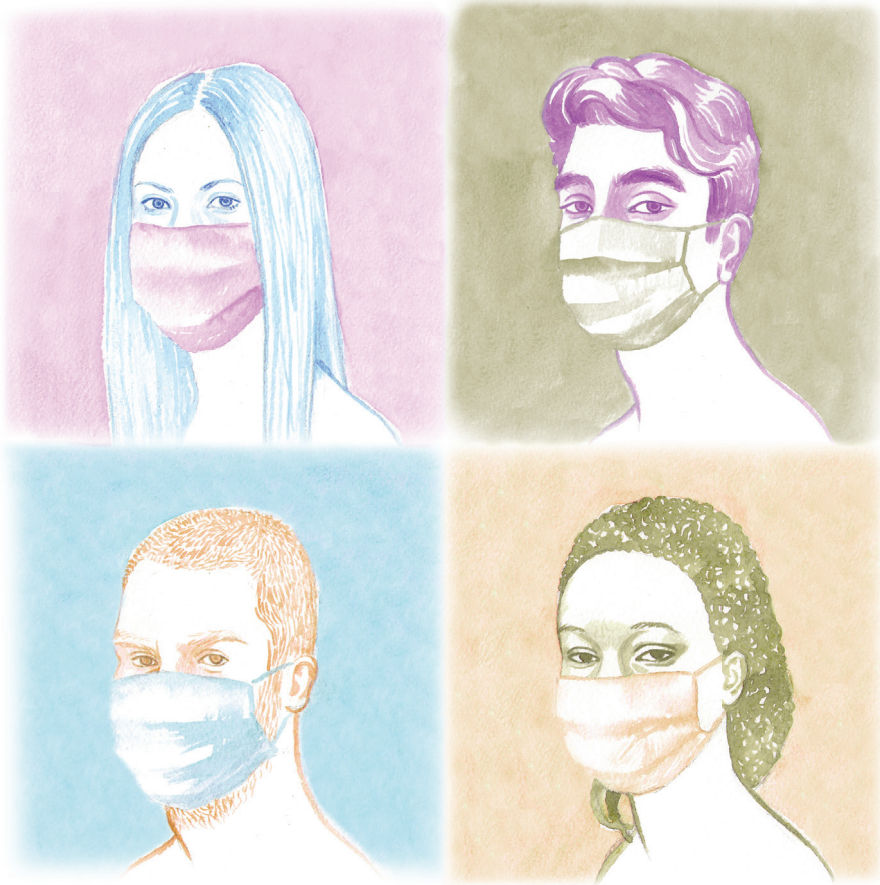


Capacity-building of affected communities
for accelerated response to drug-resistant tuberculosis
in the South-East Asia Region

Training modules







Capacity-building of affected communities for accelerated response to drug-resistant tuberculosis in the South-East Asia Region

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**World Health
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REGIONAL OFFICE FOR

South-East Asia

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Abbreviations

ADR	adverse drug reaction
CBNAAT	cartridge-based nucleic acid amplification test
CSO	civil society organization
DR-TB	drug-resistant tuberculosis
DS-TB	drug-sensitive tuberculosis
DST	drug susceptibility testing
E (or EMB)	ethambutol
EP-TB	extrapulmonary TB tuberculosis
GDF	Global (TB) Drugs Facility
H (or INH)	isoniazid
HIV	human immunodeficiency virus
IGRA	interferon gamma release assay
IPT	isoniazid preventive therapy
LAMP	loop-mediated isothermal amplification
LF-LAM	lateral flow lipoarabinomannan
LPA	line probe assay
LTBI	latent TB infection
MDR-TB	multidrug-resistant tuberculosis
MGIT	mycobacteria growth indicator tube
NGO	nongovernmental organization
NTP	National Tuberculosis Programme
Z (or PZA)	pyrazinamide
PLHIV	people living with HIV
PTB	pulmonary tuberculosis
R (or RIF)	rifampicin
RR-TB	rifampicin-resistant tuberculosis
SEA	South-East Asia
TAG	Treatment Action Group
TB	tuberculosis
TST	tuberculin skin test
WHO	World Health Organization
XDR-TB	extensively drug-resistant tuberculosis

Background

The burden of tuberculosis (TB) remains disproportionately high in the WHO South-East Asia (SEA) Region, which is home to 26% of the world's population. In 2017, an estimated 4.4 million people fell ill with TB in the SEA Region, representing 44% of the total TB incidence globally¹.

The Region experiences relatively low levels (2.7%; range 1.8–3.6%) of multidrug-resistant (MDR) and rifampicin-resistant (RR) forms of TB among newly detected cases, and 13% (range 4.3–25%) among previously treated cases. However, given the large number of TB cases in the Region, this translates into 192 000 estimated MDR/RR-TB cases emerging in 2017, of which less than 46 000 were enrolled on treatment. In 2017, the Region accounted for more than 30% of the global estimated MDR/RR-TB cases among notified pulmonary TB cases worldwide. Six out of the 30 high TB- and MDR-TB-burden countries are in the SEA Region — Bangladesh, Democratic People's Republic of Korea, India, Indonesia, Myanmar and Thailand.

The rise of drug-resistant TB (DR-TB), particularly MDR-TB and extensively drug-resistant tuberculosis (XDR-TB) is a huge challenge, specifically in the six high-burden countries.

It is now finding acceptance that closing the gap on treatment for all, and improving prevention across the Region would require extensive community involvement.^{2,3} Community involvement will require building the capacity of, and empowering community leaders and workers. This is in contrast to the decades-old strategy of a top-down push. Community members will need to be able to communicate about all forms of TB, a stigmatized disease; enable access to those who need diagnosis and treatment; contribute to

planning of services; and ensure their appropriate outreach for all those who need them.

Affected communities and community-based organizations can play a crucial role and work with national programmes in ensuring a person-centred and human rights-based approach in the management of DR-TB in the SEA countries, provided their capacity is built with appropriate training to understand the science and management of DR-TB. Community empowerment ensures meaningful participation in the TB response, leading to identifying missing persons with TB symptoms, reducing loss of time in diagnosis by the private sector or traditional healers as well as demanding care and access to means for adhering to treatment as a right. TB response has often used nongovernmental organizations (NGOs) only for delivery mechanisms of some planned programming, but has not invested in communities themselves. Meanwhile, communities have also felt the ill effects of TB stigma, and their engagement will require more than a wage activity. Empowerment and motivation requires long-term investment and engagement with opportunity for feedback and change being built into the approach.

