

AN ACTIVIST'S GUIDE TO **FIGHTING TUBERCULOSIS**



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INTRODUCTION

Tuberculosis (TB) is a disease that is caused by bacteria and passed in the air. TB bacteria are put into the air when a person with TB coughs, sneezes, speaks, or sings. These bacteria can be passed anywhere—in the homes and communities where people live, in hospitals and clinics, and on buses and trains.

Anyone can get TB. In 2013, an estimated 9 million people fell sick with TB and more than 1.5 million died. TB can be cured and the spread of TB can be prevented. This requires a comprehensive approach that has been tried and proven in a number of settings. By demanding and implementing a comprehensive approach to stopping the TB epidemic, we can save lives and reduce suffering. All people have the right to high-quality care for this preventable and curable disease.



HOW TO USE THIS GUIDE

This handbook is designed to help activists understand TB and learn what is needed to effectively fight TB. This handbook is organized into three major sections, corresponding to three major activities. The best way to stop TB is to do all three activities at the same time. For each activity, we first lay out key facts about TB and describe the current situation. We then describe what has to be done to effectively fight TB. **Bolded terms** in the text are defined at the end of the handbook in the USEFUL TERMS section. Boxes appear throughout the text to further describe concepts.



SEARCH

YOU ONLY FIND WHAT YOU LOOK FOR

The best way to find people sick with TB is to actively search for them. Searching requires 2 steps:



1

SEARCHING TO FIND PEOPLE SICK WITH TB OR EXPOSED TO TB

2

USING EFFECTIVE TESTS THAT CAN PROVIDE THE CORRECT DIAGNOSIS

SEARCH ACTIVELY

It is important to find people with TB as soon as possible. Often, people wait until they are very sick with TB to go to a hospital or clinic. At that point, some people may be too sick and weak to fight the disease, even with treatment. The sicker a person with TB is, the more likely it is that people around them can also catch TB. The earlier a person with TB receives treatment, the less likely their family and friends are to get sick.

If we can search for people with TB, we can find them before they get very sick. We can also diagnose and treat their families, and keep other people in the community from getting sick. In Box 1.1 we describe how anyone can get sick with TB, but some people are at greater risk.

HOW SHOULD WE SEARCH?

There are a few ways we can search and find people sick with TB:

1. A person sick with TB can transmit TB to those they spend the most time with. These people should be screened for TB, as described on the next page. The process of screening the people closest to a person with TB is called **contact investigation**. People who live in the same home as a person with TB often spend the most time with them, so good contact investigations generally include a visit to the person's home to look for people who may be sick. This is regularly done in rich countries and



Contact investigation is the process of screening the people closest to someone with TB. These are often people who live in the same home.

1.1

WHO GETS SICK WITH TB?

Anyone can get TB because it is an airborne disease. Some people are more likely to get sick. For example, children and people living with HIV can get very sick and die quickly from TB. If we go into the community and find people sick with TB early—especially children and people living with HIV—we can treat them.

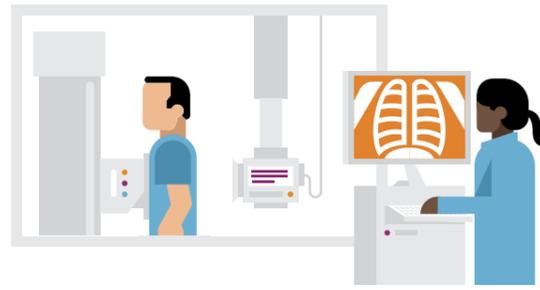
contributes greatly to finding people who need treatment and stopping the spread of TB.

2. People with HIV have a weakened immune system, making it easier for them to get sick with TB. TB is the most common cause of death among people with HIV. To ensure people with HIV do not develop TB, they should be screened regularly.
3. TB spreads faster in crowded settings where people live and work. Some of these settings include factories, mines, prisons, or worker's quarters. In these settings, if one person has TB, the crowdedness makes it very easy for the TB to spread. People living or working in these settings should be screened for TB regularly.

