TB Patient Education & Counselling Flipchart:
DSTB, MDR TB and XDR TB messages
1. What is Tuberculosis?

TB stands for Tuberculosis, a disease caused by the TB bacteria found in the air. The most common presentation of Tuberculosis is the pulmonary TB that affects the lungs and is contagious, also called Active TB. But do not be surprised if you hear that the TB bacteria can affect other parts of the body such as the brain, skin, bones, lymph nodes, kidneys, or other body parts. This type of TB is known as Extra-pulmonary TB.

**TB CAN BE CURED IF YOU TAKE THE TB DRUGS CORRECTLY.**

In the absence of enough TB drugs in a person's body during treatment, the TB bacteria slowly changes and become 'stronger'. After a while, some of the TB drugs have no effect anymore on the changed TB bacteria that now is called resistant TB. In other words, resistance occurs when the bacteria in the body learns how to avoid the effects of the drugs commonly used to treat TB. The types of resistant TB can be the Multi-Drug Resistant TB (MDR TB) and Extremely Drug Resistant TB (XDR TB).

TB can be classified by the treatment that the client needs to receive to be cured. The most common one is the DSTB, it stands for Drug-Sensitive TB and it has a treatment that is shorter.

Some TB bacteria will require a longer time to be cured, like the MDR TB and the XDR TB, both require a longer treatment. MDR-TB is resistant to TWO common TB drugs and XDR-TB is resistant to FOUR or more drugs.
1 What is Tuberculosis?

Brain
Lymph nodes
pulmonary
kidneys
Skin
Bones
DSTB
2. What are the symptoms of TB?

It is important to pay attention to the most common TB symptoms that you need to identify if they appear and persist for more than 2 weeks:

- Fever
- Weight loss
- Night sweats
- Loss of appetite
- Being tired all the time

In case of pulmonary TB, the person can have signs such as: chest pain, trouble breathing and coughing up blood. These also will persist for more than 2 weeks. Other symptoms can be related to the specific location of the infection in the body.

The following symptoms are best referred to a clinician if they persist: **FEVER, NIGHT SWEATS, AND UNEXPLAINED WEIGHT LOSS**

(OR FAILURE TO GAIN WEIGHT IN CHILDREN UNDER 5)
What are the symptoms of TB?

Common TB symptoms

Pulmonary TB symptoms
3. How is TB transmitted and prevented?

Transmission: DSTB, MDRTB and XDRTB are spread the same way. TB bacteria spreads through the air, when a person with pulmonary TB (TB from the lungs) coughs, sneezes, speaks, spits or sings and another person breathes in the small particles in the air (not the big ones that fall on the floors or the tables, but the ones that stay in the air). TB is not spread through shaking hands, sharing dishes, or using the same utensils, bedding or clothing.

Prevention: Many people are exposed to TB every day. It is almost impossible to prevent exposure, but there are things you can do to reduce your chances of getting TB or spreading TB if you are infected.

- Always open the windows when traveling by bus (kombi).
- Open the windows and ventilate your house.
- Sleep in a well-ventilated place, preferably not sharing a room with other family members while you are still infectious.
- If you have a cough you should always, cover your mouth while you cough either with a cloth, a tissue or the inside of your elbow especially when wearing long sleeves.
- Avoid crowded places when you are still infectious, e.g. church and meetings/gatherings inside enclosed spaces.
How is TB transmitted and prevented?

TB can be transmitted through:

- Close contact with an infected person
- Respiratory droplets from a cough or sneeze

TB can be prevented through:

- Good hygiene practices
- Effective patient treatment
- Vaccination
- Early detection and treatment
4. How to produce sputum?

Your clinician wants to collect some of the sputum that you cough up from your lungs. The laboratory will test the sputum for tuberculosis (TB) bacteria. Checking your sputum is the best way to find out if the medicine is working. You will be asked to come for clinical check-ups and sputum samples in order for you to become aware of your health throughout the treatment, whether you have DSTB, DRTB or XDRTB. We will see if TB is still visible in the sputum; if so, it means you are still infectious. The test will say if the sputum result is positive (when the TB bacteria is visible) or negative (when the TB bacteria is no longer visible). The result will help you and the clinicians know how you are responding to the treatment and decide on the treatment follow up (prescription and duration).