It is in this context that these modules for capacity building of the affected community have been developed. While World Health Organization (WHO) and other stakeholders will take up systemic policy change within national TB programming, this exercise will focus on empowering communities, building their capacity to be part of the TB response and translating the policy into action at the ground level.

Thematic areas

The thematic areas covered by the four modules are described below.

Module 1: Treatment literacy

This module covers the basics of TB and DR-TB including prevention, stigma, TB infection control and community level prevention methodologies. The module will bring the community representatives up to speed on treatment regimens and prevention methodologies and enable them to ascertain the appropriateness of treatment from the service provider on behalf of persons affected by TB.

Module 2: Advocacy

The advocacy module includes an overview of the legislative and governmental processes, working in partnerships, working with decision-makers and communication for advocacy, including use of social media. This module will equip community representatives to advocate with local TB service providers, area legislators and stakeholders to raise issues to a higher level and ensure the rights of people affected by TB.

Module 3: Barefoot counselling

This module covers basic theories, skills to create counselling relationships, behavioural activation and motivational techniques. It will equip the trainee to counsel persons affected by TB, support them for overcoming adverse drug reactions (ADRs) and TB drug-induced episodes and refer them for proper care before the episodes become serious.

Module 4: Community feedback systems

This module includes sessions on community engagement in employing community feedback systems, examples of various models of community feedback and monitoring employed in

global contexts and contextualizing appropriate models to develop community-centred action plans. It will enable community representatives to identify issues that need to be prioritized, highlight blockages in access and service availability and set up an appropriate feedback mechanism.

The design and structure of these modules offer flexibility for adaptation to various contexts; and as a dynamic document, new and evolving developments in the area of DR-TB may be incorporated to ensure that updated information is made available to the participants. The data on burden of TB and MDR-TB is timed and mostly regional in nature. This can be updated as and when new information is available.

The modules can be used in any sequence considered appropriate for the intended audience. They may also be used selectively if the need is so felt.

Training objectives

The training objectives are to:

- understand DR-TB and its management from a person-centred and human rights-based approach;
- increase knowledge about the science of DR-TB and existing tools, i.e. rapid diagnostics, drugs and newer regimens, ADRs;
- understand basic principles of counselling and support; and
- provide tools to community members that will enable them to partner with institutional systems to make TB response more rights-based and person-centred.

Expected outcomes

Participants will be well equipped with the knowledge and skills to mobilize, advocate and partner with programmes and stakeholders for making the TB response person-centred and rights-based. Participants would also be able to rapidly mobilize response when there is an urgent need and support those who need help using peer-based approaches.

Participants/target audience

TB affected communities and TB survivors are the core around which the modules have been developed.

The training modules have been developed to build their capacities and empower them to be valuable partners in the TB and DR-TB response.

The module development process is cognizant of the fact that TB survivors and affected communities come from a range of economic and social backgrounds.

The modules have intentionally been kept generic in order to facilitate adaptation to suit different cultural and social mores in different countries.

It is envisaged that the facilitators would be experienced trainers having in-depth understanding of working with communities in order to use the modules effectively. However, the facilitators may not necessarily have background TB information that can be gathered from these modules.

How to use this manual

Structure

This manual is organized into four separate modules. The modules are further organized into separate sessions that incrementally develop the thematic areas. Each session follows the given arrangement, although facilitators may choose to adapt the sequences and timings as per the requirements of training.

The sessions have been described under headings as given herein.

Duration: Approximate amount of time required for the session.

Training aids/materials required: A suggested list of materials required during the training including audio-visual equipment, stationery, handouts, reference materials, pre- and post-training assessment forms and feedback forms.

Learning objective/s: Describes the desired learning objective/s to be achieved by participants by the end of the session.

Methodology: Describes the step-by-step participatory methods that will be employed to engage participants in the learning process.

Facilitator's note/s: Notes to provide the facilitator with useful information on the topic or tips for facilitating an activity.

Handouts: Print material for participants to be distributed before or during the sessions.

Additional resources for facilitators: Detailed information related to topics covered in the session.

Reference list/suggested reading: List of references and suggested reading related to the specific thematic area.

Pre- and post-training assessment

Participants are required to complete a pre-workshop self-assessment questionnaire at the beginning. A post-workshop questionnaire will also need to be completed when all the sessions have been delivered. These will be analysed to assess the progress of the participants through the process of participatory learning.

Feedback forms

The participants will be given a very brief and simple feedback form at the end of each day's sessions. This feedback will help the team of facilitators and organizers to respond to their concerns, as well as to help plan the subsequent sessions appropriately.

The team of facilitators will be required to have an overview of all the topics covered in these modules (besides the specific sessions that they will be facilitating) before commencement of the training, in order to ensure a comprehensive understanding of the scope of each topic and its relevance to the process.

Prior to the training, facilitators will need to discuss with the organizers how they will use these modules to develop the knowledge and capacity of the participants and adapt them to be more culturally and geographically relevant. The sessions are designed to engage the participants in a participatory learning process based on adult learning principles.

Facilitators are encouraged to:

- identify participants' needs and expectations from the course and what is important to them;
- provide real-life situations and emphasize the application of learning to real problems;

- undertake activities that require active participation of participants;
- establish an atmosphere of respect and understanding of differences;
- provide opportunities for sharing information;
- discuss and analyse participants' experiences;
- engage participants as valued resources and encourage them to share their experiences.

Along with each session, detailed notes and additional information are provided as “facilitator’s guide”. This is to help equip the facilitator with adequate information, facts and figures that may seem technical but are important. The facilitator or trainer can decide on the level and detail of the workshop depending on the need and expectation of participants.

Introductory session

Duration 1 h

Training aids/materials required

- LCD projector and laptop
- Cards/Post-its
- Flip chart/whiteboard
- Marker pens
- Pre-test assessment questionnaire

Objectives

To introduce the participants and facilitators, record expectations of participants and provide an overview of the workshop sessions

Methodology

Step 1: Introductions (10 mins)

- Welcome the participants and conduct a round of introductions
- Conduct an icebreaker exercise to help participants to get to know each other better (see Annex 3: Icebreakers and energizers).

