

WITHIN OUR REACH:

STOPPING TB TOGETHER

A TB Literacy Toolkit for Use by
Community Health Educators, Outreach Workers,
Counselors, and Healthcare Providers



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The theme of the toolkit “Within Our Reach—Stopping TB Together,” captures the idea that it takes all of us to support TB control and treatment. The image shows many hands supporting one another and reaching toward a common goal. With unity comes strength. TB treatment is a challenge for the individual, especially someone who is living with HIV, but with support from others, it can be successfully completed. As you start to use this toolkit you may want to point out the theme and image to patients, caregivers, and members of the community. Encourage them to talk about who should come together to stop TB in your community and what they can each contribute.

Acknowledgments

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Contents

About the Toolkit 5

Basic Information about TB and HIV 6

Tools 6

The Story of Thomas: A Flipchart-assisted Activity 6

Treatment Tales: Four TB Patient Stories & “More about TB” (videos) 18

Brochures 24

Games & Activities 26

Story Creation 26

Picture Stories 28

Role Play 29

Serial Storytelling 32

Music & Art 33

Additional Resources 34

About the Toolkit

With input from community health professionals from several countries, this toolkit was developed for health educators, outreach workers, counselors, and supervisors who provide services to suspected and confirmed TB patients. The tools are designed to educate TB and HIV patients, their caregivers, and their communities about TB and what it takes to complete a full course of TB treatment.

Other supporting objectives include the following:

- Increase knowledge about TB, the link between TB and HIV, TB treatment, and TB transmission
- Raise awareness that TB is a serious but treatable disease
- Give patients confidence that they can complete TB treatment and be cured
- Educate caregivers and families about how to support TB patients
- Reduce stigma attached to TB and HIV

The kit contains the following tools that can be used with patients, their families, caregivers, and community groups:

- 1. The Story of Thomas flipchart**
- 2. Treatment Tales (patient video stories)**
- 3. TB and HIV informational brochures and a CD containing electronic versions of all the print materials**
- 4. Suggested Games & Activities**
- 5. Links to Additional Resources**

Basic Information about TB and HIV

The TB and HIV epidemics are intertwined. TB is the leading cause of death among people living with HIV.

TB infection can spread when a person who is not on treatment coughs or sneezes and those nearby breathe in the droplets. Most people's immune systems are strong enough to fight off TB infection. They may inhale TB and later have a positive tuberculin skin test, indicating that they were exposed to TB, but they will not develop active disease. These people have latent TB infection. It is not contagious and they can live with it for years without ever feeling sick. Some may not even know that they have latent TB.

For people with HIV, though, it is not so simple. Because those with HIV have weak immune systems, they are much more likely than a healthy person to develop active TB when exposed to someone with active disease. A person with latent TB who becomes HIV-infected is also much more likely to develop active TB. HIV also increases the likelihood that someone previously treated for TB will relapse.

It is important that those known to be HIV-positive are regularly tested for TB, and those with TB are tested to determine their HIV status. Latent TB in an HIV-positive person should be treated right away—before that person develops active TB disease.

Tools

The Story of Thomas: A Flipchart-assisted Activity

This is the story of Thomas and his family. Although Thomas is not a real person, his character and story are based on real stories of HIV-positive TB patients. The story is meant to educate patients and caregivers about TB and HIV, and to encourage them to reveal their own stories. Feel free to share the story with patients, caregivers, other family members, and community members you would like to involve in TB control and treatment.

The flipchart story is ten pages. Each page has a colorful image that you can show your clients. On the back of each image is Thomas's story and suggestions for messages that relate to it. You can read the story aloud, page by page, or record the story onto an audiocassette or CD so that it sounds the same every time you play it.

Read the story or play the tape while you show the pictures, then pause and talk to patients and caregivers between each picture. After finishing the entire story, you may want to summarize key points for your clients.

The following section includes more detailed suggestions for messages and discussion topics pertaining to each image. You may choose to use the suggested topics or develop your own. Only you know how to make the story relevant to your community.

The Story of Thomas: A Flipchart-assisted Activity

Introduce the Story

Describe the characters & summarize the story: This is a story about a man named Thomas and his family. They live in a village somewhere in Africa. Thomas is a recent widower, a father, and a shop owner, and is well respected in his community. Thomas's health and quality of life seem to be suffering lately. Let us listen to his story and talk about it together. Thomas may just remind you of someone you know.



Picture 1

Read aloud (or play recording)

Meet Thomas, an HIV-positive shop owner and single father who recently lost his wife to TB. She left him with baby Nando and their teenage daughter Bella. They all live with Thomas's mother Luisa.

Thomas feels guilty that he never told his wife he was HIV-positive. He fears she may have been HIV-positive too, which could have led to her TB and death. She may have even passed HIV on to their baby, who is not thriving.

After reading this page, you could:

- Explain the relationship between HIV and TB and why people living with HIV can contract TB more easily
- Encourage patients to talk about how TB is spread in the air by someone sick with TB to others in the household or working close by
- Discuss how someone with TB may or may not have HIV
- Encourage patients to talk about how HIV is spread from one person to another, especially from mother to child and through persons having sex
- Discuss ways to prevent HIV
- Encourage patients to discuss how they might feel if they were diagnosed HIV-positive and how (or if) they would tell their family
- Encourage patients to discuss Thomas's lack of disclosure to his wife
- Ask if stigma about TB or stigma about HIV/AIDS exists in the patients' community and if they have ever felt stigmatized

The Story of Thomas: A Flipchart-assisted Activity



Picture 2

Read aloud (or play recording)

If only I could turn back time, Thomas thinks, remembering his pregnant wife and her terrible cough. His mother tried taking her to Francisco, the neighborhood healer, where she got herbs and potions, but they never stopped the cough. And even as she was giving birth, she was coughing up blood.