SCREENING

What is screening for TB? Screening for TB includes an examination for TB symptoms, and in some cases **chest radiography** (commonly called chest X-ray) and laboratory testing of a sample of **sputum**. Common symptoms of TB are a cough that lasts for over 2 weeks, weakness, weight loss, chills, fever, and sweating at night. Chest X-ray is a special photo taken of the chest that allows a doctor to see if TB is present inside the chest. Sputum is phlegm or mucus that a person produces when they cough deeply; it can be tested in the laboratory for TB bacteria. The purpose of screening is to decide if someone is sick with TB so that person can start TB treatment.

Who should get screened? When a person is diagnosed with TB, everyone who lives with them or is at their home often should be screened.



Chest radiography (chest X-ray) is a photo of the inside of the chest that allows a doctor to see if TB is present.

Special attention should be given to screening children, pregnant mothers, and people with HIV. Others in the home with a greater risk of developing TB include people with diabetes or lung problems (such as chronic obstructive pulmonary disease and silicosis), those who smoke cigarettes, and those who consume alcohol regularly.

What do we demand for searching?

- 1 Contact investigations around people diagnosed with TB, with special attention to those contacts at greater risk of also becoming sick with TB
- 2 Regular screening for TB in people with HIV
- 3 Regular screening for TB in groups where TB can be easily transmitted

TEST PROPERLY

When we think someone may have TB, they need to have an effective test. In many poor settings, the most common way to test for TB is through a laboratory test called a **sputum microscopy**. During sputum microscopy, a microscope is used to look for TB bacteria in a sample of sputum.

Sputum microscopy is a test that is over 100 years old, is not always effective, and has many limitations. TB bacteria can't always be seen, so sputum microscopy misses about half of all people sick with TB—especially children and people with HIV. Sputum microscopy also cannot detect



Modern and effective diagnostic tests for TB work better than sputum microscopy.

drug resistance, a growing problem in many parts of the world. When there is drug resistance, some medicines don't work and a person sick with TB may not get better. Sputum microscopy does not work well.

Fortunately, laboratory tests that are better than sputum microscopy exist, and some countries are starting to use them. We describe below how we *should* test people when we think they may have TB.

HOW SHOULD WE TEST PEOPLE FOR TB?

When we think someone may have TB, we should test them with modern and effective diagnostic tests that work better than sputum microscopy. These tests should be able to detect drug resistance so that a person sick with TB receives the correct treatment. Examples of such tests include **sputum culture** and **DNA amplification tests** (Box 2.1).

Not everyone can be diagnosed through laboratory tests. For example, children may not be able to cough deeply enough to get a sputum sample used in some laboratory tests. People who cannot be diagnosed through a laboratory test should be diagnosed with a chest X-ray or through their symptoms. Doctors or healthcare workers caring for someone who cannot be diagnosed through a laboratory test should have a **clinical algorithm**, or a step-by-step guide that uses symptoms or a chest X-ray or both to decide if the person is sick with TB. Lastly, some

2.1

WHAT MODERN LABORATORY TESTS CAN DIAGNOSE TB?

Ways to diagnose TB other than sputum microscopy include growing the bacteria in a laboratory (a test called sputum culture) and detecting the bacteria's genetic fingerprint (a test called DNA amplification). In a sputum culture, a sputum sample will be sent to a lab. If TB bacteria in the sample grow, that tells you that the person is sick with TB. If the bacteria can grow in the presence of drugs, then the TB is drug-resistant. DNA amplification tests also use a sputum sample. DNA amplification tests look for genetic fingerprints unique to TB bacteria. DNA amplification tests can also test for resistance to TB drugs.

people get TB disease outside of their lungs, and it is difficult to use standard laboratory tests to diagnose this. These people sometimes have symptoms that are different from individuals who have TB mostly in their lungs. A doctor or healthcare worker needs to recognize these symptoms and diagnose this person as being sick with TB.

What do we demand for testing?