Step 2: Listing expectations (10 mins)

- Give out cards/Post-it note sheets to participants, asking them to write their expectations from the session
- Post these cards on the board and read the main expectations aloud
- Briefly discuss the expectations that will be addressed during the workshop, giving reasons for those, if any, that are not going to be taken up.

Step 3: Setting ground rules (5 mins)

- Ask participants for suggestions to set ground rules for the duration of the workshop. Note these suggestions on a flip chart.
- These ground rules may be referred to in subsequent sessions, especially in the case of new participants or facilitators.

Facilitator's notes

Ground-rules could include the following:

- Agree to disagree — everyone has the right to his or her opinion
- Start and finish on time
- Turn off cell phones or put them on silent mode
- Check email and text messages only during breaks
- Provide constructive and friendly feedback.

Step 4: Objectives and overview of the workshop (10 mins)

With the aid of a PowerPoint presentation (optional), explain the specific objectives of the workshop and the topics to be covered in each session.

Step 5: Pre-test assessment questionnaire (25 min)

Request participants to complete a pre-workshop self-assessment questionnaire and inform them that a similar post-workshop assessment will also be done after the last session in this series.

The facilitator explains that this simple assessment is not a test, but an exercise that will be helpful in assessing the progressive learning of the participants and also aid in measuring the effectiveness of the sessions delivered.

Comments and suggestions from participants are invited before closing the session.

MODULE 1



TB/DR-TB Treatment Literacy



Session 1.1

Basics of TB

Duration 2 h

Learning objectives

By the end of this session, participants will be able to:

- describe what is TB, how it is transmitted, the diagnosis and treatment
- describe the barriers to access in the pathway to cure
- identify the barriers and how they can be advocacy priorities.

Training aids/materials required

- LCD projector and laptop
- Flipchart/whiteboard
- Coloured whiteboard markers/pens
- Chart paper and coloured pens

Methodology

Step 1: TB game – “Who wants to be a millionaire” (30 mins)

As the participants are all TB/MDR-TB survivors or affected communities, the session will draw information from the group to ascertain their understanding of the basics of TB.

Facilitator’s notes

- Prepare a set of 8–10 questions on simple facts about TB in advance.
- Audiovisual aids may be used to make the game more interesting.

Step 2: Build on this knowledge (25 mins)

Discuss the basics of TB with the aid of PowerPoint slides.



Facilitator's note

Please ensure that the slides include the information provided in the section on “Additional resources for facilitators”.

Step 3: “Pathway to cure” exercise to map out barriers (1 h)

Preparation: Paste 7 chart papers side by side on the walls of the training hall for each of the following areas:

- Developing symptoms
 - Seeking care
 - Getting a diagnosis
 - Starting treatment
 - Completing treatment
 - Getting cured
 - Getting back on track
-
- Draw a horizontal line along the middle of each chart paper, dividing them into two sections each. The upper sections represent the barriers faced at the health system level (public or private), while the lower sections represent barriers at the individual, family or community level. Participants may need to be informed that a long lead time at a particular point of care should also be considered as a barrier, even if this is considered normal or usual by people delivering the care.
 - **Group work:** Divide participants into groups and provide them with an area from the list above. Ask them to discuss the kind of barriers faced along the pathway to cure and to identify specific points. Each point is noted on separate Post-it notes.
 - **Identify barriers:** Ask group members to gather around the chart papers posted on the walls and ask each group to decide where each of the points should be placed on the appropriate sections of the chart paper. Participants could also identify commonality in barriers and which of them are more frequent across the group.

Step 4: Summarize (5 mins)

By thinking and analysing the challenges in the health system as also in the community setting, it is possible to think about the experience in a comprehensive way that reflects the whole experience of TB and the need to be supported by both the health system and the community.

Facilitator's note

Please ensure that the chart papers remain on the wall or are within easy access for the session on advocacy on Day 2.

Additional resources for facilitators

TB key facts⁴

- TB is one of the top 10 causes of death worldwide.
- In 2017, 10.0 million people developed TB, and 1.6 million died from the disease (including 0.3 million among people with human immunodeficiency virus [HIV]) globally. Over 95% of TB deaths occur in low- and middle-income countries.
- In 2017, an estimated 1 million children became ill with TB and 250 000 children died of TB (including children with HIV-associated TB).
- TB is a leading killer of HIV-positive people. In 2017, there were an estimated 300 000 deaths among HIV-TB coinfecting individuals.
- MDR-TB remains a public health crisis and a health security threat. WHO estimates that there were 558 000 new cases with resistance to rifampicin (the most effective first-line drug), of which 82% had MDR-TB. Globally, TB incidence is falling at about 2% per year. This needs to accelerate to a 4–5% annual decline to reach the 2020 milestones of the End TB Strategy.
- Ending the TB epidemic by 2030 is among the health targets of the Sustainable Development Goals.



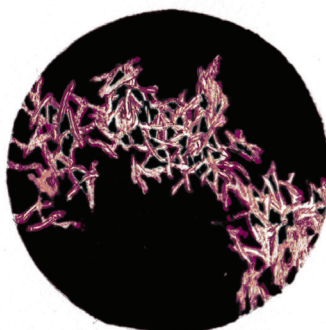
The burden of TB remains disproportionately high in the WHO SEA Region, home to 26% of the world's population. In 2017, an estimated 4.4 million people fell ill with TB in the SEA Region, representing 44% of the total TB incidence globally.

The Region experiences relatively low levels (2.7%; range 1.8–3.6%) of MDR-TB and RR-TB among newly detected cases and 13% (range 4.3–25%) among previously treated cases. However, given the large number of TB cases in the Region, this translates into 192 000 estimated MDR/RR-TB cases emerging in 2017 out of which less than 46 000 were enrolled. In 2017, the Region accounted for more than 30% of the global estimated MDR/RR-TB cases among notified pulmonary TB cases worldwide. Six out of the 30 high TB and MDR-TB burden countries are in the SEA Region: Bangladesh, Democratic People's Republic of Korea, India, Indonesia, Myanmar and Thailand.

What causes TB?

TB is caused by bacteria (*Mycobacterium tuberculosis*) that most often affects the lungs. However, TB can infect any part of the body except the hair and nails. TB is curable and preventable.

TB is spread from person to person through the air. When people with lung TB cough, sneeze or spit, they propel the TB germs into the air. A person needs to inhale only a few of these germs to become infected.