After reading this page, you could:

- Encourage patients to talk about the symptoms of TB
- Encourage patients and caregivers to talk about what to do when symptoms are present
- Talk with patients about the role of traditional healers in the community
- Encourage them to think about how community health workers can work together with traditional healers to identify TB suspects, make referrals for testing and treatment, and support people with TB
- Emphasize that TB is curable, but only with the proper treatment
- Discuss stigma associated with TB and worries about losing jobs and the cost of treatment

The Story of Thomas: A Flipchart-assisted Activity



Picture 3

Read aloud (or play recording)

Soon after Nando was born, his sister Bella got really frightened about their mother's condition, so she contacted Maria, the local community health worker. Maria visited their home, but by the time she arrived, mama was near death. Maria told the family that she suspected mama had TB and that it was time to say their goodbyes.

After reading this page, you could:

- Talk with patients about TB testing
- Explain what patients can expect after being tested
- Encourage patients to talk with community health workers when they have symptoms or questions about TB testing, treatment, and TB transmission to others
- Explain that TB can be treated (If TB is diagnosed early enough and all medications are taken correctly, TB is curable.)
- Explain that if medications are not taken properly, some patients could develop a form of TB that is more difficult to treat (multi-drug resistant TB [MDR-TB] and extensively drug resistant TB [XDR-TB])
- Encourage patients to think about the leaders and influential people who could help them access quality (HIV and) TB diagnosis and treatment in their community

The Story of Thomas: A Flipchart-assisted Activity



Picture 4

Read aloud (or play recording)

After mama's death, Maria had a heart-to-heart discussion with Thomas. Since he had lost a lot of weight and started to cough, she suggested that he might have TB or be HIV-positive. She also suggested that since the baby was not thriving, he might have TB or HIV, too. Without being judgmental, and in complete confidence, she urged that the whole family get tested for TB.

After reading this page, you could:

- Remind patients that TB is contagious and can be spread from person to person
- Discuss ways to stop TB from spreading
- Discuss why it's important to be tested for TB and HIV
- Encourage family members to get tested for TB
- Remind patients and family members that a person with TB does not always need to be isolated, especially when he/she is on treatment
- Explain that HIV makes the body's natural defenses weak, so people living with HIV can contract TB more easily
- Describe DOTS (directly observed treatment short course) and why it's so important to have a "buddy" to observe and support treatment for several months
- Ask who will be supporting their (or their family member's) treatment

The Story of Thomas: A Flipchart-assisted Activity



Picture 5

Read aloud (or play recording)

This presented a huge conflict for Thomas. He felt very guilty about not telling his wife that he was HIV-positive. He blamed himself for his foolish ways, for taking his wife for granted, and for not getting her the medical help she needed sooner. He took full responsibility for his wife's death.

After reading this page, you could:

- Discuss why it might be difficult to tell a spouse that you are HIV-positive
- Talk about the benefits and barriers to disclosure, and how families might react
- Talk about HIV/AIDS and TB treatment and remind your audience that both diseases can be treated, and TB can be cured
- Inform them that people living with HIV have the power to lead a healthy life and prevent HIV from spreading to their loved ones
- Discuss the different (and sometimes unequal) roles of men and women
- Encourage men and women in the family to play an active role in their family's health and well-being

The Story of Thomas: A Flipchart-assisted Activity



Picture 6

Read aloud (or play recording)

Unable to cope, Thomas goes to Francisco, a healer and long-time family friend, and pours his heart out. Francisco, apologetic that he did not have the power to save Thomas's wife, recommends that he follow Maria's advice and get himself and his family tested for TB. In addition, he tells Thomas to think about disclosing his HIV status, at least to his family, and to get his baby tested for HIV to avoid further pain, sickness, and death.

After reading this page, you could:

- Talk about how community health workers and traditional healers might work together to support people living with TB and/or HIV
- Discuss the importance of TB (and HIV) testing for those close to you
- Bring up stigma once again and ask what role each one of us can play to help decrease stigma and discrimination
- Ask patients whether they have experienced worse stigma associated with TB or HIV
- Ask patients to discuss how one might disclose HIV status to family members. What are the risks? Rewards?
- Encourage patients to talk about disclosing their (HIV) status to loved ones

The Story of Thomas: A Flipchart-assisted Activity



Picture 7

Read aloud (or play recording)

Thomas takes Francisco's advice and visits the local health clinic. He learns that he has TB and begins treatment. That night, Thomas has a dream. In his dream, he has the strength and power to make a huge difference in the future of his family and community. He wakes up with an idea and visits Maria to discuss the idea and get her involved.

After reading this page, you could:

- Discuss the importance of starting TB treatment right away
- Tell patients that it is safe and advisable to treat TB when a person is HIV-positive (and treat TB even if a person is already taking anti-retrovirals for HIV/AIDS)

The Story of Thomas: A Flipchart-assisted Activity



Picture 8

Read aloud (or play recording)

Thomas shares his idea with his mother and daughter as well. He asks them to extend an invitation to store customers, neighbors, and community leaders to attend a big community meeting at his store.

After reading this page, you should turn to Picture 9 unless participants want to discuss further.

The Story of Thomas: A Flipchart-assisted Activity



Picture 9

Read aloud (or play recording)

With the whole community gathered in front of his store, Thomas shares some of the valuable lessons he's learned. He tells them that TB is contagious and deadly, but when discovered and treated, it is curable. He announces his plan to sponsor a Community TB Testing Day at his store, with transportation and refreshments provided. He asks Francisco to say a few words before introducing Maria, who educates the community about TB symptoms, testing, and treatment.

After reading this page, you could:

- Encourage patients to think about how they can get more involved in the health of their community
- Discuss what they might like to change in their community
- Remind them that they have the power to make change
- Review what they know about TB symptoms, TB testing, and TB treatment
- Remind them that we all play an important role in controlling the spread of TB in our community
- Ask them if they think Thomas should have shared his HIV status. If so, with whom? What are the benefits? Risks?
- Remind them that **EVERYONE** with TB should be tested for HIV because of the strong link and because HIV is also treatable

The Story of Thomas: A Flipchart-assisted Activity



Picture 10

Read aloud (or play recording)

TB Testing Day was a success. With the support of his family and friends, Thomas is staying on treatment without much difficulty. Baby Nando tested HIV-positive, but has started treatment and is thriving. Bella feels proud that her dad has become a leader in the community and tells him how proud mama would have been. She tells Thomas not to feel guilty for mama's death and that he has taught her some valuable lessons, most importantly, that we all have the ability to learn and change, and truth is the healthy choice.

