations who could benefit from services but with whom we have little contact at the moment?
- What benefits will this partnership provide to our organisation?
- What contributions will our organisation make to this partnership?

When choosing partners, think creatively. There may be useful partners from other sectors, such as large for-profit companies, local businesses, private providers, influential individuals, and community groups outside the health sector. Having a good cross-section of partners with different experience and opinions can lead to new approaches in the way you implement your activities, with better results. However, in order to keep your partnerships to a manageable size and complexity, choose partners carefully and deliberately and keep them to the smallest number possible to accomplish your goals.

GOOD PRACTICE STANDARD 2 (COLLABORATING WITH OTHER TB AND HIV ORGANISATIONS TO ACHIEVE THE OBJECTIVES OF THE NATIONAL HIV AND TB PROGRAMMES)

Creating and maintaining effective partnerships

The basic purpose of partnerships is simple and straightforward: to identify common ground between groups, organisations and institutions, and to combine their skills and expertise for mutual benefit. Effective partnerships can make it possible to overcome challenges that are too difficult, complex, or costly for one organisation or sector to address alone. In other words, partnerships are built to do something you could not do on your own, or to enhance the success of the activities you are already doing.

There are some characteristics of all successful and effective partnerships that can help guide you as you develop your partnerships:

- voluntary, willing, and active participation of all partners
- an explicit written agreement between the partners that defines the terms of engagement – a partnership plan
- mutual trust and respect
- commitment to a shared vision and purpose
- willingness to compromise and adapt as needed to benefit the partnership

- skilled leadership
- sharing of risks, responsibilities, resources, and benefits
- a good match of complementary skills and resources among the partners
- meaningful participation of all member organisations in planning, managing, and assessing partnership activities
- well-defined, realistic goals and objectives
- clear roles and responsibilities for each partner
- open and frequent communication
- open sharing of data and other important information
- regular assessment of the partnership and adjustments as needed to improve its effectiveness

Preparing a partnership plan

Once you have identified and invited key partners to work with you, you will then develop the partnership plan together as a group. The plan defines all the components necessary for working together effectively, including how the partnership will be governed and administered, who will be involved in planning activities and making decisions related to the partnership, the roles and responsibilities of each partner, the methods and frequency of communication, how data will be shared, how financial and material resources will be shared to accomplish the activities, and how the partnership will be evaluated.

Assessing your partnerships

Periodically, you will want to monitor how your partnership is functioning and make changes as needed to address partner concerns and improve your effectiveness. You can use the partnership plan checklist In Workbook Tool 4.2 as an outline for discussions you have with partners on the functioning of the partnership. In the early stages of a partnership, you may want to have check-ins on a frequent (monthly) basis. After you have established your relationship and things are running smoothly, annual review and discussion may be often enough. The frequency will depend on the nature of your partnership and the work you are doing together. In general, these discussions will be best conducted in person at a roundtable meeting of all partners, unless there are specific issues to discuss with only one of your partners. Record the key points of the discussions and any decisions that were made. Circulate the written minutes to all partners for their review and comment before finalising the minutes of the meeting for your records. This is important in case disagreements arise later on, so that all partners can refer back to the written record of what was agreed.

WORKBOOK ACTIVITY

Workbook Tool 4.2 includes a checklist for the components of a partnership agreement, and sample agreements with the local NTP unit or with another CSO. Use this to develop a written document for your new partnerships or to review your existing agreements to see if there is anything you would like to add to make them more specific.

CASE STUDY: A PARTNERSHIP TO IMPLEMENT INTENSIFIED TB CASE FINDING AMONG PEOPLE AT RISK FOR HIV IN INDIA

The Alliance India is a lead partner in the Avahan Initiative in Andhra Pradesh (one state of India), working through a network of NGOs to implement HIV prevention among female sex workers, men who have sex with men, and transgender populations. The project's guiding principles are centred around community mobilisation and integrated service delivery. To date, the network of NGOs has emphasised behaviour change communication and has mobilised people at risk to visit clinics to be examined for sexually transmitted infections (STIs). These facilities provide screening and treatment for STIs, HIV testing, risk-reduction counselling, condoms, and linkages to ART programmes.

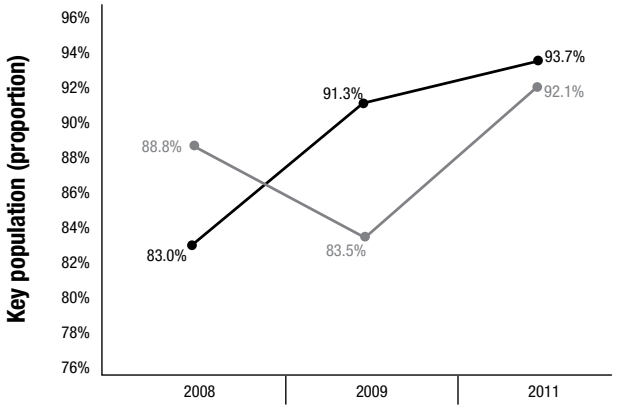
In addition to large numbers of people living with HIV, every year India has the highest total number of people with TB in the world. Clearly, intensified case-finding through screening for symptoms of TB among HIV-infected people was needed. Evidence showed that TB screening using a symptom questionnaire about chronic cough, fever, night sweats, and weight loss was a reliable method of identifying TB in HIV-positive adults.

Taking this into consideration, Avahan and partners entered into a memorandum of understanding with the NTP in March 2007 with the aim of increasing intensified case-finding and access to TB treatment for key populations across six Indian states with high HIV prevalence. This was an add-on to the Avahan programme's model of using peer educators to deliver STI and HIV prevention services to key populations. The project went through the following stages:

- forming state level partnerships
- orienting service providers
- piloting the new intervention (TB screening)
- strengthening the capacity of health workers (training on TB)
- introducing new tools and protocols for case management
- integrating TB screening into HIV and STI services.