- 1 Modern diagnostic tests that can quickly and effectively diagnose TB
- 2 Rapid and sensitive drug resistance tests for all
- 3 A clinical algorithm to guide TB treatment in those without laboratory confirmation of TB, especially for children and people living with HIV

TREAT TREATMENT IS MORE THAN PILLS

TB is a curable disease. Once we find people sick with TB, we need to treat them. Treating someone who is sick with TB generally involves two steps:



1

TREATING QUICKLY
WITH THE CORRECT
MEDICINE

2

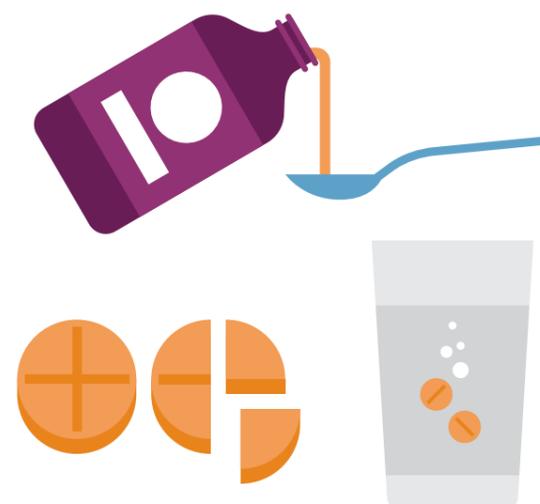
SUPPORTING PEOPLE
SICK WITH TB
THROUGH TREATMENT

TREAT EFFECTIVELY

When someone sick with TB is diagnosed, they should be treated immediately. It is critical that they receive the *correct* medications for the *entire duration* of treatment to get better. Different medications are needed to treat different types of TB. Soon after a person with TB starts taking the correct medications, he or she is no longer contagious.

The standard treatment for TB disease in someone without drug resistance contains 4 medications, known as **first-line drugs**. These first-line drugs are taken for 6-9 months. If a person sick with drug-resistant TB is given the standard treatment, they will not get better. Unfortunately, in many places, people with TB are automatically given the standard treatment, so those with drug-resistant TB remain sick.

People suspected of having drug-resistant TB must be given special treatment for drug-resistant TB. These people include those with laboratory tests that show drug resistance, those who remain sick while receiving the standard treatment, and those who live with someone who is sick with drug-resistant TB. Treatment for drug-resistant TB can contain 5 or more medications and last as long as 2 years. The medications used to treat drug-resistant



Child-friendly formulations contain small doses and are easy for children to swallow. These include syrups and tablets that can be broken into smaller pieces and that dissolve in liquid.

3.1

WHAT ARE CHILD-FRIENDLY FORMULATIONS?

Children need TB medications with doses appropriate to their body weight. **Child-friendly formulations** are medications that contain small doses of each ingredient and are easy for children to swallow.

Examples of child-friendly formulations of medications include syrups and scored dispersible tablets, which are tablets that easily dissolve in liquid and that have a line cut into them so that they can be broken into a smaller dose.

TB are called **second-line drugs**. Many second-line drugs have **side effects**, like nausea, vomiting, or a skin rash. There are new second-line drugs that have fewer side effects.

In some countries, second-line drugs are often unavailable. In these places, people sick with drug-resistant TB may be put on waiting lists before they can receive treatment. They may also be required to pay a lot of money for the drugs, even in places where TB treatment is supposed to be free. When people with drug-resistant TB do not receive second-line drugs, many of them die, and drug-resistant TB spreads further through their families and communities.

TB treatment in children (whether for regular TB or drug-resistant TB) is different than in adults. Children need to take different doses of medication than adults. For many TB drugs, child-friendly formulations are not available (Box 3.1).

HOW SHOULD WE TREAT PEOPLE SICK WITH TB?

First, everyone sick with TB should be promptly treated with the correct medications for the kind of TB they have—first-line drugs for regular TB, and second-line drugs for drug-resistant TB.

Each patient should receive these drugs as soon as he or she is diagnosed. The complete course of the drugs in the treatment should be assured for each patient.

Both first-line and second-line drugs should be available at all times and provided free of charge. Since TB treatment can have side effects, the medications to help patients tolerate these side effects should also be available and provided free of charge.

As described in Box 3.1, children need special medications that contain different doses and are easy for children to take. National TB programs and others treating TB should request child-friendly formulations from drug manufacturers to ensure they are available for any child found sick with TB. These child-friendly drugs should also be available at all times and provided free of charge.

What do we demand for treatment?