After reading the whole story, you may want to ask questions like these:

- How do you feel after hearing Thomas's story?
- Does Thomas remind you of anyone you know?
- Does his story sound like it could have happened in your own community?
- Did you learn anything new from Thomas's story? Anything else?
- Does it make you feel any differently about your own or your family member's diagnosis?
- Does his story motivate you to take any action?
- What can you do to help educate others (in your community) about TB symptoms, testing, treatment, and control?

The Story of Thomas: A Flipchart-assisted Activity

Remind them of key points that came out of the story:

- People living with HIV can contract TB more easily
- TB is curable, even in persons who are HIV-positive
- HIV can be treated so people can live a long, healthy life
- HIV can be spread from mother to child, and between people who are sexual partners, but HIV can be prevented
- Families, neighbors, and health workers can help you get diagnosed and stay on TB treatment
- TB treatment is easier when someone supports you
- Communities that come together can speak with a strong voice and demand quality TB and HIV services for testing, care, and treatment

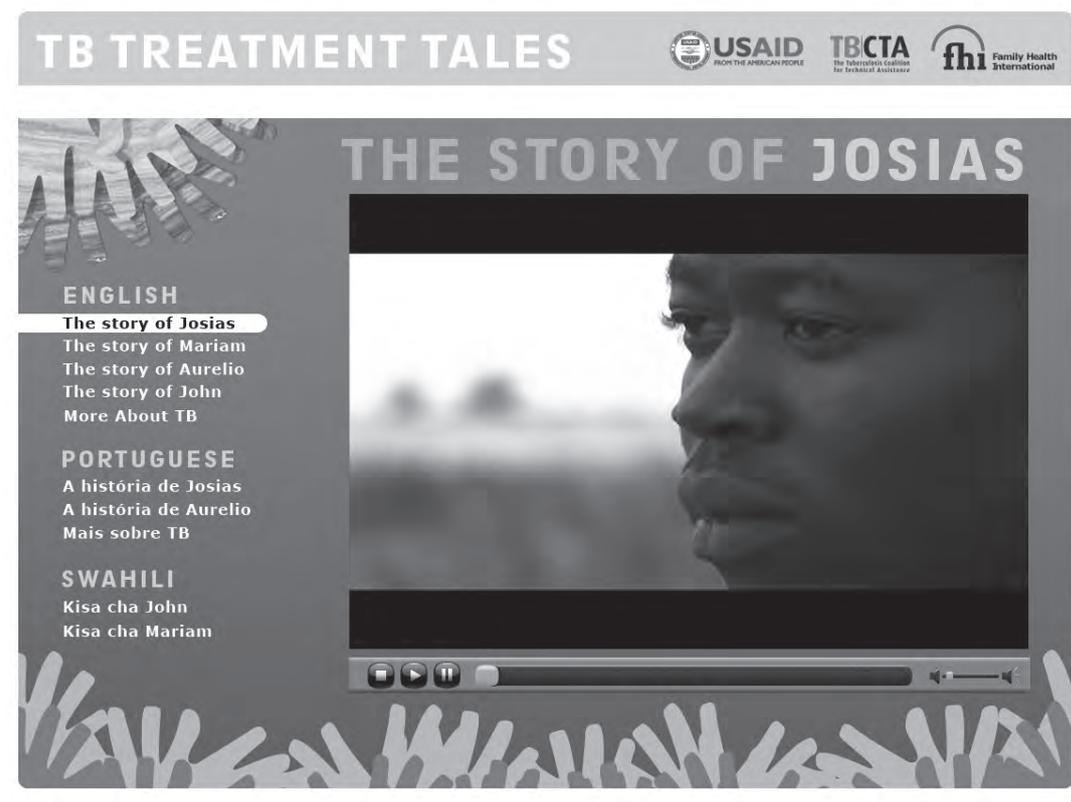
If time permits, you may want to do an activity like this:

Change the ending of the story: Ask patients how Thomas's story would have changed if one detail were different. For example, what if Thomas had told his wife that he was HIV positive?

Take a new look at the "Hand Tree": Return to the cover of the flipchart that shows the "hand tree" image. You may want to ask your client how this image reminds him/her of Thomas's story. Also, how does it remind him/her of their own community? (Whose hands should be part of the tree?)



Treatment Tales: Four TB Patient Stories & “More about TB” (videos)



Meet Aurelio, Josias, Mariam, and John. All of them suffered from TB, successfully completed treatment with the support of family and community, and survived to tell their stories. Most of them live with HIV as well and have told us of the challenges and successes they face every day. Each story is presented in the person’s native language (Portuguese and Kiswahili) in addition to English. You may want to adapt the stories into your own local language before showing them. The stories feature many common themes such as fear, stigma, support, and hope, and they demonstrate the potential for healthcare providers, patients, and their family members to serve as role models and spokespersons in their communities.

Depending on the amount of time available, you may want to show select stories when you meet with your patients and their caregivers. Or you can organize a group of people from your community and show the stories in conjunction with a group discussion. A group event like this, especially one that includes community and religious leaders, can go a long way to reduce stigma and gather much needed support for quality TB treatment in your community. You can show the stories in clinic waiting rooms, at health fairs, or at other community events.

We recommend that you watch each story before showing it to others so that you are familiar with it. After showing each story, take the opportunity to talk it over with the patient, caregiver, or group to learn more about their knowledge and attitudes. Ask them to share their own stories.



“The Story of Aurelio”

Aurelio, a young husband and father living in a village in Mozambique, was ill. He tried traditional medicines, but they did not work. That’s when he turned to Valeriano, a community health worker and TB activist. Aurelio learned that he had TB. Valeriano and Aurelio’s wife supported him through his long treatment. Later, Aurelio and his wife were both tested for HIV. The whole experience taught them several important life lessons. Learn more by watching his story.

After watching the story, take the opportunity to talk with the patient, caregiver, or group. Here are some suggestions for questions. You can also create your own questions and discussion points.