Your clinician will give you a sputum bottle, for collecting your sputum. Follow these steps carefully:

- The sputum bottle is sterilized. Do not open it until you are ready to use it.
- Choose an open space that is far from other people, and if possible, go outside before collecting the sputum sample.
- Do it as soon as you wake up in the morning (before you eat or drink anything).
- Rinse your mouth with water and then spit before producing the sputum sample.
- Breathe deeply through your nose, for two or three times, retaining the air for a few seconds each time.
- Cough hard to expel the sputum.
- Take the sterilized sputum bottle to the mouth and spit out the sample inside of it.
- Must close the sterilized sputum bottle very carefully, to prevent the sputum from spilling.
- It is important that the sputum comes from the lungs; this is the one that will help with the diagnosis.
How to produce sputum?
5. Drug-sensitive TB treatment

There are a number of medicines that combined are used to fight TB. The fight is not easy: each medicine is not strong enough on its own, so we need a combination of at least 4 medicines to fight the TB. For the treatment of DSTB, they are often put together in one tablet (a fixed dose combination or FDC).

The treatment takes at least 6 months for one to be cured. Most of the time and if you’re taking well your treatment, during this period the sputum result changes from positive to negative. We will check for the change in the sputum results to best decide about the treatment duration and the drugs we are using.

The recommended TB protocol for most clients consists of the following:

- **Intensive phase:** 4 oral TB medicines are taken for 2 months. They are often combined in one FDC tablets, but you need to take several of these FDC pills each day (the exact number depends on your weight).
- **Continuation phase:** 2 oral TB medicines are continued for an additional 4 months, or more in special cases.

Regardless of the duration of the treatment, whether 6 months or more, the TB medicines need to be taken every day.

Special cases: if you have TB of the bones or of the brain, your clinician can give you a longer treatment, up to 9 months.

One of the medicines (Rifampicin) needs to be taken on an empty stomach, since its absorption is reduced by food. An empty stomach means that medicines should be taken at least 30 minutes before a meal or 2 hours after. Water is allowed.

It is necessary to analyse the sputum (or other specimen) a few times, to see how the treatment is going and sometimes blood tests, according to the request of the clinician. These tests are used to confirm that the body is responding well to treatment. Following the TB treatment well allows the body’s defence system to grow stronger again.
Drug-sensitive TB treatment
6. What are the possible side effects of DSTB treatment?

Some people suffer from side effects of TB treatment, especially at the beginning of the treatment. It is not guaranteed that you will experience side effects, but in case you do, you need to be informed and able to identify them in order to report to your clinician.

Side effects that are commonly experienced but without serious consequences include fatigue and nausea. These usually improve with time. If they do not improve with time, then you will need to see the clinician before your next scheduled appointment.

Rifampicin causes red discoloration of urine, stool and tears, but this only lasts for the duration of the treatment and is not serious, so you should not worry.

Other side effects can be serious:
- Yellow skin and/or eyes
- Severe abdominal pain
- Skin rash all over the body, especially if itchy or blisters
- Visual changes
- Aches or tingling in your feet or hands

If you have any of these serious side effects, you should not abandon treatment, but come to see your clinician straight away or tell your treatment supporter. It is best to reduce your alcohol intake during the entire period that you are taking your TB drugs. Heavy alcohol consumption can have a bad effect on your liver and your nerves, leading to poorer health outcomes.
6 What are the possible side effects of DSTB treatment?

Common Side Effects

Side Effects you should report at the facility as soon as you feel any of these symptoms
7. What is Multi Drug Resistant TB

Resistance to the TB drugs occurs when the bacteria in your body learns how to avoid the effects of the drugs commonly used to treat TB. The bacteria gets used to the drugs used in DSTB treatment and learns how to escape from being eliminated by the drugs. This occurs when:

(a) You stop and re-start the TB drugs, or
(b) You’re not taking the drug in the right time or in the right dosage, or
(c) You got infected by TB bacteria that were already resistant.