About one quarter of the world's population has latent TB, which means people who have been infected by TB bacteria but are not

yet ill with the disease and may not transmit the disease. People infected with TB bacteria have a 5–15% lifetime risk of falling ill with TB. However, persons with compromised immune systems, such as people living with HIV (PLHIV), malnutrition or diabetes, or people who use tobacco, have a much higher risk of falling ill.

When a person develops active TB disease, the symptoms (such as cough, fever, night sweats or weight loss) may be mild and go unnoticed for many months. This can lead to delays in seeking care, and results in transmission of the bacteria to others. People with active TB can infect 10–15 other people through close contact over the course of a year. Without proper treatment, 45% of HIV-negative people with TB on average and nearly all HIV-positive people with TB will die within 2 years.

Who is most at risk?

TB mostly affects adults in their most productive years. However, all age groups are at risk. Over 95% of cases and deaths occur in developing countries.

People who are infected with HIV are 20 to 30 times more likely to develop active TB (see section on TB and HIV below). The risk of active TB is also greater in persons suffering from other conditions that impair the immune system.

One million children (0–14 years of age) fell ill with TB, and 250 000 children (including children with HIV-associated TB) died from the disease in 2017.

Tobacco use greatly increases the risk of TB disease and death. About 8% of TB cases worldwide are attributable to smoking.



Global impact of TB

TB occurs in every part of the world. In 2017, the largest number of new TB cases occurred in Asia with 45% of new cases, followed by Africa with 25% of new cases.

In 2016, 87% of new TB cases occurred in the 30 high TB burden countries. Seven countries accounted for 64% of the new TB cases: India, Indonesia, China, Philippines, Pakistan, Nigeria and South Africa. Global progress depends on advances in TB prevention and care in these countries.

Types of TB

Based on the anatomical location, there are two types of TB:

Pulmonary TB: Pulmonary TB refers to a disease situation involving the lung parenchyma. Miliary tuberculosis (widespread disease) is classified as pulmonary TB because there are lesions in the lungs. A patient with both pulmonary and extrapulmonary TB should be classified as a case of pulmonary TB.

Extrapulmonary TB: Extrapulmonary TB refers to a disease situation involving organs other than the lungs, e.g. pleura, lymph nodes, abdomen, genitourinary tract, skin, joints and bones and meninges. Extrapulmonary TB cases could be either bacteriologically confirmed, i.e. evidence of harbouring bacteria is available, or clinically diagnosed, i.e. evidence of harbouring bacteria is not available. Identification of *M. tuberculosis* is the basis of bacteriological confirmation of extrapulmonary TB.

Symptoms

Common symptoms of active lung TB are cough with sputum and blood at times, chest pains, weakness, weight loss, fever and night sweats. However, TB can also infect other parts of the body. In such cases, symptoms may be just a low-grade fever, weight loss and/or symptoms related to the affected body part. Sometimes TB may appear as a “cold swelling” due to enlargement of lymph nodes.

Diagnosis

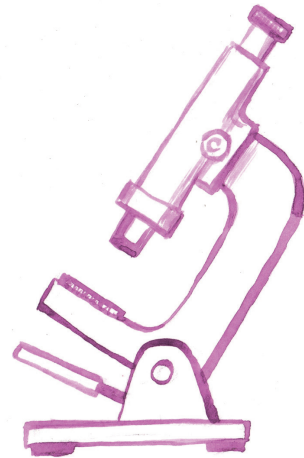
One of the biggest challenges to TB response today is getting an early and accurate diagnosis. People with symptoms of TB who are not diagnosed and put on treatment continue to transmit the infection in their community and families with a possibility of developing drug resistance if inappropriately treated.

Early and accurate diagnosis is essential to reducing TB transmission, sickness and death.

Diagnostic methods

The different diagnostic methods available today are discussed below.

Smear microscopy: This is a very simple test used by most countries as the first step in diagnosing TB. This involves the examination of sputum under a microscope to identify the TB mycobacteria. The testing takes place over 2–3 days in most settings but is not a very sensitive technique. Microscopy misses around half of the cases and is not good for detecting TB in PLHIV and children, and in cases where the person is unable to produce enough bacteria in the sputum. Microscopy cannot determine if the strains of mycobacterium are resistant to standard first-line drugs or not.



Culture: This test involves the observation for detection of mycobacterial growth during a 6-week incubation period.

Growth on a culture medium in the laboratory is a more sensitive test than microscopy, but precious time in treatment may be lost if the health facility relies on this test for diagnosis. An advanced tool is using liquid culture, which takes 2 weeks and is highly sensitive. However, liquid culture is relatively expensive and the lead-time of 15 days may also not be appropriate for a patient who needs immediate start of treatment.

Liquid culture: The mycobacteria growth indicator tube (MGIT) system uses liquid culture to test if TB bacteria will grow. MGIT results take up to 15 days, but are available much quicker than conventional solid culture, where TB bacteria are grown on a solid surface in a laboratory (in a container called a petri dish) over a long period of time, usually more than 30 days. MGIT must be hosted in a laboratory facility with adequate equipment and trained personnel.

Drug susceptibility testing (DST): DST provides information on which standard first-line drugs the TB bacteria is susceptible to, which is necessary for detecting any form of resistance like mono, poly, multi or extensively drug-resistant TB (M/XDR-TB) and for getting patients on appropriate and effective treatment regimens. This may follow solid or liquid culture and is done by growing the bacteria in the presence of anti-TB drugs at specific concentrations.

GeneXpert/Xpert MTB/RIF Cartridge-based nucleic acid amplification test (CBNAAT): Xpert MTB/RIF is a molecular diagnostic test that can detect TB and resistance to the key first-line TB drug, rifampicin, in just 2 h. Rifampicin resistance is commonly considered a surrogate marker of MDR-TB.⁵ In addition to being faster than traditional smear microscopy, Xpert MTB/RIF can better detect TB in samples from PLHIV and children. While Xpert MTB/RIF may give a faster and more sensitive result, it is relatively more expensive and requires an uninterrupted supply of electricity.

The use of the rapid test Xpert MTB/RIF® has expanded substantially since 2010, when WHO first recommended its use. The test is now recommended by WHO as the initial diagnostic test for all persons with signs and symptoms of TB, if necessary funding can be mobilised by countries.