- How do you feel after hearing Aurelio’s story? Why?
- What, if anything, did you learn from Aurelio’s story?
- Does Aurelio’s story remind you of any stories from your community? Can you share those stories?
- Do you know anyone who has had TB? What symptoms did he have? Did he seek treatment? How did he deal with the treatment process?
- Do people in your community go to traditional healers? Why or why not? (Emphasize that only medicines from a clinic or hospital can cure TB.)
- Patients have to take TB medicines every day for many months. What are some ways people can remember to take their pills each day?
- Do you know anyone who has left their wife or husband because that person was diagnosed with HIV or TB? How do you feel about that? (Remind people that TB can be cured, and that TB becomes less and less infectious every day they are on medicines. After two weeks of treatment, most people are no longer contagious.)
- Have you or anyone you know been tested for HIV? Describe your (friend’s) experience?
- Where can people get tested for HIV? Do you know what happens if a person tests positive?
- Does Aurelio’s story motivate you to do anything? If so, what?



“The Story of Josias”

Josias, a Mozambican college student, got very sick while visiting his family during school break. He was tested at the local hospital and found to have TB. Bila, a community health worker and TB activist, worked closely with volunteers and family members to help Josias get through treatment. After successful treatment, a very grateful Josias returned to his studies to follow his dreams.

After you show the story, take the opportunity to discuss it with the patient or group. Here are some questions you might ask. You can also create your own questions and discussion points.

- How do you feel after hearing Josias’s story? Why?
- What, if anything, did you learn from Josias’s story?
- Do you know anyone who was sick like Josias? What symptoms did he or she have?
- Do you know anyone who has been tested for TB? Did that person tell you what the test was like?
- Have you heard of DOTS (Directly Observed Treatment)? Do you know anyone who has been through it? Can you share the story?
- Why is it so important to have family and/or volunteers support treatment by observing the patient taking his or her medicines each day? Some patients may feel that others want to observe their treatment because they do not trust them. Ask the group to speculate on what the consequences might be if someone did not take his or her medicine daily. Under what circumstances could even a very reliable person forget to take medicine?
- Does the story motivate you to do anything? If so, what?



“The Story of Mariam”

Mariam, a widow and mother living with HIV on the coast of Kenya, became sick with TB. Both family and community helped her accept her illness, complete her TB treatment, and disclose her HIV status to her children. Without the love and support of family and friends, Mariam does not think she would have been cured. Since completing treatment, she is more inspired than ever to take care of others in her community and motivate them by sharing her story.

After you show the story, take the opportunity to talk with the patient or group. Here are some suggested questions. You can also create your own questions and talking points.

- How do you feel after hearing Mariam’s story? Why?
- What, if anything, did you learn from Mariam’s story?
- Mariam says she wants to save money and leave a nice house to her children. What else does she need to do to ensure that they have healthy futures?
- Does Mariam remind you of anyone from your own community? Who?
- Mariam’s mother and sister supported her HIV treatment. How can families support each other?
- Do you know anyone who has been sick with TB? What symptoms did that person show? Can you share his or her story?
- How would you feel if you found out you had TB? Why? What would you do to feel better?
- Do you know people in the community who have supported TB patients? What did they do?
- What do people in your community think about TB patients? How about people living with HIV? What, if anything, could you do to help reduce stigma?
- Does the story motivate you to do anything? If so, what?



“The Story of John”

John, a devoted husband, father, and community educator, has been living with HIV for several years. He is diagnosed with TB. The strong women in his life—his wife, clinician, and a fellow community health worker—forge a strong and lasting partnership to help him adhere to treatment. With a clean bill of health and a new outlook on life, John plays an even more active role in promoting the spirituality and well-being of his Kenyan community.

After showing John’s story, take the opportunity to talk with the patient, caregiver, or group. Here are some questions you can ask. You can also create your own questions and discussion points.

- How do you feel after hearing John’s story? Why do you feel that way?
- What, if anything, did you learn from John’s story?
- Does John remind you of anyone in your community? Who?
- Do you know people living with HIV in your community? How do others treat them? Why?
- Do you know anyone who has supported a TB patient with his or her treatment? Can you share the story?
- Do you know anyone who has gone through TB? Did they tell you what it was like?
- Are there people in your community who help TB and HIV patients? Can you share their stories? Why do they help? How could others help?
- How are people living with HIV and TB treated in your community? What could you do to improve the way people are treated?
- Does the story motivate you to do anything? If so, what?



“More about TB”

If you only have a couple of minutes to educate patients, caregivers, or community members about the link between HIV and TB, you may want to show them “More about TB.” This clip features Bila, the community outreach worker and TB activist introduced in “The Story of Josias.” Bila tells us all about TB, how it is spread, detected, controlled, and cured. Bila shares his impressions of DOT (Directly Observed Treatment), which allows patients to undergo TB treatment in the comfort of their own homes. Families, friends, neighbors, and community health workers need to help patients finish their treatment so they can be cured.

After you show this video clip, you can discuss it with the patient or group. The following are some examples of the kinds of questions you can ask. However, only you know how to tailor the discussion to what's happening in your community.

- What, if anything, did you learn from this video clip?
- Who is at risk for TB? Do you know people in your community who have had TB? Can you tell us anything about their experience?
- Have you known anyone who has gone through TB treatment? What did they say it was like?
- Have you heard of DOT (Directly Observed Treatment)? Do you know anyone who has been through it? Can you share that person's story?
- What can families, neighbors, and other volunteers do to support TB patients? Do you know someone who has supported a TB patient? Can you share that person's story?
- Does this video motivate you in any way? If so, what does it motivate you to do?

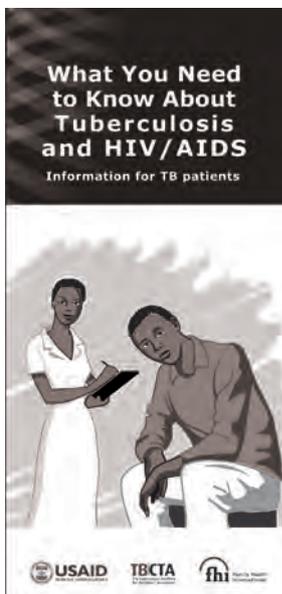
Brochures

This toolkit contains two brochures in hard copy format that provide information about TB and HIV. Electronic versions may also be reproduced from the brochure files found on the flash drive included in this kit.

