



A New Tool for the Toolbox: The Patient Latent TB Infection Treatment Decision Aid

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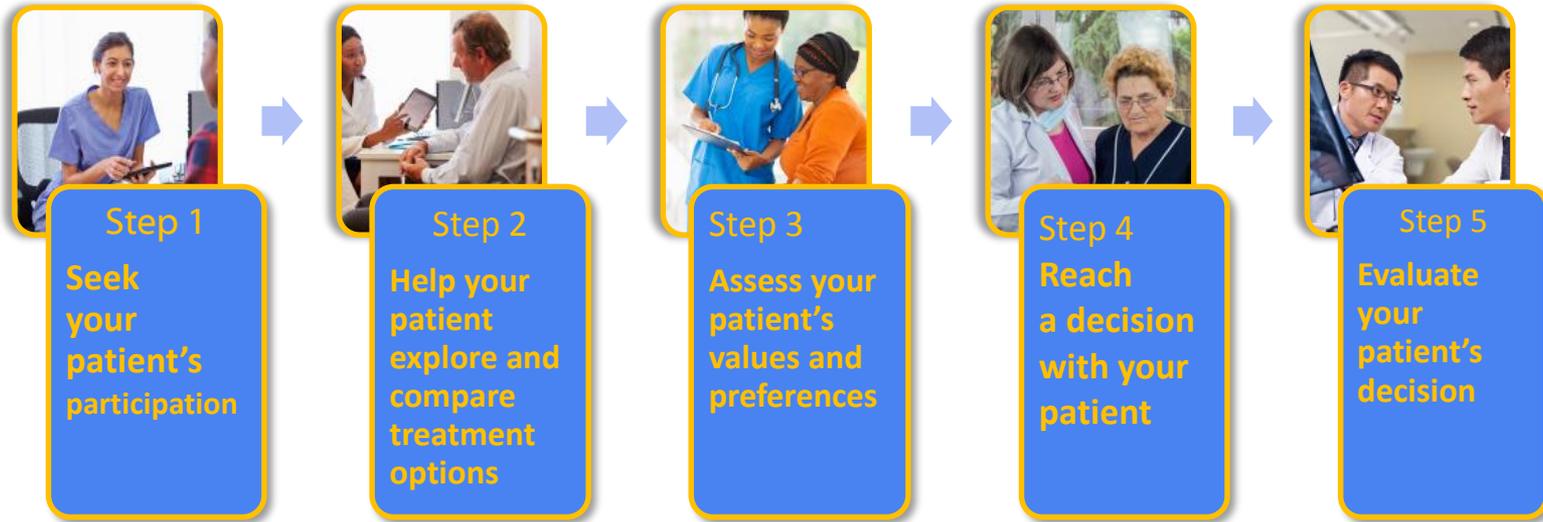
Communications, Education, and Behavioral Studies Branch

Division of Tuberculosis Elimination

Presentation Outline

- **Health literacy and shared decision-making**
 - **Framework for developing patient decision aids**
 - **Developing a patient decision aid for latent TB infection treatment**
 - **Next steps**
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- A decorative horizontal bar at the bottom of the slide, composed of several colored rectangular segments: teal, purple, red, light blue, orange, and dark blue.

The SHARE Approach: A Model for Shared Decision-Making



The SHARE Approach—Essential Steps of Shared Decisionmaking: Quick Reference Guide. Content last reviewed July 2014. Agency for Healthcare Research and Quality, Rockville, MD.

Practical Approaches to Promoting Shared Decision-Making

Patient Decision Aids (PDA)

Educational tools that can help patients make an informed decision about their treatment options.