- 1 Prompt and effective treatment with the correct drugs
- 2 Access to first- and second-line TB treatment, and medication to manage side effects, all free of charge
- 3 Child-friendly formulations of first- and second-line TB treatment

SUPPORT THROUGH TREATMENT

People sick with TB face a number of obstacles during treatment. It is critical to provide support systems to overcome these challenges and help people sick with TB complete their course of treatment so they can fully recover.

A person sick with TB can be **stigmatized**, or shunned and treated badly, by their community, leading to feelings of isolation and depression. Children may stay out of school while on treatment because either the illness or the side effects of the drugs make them too weak to go to school.



Supporting a patient through TB treatment may include treatment supporters, food assistance, and transportation assistance.

People sick with TB need social support to get through treatment, but this is rarely available.

A person sick with TB may also suffer financially because they cannot work. Transportation to get to a hospital or clinic for TB treatment checkups may also be costly, especially when care must be sought from many providers in different locations. People sick with TB often need financial support to get through treatment, but this is rarely available.

HOW SHOULD WE SUPPORT PEOPLE SICK WITH TB THROUGH TREATMENT?

Social and financial support should be provided to help people sick with TB get through treatment successfully. Because TB affects the whole family, support should be given to both the person sick with TB and the family.

Social support may be provided by **treatment supporters** and **patient support networks**. Treatment supporters are people who commit to helping a person sick with TB through the long treatment and uncomfortable side effects that may appear. Treatment supporters can be community health workers, family members, or friends. Patient support networks are groups of people who know about TB and gather together to provide an opportunity for people affected by TB to talk openly about feelings of isolation or depression. Patient support networks often include people who have had TB in the past or their family members.

What do we demand for support?

- 1 Social support for people sick with TB and their immediate family, including treatment supporters, patient support networks, transportation assistance, and food assistance
- 2 Integrated care for TB and other medical conditions such as HIV, diabetes, and depression

WHAT IS INTEGRATED CARE?

Integrated care is a system where a person can receive all medical care at the same time and place. For example, care for TB, HIV, diabetes, hypertension, and depression could all be completed in a single visit to a health facility. Integrated care can save time and transportation costs, as it reduces the number of trips a person must make to a health facility.

People sick with TB should be provided support to help them overcome the financial barriers and other challenges that can arise during treatment. Transportation assistance to clinic visits should be provided to help people sick with TB stay on treatment. Food assistance should be provided for people with TB who are undernourished. Some programs may choose to give financial support to people sick with TB while they are on TB treatment.

Integrated care, or TB care at the same time as care for other medical needs, should be provided to lessen the transportation and time burden for people sick with TB (Box 4.1).

PREVENT STOPPING TB AT THE SOURCE

Preventing future cases of TB is essential to stopping the TB epidemic. We can prevent future cases of TB in two ways:



1

PREVENTING PEOPLE FROM BEING EXPOSED TO TB

2

TREATING PEOPLE WHO HAVE BEEN EXPOSED TO TB SO THAT THEY DO NOT BECOME SICK WITH TB

PREVENT EXPOSURE

If we can prevent people from being exposed to TB bacteria, we can prevent them from getting infected and becoming sick with TB. Because TB is airborne, the spread of TB bacteria can occur anywhere. However, it is more likely to occur in crowded, poorly ventilated, indoor places where there is someone sick with TB who is not receiving treatment. Some places where there is a high risk of being exposed to TB bacteria are described in Box 5.1.

HOW SHOULD WE PREVENT EXPOSURE TO TB?

Exposure to TB can be reduced in hospitals and clinics by providing people who are coughing with paper masks and having people who are coughing wait in a separate area from others. Where the weather is mild, outdoor waiting areas can be better for preventing exposure to airborne diseases than crowded indoor waiting areas. Staff at hospitals or clinics should watch for people with symptoms of TB, like cough, and screen them for TB. Exposure in other crowded settings, as well as in hospitals and clinics, can be reduced by opening windows to increase ventilation, installing ultra-violet lighting, or installing ventilation systems.

The earlier a person sick with TB is treated, the less chance there will be for TB bacteria to spread from that person to others. Therefore, in

5.1

WHERE CAN A PERSON BE EXPOSED TO TB?