The project resulted in increased coverage of services, improved capacity of local organisations to deliver TB services; and – most important – increased access to TB diagnosis and treatment for vulnerable populations. During the three-year implementation period from 2008 to 2010, an annual average of 53,749 people in key risk groups (female sex workers, men who have sex with men, and transgender people) received at least one type of service from the project (HIV, STI, or TB prevention, treatment, or care). On average, 88% of service recipients were screened verbally for TB every year. In addition, peer educators provided 35,086 referrals to STI clinics following verbal TB screening during the project.

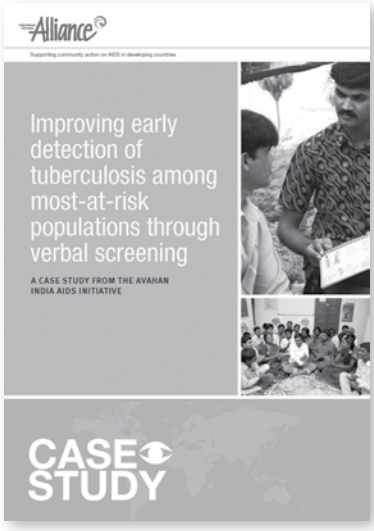
Proportion of all key populations screened for TB and proportion of those diagnosed with TB offered treatment



Proportion of key population members screened for TB

Proportion of key population members diagnosed with TB and subsequently offered treatment

Source: Alliance Clinical Management Information System



SOURCE: Case study courtesy of Alliance India. The full case study is available at: **indiahivaidsalliance.files.wordpress.com/2012/06/tb-verbal-screening-case-study.pdf**

KEY MESSAGES

- Partnerships can be valuable in achieving your TB/HIV objectives by giving your organisation access to the information, expertise and resources of other organisations.
- The NTP and national AIDS programmes will be key partners for any CSOs working on TB/HIV integration. Understanding how they work and the timing of their annual cycles for work planning and budgeting will help you work more effectively with them.
- Maintaining effective partnerships requires clear communication and a lot of time. Be strategic in joining or creating partnerships. To the extent feasible, use existing partnerships to support your work.
- Documenting partnership agreements and decisions in writing and following up on action items are critically important steps in maintaining effective partnerships.
- Evaluate your partnerships periodically and make adjustments as needed to ensure maximum effectiveness.

Action 5: Plan, implement and measure the success of your activities

In this section:

- The project planning, implementation, and evaluation cycle
- Share your results
- Case study: Advocacy in Kenya helps free up resources for TB work

The project planning, implementation and evaluation cycle

Now that you have chosen the activities your organisation will implement, it is important to plan them carefully so that you will have the greatest chance of succeeding and will be able to measure your success in a way that the NTP understands and recognises.

Often, not enough time and attention is given to planning activities well because we are all under a lot of pressure to implement them quickly. As a result, we may make avoidable mistakes or we may not be able to measure the success of what we did, both of which could endanger future funding. Spending a little more time ensuring you have a good plan can help yield better results.

A typical project cycle consists of three main phases – planning, implementation, and evaluation.