The brochures are:

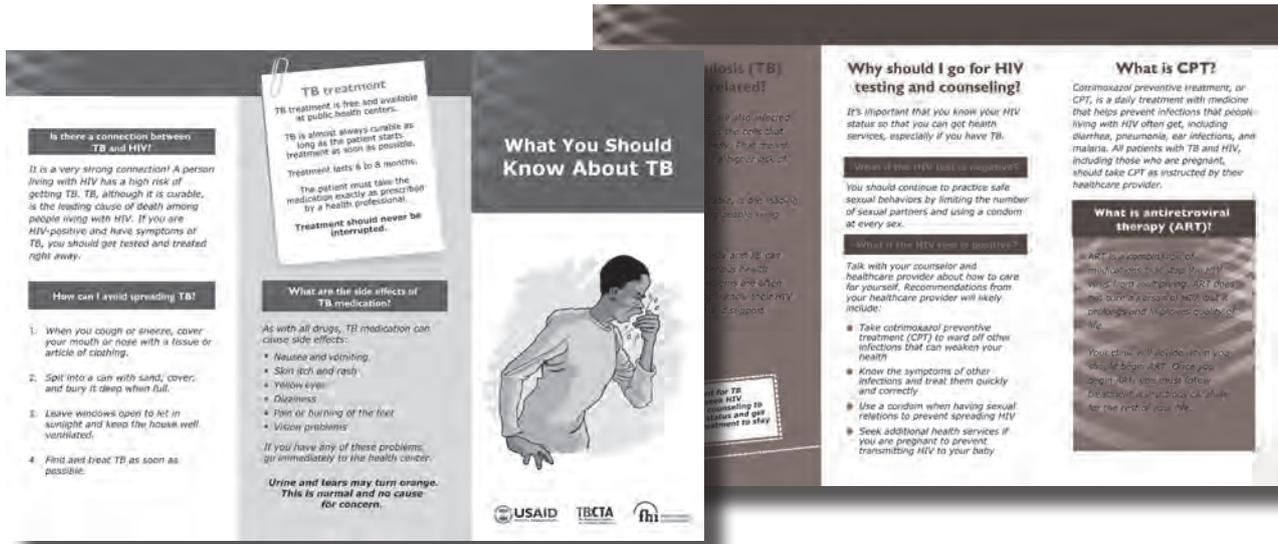
What You Should Know About TB:

Provides information on what tuberculosis is, its symptoms, how a person becomes infected with TB, how TB is cured, and the relationship between TB and HIV.



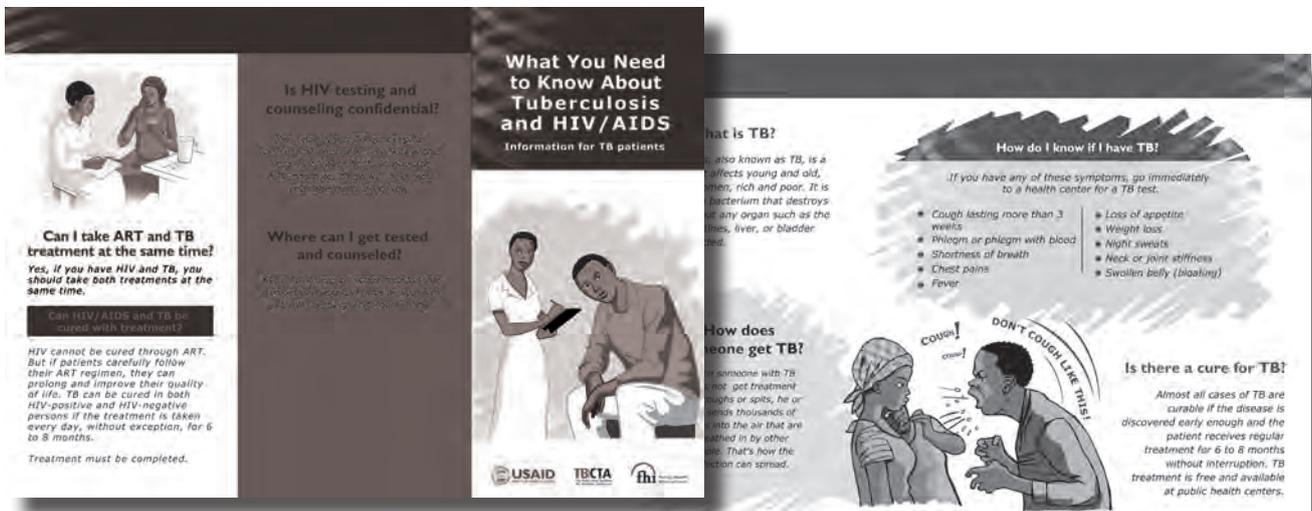
What You Need to Know about Tuberculosis and HIV/AIDS: Information for TB Patients:

Provides information on the relationship between TB and HIV; HIV counseling and testing and the importance of knowing one's HIV status, particularly if a person has TB; actions to take following an HIV test; and information on Cotrimoxazole preventive therapy (CPT) and antiretroviral treatment.



Some suggestions on how to use the brochures are:

- **Read aloud** in group sessions to explain the basic facts about TB and HIV
- **Hand out** after sessions to reinforce the information you have shared with patients
- **Hand out to caregivers** so they can learn more about TB and HIV
- **Distribute to outreach workers** so they can better support TB and HIV patients
- **Hand out at community events or health fairs** so that the community is more aware about HIV and TB
- **Display in clinic waiting rooms** for patients and caregivers to read while waiting



Games & Activities

Learning about TB and HIV is crucial for patients and their families. Everyone learns in different ways. The tools in this kit are designed to help people learn through interactive storytelling and information sharing. This section is meant to help people learn and think about TB, stigma, and community support by simulating them through games and activities.

These activities allow people to improvise in different situations in which they play different roles.

Story Creation

Time:	5-10 minutes
How many people:	One or more
Materials:	Fill in the blank story

Read one of the stories below out loud. For each blank space, ask the patient/caregiver to fill in a word that might fit in the story (the first two blanks have been filled in below as examples). You may need to suggest a few words at the beginning so that everyone understands the activity. Write in the suggested words as your audience shares them and read the full story once completed. Discuss each story. Ask audience members about the characters' actions. Do they agree with their actions? If relevant, how would they counsel the characters to behave differently?