A person can be exposed to TB bacteria wherever there is an untreated person sick with TB. This can happen anywhere, but common places include:

In the home where a family or friend is sick with TB

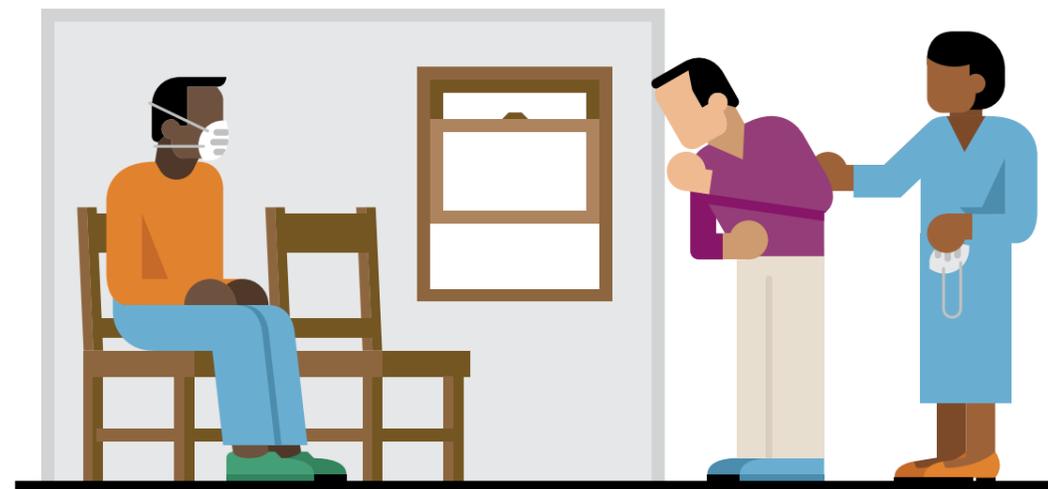
.....

In a hospital or clinic where people are sick with TB

.....

In crowded and poorly ventilated workplaces like factories or mines

the community, the spread of TB can be reduced by educating people about TB symptoms and encouraging them to seek medical care if they have any of these symptoms, before they become very sick. TB screening and treatment should be provided for people who live or work in crowded indoor conditions such as mines, factories, or prisons, especially if they have TB symptoms.



TB exposure in health facilities can be reduced by opening windows, providing people who are coughing with masks, and asking them to sit in a separate area.

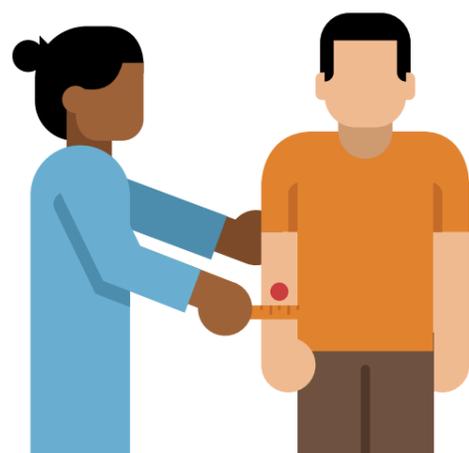
What do we demand to prevent exposure?

- 1 Separation and the use of paper masks for people coughing in hospital and clinics
- 2 Screening and treatment for people with TB symptoms working or living in crowded settings like mines, factories, or prisons

TREAT EXPOSURE

Not everyone who is infected with the bacteria that cause TB will become sick immediately. Sometimes, a person is **infected**, but the TB bacteria are “sleeping,” so the person is not contagious and does not show symptoms of TB. However, the TB bacteria can “wake up” at any time (even after many months or even years). When this happens, the person will become sick with TB and will be able to spread TB bacteria to others.

The good news is that we can test for and treat infection in people who have been exposed to TB. Treating infection kills the “sleeping” bacteria and prevents the infection from becoming disease and making the person sick. This treatment is given in rich countries, and it has been proven to work well and be safe. Unfortunately, the treatment of TB infection before it progresses to disease does not happen in most of the world.