MDRTB is caused by bacteria that are resistant to the two most potent TB drugs (Isoniazid and Rifampicin). The resistance can be diagnosed and confirmed by laboratory analysis of lung sputum (or other specimen), where the presence of TB bacteria is identified. This analysis tells you whether the bacteria are, whether it is DSTB, MDRTB or XDR-TB.
What is Multi Drug Resistant TB
8. Multi Drug resistant TB treatment

There are different types of TB. The MDRTB is more complex to treat; you need to take drugs during longer period to eliminate the resistant germs.

MDR TB treatment takes from 9 months to 2 years, with an intensive and a continuation phase:

• **During the intensive phase**, you will receive daily injections. At the same time, you will get a number of pills to take every day.

• **During the continuation phase**, you may stop the injection and you will continue with at least 4 to 5 different types of pills every day (depending on your regimen, some can be taken for the duration of the whole treatment). Most of the MDR-TB drugs can be taken with food.

Some clients may have to be hospitalized during the treatment initiation because they are too ill to come to the clinic each day or during their whole treatment if they later develop a serious side effect. The length of stay in hospital will depend on a number of factors, and will be determined by the teams of HCWs.

If you are HIV positive and on ART, you should continue to take your ART. It’s possible that your HIV treatment will be slightly changed during the initiation phase of your DR TB treatment, to make sure both treatments work well together.

If you are HIV positive and not on ART yet, you will start ART after (MDR) TB treatment initiation. Taking treatment for both TB and HIV at the same time is not a problem, in fact it is important to treat both in order to give your body’s defence system a boost, and have a better recovery.
Multi Drug resistant TB treatment

Intensive phase

Continuation phase
9. What are the possible side effects of MDRTB treatment?

- It is not guaranteed that you will experience side effects, but in case you do, you need to be informed and able to identify them in order to report to your clinician.

- **Side effects commonly experienced:** some don’t have any serious consequences, these include fatigue and nausea. These usually improve with time. If they do not improve with time, then you will need to see the clinician before your next scheduled appointment.

- **Other side effects can be serious, such as:** persistent diarrhoea or loss of appetite, severe abdominal pain, blurred or changed vision, ringing in the ears or hearing loss, tingling or numbness, aching joints, dizziness, yellowed skin or yellow eyes, or skin rashes. Additionally, disruptions in thinking or emotional states, such as sleeping problems, difficulties to think, anxiety, loss of interest in daily activities, or even hallucinations (seeing or hearing things others do not).

- If you have any of these serious side effects, you should not abandon treatment, but consult your clinician or talk to your treatment supporter.
What are the possible side effects of MDRTB treatment?

Common side effects

Side Effects you should report at the facility as soon as you feel any of these symptoms
10. What is Extremely Drug resistant TB?

XDR TB stands for Extremely Drug Resistant TB. Clients diagnosed with XDRTB are, MDRTB clients with TB bacteria that is also resistant to many other drugs like injectable ones (Kanamycin, Capreomycin) and other TB drugs (Fluoroquinolone: Levofloxacin, Moxifloxacin). The XDRTB is much more complex to treat. But there are new drugs which are good and can treat XDRTB. XDRTB is a more severe form because of the increased number of drugs to which it is resistant to treatment. The same treatment taken for TB previously will no longer work to eliminate XDRTB; a much stronger or complicated regimen is required to have a chance to overcome the more resistant bacteria. You will need the same monitoring test that all clients on MDR-TB treatment need. In addition, you will need extra heart monitoring and extra blood tests to measure the functioning of your body, something called liver function and electrolyte balance that influence your health. Talk to your clinician about the schedule of all your monitoring tests and regular clinical visits.

Your heart will be monitored periodically with a machine called an ECG that checks that the heart rhythm is normal.
What is Extremely Drug resistant TB?
**11. Extremely Drug resistant TB Treatment**

XDRTB needs more efforts to be cured than MDRTB, however, there are new drugs (called Bedaquiline and Delamanid), that can be used. You are being offered these new drugs if:

- Your MDRTB has not responded to the usual treatments, or
- If there are no other effective drugs available to add to your treatment, or
- Because your type of TB is known to respond poorly to the available treatments.

These new drugs have to be given with other drugs in order to work. The treatment varies from client to client, and depends on which drugs the TB bacteria are resistant to. The new drugs are given orally, but they could need other drugs to be given with them, and these other drugs could be injectable (buttocks muscle) or even in the vein.