- PDAs have been developed for a range of treatment decisions
- International Patient Decision Aid Standards Collaboration
- PDAs have been shown to improve several attributes of the decision-making process



Cochrane
Library

Cochrane Database of Systematic Reviews

Decision aids for people facing health treatment or screening decisions (Review)

Stacey D, Légaré F, Col NF, Bennett CL, Barry MJ, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Thomson R, Trevena L, Wu JHC

Development of a Patient Decision Aid for Latent TB Infection Treatment

Systematic Approach to Health Education



Patient Decision Aid Standards



**Patient
decision aid
for latent
TB infection
treatment**

Steps in the Systematic Process

Needs Assessment and Formative Research

- Literature documenting risk for developing active TB disease among target populations
- Examples of decision aids created for other health conditions, and existing CDC LTBI health education materials

Development

- Content validity

Formative Evaluation

- Local health departments and a TB control clinic (providers, patients, and provider-patient encounters)
- Teachable moment: Existing patients may not be the best choice for testing materials

Review the Facts about Latent TB Infection

You were tested for tuberculosis (TB). Your test results show that you have latent TB infection. Below are questions people often have about latent TB infection. This information will help you decide if you should take medicine to treat your latent TB infection.

How was I infected with TB germs?

When someone who is sick with TB disease coughs or talks, TB germs enter the air. If other people breathe in the germs, they can become infected too.

What is the difference between latent TB infection and TB disease?

After causing an infection, the TB germs may be inactive or active in the body.

- When the germs are not active, this is called latent TB infection. People with latent TB infection do not feel sick.
- If the germs become active and multiply, a person will become sick with TB disease.



Tests show that you have latent TB infection.

How does the BCG vaccine affect testing for latent TB infection?

Many people born outside of the U.S. got the BCG vaccine to protect against TB when they were a baby. This protection becomes weak over time. People who were vaccinated can become sick with TB. Sometimes the BCG vaccine can cause a positive result on the TB skin test. The vaccine does not affect TB blood test.

What are the risk factors for latent TB infection becoming TB disease?

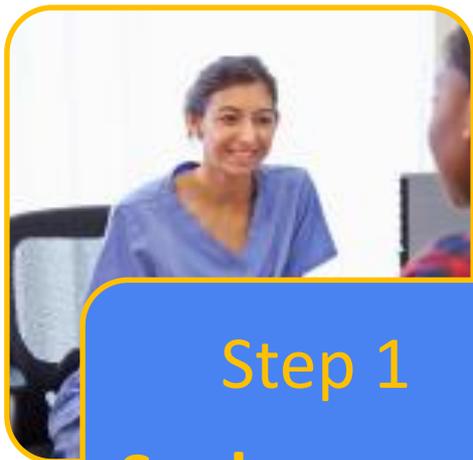
Some people who have latent TB infection are more likely than others to become sick with TB disease. On the next page, you and your doctor will look at your risk factors. This will help you see how likely you are to become sick with TB disease.

What would happen if my latent TB infection develops into TB disease?

If you get sick with TB disease you

- can pass TB germs to your family members and friends
- will have to stay at home and away from other people to avoid infecting others
- may have lasting damage to your lungs or other parts of your body
- could die at a younger age even after completing treatment for TB disease

- A visual aid that reinforces why they are being encouraged to undergo treatment for latent TB infection.
- A written account of the patient-provider conversation.
- Engages patient in decision-making process.



Step 1 Seek your patient's participation

Should You Begin Treatment for Latent Tuberculosis Infection?

Your test results show that you have TB germs in your body. However, the TB germs are not active at this time. This is called latent TB infection. This tool will help you make a decision about taking medicine to treat your latent TB infection.

There are two options:

1. Take treatment now for latent TB infection. Protect yourself from developing TB disease.
2. Do not take treatment now. Watch for symptoms of TB disease. Contact your health department or primary care provider if you start to have symptoms of TB disease. This choice can put your health at risk, as well as the health of those around you.

1. Consider Your Risks

With your health care provider's help, mark your risk factors for becoming sick with TB disease.