Story 1

I had this awful cough that just wouldn't go away, even after trying herbs that the local healer gave me. I felt terrible, and noticed that I was coughing up blood. My husband came home from a trip and also had a cough. He said his cough was from _____. His health was not good and I was worried. He started taking medicines. When I asked him about them he said he was suffering from _____. He encouraged me to go to the clinic for a checkup. When I visited the clinic, I found I had TB. I was started on medication. I visited the VCT clinic, where I had an HIV test and found I was _____. I found out later that my husband had _____. I told him about my TB and he _____. Now I am taking my medicines, and I feel _____. I hope that _____.

Games & Activities - Story Creation Cont.

Story 2

My daughter was brought back to me by her in-laws because she was so sickly. She tested _____ for HIV during her last pregnancy. She was put on _____ and delivered a healthy baby. About five months later, she started coughing very badly and was taken to _____, where she found she had TB. The baby is weaned and is staying with _____. My daughter's husband has _____ to be tested for TB and HIV. He says he does not want her back, because _____.

Story 3

I tested HIV-positive in 2005. All of last month, I had this _____ that wouldn't go away, regardless of taking medications. In addition to my ARV drugs, I have been taking some _____ that I was advised to take by a friend. During one of my ART clinics, I was advised to take a TB test, which confirmed I had TB. I am now on medication. I remember to take my medicine every day by _____. I decided not to tell my family about my TB, as I think this will _____. I can get away with lying that my TB drugs are _____.

Story 4

I have been HIV-positive for the last six years. Late last year, I developed this irritating cough. A _____ in my village gave me some _____ to clear it. The coughing stopped for a week, but now it is back with a vengeance. I decided to visit this clinic, and now _____ has confirmed that I have TB. I feel _____. I am already stigmatized in my family, and they do not _____. If I tell them that I have TB, they will _____, so I will not tell them. I refused to attend the health center near my home because I feared _____. So I travel here to seek treatment. My health is _____. I hope the drugs will _____. I worry that if my husband finds out, he will _____, so I will keep the secret to myself as long as I can.

Games & Activities

Picture Stories

Time: 10-15 minutes

How many people: One or more people

Materials: Pictures or drawings of objects related to TB

In advance of the activity, assemble pictures or drawings of objects or items related to TB. Then, distribute the pictures to participants and ask them to order the pictures and tell a story in pictures. As the storyteller mentions an object in the pictures, he/she should paste the picture on the wall or on a flip chart so that others may follow the visual story as it develops.

The objects listed below all have something to do with TB and TB treatment and are suggestions for use in this activity. You may use those objects or think of your own.

- **Bicycle**
- **Healthcare provider**
- **Clinic**
- **Patient**
- **Pills/medicine**
- **Volunteer or caregiver**
- **Open window**
- **Bed or mat**
- **Soap and water**
- **Person coughing into handkerchief**
- **Bowl of food**
- **Baby**
- **Calendar**
- **Family members**

After each participant has told a story, ask for the audience's reaction. Ask the storyteller to explain his/her rationale for telling the story he/she did.

Role Play

Time: 10-15 minutes
How many people: Two or more people
Materials: Large piece of paper

Recruit two volunteers who would like to do a role play. Choose from the stories and characters that follow and describe them to the volunteers. (Give your directions to the volunteers quietly so the group doesn't hear.) Volunteers will act out the story. (Note that it is OK for women to play men and men to play women.) Afterwards, you can lead the group in a discussion about what they saw. Based on the role play, you may wish to explore with the group some of the themes and messages suggested for each role play or develop some of your own. If time permits, two others from the group can act out the same story with their changes to see how the drama might end differently.

Role Play 1 - Characters

Helen: You are married and have two children. You married your husband Joseph after his first wife died. You heard she was bewitched, and had a cough that wouldn't go away and withered her body.

You are expecting your next baby, and got tested for HIV at the clinic. You found out you are HIV-positive. The clinic enrolled you in a program to take drugs so your baby does not get HIV.

You want to tell Joseph, but you are scared about how he will react. He has had a bad cough lately, and you are worried about his health, too.

Joseph: You are a hard-working man who believes in tradition. You seem to have had bad luck with women. Your first wife was bewitched by an angry neighbor. She got a cough and wasted away.

After your first wife died, you married Helen. She seemed nice enough at first, but soon she was too busy with the children to pay much attention to you. Lately you have been seeing another woman—just when you travel to the city—to take care of your manly needs.

In the last week, Helen acts like she's worried about something. She has had two daughters, and you are hoping she will give you a son—perhaps she is worried about that. You can't really think too much about it; your cough hurts your head too much.

Themes and messages:

- Traditional beliefs (bewitching) and medical fact
- Prevention of mother to child transmission of HIV
- TB testing
- Communication in the family
- Family responsibility for one another's health
- HIV prevention

Role Play 2 - Characters

Mary: You are a young wife and the proud mother of two healthy children. You love your husband, Stephen, and are very proud of his success. His job keeps him away from home much of the time, but he is a good father and provider.

Lately you have not been feeling well, and you have a cough that won't go away. You decided to go to the clinic two weeks ago, while your husband was out of town. Last week you learned that the cough was TB, and the health provider at the clinic asked you to get tested for HIV, too. The world seems to be ending—you found out you are HIV-positive. You started medicines for TB and will return to the clinic shortly to discuss if antiretroviral treatment is also advised.

Your husband is coming home for a visit next week. You are worried that he will leave you if he finds out about your illness. Nonetheless, you plan to tell him you have TB and HIV so that he can get tested as well. You know that your children need to be tested too. You are ashamed and feel very guilty, but you know that telling your husband and caring for your children is the right thing to do.

Stephen: You are Mary's husband. You work hard in the mines to provide for your family. The mines are several hours from your village, so you live in housing provided for the miners and come home to visit your family a couple of times each month. You miss your wife and children but it is the only way you can make enough money to support them. Sometimes you get very lonely.

You are excited to see your family. When you last communicated with your wife to tell her you would be coming for a visit, she said she has to talk to you about something very important. She sounded nervous and upset. You love your wife and want her to feel comfortable talking to you.