You will take *Bedaquiline and/or Delamanid* for 6 months, however, you will need to continue with other drugs for some time.  

- **How you will need to take Bedaquiline (100 mgs each):**
  - **Week 1 to 2:** you will take 4 tablets, once a day, for 7 days a week (every day).
  - **Week 3 to 24:** you will take 2 tablets, once a day, 3 times a week.

  For example, you may take Bedaquiline on Monday, Wednesday, and Friday. But it has to be every week, for a total of 5 and a half months.

- **How you will need to take Delamanid (50 mgs each):**
  - **Week 1 to 24:** you will take 2 tablets, twice a day, 1 in the morning and 1 in the evening, 7 days a week, every day for 24 weeks. The tablets should be taken during or just after a meal.

  This means that you need to take Bedaquiline and/or Delamanid for a total of 24 weeks (6 months).

- Always take Bedaquiline and/or Delamanid with a light meal (not heavy in fat) and swallow the tablets with water.

- There will be other TB treatment that will require you to take medicines for more than 24 weeks, and these are taken for a total of 20 (twenty) months at least.

- The standard recommendations to stop the injectable drugs in MDRTB clients after 8 months do not apply.

- The length of use of injectable drugs depends on the number of effective drugs in the regimen. Some patients will continue injectable drugs for the entire period of the treatment if there are not enough effective drugs left in their regimen. If the regimen has sufficiently effective drugs, injectable drugs can be stopped after 6 months if sputum result is negative.

*Because the treatment combination depends on each patient, you will adapt the message to the specific regimen prescribed to the patient. Whether Bedaquiline, or Delamanid, or both new drugs.*
Extremely Drug resistant TB Treatment
12. Before you take Bedaquiline or Delamanid, tell your health care provider if:

These are important aspects that need to be known before you start treatment, in order to be sure that you receive treatment that is appropriate to your physical conditions.

- Are you taking any prescription and non-prescription medicines, vitamins, traditional medicine and herbal supplements?
- Have you ever had a strange heart rhythm or other heart problems?
- Is there anyone in your family that has or has had a diagnosed heart problem called congenital long QT syndrome?
- Do you have liver or kidney problems or any other medical conditions, including HIV infection?

Specific to those prescribed with Bedaquiline:

- Are you pregnant or plan to become pregnant? It is not known if Bedaquiline will harm your unborn baby.
- Are you breastfeeding or planning to breastfeed? It is not known if Bedaquiline passes into breast milk. You and your health care provider should decide if you will take Bedaquiline or breastfeed.
Before you take Bedaquiline or Delamanid, tell your health care provider if
13. What are the possible side effects of Bedaquiline and/or Delamanid?

Since this/these (Bedaquiline and Delamanid) is/are new drug/s, there could be unknown risks and side effects.

It is not guaranteed that you will experience side effects, but in case you do, you need to be informed and able to identify them in order to report to your clinician.

Side effects for Bedaquiline: Inform your clinician if you present with a fast or irregular heartbeat (called palpitations), chest pains, fainting or near fainting, yellow skin or abdominal pain.

Side effects for both Bedaquiline and Delamanid:

- Serious heart rhythm changes: Tell your health care provider right away if you have a change in your heartbeat (a fast or irregular heartbeat), or if you faint.

- You will also undergo monitoring with an electrocardiogram (ECG) while on the new drugs to check for possible side effects affecting the heart.

- Liver problems (hepatotoxicity): Problems with your liver can show up in many ways. Tell your clinician if you have symptoms such as nausea or vomiting, stomach pain, fever, weakness, itching, unusual tiredness, loss of appetite, light coloured bowel movements, dark coloured urine, yellowing of your skin, or yellowing of the white of your eyes.
What are the possible side effects of Bedaquiline and/or Delamanid?
14. HIV co-infected patients

TB is the most common serious opportunistic infection among people living with HIV/AIDS (PLHIV).

HIV attacks the “soldiers” (CD4 cells) of the immune system that protect the body from infection. As the immune system of PLHIV is weak, TB infection much more easily develops into active TB disease in the body and the person gets sick.

Since TB is common in PLHIV, it is important to do an HIV test in all those having either drug-sensitive or drug-resistant TB (Counsellor: propose an HIV test if status still unknown).