HIGH RISK FOR TB DISEASE

- You were born or lived in an area of the world where TB is common (these areas include Asia, Africa, Eastern Europe, Latin America, and former Soviet States)
- Abnormal chest x-ray (fibronodular disease)
- Kidney failure
- Head or neck cancer
- HIV / AIDS
- You have abused drugs or alcohol
- Silicosis (a lung disease caused by breathing in silica dust working in mines, concrete or cement work, building and road construction, demolition work, sandblasting)
- You are taking a medicine that suppresses the immune system. People who take these medicines have organ transplants, autoimmune diseases, or chronic inflammation (examples are: Lupus, Rheumatoid Arthritis, or Psoriasis). These medicines include TNF-alpha inhibitors, glucocorticoids, steroids, and other immunosuppressive medications.

You may have been recently infected with TB germs if

- You have been in close contact with a person who has TB disease.
- You have experienced homelessness.
- You have lived or worked in a homeless shelter.
- You have lived or worked in a hospital, nursing home, or rehabilitation center.
- You have lived or worked in a group home.
- You have lived or worked in any type of correctional facility (jail, prison, half-way house).

MEDIUM RISK FOR TB DISEASE

- Diabetes (all types)
- Cigarette smoker
- Abnormal chest x-ray (granuloma)
- Extremely underweight/undernourished

The items above are the most well recognized risk factors for becoming sick with TB disease. If these do not apply to you, discuss with your provider the reasons they have suggested you take treatment for latent TB infection.

2. Compare Your Choices

If you take treatment for latent TB infection	
What are the benefits of taking treatment for latent TB infection?	The medicine will kill the TB germs. You will avoid becoming sick. You will not pass TB germs to others.
What can you expect to happen if you take treatment for latent TB infection?	 <p>You will need to take medicine every day.</p>
What are the risks of taking treatment for latent TB infection?	<p>Most people can take the medicine without any problems. However, some side effects are:</p> <ul style="list-style-type: none"> Stomach upset, nausea Severe tiredness or weakness Fever or chills Pain or tingling in your hands, arms, and legs <p>For a few people, their health care provider can talk to you about the risks.</p>
If you do not take treatment for latent TB infection	
What are the benefits of not taking treatment for latent TB infection?	You do not take medicine, so you avoid the side effects.
What can you expect to happen if you do not take treatment for latent TB infection?	<p>The TB germs will stay in your body. You will need to watch for symptoms of TB. If you develop TB disease, you will need to take medicine every day. You will miss work or school until you are not able to infect others. You will have to take multiple drugs every day. Some of these drugs have side effects.</p>

What are the risks of not taking treatment for latent TB infection?	The TB germs in your body will stay in your body. You will need to watch for symptoms of TB. If you develop TB disease, you will need to take medicine every day. You will miss work or school until you are not able to infect others. You will have to take multiple drugs every day. Some of these drugs have side effects.
	<ul style="list-style-type: none"> You can pass TB germs to your family members and friends. You will have to stay and away from other people to avoid infecting others. You will miss work or school until you are not able to infect others.