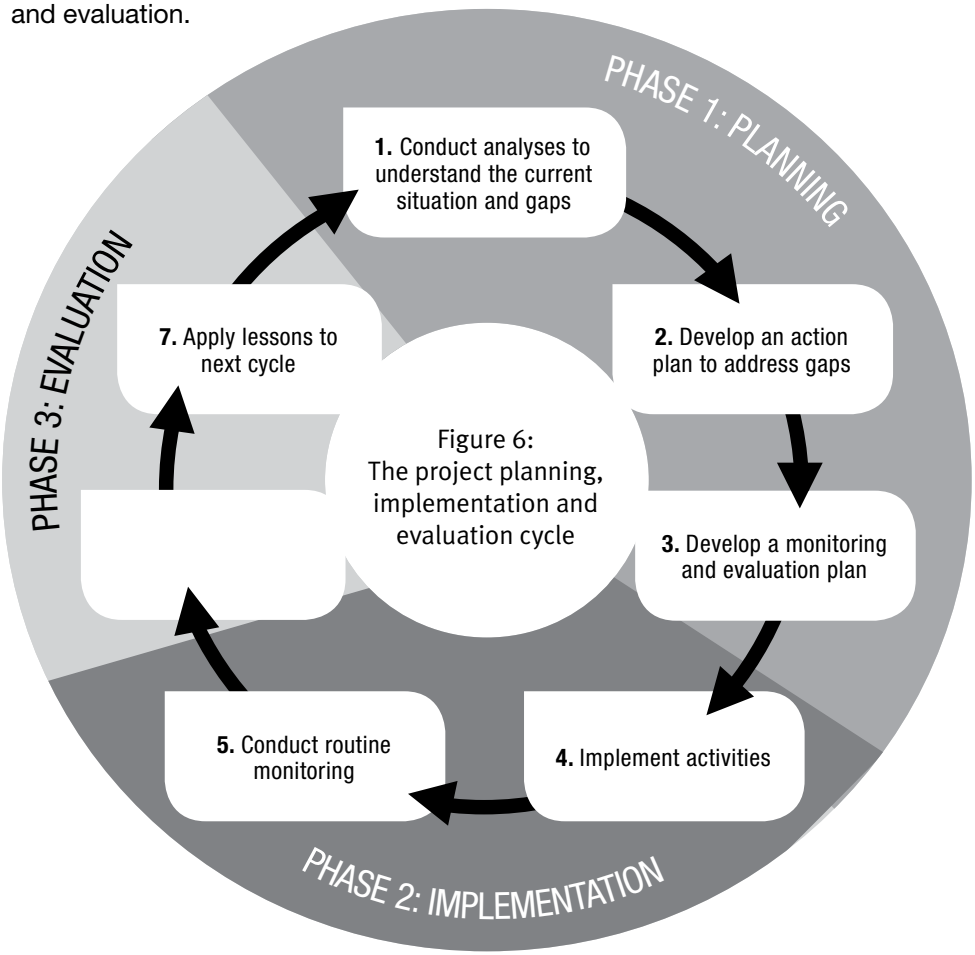


Figure 6:
The project planning, implementation and evaluation cycle

Just as you did in Action 4, you first take time to understand the situation in your area and identify the performance gaps based on the NTP's targets and community feedback. You then develop your action plan to link your objectives and activities to filling the identified gaps. These in turn relate to reaching the national TB targets and meeting the needs of the community. Once you have your action plan, you develop a method for monitoring whether you are making progress and evaluating what the outcomes of your activities have been. Once all of those pieces are in place, you begin implementation, monitor your activities, measure your success and document what lessons you learnt from things that did or did not go well. Finally, you use that information to feed into the next round of planning to improve your performance and/or replicate your successes.

In addition to your action plan, you need to develop a simple ***monitoring and evaluation*** (M&E) plan so that you can monitor the progress of your activities and evaluate the results. An M&E plan is built on your action plan's objectives,

WORKBOOK ACTIVITY

To practise developing a plan for your activities, go to Workbook Section 5. Tool 5.1 provides a checklist with all the steps needed to plan and monitor your activities. To create a work plan, use the template in Tool 5.2. You can refer back to any activities you mapped out in Tools 2.7–2.11 and incorporate them into one table in Tool 5.2. In addition, you will find some sample tools that may be useful to you in implementing your activities, such as samples of a TB symptom screening tool (Tool 5.3) and a referral slip (Tool 5.4) that you may adapt for use in your activities.

WORKBOOK ACTIVITY

To practise developing an M&E plan for your activities, use Workbook Tools 5.5 and 5.6.

activities, and targets. It will define how you are going to make sure that your activities are on track and on time, you are making progress toward your targets, and you have been successful at what you were trying to accomplish.

Monitoring is important because it allows you to see if things are going as planned or if you need to make adjustments to your action plan because of challenges you may not have anticipated. It focuses on the activities in your action plan, and will tell you whether you performed the actions you said you would do.

Evaluation is important because it allows you to show whether you have actually produced the results you intended with your activities, and have therefore made a positive change in the TB prevention and care situation in your area. Evaluation focuses on your objectives and whether you had the effect you hoped to see.

On page 58 is an example showing how monitoring and evaluation works.

HOW DO WE MEASURE SUCCESS IN ACTIVITIES SUCH AS STIGMA REDUCTION OR ADVOCACY?

Some results you are trying to achieve may not have specific numerical data associated with them, and you may find it harder to talk about your achievements. For instance, in the case study on the photography project (see page 44), there were no numbers available – it just reported that stigma was reduced and more people went to the clinic for testing. We could make this case study stronger and improve the chances that the community will be credited with producing positive results by doing several things. First, before we start the stigma reduction campaign, we need to understand what we want as the end result of the activity: we want to reduce stigma, but we also want other things to happen as a result of the decreased stigma. In this case, we want people to feel more comfortable admitting that they might have TB/HIV, and therefore going to the clinic to be tested. Second, we can identify what we could measure to give us some objective proof that things have changed. For this example, we could measure levels of stigma in the community before and after our activities. We could also measure the number of people who visit the clinic to be tested for TB and/or HIV before and after our activities, which would be the best proof our intervention made some improvement in the current situation.

Measuring stigma could be done with questionnaires administered to community members, people living with TB/HIV, and health care providers. The same questionnaire would be given before you start your activity and then after you have completed it, to measure any changes. It is important to use validated tools and questions so that the results are a true representation of the impact of your work. Results might be reported as the percentage of people interviewed who expressed some stigma towards people with TB/HIV, and the percentage of people with TB/HIV who had experienced isolation or discrimination as a result of their disease.

To measure any change in behaviour, you might review your local clinic's records to see how many people came for TB examinations in each of the six months before your intervention, and then collect this information every month following the start of your activities. You could then create a month-by-month graph showing any changes over time in the number of people coming for testing. Your hope is that you see an increase!

The same idea holds true for advocacy efforts. In the case study example for Kenya (see page 59), it reported that funds were released and the governance of the Global Fund grants was restructured. This was exactly what the coalition wanted. Their advocacy was focused, as all advocacy efforts should be. They had specific demands, and they could measure whether or not their demands were met with a simple yes/no answer. They could have included some more specific details, such as the amount of funds that were released, or the specific changes that were made to the governance structure. The main point is to be as specific as possible about what you want to have happen, and be able to report on whether it did happen or not.

There are many activities community organisations do that fall into these categories. Think creatively about what your end result is, and how you might be able to measure an outcome that will help you make your case that your work is contributing in an important way to fighting TB in your community. And get help when you need it – from other CSOs, local universities, NTP staff, or others who have experience in measurement.

MONITORING AND EVALUATION EXAMPLE

Let's use an example to show how M&E works:

Suppose your country has set a national target of 90% or more for the proportion (percentage) of people with TB who receive HIV counselling and testing (HCT). Imagine your organisation is working in a district where HIV counselling and testing is not being routinely offered to people with TB and the district is not reaching the national target. Your analysis shows that HIV counselling and testing is not being offered because the health workers in the TB clinic are not trained in HCT, and they also don't know where to refer clients for HCT services. Your organisation therefore decides to implement an activity designed to improve the percentage of people with TB who receive HIV counselling and testing.