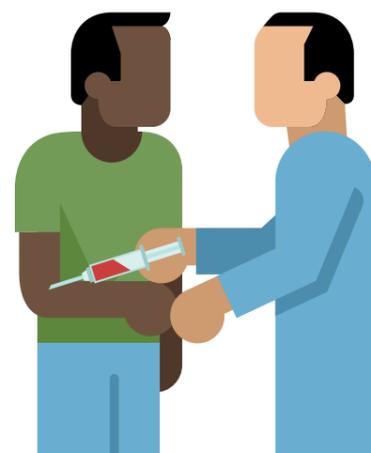
6.1

HOW DO WE TEST FOR TB INFECTION?

There are two tests for TB infection: the **tuberculin skin test (TST)** and **interferon-gamma release assays (IGRAs)**. A TST is a test on the skin and an IGRA is a blood test. Both tests measure the body's immune response to TB.

HOW SHOULD WE PREVENT PEOPLE FROM GETTING SICK WITH TB?

People who have been exposed to a person sick with TB should be tested for TB infection and offered treatment if they need it. The most



There are two tests for TB infection: a skin test and a blood test

important people to test and treat are those who spent the most time with the person sick with TB and those at greatest risk for getting sick with TB. These include people who spend a lot of time with or live in the same home as the person sick with TB, young children, and people with weakened immune systems, like those with HIV. When infected with TB bacteria, children and people with HIV are at greater risk of becoming sick with TB than healthy adults, so special attention should be focused on treating them for infection.

There are two ways to test for TB infection, as described in Box 6.1. If a person tests positive for TB infection, they should be checked to make sure they aren't sick with TB. If they are not sick with TB, they should be treated for TB infection so that they do not become sick in the future.

There are a few different ways to treat TB infection, as described in Box 6.2.

What do we demand to treat exposure?

- 1 Testing and treatment for TB infection in those exposed to TB, especially children
- 2 Regular testing and treatment for TB infection in people living with HIV
- 3 Treatment of drug-susceptible TB infection with the new once-weekly 12-dose treatment (isoniazid/rifapentine)

6.2

HOW DO WE TREAT TB INFECTION?

TB infection can be treated with a new medication combination (isoniazid/rifapentine) taken once a week for 12 weeks. This treatment is as effective as an older treatment of medication taken every day for 6 or 9 months. If a person was exposed to someone with drug-resistant TB, the TB infection will be treated differently, but they should still receive treatment for the infection.

OUR DEMANDS

Drawing from the information in this handbook, we summarize the demands made at the end of each section here. These demands are intended to guide your campaign. They should be directed at policymakers to ensure the best policies and practices are put in place so people no longer suffer and die from TB.

SEARCH

SEARCH ACTIVELY

- 1 Contact investigations around people diagnosed with TB, with special attention to those contacts at greater risk of also becoming sick with TB
- 2 Regular screening for TB in people with HIV
- 3 Regular screening for TB in groups where TB can be easily transmitted

TEST PROPERLY

- 1 Modern diagnostic tests that can quickly and effectively diagnose TB
- 2 Rapid and sensitive drug resistance tests for all
- 3 A clinical algorithm to guide TB treatment in those without laboratory confirmation of TB, especially for children and people living with HIV

TREAT

TREAT EFFECTIVELY

- 1 Prompt and effective treatment with the correct drugs
- 2 Access to first- and second-line TB treatment, and medication to manage side effects, all free of charge
- 3 Child-friendly formulations of first- and second-line TB treatment

SUPPORT THROUGH TREATMENT

- 1 Social support for people sick with TB and their immediate family, including treatment supporters, patient support networks, transportation assistance, and food assistance
- 2 Integrated care for TB and other medical conditions such as HIV, diabetes, and depression