Summary of diagnostic tests and use

Other commonly used screening tests include symptom screening, tuberculin skin test (TST) and chest X-ray. Clinical symptoms of TB include cough, fever, night sweats, chest pain, weight loss and blood in sputum. Symptom screening is more challenging in patients with extrapulmonary TB. Chest X-rays is a very sensitive tool for lung TB and it is a good screening tool, to identify people who need further test like Genxpert to diagnose TB.

TSTs cannot distinguish between active and latent TB and can be falsely positive in people vaccinated with Bacillus Calmette-Guérin (BCG). They require refrigeration and a TB protein derivative to be injected under the skin. Chest X-rays can be used to rule out or confirm active pulmonary TB in people with positive TST results.

Interferon gamma release assays: Interferon gamma release assays (IGRAs) such as QuantiFERON-TB Gold manufactured by Qiagen, Immuccheck TB Platinum manufactured by Immunoshop and other serological tests are blood-based and measure a person's immune response to TB bacteria. T-cells in someone infected with TB will release interferon-gamma when mixed with protein derivatives of TB.

Both IGRAs and the TST are surrogate markers of *M. tuberculosis* infection, indicating a cellular immune response to recent or remote sensitization with *M. tuberculosis*. Currently, there is no gold standard for the detection of *M. tuberculosis* infection, and neither TST nor IGRAs can distinguish TB infection from active TB disease.



TB in children is particularly difficult to diagnose because of their inability to produce sputum and since the symptoms are often non-specific, e.g. only weight loss. If sputum or another relevant sample is available, Xpert MTB/RIF assay should be used as it is more sensitive than microscopy for diagnosis of mycobacterium.

Drug-resistant TB case finding among extrapulmonary TB patients⁶

Drug-resistant extrapulmonary TB can be detected using Xpert MTB/RIF or conventional culture and DST. In 2013, WHO updated its policy guidance on use of Xpert MTB/RIF, issuing the following recommendations for the use of Xpert MTB/RIF in detection of EPTB:

- Xpert MTB/RIF should be used in preference to conventional microscopy and culture as the initial diagnostic test in testing cerebrospinal fluid specimens from patients presumed to have TB meningitis.
- Xpert MTB/RIF may be used as a replacement test for usual practice (including conventional microscopy, culture, and/or histopathology) for testing of specific nonrespiratory specimens (lymph nodes and other tissues) from patients presumed to have extrapulmonary TB.

Diagnosis of TB in children⁶

It is recommended that Xpert MTB/RIF be used rather than conventional microscopy and culture as the initial diagnostic test in all children suspected of having TB.

Children suspected of having pulmonary TB but with a single Xpert MTB/RIF negative result should undergo further diagnostic testing, and a child with high clinical suspicion for TB should be treated even if an Xpert MTB/RIF result is negative or if the test is not available.

Treatment

TB is a treatable and curable disease. Before starting treatment every attempt should be made to ensure that drug sensitivity tests (DST) are done and Rifampicin resistance is ruled out. If GenXpert is used to diagnose TB, Rifampicin resistance is already available with the result. Otherwise DST should be done either using GenXpert, LPA or MIGIT. Active, drug-susceptible TB disease is treated with a standard 6-month course using four antimicrobial drugs that are provided with information, supervision and support to the patient by a health worker or trained volunteer. Without such support, treatment adherence can be difficult for the patient, leading to spread of the disease. The vast majority of TB cases can be cured when medicines are taken regularly and for the complete prescribed duration.

TB and HIV

PLHIV are 20 to 30 times more likely to develop active TB disease than people without HIV.

HIV and TB form a lethal combination, each speeding the other's progress if not treated. In 2017, about 0.3 million people died of HIV-associated TB. In 2017, about 40% of deaths among HIV-positive people were due to TB. In the same year, there were an estimated 920 000 new cases of TB among people who were HIV-positive globally, 72% of whom were living in Africa.

WHO recommends a 12-component approach of collaborative TB-HIV activities to reduce deaths, including actions for prevention and treatment of infection and disease. Affected people should be at the heart of the TB/HIV response. The delivery of effective integrated TB/HIV quality care should be targeted within holistic systems for health; and under the umbrella of universal health coverage (UHC), ensuring the most vulnerable are reached and no one is left behind.



Session 1.2

Drug-resistant TB

Duration: 1h 30 mins

Learning objectives

By the end of this session participants will be able to describe:

- what is DR-TB, MDR-TB, and XDR-TB
- the treatments available – non-injectable regimen, shorter regimen
- the adherence support and package of care
- peer support.

Training aids/materials required

- LCD projector and laptop
- Flipchart/whiteboard
- Coloured whiteboard markers/pens
- Chart paper and coloured pens
- Copies of Handout 1.2.1 and 1.2.2

Methodology (sequence of the first three steps can be interchanged)

Step 1: Facts about DR-TB (20 mins)

Use PowerPoint slides to convey essential information on DR-TB. Provide participants with Handout 1.2.1.

Step 2: Film screening (20 mins)

Screen an appropriate documentary film such as “Two countries, two choices: India, South Africa and the struggle against multidrug-resistant tuberculosis” by AIDS-Free World.

Step 3: Personal stories and experiences: moderated discussion (25 mins)

Invite participants to share experiences on DR-TB (when the physician told that TB bacillus being harboured cannot be treated with the usual first-line drugs) that they have encountered – what led to suspicion of resistance, how much time it took for the decision to be made, how was the news delivered, was there any counselling by health staff, what was the initial reaction, was there any support offered by health staff or external agencies/ organizations and other personal experiences.

Step 4: Discussion (10 mins)

Ask participants to respond to the message in the film and whether they thought that it appropriately addressed the issues that were faced by the community.

Step 5: Peer support (10 mins)

Discuss ways in which peer support can aid adherence.

Step 6: Summarize (5 mins)

Close the session by summarizing the main points that have been addressed.

Additional resources for facilitators

DR-TB is a form of TB that does not respond to the usual TB drugs. It can be resistant to one or many of the drugs available.