Your objective in your action plan is written as follows: *By December of this year, improve the percentage of people with TB who receive HIV counselling and testing in District X from the current 50% to 70% or more.* To do so, you are providing HIV counselling and testing training to health care workers in the TB clinic and training volunteers with your organisation on how to refer people with TB for HCT. In your action plan, one of your activities to support this objective is written as follows: *Conduct three trainings on HIV counselling and testing for 50 health workers by 1 July.* Your monitoring plan will focus on your activities – in this case, you will monitor your progress in conducting trainings for health workers.

You decide to monitor progress on a monthly basis by reviewing project documents and talking with the staff in charge of the training. You will *monitor* the intermediate tasks needed to finish training by July – for example, the training materials must be developed and approved, the trainings must be scheduled with the health facilities, a training venue must be identified, the participants must be invited, and many other tasks. By July, if everything goes as planned, your final monitoring for this activity will be done and you will be able to verify that you have trained 50 health workers and have conducted three trainings on HCT as you promised to do in your action plan.

However, knowing that you have conducted the trainings and 50 people have been trained is not enough. You want to know what effect the training has had. For example, you might want to know if the health workers now feel confident in their ability to perform HCT. To do so, you might administer a questionnaire to the workers before and after your training, or you might observe them in the clinic before and after the training to see the changes in how they perform. Most important, though, you want to know what effect this training has had on the percentage of people with TB who receive HCT in District X. The result you want (as stated in your objective) is that the percentage has increased to 70% or more by the end of December. To determine whether your objective was reached, you will conduct an *evaluation* at the end of the project. You will review quarterly programme data on the percentage of people with TB receiving HCT. You will want to collect information about the situation before you did the training (your ***baseline data***) and then look at what happened after your training to see if the percentage has improved.

Your evaluation data might look like this:

	BEFORE TRAINING		AFTER TRAINING	
	Quarter 1	Quarter 2	Quarter 3	Quarter 4
Number of people with TB	358	366	275	412
Number of people receiving HCT	172	183	165	288
% of people receiving HCT	48%	50%	60%	70%

What you can say from this information is that you met your objective: in the last quarter, 70% of people with TB received HCT and had the result recorded in the TB register, so you have succeeded! You will then, of course, think about what you learnt during the training process that can be applied to make further improvements in the numbers and reach the national target of 90% or more. Now you have gone through one complete project cycle.

WORKBOOK ACTIVITY

Review the sample results summary in Workbook Tool 5.7 and use it to practise writing a one-page summary of one of your organisation's activities.

Share your results

For your organisation to be successful, it is not enough to do the work and perform monitoring and evaluation. It is equally important to share your results with the NTP, donors, your partners, and the communities you serve. Reporting back on your successes and lessons learnt helps demonstrate your commitment to your community and to TB work and your ability to use your data, improve your performance, and develop best practices. It is also essential for continued funding.

Report your results in a form that allows your audience to see the impact of what you have done. As we discussed above, it is not the direct output of your activities that is most interesting or relevant, it is what happens as a result of that work. For example, if you have done training with health workers and community volunteers on TB case-finding, your audience will want to hear how that training has led to more people with TB symptoms being evaluated at health facilities and more people being diagnosed with TB at an earlier time, not just how many people you trained. To the extent it is possible, focus on the end result of the activities that you have done. Try to include some personal stories to illustrate in human terms how your work has improved the lives of the people in the communities you serve. Use photographs and quotes, present data using graphs and charts, and try to bring your project to life for the people with whom you are communicating.

CASE STUDY: ADVOCACY IN KENYA HELPS FREE UP RESOURCES FOR TB WORK

In 2005, progress in Kenya on TB had stalled because Global Fund TB grants were being delayed in government bureaucracies and at Country Coordinating Mechanism level. To address this bottleneck, Kenyan activists identified the Kenya AIDS NGO Consortium (KANCO) as a starting point for creating a broader coalition and launching an advocacy effort to advance TB work in Kenya.

The coalition they created with more than 20 CSOs, called the United Civil Society Coalition against AIDS, TB and Malaria (UCC-ATM), ensured that their powerful partnership was impossible to ignore as it took its message to the public as well as national and international stakeholders. These included politicians from Kenya and other countries, the head of Kenya's national TB programme, other health and government officials, celebrities, public health champions and journalists. RESULTS UK supported them by bringing four UK members of parliament (MPs) to Kenya to learn about the scale of the TB problem and what the UK and Kenyan governments, as well as the Global Fund, were doing to address it. The MPs visited TB clients, health workers, NGOs, donor representatives and ministry of health officials. As well-respected outsiders, they were well-placed to speak frankly about the key issues at a well-attended news conference. A conference call that included 60 grassroots activists in the UK also supported UCC-ATM.

Within months, UCC-ATM had facilitated the processing of two grants that had been held up, and was instrumental in restructuring Kenyan Global Fund governance in the ministry of health and the Country Coordinating Mechanism (including designated representation for TB clients). As a result, the flow of Global Fund TB resources in Kenya resumed. KANCO and the UCC-ATM are continuing to monitor these and other resource flow issues, and carry out advocacy for improved policies and increased resources for TB and other health issues.