PREVENT

PREVENT EXPOSURE

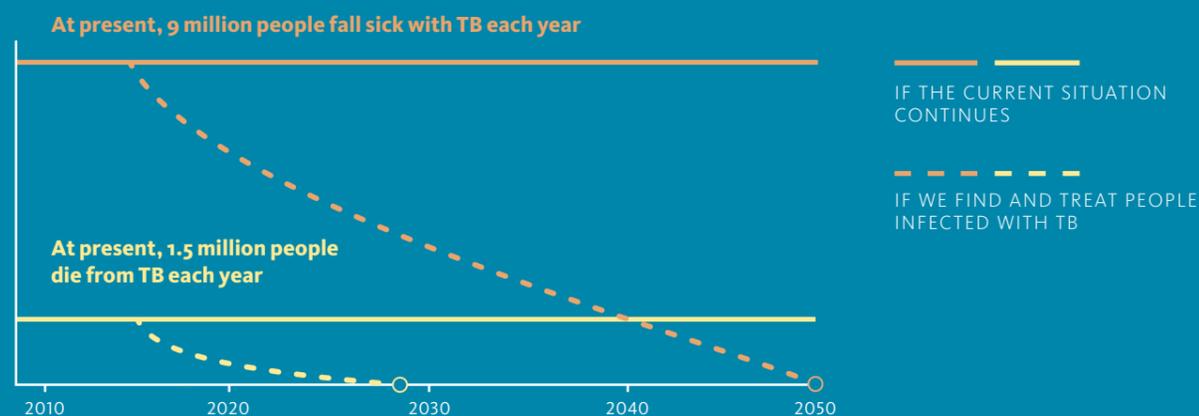
- 1 Separation and the use of paper masks for people coughing in hospital and clinics
- 2 Screening and treatment for people with TB symptoms working or living in crowded settings like mines, factories, or prisons

TREAT EXPOSURE

- 1 Testing and treatment for TB infection in those exposed to TB, especially children
- 2 Regular testing and treatment for TB infection in people living with HIV
- 3 Treatment of drug-susceptible TB infection with the new once-weekly 12-dose treatment (isoniazid/rifapentine)

IMPACT

You now know what must be done to find people sick with TB, cure them, and prevent others from getting TB. These three activities must all be done at the same time to truly make a difference in the fight against TB. When they are done together, we can stop millions of people from getting sick and dying from this curable disease. The figure below shows what we could expect to happen globally to deaths from TB if all of these activities were done everywhere.



Adapted from Dye et al. Prospects for tuberculosis elimination. Annu Rev Public Health. 2013;34:271-86

For years, TB programs in poor countries have not provided a comprehensive package of care to those sick with TB and their families and communities. Without this comprehensive approach—all three activities—the TB epidemic will not be stopped. By demanding a comprehensive approach to the TB epidemic—the same as what is used in rich countries—we can save lives, reduce suffering, and prevent millions from becoming sick and dying of TB.

USEFUL TERMS

chest radiography (chest x-ray) A photo of the inside of the chest that allows a doctor to see if TB is present

child-friendly formulation Medications that contain small doses of each ingredient and are easy for children to swallow

clinical algorithm A step-by-step guide to determine whether someone is sick with TB

contact investigation Process of screening the people closest to a person with TB

DNA amplification A test to diagnose TB where a sputum sample is sent to a lab and examined to look for genetic markers unique to TB

first-line drugs Standard medications for someone sick with TB without drug resistance

integrated care Receiving TB care at the same time as care for other medical needs

interferon-gamma release assay (IGRA) A blood test to diagnose TB infection by measuring the body's immune response to TB

tuberculosis infection A form of TB where a person has come into contact with TB bacteria but the bacteria are “sleeping” and the person is not sick, contagious, or showing symptoms; without treatment, the TB bacteria can “wake up” and the person can become sick, contagious, and show symptoms

patient support network Groups of people who know about TB and gather together to provide an opportunity for people affected by TB to talk openly about their experience

second-line drugs Medications for someone sick with drug resistant TB

side effects Undesirable effects from a medication like nausea, vomiting, or skin rash

sputum culture A test to diagnose TB where a sputum sample will be sent to a lab; a person is sick with TB if TB bacteria in the sample grow

sputum microscopy A century-old test to diagnose TB where a microscope is used to look for TB bacteria in a sample of sputum

sputum Phlegm or mucus that a person produces when they cough deeply that can be tested in the laboratory for TB bacteria

stigma Being shunned or treated badly for having a particular circumstance or quality, such as being sick with TB

treatment supporter People who commit to helping a person sick with TB through the long treatment and uncomfortable side effects they may experience

tuberculin skin test (TST) A test on the skin to diagnose TB infection by measuring the body's immune response to TB

tuberculosis (TB) A disease anyone can get that is caused by bacteria and passed in the air when a person with TB coughs, sneezes, speaks, or sings



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