If you are HIV positive and you are on ART, you should not stop taking it. It is possible that your HIV treatment may be changed slightly by the clinician at the beginning of the treatment to make sure that both treatments work well together.

It is important to continue ARV treatment.

If you are HIV positive, but not on ART, you will start ART within 2 to 4 weeks after the start of treatment for drug resistant tuberculosis.

It is extremely important to continue taking your ARVs, even when you have completed your TB treatment. ART is a lifelong treatment to control the virus in your system.

XDR TB is of special concern for people with HIV infection or other conditions that can weaken the immune system. These people are more likely to develop TB, and have a higher risk of death once they develop TB.

TB can be treated and cured (unlike HIV, which can be treated but not cured).
HIV co-infected patients

Life long Antiretroviral Treatment

Complete the TB treatment
15. Adherence to Treatment Recommendations

- Adhering to the TB treatment helps to eliminate the risk of developing a more resistant form of TB.
- Do not get Pregnant during the treatment. If you are pregnant, notify the HCW so that the treatment can be adapted. I will refer you to the nurse to talk to you about Family planning/Contraception services available here.
- Maintain cough etiquette to prevent infecting others with resistant TB. If possible, sleep alone to avoid exposing family and other people who live with you.
- Bring family and people who live with you to do the TB screening and test. This way you can protect those you love.
- Take TB drugs as instructed by the clinician, completing the entire treatment cycle, without missing a single dose.
- Integrate the TB treatment in your daily routine,
- This medicine works much more effectively if taken before breakfast,
- Look for ways to remember to take pills such as:
  - Alarm (clock / cell)
  - Favourite Radio or TV Show,
  - Before the time you normally have your meals,
  - Before or after your prayer hours,
  - When you leave for work / school etc.
- Take your tablets with you when you know you will be away from home (eg, vacation, work, parties, etc.) and plan for the full duration of your absence from home,
- You should tell the health unit, in case you need to travel for some time,
- Talk to our staff about cutting or dramatically reducing your cigarette use, or alcohol intake, more specifically if you have MDRTB/XDRTB and are taking Bedaquiline,
- Use cough hygiene at any time and place, like home and health facilities – protect those around you from airborne TB as it is possible to infect others with the same Extremely-Drug Resistant form of TB which is rather long and hard to treat.
Adherence to Treatment Recommendations
16. Close Contacts Tracing

“Close contacts” of TB patients are defined as people living in the same household, or spending many hours a day together in the same indoor space.

For DSTB, contact tracing includes the treatment of active or latent (hidden) TB. For MDR-TB, however, the priority in most countries is on finding and treating contacts that have symptoms of what could be drug-resistant TB, which has more serious health effects, is more complicated to treat, and takes longer.

“Contact tracing” means that we will ask you to bring his close contacts to get tested for TB, so that the transmission of TB strains can be prevented.

Contact tracing is a really important way to diagnose people early so they can get treatment earlier.

It is also a way to identify all those that are healthy but at risk for TB and need preventive treatment. These are especially children under 5 and HIV-positive people.

Remember that pulmonary TB bacteria are transmitted very easily from one person to another. Because of this, it is really important for someone who has TB to think about everyone they come in contact with often, especially in their home and work environment.
This flipchart is a complementary educational tool to be used during counselling and education session to TB and TB/HIV co-infected (who have started or not the antiretroviral treatment) patients diagnosed with active (TB) disease, be it DSTB, DRTB or XDR-TB.

To be able to use this tool during the counselling session, the healthcare provider must be trained on the messages mentioned in the flipchart. Must have knowledge and skills necessary to adapt this tool to the different categories of patients affected by TB and HIV in the different stages.

Before starting the session, the healthcare provider should assess the patient's level of understanding and adapt the language used, giving special attention to technical terms. It is important to use clear language, simple, brief, and where necessary, transmit messages in the local language.

This tool is to be used as complementary to the counselling protocols and other IEC materials available at the facility.

The healthcare provider should engage the patient into discussions about previous knowledge about the topics, understanding and interpretation of the images used and capacity to assimilate the main messages. At the end of the session, summarize the key messages.

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References
- [International Tuberculosis and Lung Health Society] (2015), The ABC of TB: A simplified guide to the management of TB and HIV/AIDS.
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