SOURCE: Adapted from CORE Group (2008). 'The expansion of community-based tuberculosis programming: critical program design issues for new partners'. Available at: **www.coregroup.org/storage/documents/Workingpapers/CORE_TB_web.pdf**

KEY MESSAGES

- Involve affected community representatives in the planning process to ensure that your activities will meet the community's needs in the most appropriate way.
- Involve your partners in planning activities to ensure good coordination and avoid duplicating efforts.
- Define how you will monitor and evaluate your activities as an integral part of your planning step – not after you have already started implementing! Use the fewest possible key indicators to get the information you need while being realistic about the time and resources you have to do M&E.
- Share your plans with the appropriate NTP staff so they understand what you will be contributing. Then they can provide any information or feedback to you on how to make things work as smoothly as possible with the NTP recording and reporting system.
- By measuring what you are accomplishing, especially using numbers, you significantly increase your opportunities to show how your work contributes to stopping TB. In addition, it allows you to make improvements in how you do your activities, gain the respect of the NTP, and continue to receive funding from donors.
- Think creatively about how you can measure your success for activities that may not have specific numbers associated with them, such as advocacy or stigma reduction activities. For example, ask "What do we want to have happen as a result of our activity?" and then figure out how you can answer the question "Did it happen?" Often, you can find some numbers to measure that will tell the story of your achievements.
- Report your results back to the NTP, the community, donors, and other stakeholders to ensure that everyone is aware of your contribution and you get credit for your good work.

Action 6: Fund your activities

In this section:

- How do we start?
- Potential funding sources
- How do we find other funding sources?
- What do we do next?

Finding enough money to implement activities and support running costs is a constant challenge for all organisations. Fundraising is an action that you will be involved in throughout the timeline of a project or activity. It is placed at the end in this guide only because it is important for you to clarify some of the decisions you have made in the other steps before you can ask for funding for your activities.

Fundraising is often the most difficult job in a CSO. Most people have little experience in writing funding proposals and it is very time-consuming to get all the necessary documentation together for each proposal, especially when all of your staff are working hard just to implement activities. You may consider whether you want to designate one person or a small team to be in charge of proposal writing, or whether you will consider seeking outside help to submit proposals and
raise funds.

This section provides some basic steps to use and resources on how to find the funding for the TB/HIV activities you have planned.

How do we start?

1. **Know clearly what you need money to do.** It is important to be able to define very clearly what your purpose is in seeking funds. To begin, clearly state your organisation's or project's purpose and define your goals and objectives.

2. **Be specific about how the money will be used.** To identify the appropriate funding sources and develop the information you will include in a funding proposal, answer the following questions:

   - How will the funding be used (for service delivery, advocacy, equipment, educational sponsorships, organisational capacity-building)?
   - What are our intended results – what do we hope will happen as a result of this work?
   - Who will benefit from these activities (such as people living with HIV, children, prisoners)?
   - What is the geographic location of this work (local, national, regional in scope)?
   - On what scale do we need funding (a few thousand dollars, tens of thousands, a million)?

Knowing the answers to these questions will help you identify funders that share common interests with you, which in turn will improve your chances of receiving funding for your project.

3. **Develop a fundraising plan.** Raising money takes time. Have a plan that spells out what activities or projects need funding, an estimated amount of funding needed, how potential funders will be identified, who is responsible for developing and submitting proposals, and when proposals are due. Before you even start to write applications, consider the following questions to help you prepare:

   - How well-prepared is our organisation (in terms of organisational capacity, financial systems, governance) to raise, receive, and manage funds? Is there anything else we need to do to be better prepared or meet the requirements of our potential donors?
   - What is realistic to accomplish in terms of fundraising in one year? In five years?
   - What human resources do we need to do our fundraising?
   - What else might we need to do it (for example, equipment)?
   - Approximately how much money will we need to reach our goal?
   - Are there specific sources of funding we prefer or require for institutional reasons (international, local, government, corporate, individual)?

4. **Put together a standard package of your administrative materials for use in proposals.** All funders will require you to provide certain materials for your applications, such as proof of your organisation's legal status, financial records, and other administrative documents. To save yourself time, put together a current package of those materials and update them once per year. In this way, you can easily find what you need for any application you are submitting without having to recreate it from the beginning.

Potential funding sources

In this time of global economic difficulties, it is important to think creatively about how to raise funds. There are a number of different sources of funding that may be useful for you to consider. First, think about any local sources of funding. These might include community groups, for-profit companies that are located in the community, local donors, or local government. You also may consider whether your organisation has the ability to conduct income-generating activities of its own to raise funds.

There are some typical sources of funds to explore as well. The chances of your receiving funds from any of these sources will be improved if you can establish a relationship with them prior to any call for proposals. Make a point of being in regular contact to let them know what your organisation is doing and what your successes and strengths are. Then when it is time to put together a funding proposal, they will be much more likely to think of your organisation as a useful partner. These are some typical sources of funds in many countries:

- Large NGOs, either domestic or international, often receive foreign donor money to implement projects in your country and may provide sub-grants to organisations like yours. Become familiar with which donors are funding them, what work they are doing, what their grant timelines are, and what they are looking for in partner organisations.
- You may be able to access funds directly from foreign donors such as USAID or the Department for International Development (DFID) in the United Kingdom. To do so, you will have to have the appropriate financial management systems in place, understand and be able to meet their funding requirements, and work on their priority issues. Having a contact person at these organisations with whom you speak regularly can help you prepare for and win funding awards from them.
- If your country has Global Fund monies, you may be able to access funds through Global Fund principal recipients or sub-recipients. In general, it is best if your organisation develops relationships with those organisations before applications get prepared and submitted so that your organisation is named as a recipient of funds in the application.

How do we find other funding sources?

There is a wide variety in the funding sources that may be useful to your organisation. Methods to identify potential funders should be part of your fundraising plan, and are described briefly below.