3. Compare Your Treatment Options

	Take treatment	Don't take treatment
What can I expect to happen for each treatment option?	If you take medicine to kill the TB germs, you will prevent TB disease from developing. You will need to take pills for 3, 4, 6, or 9 months, depending on which medicine your doctor thinks is best for you.	If you do not take treatment at this time, you may develop TB disease in the future. If you get sick with TB disease, you can pass TB germs to your family members and friends. You will have to stay at home and away from other people to avoid infecting others. You will miss work or school until you cannot (are not able to) infect others. You may have permanent damage to your lungs or other organs, and you could die prematurely even after completing treatment. You will have to take multiple drugs every day. Some of these drugs have side effects.
What are the benefits of each treatment option?	You will prevent yourself from developing TB disease. The medicine will kill the TB germs in your body. By not developing TB disease, you will protect your family and friends from being infected with TB.	You avoid the possible side effects of the TB medicine. However, if you develop TB disease, you will have to take several medications that have side effects.
What are the risks of taking treatment, and not taking treatment?	<p>Most people can take their TB medicine without any problems. However, some side effects can include:</p> <ul style="list-style-type: none"> Stomach upset, nausea, or vomiting Severe tiredness or weakness Fever or chills Brown or tea-colored urine Skin or whites of your eyes appear yellow Bruises, or red and purple spots on your skin Nosebleeds, or bleeding from your gums or around your teeth Pain or tingling in your hands, arms, and legs 	<p>You could develop TB disease. If you develop TB disease, you may have permanent damage to your lungs or other organs, and you could die prematurely even after completing treatment. You will be required to take multiple drugs that all may have side effects. If you develop TB disease, you may infect family and friends with TB. You will need to watch for symptoms of TB disease. Contact the health department right away if you experience any of the following symptoms:</p> <ul style="list-style-type: none"> Fever or weakness Cough Weight loss Night sweats <p>The symptoms of TB disease of the lungs also include chest pain and the coughing up of blood. Symptoms of TB disease in other parts of the body depend on the area affected.</p>



Step 2
 Help your patient explore and compare treatment options



Step 3

Assess your patient's values and preferences

3. Think About What Matters Most To You

Your personal feelings are just as important as the medical facts. The questions below will help you think about common concerns others have when making a decision about treatment for latent TB infection.

Circle the statement below each question that best describes your feelings.

1. How concerned are you that you will get friends and family sick if you develop TB disease?

I am not concerned

I am unsure

I am very concerned

2. How concerned are you that you will miss work or school if you get sick with TB?

I am not concerned

I am unsure

I am very concerned

3. How concerned are you about having permanent damage to your lungs or other organs if you get sick with TB?

I am not concerned

I am unsure

I am very concerned

4. How willing are you to take pills for several months to avoid getting sick with TB disease?

I am not willing to do this

I am unsure

I am willing to do this

5. How willing are you to cope with possible side effects from the medicines to avoid becoming sick with TB disease?

I am not willing to do this

I am unsure

I am willing to do this

Reasons to not take treatment

Reasons to take treatment

- If most of the statements you circled are on the right side of the page, you value reasons to *take* treatment.
- If most of the statements you circled are on the left side of the page, you value reasons to *not* take treatment.

What other concerns do you have about taking treatment for latent TB infection?

4. Make The Decision That Is Right For You

Now it is time to make your decision about taking medicine to treat your latent TB infection.

1. Check the box below that describes your choice.
2. Use the space provided to write notes as needed.

I am ready to start treatment for latent TB infection.

I need to have questions answered. My questions are:

I want to discuss this decision more. The people I want to talk to next are:

I have decided I will not take treatment for latent TB infection at this time.

I understand that I can change my mind and begin treatment for my latent TB infection in the future to prevent active TB disease.

I will talk to the health department or my primary health care provider right away about my diagnosis of latent TB infection:

- ✓ If I begin to cough, lose weight, have night sweats, or any other TB symptoms
- ✓ If I develop cancer, diabetes, or any other medical problem that weakens my body's ability to fight infections
- ✓ If my primary health care provider wants me to begin taking medicine that can suppress my immune system



"If I get TB disease, I can become very sick and can pass TB germs to others. I don't want that to happen, so I'm doing what my doctor thinks is best, and starting on the TB medicine right away."



Step 4
Reach a
decision
with your
patient



Step 5
Evaluate
your
patient's
decision

Next Steps

- **Conduct next round of formative evaluation**
 - High-risk patient populations
- **Incorporate revisions based on next round of formative evaluation**
- **Release on CDC's TB website and promote via communication channels**
- **Develop pilot study to evaluate effectiveness of revised decision aid**
 - Treatment initiation
 - Adherence

Thank you!

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TTY: 1-888-232-6348 www.cdc.gov

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