Themes and messages:

- Stigma
- Disclosure
- Violence
- TB and HIV testing
- TB is curable with proper treatment
- ART, HIV prevention for positives
- Communication in the family
- TB transmission
- Shared responsibility for health

Role Play 3 - Characters

Matthew: You are a young man who works at the local mechanics shop. You are very popular with the ladies, and have had a lot of girlfriends. You are happy with your life, and dream of one day taking over the shop from the older owner, Manuel.

A few weeks ago, you went to the traditional healer in town for treatment for a bad cough you've had for a few weeks now. The traditional healer gave you a cough syrup, but it didn't help. The healer told you to go to the clinic to see if they could help you.

Last week, you went to the clinic and found out you have TB. They gave you medicines, and explained that you have to take them once a day for many months.

Now you are worried—what will people think? People are afraid to be around TB patients; everyone is scared they'll get it. You decide not to tell anyone, and to hide it even from your family. No one has to know.

Manuel: You are an older gentleman who owns the local mechanics shop. It is a good business and you like it, but you would like to spend more time with your family, especially with your young grandchildren.

You are thinking about passing on the shop to a promising young man who works for you named Matthew. You know Matthew can sometimes be foolish around girls, but he is always serious around the shop, and works hard. He has a knack for mechanics, and you think he will make a good manager one day.

Lately you've noticed Matthew has been coughing, and seems to be losing weight. He doesn't seem to be sleeping well either. You know he visited the traditional healer in town, but you don't trust those potions. You know that people from the clinic can give medicines that really cure people.

Another mechanic in your shop thinks Matthew has TB. You think he might be right, though you know that will be hard for Matthew. You want to support Matthew, but you are not sure what to do.

Themes and messages:

- Stigma
- TB can be cured with proper treatment
- Community health workers and other healthcare providers as resources for information, counseling, and support
- TB transmission and testing for family and friends
- HIV testing and prevention
- Community support

Serial Storytelling

This activity helps people share ideas and learn by telling stories.

Time: **10-15 minutes**

How many people: **Two or more**

Materials: **None**

The group sits facing one other (a larger group can sit in a circle). You can start the story with one of these sentences, or you can make up the beginning of your own story.

Ask who wants to tell the next sentence of the story. The next person in the circle adds another sentence. The group continues taking turns until the story has ended. The group can talk about the story they told, and how it reminds them of their own stories.

- *Michael had a terrible cough that just wouldn't go away no matter what traditional medicines he took.*
- *Lucy couldn't believe she had TB. How would her family treat her now?*
- *John felt sick with worry. The community health worker had told him he should get tested for HIV.*
- *Helen was worried about her daughter who was coughing and losing weight.*
- *David walked home from the clinic after finding out he had TB.*
- *Mary awoke to see the community health worker. It was time to take her pills again.*
- *Sam knocked on the door. He hoped the TB patient was doing better today.*

Music and Art

Sing a Story

Time: 5-10 minutes
How many people: One or more
Materials: None

Ask the patients (or just one person) to find something in the room that can be used as a musical instrument. (They may only want to use their own hands, feet, and voices.) Then ask them to make up a short song based on one of the titles below. They can also make up their own title:

- My TB
- Just a germ
- Whom shall I tell?
- Treatment for tomorrow
- Stopping TB together

Picture Your Role

Time: 10 minutes
How many people: One or more
Materials: Paper and pens/markers

Give each person a pen, pencil, crayon, or marker. Ask them to draw a picture of something that people can do in their community to support people on TB and/or HIV treatment. Talk with them about their pictures and the steps they can take to turn them into reality.

Additional Resources

These resources help the toolkit user locate additional information on TB and TB/HIV co-infection. It is not an exhaustive list, but rather a selective list targeted to issues and discussion topics that might emerge during use of the TB Literacy Toolkit.

Tuberculosis

1. US Centers for Disease Control and Prevention (CDC)

www.cdc.gov/tb/publications/factsheets/default.htm

Fact sheets on TB-related topics may be found at the website above or by following the links below. Materials are available in English and Spanish.

General Information

www.cdc.gov/tb/publications/factsheets/general.htm

Basic TB information, difference between latent TB and active TB disease

Drug-Resistant TB

www.cdc.gov/tb/publications/factsheets/drtb.htm

Multidrug-resistant TB (MDR TB), extensively drug-resistant TB (XDR TB)

Infection Control and Prevention

www.cdc.gov/tb/publications/factsheets/prevention.htm

Respiratory protection, healthcare settings, international travelers

TB in Specific Populations

www.cdc.gov/tb/publications/factsheets/specpop.htm

TB and HIV, pregnancy, international travelers

Treatment

www.cdc.gov/tb/publications/factsheets/treatment.htm

Treatment regimens for latent TB infection and TB disease, drug-resistant TB, TB, and HIV

Testing and Diagnosis

www.cdc.gov/tb/publications/factsheets/testing.htm

Tuberculin skin testing, QuantiFERON® TB Gold Test, diagnosis of TB

Vaccines and Immunizations

www.cdc.gov/tb/publications/factsheets/vaccines.htm

BCG vaccine

Get the Facts about TB Disease

www.cdc.gov/tb/publications/pamphlets/TB_disease_EN_rev.pdf

A 16-page booklet, designed for low-literate audiences, which explores the basics of TB, transmission, treatment, and how to talk about TB with friends and family.

TB Education and Training Resources

www.findtbresources.org

A website managed by CDC that offers a searchable database of TB educational materials in a variety of formats and languages.

2. World Health Organization (WHO) TB Pages

www.who.int/tb/en

WHO's Stop TB Department aims to dramatically reduce the global burden of TB by 2015 in line with the Millennium Development Goals and the Stop TB Partnership targets. The WHO TB Pages offer publications and fact sheets on TB, DOTS, global strategies, community mobilization, and global and regional TB statistics. Resources are available in English, French, Spanish, Arabic, Chinese, and Russian.