To identify international funding resources, there are several techniques you can try:

- Join listservs on topics related to your work that distribute announcements about funding opportunities or regularly report on donor-funded projects so that you become familiar with funding opportunities. The Stop TB e-Forum, available at **http://www.aidsportal.org/web/guest/stop-tb-eforum** is one example of such a listserv.
- Do internet searches for funders using relevant keywords. For instance, you can search using the terms “funding” AND “tuberculosis” AND “Zimbabwe” if you are looking for any organisations that support TB work in Zimbabwe.

- Look at annual reports of foundations. You may know of international foundations working in your country. Perhaps you see their logos on buildings, on hoardings, or on project literature. You can go online to find their latest annual reports. These documents will give you an idea of the kinds of projects they are interested in funding, where they work, and the size of the grants they give. Then you can try to match your project with the right foundation.
- Talk to people! One of your best sources of information may be other people who have experience working with international donors. Use your professional connections to help you identify relevant funding sources.

To identify national, regional, and local funding resources, here are some useful strategies:

- Read the newspaper to find out what projects are being implemented in your country.
- Do internet searches on keywords, as described above.
- Understand how your government's budgeting process works and how funds are allocated so you can identify any funds that your organisation may be able to access.
- Understand rules and regulations governing CSOs in your country so you know what funds you can accept.
- Ensure there is community representation on Country Coordinating Mechanisms (CCMs) and participate in Global Fund applications.
- Identify prominent individuals in your country to champion your cause and help raise funds.
- Know what companies are funding corporate social responsibility projects in your country and develop relationships with them.
- Talk to people! Again, use your professional connections to help identify other local funding sources.

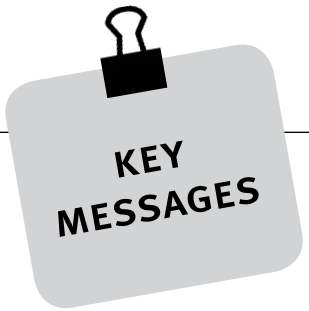
What do we do next?

There are two important steps in making funding applications successful once you have identified a potential pool of donors for your work.

- Match your needs with donors' interests. You will have the greatest chance of success if your work is well-aligned with the way the donor works. Ask yourself the following questions:
- What topics are they interested in funding?
- What geographic regions do they invest in?
- What size grants do they give?
- What time periods do their grants cover?
- Understand the application procedure. Getting grants is competitive. It is important to follow the rules to give yourself a better chance of winning a grant. Ask the following questions:
- What types of organisations does the donor fund? Does your organisation qualify?
- What are the restrictions on their funding?
- Does the funder accept unsolicited proposals?
- What is their grant-making cycle and what are the deadlines?
- What format do they require for submissions?

WORKBOOK ACTIVITY

Go to Workbook Section 6 to start a funding plan for your TB activities. You will find several tools there to help you with fundraising. Tool 6.1 will help you identify existing and potential donors to fund your work. Tool 6.2 helps you develop a plan with a timeline for fundraising activities. Tool 6.3 provides a checklist for preparing a funding application.



- Adequate funding is critical to ensure the success of your TB/HIV activities. Develop a plan for fundraising to help you identify how much money you will need, for what purposes, and what donors might be interested in funding your activities.
- Donors can include many different people and groups, from individuals living in your community to private corporations, foundations, governments, or multinational donors such as Global Fund. Understanding what various potential donors are interested in funding will help you focus your fundraising efforts.
- You may consider partnering with other organisations that are more experienced in working with donors to begin your work. That way you can learn about the donor's requirements without being responsible for the overall administration of the grant.
- Develop ongoing relationships with your donors and make sure to report back to them on the progress of your work and your successes and challenges.
- Prepare a package of background documents that most funders request, such as financial statements or registration papers, and update it on a yearly basis so you do not have to start from scratch for every funding application.
- Pay close attention to the requirements for funding applications so you can ensure your documents will be accepted.

Glossary

Active TB (TB disease): TB in the body that is causing illness. A person with active TB feels sick, has signs of disease, and can transmit (spread) TB to others.

Antibiotics: Medications that are used to treat illnesses caused by bacteria and some other germs. TB is caused by bacteria and the drugs used to treat it are antibiotics.

BCG vaccine (Bacille Calmette–Guérin): A vaccine used to help protect people against TB. The BCG vaccine is helpful in protecting young children from getting very sick with TB, but is not considered to be a very effective vaccine for preventing TB disease.

Bacilli: Bacteria that look like small rods (sticks) when examined under a microscope. TB bacteria are bacilli. They are called acid-fast bacilli because when they are stained with special dyes and then washed with acid, they keep the dye colour – it is not washed away.

Bacteria: A category of living things composed of one-celled organisms. Some bacteria are helpful, and others are harmful. TB is caused by harmful bacteria known as *Mycobacterium tuberculosis*. Bacteria can be killed with antibiotics.

Bacteriologically confirmed: A diagnosis of TB based on a positive laboratory test result that confirms the presence of TB bacteria in a sputum (or other) specimen from a person who is at risk for or has symptoms of TB.

Baseline data: Information on the current status of TB prevention and care in an area collected before a project or intervention is started. Baseline data allow you to compare what has happened as a result of your work with what things were like before you started.

Biopsy: A tiny piece of the body removed for laboratory examination or testing. Biopsies may be taken to diagnose extrapulmonary TB.

Case: A medical and epidemiological expression that means a person who has been diagnosed with a specific disease. In this instance we are discussing TB, but this term can also be used for any other disease.

Case notification (TB case notification): The public health activity of reporting and recording a person who has been diagnosed with TB as a TB case in the public health information system, thereby capturing that information in the TB statistics of the country.