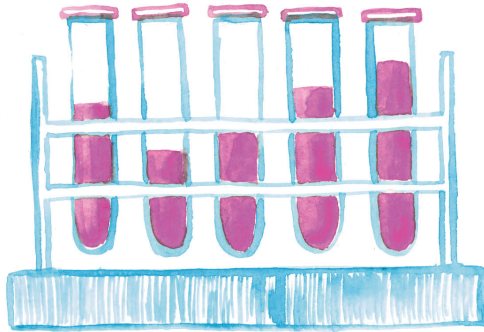
Classification of DR-TB

Classification of DR-TB is as below:^{7,8}

- **Isoniazid-resistant TB.** This refers to *Mycobacterium tuberculosis* strains with resistance to isoniazid and susceptibility to rifampicin confirmed in vitro



- **Monoresistance.** Resistance to one first-line anti-TB drug only
- **Polydrug resistance.** Resistance to more than one first-line anti-TB drug (other than both isoniazid and rifampicin)
- **Multidrug resistance.** Resistance to at least both isoniazid and rifampicin
- **Extensive drug resistance.** Resistance to any fluoroquinolone and to at least one of three second-line injectable drugs (capreomycin, kanamycin and amikacin), in addition to multidrug resistance.
- **Rifampicin resistance.** Resistance to rifampicin detected using phenotypic or genotypic methods, with or without resistance to other anti-TB drugs. It includes any resistance to rifampicin, whether monoresistance, multidrug resistance, polydrug resistance or extensive drug resistance.



More about severe forms of resistance — MDR-TB and XDR-TB

Anti-TB medicines have been used for decades and strains that are resistant to one or more of the medicines have been documented in every country surveyed. Drug resistance emerges when anti-TB medicines are used inappropriately, through incorrect prescription by health-care providers, poor quality drugs, patient suffering from

additional diseases or taking other interacting drugs and patients stopping treatment prematurely or when a person comes in close contact with another person who is suffering from DR-TB.

MDR-TB is a form of TB caused by bacteria that do not respond to both isoniazid and rifampicin, the two most powerful, first-line anti-TB drugs. MDR-TB is treatable and curable using second-line drugs. However, second-line treatment options are limited and require extensive chemotherapy (up to 2 years of treatment) with medicines that are expensive and toxic. As mentioned earlier, RR-TB is as equally threatening as MDR-TB and is therefore treated on similar lines, with second-line drugs.

XDR-TB is a more serious form of MDR-TB, caused by bacteria that do not respond to the most effective second-line anti-TB drugs in addition to first-line drugs, often leaving patients with very few treatment options.

In 2017, RR/MDR-TB remained a public health crisis and a health security threat. WHO estimates that there were around 558 000 cases with resistance to rifampicin emerging globally, of which most had additional resistance to isoniazid as well. About 8.5% of MDR-TB cases had XDR-TB in 2017.

Worldwide, only 55% of MDR-TB and 34% of XDR-TB patients were successfully treated in the most recent cohort. In 2016, WHO approved the use of a short, standardized regimen for RR/MDR-TB patients who do not have strains that are resistant to second-line TB medicines and meet certain other conditions.⁹ This regimen takes 9–11 months and is much less expensive than the old longer treatment for MDR-TB, which can take up to 2 years. However, patients with XDR-TB or resistance to second-line anti-TB drugs cannot use this regimen; they need to be put on longer MDR-TB regimens using the new classification of drugs by WHO in 2018.



In 2016, WHO also approved a rapid diagnostic test to quickly identify patients having bacillus that is resistant to some second-line drugs to triage patients who could be put on a shorter regimen. More than 35 countries in Africa and Asia have started using shorter MDR-TB regimens. By June 2017, 89 countries had introduced bedaquiline and 54 countries had introduced delamanid in an effort to improve the effectiveness of second-line treatment regimens.

In August 2018, WHO provided the document “Rapid Communication: Key changes to treatment of multidrug- and rifampicin-resistant TB (MDR/RR-TB)” using more effective drugs for an all-oral regimen.¹⁰



Handout 1.2.1 Treatment for drug-sensitive TB (DS-TB)

The standard 6-month course of treatment consists of two phases:

- Intensive phase (the first 2 months)
- Continuation phase (the last 4 months).

The description of treatment as provided below is applicable in most cases with this form of the disease. However, in some cases a longer duration or additional drugs may be needed, depending on site of the disease.

During the intensive phase of standard treatment, patients take a daily combination of four medications: isoniazid, rifampicin, pyrazinamide and ethambutol. These four drugs are referred to as first-line anti-TB drugs. First-line drugs are cheap and generally tolerated well. These medicines are used in combination to prevent the bacteria from developing resistance. Within a few weeks of beginning treatment, most patients will start to feel better. If treatment is working, most patients become non-infectious in about 2 weeks' time after start of effective treatment.

Once the intensive phase is completed, the continuation phase of treatment begins. During this 4-month phase, normally only isoniazid and rifampicin are taken daily. If the patient has taken medications regularly for the complete duration and achieves two negative TB tests during the continuation phase, his/her TB is considered cured upon completion.

Side effects, particularly nausea and abdominal pain, are relatively common. Urine and tears can turn orange, which is harmless but disconcerting if patients are not warned in advance. More severe side effects, such as joint pain, visual impairment, liver damage and



peripheral neuropathy (nerve damage) are less common but can be serious when they do occur and are not identified early. More information about each first-line drug and its side effects can be found in TAG's Activist's Guide to TB Drugs.

First-line drugs:

- Isoniazid (H or INH)
- Rifampicin (R or RIF)
- Ethambutol (E or EMB)
- Pyrazinamide (Z or PZA)

Treatment for DR-TB

DR-TB is a form of TB that has developed mutations that make at least one of the four standard first-line drugs ineffective. Drug resistance can arise when medicines are sub-standard, doses are skipped, treatment is interrupted or stopped too soon, or when treatment regimens are inappropriately designed or dosed. People in community or health-care settings can also be directly infected with DR-TB from a patient who already has the disease and is either not being treated, being treated with ineffective drugs or is at an initial stage of treatment.

TB that is resistant to at least isoniazid and rifampicin is called MDR-TB. XDR-TB is MDR-TB that is also resistant to second-line injectable drugs and fluoroquinolones. Pre-XDR-TB is MDR-TB that is resistant to either a second-line injectable or a fluoroquinolone. Treatment for DR-TB takes longer (up to 2 years), and has more side effects. DR-TB treatment is lengthier, more expensive and more difficult to treat than drug-sensitive TB.

WHO guidelines on how to construct an appropriate regimen for DR-TB are available on the WHO website www.who.int.