Empowerment and Involvement of Tuberculosis Patients in Tuberculosis Control: Documented Experiences and Interventions (WHO)

http://whqlibdoc.who.int/hq/2007/WHO_HTM_STB_2007.39_eng.pdf

A review of documented experiences involving patients in TB control, including the means used to enable patients to take more responsibility for their health and, in particular, for adherence to treatment; organizing TB patients into groups and clubs; ensuring patient-centered TB and general health; and helping TB patients use advocacy to improve TB control.

Community Contribution to TB Care: Practice and Policy (WHO)

http://whqlibdoc.who.int/hq/2003/WHO_CDS_TB_2003.312.pdf

Reviews of case studies of community-based approaches to TB care and a guide for TB treatment supporters. Intended for use by national TB programs, health workers at all levels, communities, and community groups and organizations.

3. Tuberculosis Coalition for Technical Assistance (TBCTA)

www.tbcta.org/Home/

The Tuberculosis Coalition for Technical Assistance (TBCTA) is a coalition of major international organizations working in TB and TB/HIV.

Members include:

- **The American Thoracic Society (ATS)**
- **Centers for Disease Control and Prevention (CDC)**
- **Family Health International (FHI)**
- **International Union Against Tuberculosis and Lung Disease (The Union)**
- **Japan Anti-Tuberculosis Association (JATA)**
- **KNCV Tuberculosis Foundation**
- **Management Sciences for Health (MSH)**
- **World Health Organization (WHO)**

The TBCTA implements the Tuberculosis Control Assistance Program (TB CAP), a USAID five-year cooperative agreement (2005–2010) led by the KNCV Tuberculosis Foundation. The TB CAP produces global tools and implements country and regional programs in TB. The project developed the TB CAP Toolbox, a compilation of electronic materials on TB and TB/HIV produced by the project. Many of the tools and guidelines were developed with country stakeholder input and are designed for adaptation and use at the country level, including this TB Literacy Toolkit. The full table of contents of the TB CAP Toolbox can be found at:

www.tbcta.org/TB_CAP_Toolbox/

Additional Resources - Tuberculosis cont.

4. Stop TB Partnership

www.stoptb.org

The Stop TB Partnership is a network of organizations, countries and donors working together to eliminate tuberculosis as a public health problem and ultimately to realize a world free of TB. The Stop TB Partnership website offers access to publications on the global Stop TB strategy, advocacy and program management. Users can also download videos on the TB epidemic and global strategies to stop TB. All resources are in English.

5. Tuberculosis Survival Project

www.tbsurvivalproject.org

The Tuberculosis Survival Project was created to address the emotional and psychological needs of patients, and to raise TB awareness. The website enables people with TB to relate their own and read stories about having TB. There is also a one-to-one mentoring service whereby individuals can chat in confidence to someone who has already been through TB treatment. The website offers various factsheets about TB and MDR TB and The Tuberculosis Survival Handbook.

6. World Care Council: The Patients' Charter

www.worldcarecouncil.org/content/about-world-care-council

The World Care Council strives to raise the standards of care for people with TB, HIV/AIDS, and malaria. The World Care Council developed The Patients' Charter, which was adopted as a key element of the WHO Stop TB Strategy. The Charter outlines the rights and responsibilities of people with tuberculosis. Initiated and developed by patients from around the world, the Charter supports making the relationship with healthcare providers a mutually beneficial one. The Charter may be downloaded at:

www.worldcarecouncil.org/content/patients-charter-tuberculosis-care

Tuberculosis and HIV/AIDS

1. Stop TB Partnership TB/HIV Working Group

www.stoptb.org/wg/tb_hiv

The TB/HIV Working Group aims to advise WHO and other partners on how to use field experience in tackling TB/HIV, advise on implementation of the new Stop TB strategy, share experiences among Stop TB partners on implementing the TB/HIV strategy and disseminate lessons learned, and promote collaboration between TB and HIV/AIDS programs. The TB/HIV Working Group website offers a number of policy papers and reports.

2. Treatment Action Group (TAG)

www.treatmentactiongroup.org

TAG is an independent AIDS research and policy think tank working for better treatment, a vaccine, and a cure for AIDS. TAG works to ensure that all people with HIV receive life-saving treatment, care, and information. It promotes collective action by all affected communities, scientists, and policymakers to end AIDS. TAG implements a TB/HIV project that aims to strengthen global advocacy to improve research, programs, and policy for people with TB and HIV. The TAG website offers various reports, assessments, and studies related to HIV, TB, and community mobilization. All materials are in English.

3. Consortium to Respond Effectively to the AIDS/TB Epidemic (CREATE)

<http://tbhiv-create.org>

The CREATE mission is to reduce death and disease from TB in populations with high rates of HIV/AIDS. The CREATE Consortium implements research studies to assess the impact of new public health paradigms for controlling the AIDS/TB epidemic. A link to their anti-TB Stigma toolkit can be downloaded here:

http://tbhiv-create.org/sites/default/files/TB_and_Stigma_Eng2.pdf

The CREATE website offers links to various training resources and organizations. All information is offered in English.

4. HIV Testing for Life: HIV Testing for all Tuberculosis Patients (WHO)

This book is for healthcare workers responsible for TB clinics, outpatient and inpatient departments, and HIV counseling and testing for TB patients, but who may lack experience in or who do not recognize the importance of HIV testing. The book promotes every TB patient's access to HIV counseling and testing, so that they can have equal access to HIV prevention and care. (In English; Thailand-specific)

Download at:

www.searo.who.int/LinkFiles/Publications_HIV-testing2603.PDF

5. TB/HIV Advocacy Training Manual (WHO)

This training manual was prepared to help representatives of nongovernmental organizations (NGOs) and other civil society groups to create advocacy networks and develop effective TB/HIV advocacy skills. The tools and approaches can be used to influence TB/HIV policy decisions at the international, national, regional, and local levels. (English)

Download at:

www.stoptb.org/wg/tb_hiv/assets/documents/Final%20Manual_edited.pdf

6. HIV and TB in the Context of Universal Access: What Is Working and What Is Not?

This WHO report summarizes the discussion from an open meeting at the 16th International AIDS Conference (2006) in Toronto, Canada. Participants discuss current models and best practices, and several case studies are presented.

Download at:

www.stoptb.org/wg/tb_hiv/assets/documents/Meeting%20report%20TBHIV_Toronto_2.pdf





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