Chest x-ray: A picture of the lungs taken with an x-ray machine. A chest x-ray is used to see if there are changes to the lung that could be caused by TB. It cannot make a definite TB diagnosis, but it is an important screening tool, especially in people with HIV and young children.

Clinical diagnosis: A diagnosis of TB that is made based on a health care provider's best guess about the cause of a person's illness, without having the proof from a laboratory test that confirms the diagnosis by finding TB bacteria in a specimen. This is often the case for young children with TB, who have difficulty producing a sputum specimen for examination.

Close contact: A person who has shared the same space in an enclosed environment (such as household or sleeping quarters) for a long time with a person with active TB disease and who is therefore considered to be at risk of infection with TB.

Cohort analysis: The process of reviewing information on diagnosis, treatment progress, and treatment outcomes for a group of people diagnosed during a specific timeframe. In TB, cohorts are usually analysed for each quarter (three-month period) of the calendar year, and for each whole year.

Co-infected: see TB/HIV co-infection.

Constituency: A group of people or organisations that have their collective opinion represented by one person or group within a larger decision-making body.

Contact tracing: The search for people who have been in close contact with a person who has been diagnosed with TB, and therefore may be at risk of TB infection and disease.

Continuation phase (of TB treatment): The second and final phase of TB treatment, after the intensive phase, when TB treatment is completed using a reduced number of anti-TB drugs. Often, isoniazid and rifampicin are the two anti-TB drugs given in the continuation phase of treatment.

Cough-to-Cure Pathway: A tool that can be used to analyse what barriers exist to achieving good TB outcomes by looking from a client perspective.

Directly observed therapy or directly observed treatment (DOT): The process in which a trained and supervised person observes and records that the person swallows the anti-TB medicines at each dose to support that person in completing treatment and avoiding the development of MDR-TB.

DOTS: DOTS used to stand for directly observed therapy, short course. It is the basic WHO-recommended approach to TB prevention and care, and is now the first component of the wider Stop TB Strategy.

Drug interactions: The effect of one drug on the absorption, metabolism and activity of another. Several important drug interactions occur between key TB drugs such as rifampicin and other drugs, including some antiretroviral drugs given to those infected with HIV.

Drug resistance: The ability of a germ to survive exposure to a drug that would normally destroy it.

Drug-resistant TB: TB that is resistant to one or more anti-TB drugs.

Epidemiology: The study of the distribution of disease across different geographic areas, populations, and times.

Extensively drug-resistant TB (XDR-TB): Multidrug-resistant TB that,in addition to being resistant to isoniazid and rifampicin is resistant to i) any fluoroquinolone (such as ofloxacin or levofloxacin) and ii) at least one of three injectable second-line drugs (capreomycin, kanamycin and amikacin). XDR-TB is difficult (although not often impossible) to cure.

Extrapulmonary TB: TB affecting parts of the body other than the lungs, most commonly the lining around the lungs (pleura), lymph nodes, spine/bone, genitals, urinary tract, brain, abdomen or major joints.

First-line drugs (FLDs): The antibiotic drugs that are most commonly used for treatment of people with TB that is sensitive to all medications (has not developed resistance). The first-line drugs available globally, include isoniazid, rifampicin, pyrazinamide, ethambutol, and (sometimes) streptomycin. They are combined in treatment regimens for people categorised as “new” or “retreatment” cases. These antibiotics are generally inexpensive, very effective and have fewer side effects. A basic discussion of anti-TB drugs can be found at **www.tbfacts.org/tb-drugs.html**.

Fixed dose combination drugs (FDCs): Anti-TB drugs combined into a single tablet in specific dosages to make it easier to take the correct dosage of the drugs and to reduce the number of pills a person with TB must take.

High-burden countries (HBCs): The countries that together account for more than 80% of the TB cases that occur in the world. At present, the HBCs include 22 countries, most of which are in Africa and Asia.

Infection control: Measures taken to prevent the transmission of disease. For TB, these include actions such as having people with TB cover their coughs, separating people with infectious TB from others at health facilities, ensuring good air circulation in crowded areas, using equipment such as ultraviolet light to kill TB bacteria in indoor air, and wearing personal protective equipment such as N-95 respirators (masks).

Infectious: Capable of causing infection by being passed from one person to another person, or from the environment to a person.

Intensified case finding (ICF): Increasing the search for people with TB by actively looking for people with signs and symptoms of TB. For people with HIV, this includes screening each person at each visit to a health facility for signs and symptoms of TB. ICF is one of the Three I's.

Intensive phase (of TB treatment): The starting period of TB treatment during which a combination of (usually) four drugs is given to kill as many of the TB bacteria as possible as quickly as possible. The intensive phase of treatment usually lasts for a period of two to three months. At that point, the person with TB goes on to the continuation phase of treatment.

Isoniazid: One of the most important first-line anti-TB drugs. It is also used for preventive therapy in those with latent TB infection.

Latent TB infection: see TB infection.

Liquid culture: A laboratory procedure in which sputum is added to a test tube containing a liquid that encourages the growth of TB bacteria. If TB bacteria grow in the tube, it confirms that the person who provided the sputum has TB disease.

Monitoring and evaluation (M&E): Tracking the progress of project activities and measuring their results. Monitoring relates to whether activities are being accomplished as planned and on schedule, and evaluation is concerned with whether those activities are having the desired effect or result.

Multidrug-resistant TB (MDR-TB): TB that is resistant to at least isoniazid and rifampicin, the two most powerful first-line anti-TB drugs.

Mycobacterium tuberculosis: The scientific name for the germ (bacterium) that causes TB.