Second-line drugs

GROUPS & STEPS	MEDICINE	
Group A: Include all three medicines	Levofloxacin or Moxifloxacin	Lfx Mfx
	Bedaquiline	Bdq
	Linezolid	Lzd
Group B: Add one or both medicines	Clofazimine	Cfz
	Cycloserine or Terizidone	Cs Trd
Group C: Add to complete the regimen and when medicines from Groups A and B cannot be used	Ethambutol	E
	Delamanid	Dlm
	Pyrazinamide	Z
	Imipenem-cilastatin or Meropenem	Ipm-Cln Mpm
	Amikacin (or Streptomycin)	Am (S)
	Ethionamide or Prothionamide	Eto Pto
	<i>p</i> -aminosalicylic acid	PAS

Note: This table is intended to guide the design of individualised, longer MDR-TB regimens. The composition of the recommended shorter MDR-TB regimen is largely standardized. Medicines in Group C are ranked by decreasing order of usual preference for use, subject to other considerations.





Handout 1.2.2 WHO new guidelines for treatment of RR/MDR-TB

Key changes to treatment of MDR/RR-TB 2019¹¹

Treatment principles

- Ahead of enrolment on RR/MDR-TB treatment, all patients should receive appropriate counselling to enable informed and participatory decision-making. This is specifically essential for making a choice between a shorter regimen that uses injectables for 4–6 months with the associated adverse events against an all-oral regimen that is considered more effective but needs a much longer duration of treatment.
- Patient information material needs to reflect the new changes so that patients are appropriately informed about their treatment options.
- Social support to enable adherence to treatment is very important to ensure a patient-centred approach to the delivery of care.
- Active TB drug safety monitoring and management is essential for all patients enrolled on RR/MDR-TB treatment.

Key medicine changes

Longer MDR-TB regimens¹²

The revised grouping of TB medicines recommended for use in longer MDR-TB regimens is presented in [Table 1.1](#). Medicines have been regrouped into **three categories and ranked** based on the latest evidence about the balance of effectiveness to safety:

- **Group A:** Medicines to be prioritised: levofloxacin/moxifloxacin, bedaquiline and linezolid
- **Group B:** Medicines to be added next: clofazimine, cycloserine/terizidone

- **Group C:** Medicines to be included to complete the regimens and when agents from Groups A and B cannot be used: ethambutol, delamanid,¹³ pyrazinamide, imipenem-cilastatin, meropenem, amikacin (streptomycin), ethionamide/prothionamide, p-aminosalicylic acid.

Medicines no longer recommended are kanamycin and capreomycin, given the increased risk of treatment failure and relapse associated with their use in longer MDR-TB regimens. Amoxicillin-clavulanic acid is only to be used to accompany the carbapenems.

Table 1.1 also indicates the overall approach to designing longer MDR-TB regimens for adults and children based on the revised grouping. The regimen is designed by adding medicines sequentially going down the three groups.

Apart from the ranking by balance of effectiveness and harms, choice is also determined by: a preference for oral over injectable agents; the results of drug-susceptibility testing (DST); the reliability of existing DST methods; population drug resistance levels; history of previous use of the medicine in a patient; drug tolerability; and potential drug–drug interactions.

Options for the choice of agents for the intensive and continuation phases, more detailed guidance on patient selection criteria, number of medicines and duration of treatment, adult and paediatric dosing, treatment of XDR-TB and the use of DST results will be provided at the time of release of the final WHO guidelines.



Table 1.1. Grouping of medicines recommended for use in longer MDR-TB regimens

GROUPS & STEPS	MEDICINE	
Group A: Include all three medicines	Levofloxacin or Moxifloxacin	Lfx Mfx
	Bedaquiline	Bdq
	Linezolid	Lzd
	Clofazimine	Cfz
Group B: Add one or both medicines	Cycloserine or Terizidone	Cs Trd
	Ethambutol	E
Group C: Add to complete the regimen and when medicines from Groups A and B cannot be used	Delamanid	Dlm
	Pyrazinamide	Z
	Imipenem-cilastatin or Meropenem	Imp-Cln Mpm
	Amikacin (or Streptomycin)	Am (S)
	Ethionamide or Prothionamide	Eto Pto
	p-aminosalicylic acid	PAS

Notes:

- Evidence on concurrent use of Bdq and Dlm is not available but may be used in specific circumstances when other options for patients are not available.
- Z is only counted as an effective agent when DST results confirm susceptibility.
- Amoxicillin-clavulanic acid is administered with every dose of Imp-Cln or Mpm but is not counted as a separate agent and should not be used as such.
- Am and S are only to be considered if DST results confirm susceptibility and high-quality audiology monitoring for hearing loss can be ensured. S is to be considered only if Am cannot be used and if DST results confirm susceptibility, i.e. S resistance is not detectable with second-line molecular line probe assays and phenotypic DST is required.

To fill the current gaps in treatment, advocates must call for better availability of tests ruling out resistance to second-line drugs to decide on use of appropriate regimen. This calls for action to:

- encourage ministries of health and country programmes to incorporate bedaquiline into their treatment regimen;
- call all stakeholders (including the manufacturer) to expand the eligibility criteria for accessing bedaquiline;
- urge all stakeholders (including the manufacturer) to lower the price of bedaquiline for all low- and middle-income countries when the USAID donation programme ends in 2019;
- press for voluntarily license of the drug to generic drug manufacturers if pricing barriers remain, or urge governments to exercise compulsory licensing to allow the manufacturing of more affordable generic versions; and
- call for additional research to better understand how bedaquiline interacts with HIV medications, and to determine bedaquiline's effects on people who use drugs or alcohol and in people being treated for hepatitis B or C.

The other new drug, delamanid, remains widely inaccessible to patients under programme conditions; uptake is much lower than that of bedaquiline despite having a broader application for use as per WHO guidance.