New case: A person diagnosed with TB who has either never received treatment for TB before, or received less than one month of anti-TB treatment.

Pan-sensitive or pan-susceptible TB: (also called drug-sensitive TB) TB that can be treated with all medications – the bacteria are not resistant to any anti-TB drugs.

Isoniazid preventive therapy (IPT): Treatment of a person with latent TB infection using the anti-TB drug isoniazid to prevent the development of active TB disease.

Pulmonary TB: TB disease in the lungs, the most common disease site for TB.

Rapid molecular tests: New methods of diagnosing TB that rely on finding genetic material from TB in sputum specimens. These methods can provide a result in a few hours or a few days, compared to 10 days to two months for current culture methods.

Relapse: A person previously treated for TB who has been declared cured or treatment completed, and is then diagnosed with bacteriologically positive (smear or culture) TB again.

Second-line drugs (SLDs): A group of antibiotics used for the treatment of people with MDR- TB or XDR-TB. They are generally much more expensive and less effective than first-line drugs, and cause more side-effects for people. A list of second-line drugs can be found at **www.tbfacts.org/tb-drugs.html**.

Solid culture: A laboratory procedure in which sputum is processed and then placed in a covered dish or test tube that contains a solid material on which bacteria will grow. Growth of TB bacteria confirms that the person who provided the sputum has TB disease. Solid culture is currently the "gold standard" (most reliable method) for diagnosing TB. Unfortunately, it can take up to two months to get a result.

Sputum (sputum specimen): Phlegm coughed up from deep in the lungs into a cup or jar with a lid. The specimen is then taken to a laboratory for TB testing. Sputum is not saliva (spit) from the mouth.

Sputum smear microscopy: A laboratory test in which sputum from someone with TB symptoms is smeared on glass slides and stained with a dye, then, examined under a microscope to look for the presence of TB bacteria (acid-fast bacilli).

Sputum smear-negative (smear-negative): TB in which all sputum specimens that have been examined under a microscope do not show the presence of any bacteria that look like TB (no acid-fast bacilli). People with HIV are more likely than other people to have smear-negative TB, but not all people with smear-negative TB have HIV.

Sputum smear-positive (smear-positive): TB in which a sputum specimen that has been processed and examined under a microscope shows the presence of bacteria that look like TB (acid-fast bacilli).

Stop TB Strategy: The globally agreed-upon public health strategy for working towards TB elimination, which includes six interrelated components.

Strategic partnerships: Formal relationships with other organisations that are created to strengthen the ability of each organisation to accomplish a common goal.

TB programme: The institutional structure and strategy (usually government-led and statutory) that uses a combination of measures with the highest impact on reducing the spread of TB infection and minimising the number of people who get the disease, and die from it. The Stop TB Strategy is the basic TB strategy accepted worldwide.

TB disease: see Active TB.

TB infection, or latent TB infection: TB in the body that is currently dormant (inactive), and is not causing illness.. Individuals with latent TB feel well and cannot pass TB to other people.

TB/HIV co-infection: The presence of both HIV infection and latent TB infection in the same person at the same time. People with TB/HIV co-infection have a high risk of becoming ill with TB disease.

Three Is: A strategy endorsed by the World Health Organization to prevent the spread of TB in people living with HIV. The Three Is are: Intensified case finding, Isoniazid preventive therapy, and Infection control.

Transmitted: Passed from one person or thing to another.

Treatment adherence support: A package of services offered to a person with TB to help that person complete treatment and be cured. Treatment adherence may consist of a treatment supporter who will watch the person with TB take the anti-TB drugs and provide emotional support, transportation money to go to the clinic, nutritional support, or other incentives and enablers to help that person complete treatment.

Treatment outcome: The final result for a person who has been treated for TB, as reported in the public health system.

Treatment regimen: The course prescribed by a health care provider to cure a person with TB, including the types of drugs, the doses of the drugs, and the length of treatment. All of these three elements must be correct to make sure the person is cured.

Trends: Epidemiological patterns in the occurrence of a disease through time (for example, decreasing, increasing, or staying the same over five years).

Tuberculosis case: The recording of a person who has bacteriologically confirmed or clinically diagnosed TB disease within a national TB recording and reporting system.

Vaccine: A substance, usually in liquid form, containing small amounts of dead or live germs that is given to a person to help him or her develop immunity to that germ (such as smallpox or flu).

A global partnership:
International HIV/AIDS Alliance
Supporting community action on AIDS in developing countries

GOOD PRACTICE GUIDE

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Established in 1993, the **International HIV/AIDS Alliance** (the Alliance) is a global alliance of nationally-based organisations working to support community action on AIDS in developing countries. To date we have provided support to organisations from more than 40 developing countries for over 3,000 projects, reaching some of the poorest and most vulnerable communities with HIV prevention, care and support, and improved access to HIV treatment.

The Alliance's national members help local community groups and other NGOs to take action on HIV, and are supported by technical expertise, policy work, knowledge sharing and fundraising carried out across the Alliance. In addition, the Alliance has extensive regional programmes, representative offices in the USA and Brussels, and works on a range of international activities such as support for South-South cooperation, operations research, training and good practice programme development, as well as policy analysis and advocacy.

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PATH is an international nonprofit organisation that transforms global health through innovation. We take an entrepreneurial approach to developing and delivering high-impact, low-cost solutions, from lifesaving vaccines and devices to collaborative programmes with communities. Through our work in more than 70 countries, PATH and our partners empower people to achieve their full potential.

Headquartered in Seattle, Washington, PATH operates offices in 39 cities in 22 countries. PATH currently works in the areas of health technologies, maternal and child health, reproductive health, vaccines and immunisation, and emerging and epidemic diseases.

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