As for bedaquiline, advocates should:

- demand that Otsuka Pharmaceutical Co. rapidly file for registration in all high DR-TB burden countries and where it has conducted clinical trials;
- urge country programmes to procure delamanid through the Global Drug Facility (GDF), using import waivers where necessary;
- call on all stakeholders (including the manufacturer) to lower the price of delamanid for all low- and middle-income countries;





Handout 1.2.3 Summary of WHO-recommended diagnostics

Table 1.2. Summary of WHO-recommended diagnostics ^{a 14}

TEST OR PROCEDURE	DESCRIPTION	LABORATORY TURNAROUND TIME ^b	COMMENTS
Smear microscopy	Conventional light microscopy with Ziehl–Neelsen staining	24 h	Less sensitive than fluorescence microscopy
Direct smear microscopy may be done in a low-risk level TB laboratory	Conventional fluorescence microscopy (using mercury vapour lamps)	24 h	Requires a quartz halogen or mercury vapour lamp. Microscopes are expensive Requires a dark room
	LED fluorescence microscopy		LED microscopy is about 10% more sensitive and the observation time is significantly shorter than for conventional light microscopy
Culture using solid media	Löwenstein – Jensen medium	3–8 weeks on average	Processing of samples for inoculating cultures should be done in a moderate risk-level TB laboratory
	Middlebrook 7H10 or 7H11 media		

TEST OR PROCEDURE	DESCRIPTION	LABORATORY TURNAROUND TIME ^p	COMMENTS
Culture using liquid media	Commercial and non-commercial test systems ^c	8 days to 6 weeks	A commercial example of an automated TB culture system is the BACTEC™ MGIT™ 960 TB System (Becton Dickinson Microbiology Systems, Sparks, USA)
Immunochromatographic assay for rapid species identification	Commercial test systems to be performed on bacteria recovered from solid or liquid cultures	15 mins (testing time)	Rapid identification of MTB isolated from solid or liquid cultures Because of the need to process cultures, testing should be done in a high risk-level TB laboratory Commercial examples of this test include: <ul style="list-style-type: none"> • Capilia TB-Neo® (Tauns Laboratories, Numazu, Japan) • TB Ag MPT64 Rapid Test© (SD Biotec, Kyonggi-do, South Korea) • TBcID© (Becton Dickinson Microbiology Systems, Sparks, USA)
Phenotypic DST using solid media — first-line	Löwenstein–Jensen or Middlebrook 7H10 or 7H11 media	3–4 weeks from positive culture (indirect DST)	Capacity to perform DST at least to rifampicin and isoniazid is needed Because of the need to process cultures, testing should be done in a high risk-level TB laboratory
Phenotypic DST using liquid media — first-line	Commercial and non-commercial test systems ^d	1–3 weeks from positive culture (indirect DST)	



TEST OR PROCEDURE	DESCRIPTION	LABORATORY TURNAROUND TIME ^b	COMMENTS
Phenotypic DST using solid media — second-line	Löwenstein–Jensen or Middlebrook 7H10 or 7H11 media	3–4 weeks from positive culture (indirect DST)	Capacity to perform DST at least to a second-line injectable drug (SLID) and a fluoroquinolone (FQ) is needed ^a Because of the need to process cultures, testing should be done in a high risk-level TB laboratory
Phenotypic DST using liquid media — second-line	Commercial and non-commercial test systems ^d	1–3 weeks from positive culture (indirect DST)	
Molecular testing	Xpert MTB/RIF assay Detects MTB and assesses resistance to rifampicin	2 h (testing time)	The Xpert MTB/RIF assay is suitable for all levels of the health system, although certain operational requirements apply such as uninterrupted power supply and temperature controlled setting. This test may be used rather than conventional microscopy and culture as the initial diagnostic test in all adults and children being evaluated for pulmonary TB. As a priority, the test should be used as the initial diagnostic test for adults and children being evaluated for MDR-TB or HIV-associated TB

TEST OR PROCEDURE	DESCRIPTION	LABORATORY TURNAROUND TIME ^a	COMMENTS
Molecular testing (continued)	<p>First-line line probe assay (FL-LPA)</p> <p>Detects MTB and assesses resistance to rifampicin and isoniazid</p>	<p>1–2 days (testing time)</p> <p>Batching of samples may increase turnaround time</p>	<p>FL-LPA is suitable for use on culture isolates and AFB smear-positive sputum specimens</p> <p>Commercial FL-LPAs may be used as the initial test instead of phenotypic culture-based DST to detect resistance to rifampicin and isoniazid</p> <p>Because of the need to process samples, direct testing of AFB smear-positive sputum specimens should be done in a moderate risk-level TB laboratory and testing of cultures done in a high risk-level TB laboratory</p> <p>Commercial examples of this test are the GenoType® MTBDRplus (Hain Lifescience, Nehren, Germany) and the NTM+MDRTB Detection Kit (NIPRO Corporation, Osaka, Japan) tests</p>
Molecular testing (continued)	<p>Second-line line probe assays (SL-LPA)</p> <p>Detects MTB and assesses resistance to FQs and SLIDs</p> <p>DNA targets are amplified by PCR and hybridized to immobilized oligonucleotide targets; results can be read visually or using an automated reader</p>	<p>1 to 2 days</p>	<p>For patients with confirmed RR-TB or MDR-TB, SL-LPA may be used as the initial test instead of phenotypic culture-based DST to detect resistance to FQs and the SLIDs</p> <p>SL-LPA is suitable for testing of cultured isolates of MTB and direct testing of sputum specimens from RR-TB or MDR-TB patients, irrespective of the smear status</p> <p>The currently commercially available SL-LPA cannot be used to identify individual drugs to be used for treatment because of incomplete cross-resistance among individual drugs</p> <p>The commercial example of this test is the GenoType® MTBDRsl test (Hain Lifescience, Nehren, Germany)</p>



TEST OR PROCEDURE	DESCRIPTION	LABORATORY TURNAROUND TIME ^b	COMMENTS
Molecular testing (continued)	TB-LAMP test Detects MTB in sputum specimens; it does not assess drug resistance DNA targets are amplified using loop-mediated isothermal amplification and results read visually under ultraviolet light	1.5 h (testing time)	<p>The TB-LAMP test may be used as a replacement for sputum smear microscopy for the detection of MTB in adults and children being evaluated for pulmonary TB</p> <p>It may also be used as a follow-on test to smear microscopy when further testing of smear-negative sputum specimens is necessary</p> <p>TB-LAMP should not replace the use of rapid molecular tests that detect MTB and resistance to rifampicin, e.g. Xpert MTB/RIF especially among populations at risk of MDR-TB when there are sufficient resources and infrastructure to support their use</p> <p>The TB-LAMP test is suitable for use at a peripheral health centre level where microscopy is performed, given similar biosafety requirements (e.g., low risk)</p> <p>The commercial example of this test is the Loopamp™ MTBC Detection Kit (Eiken Chemical Company Ltd., Japan)</p>

TEST OR PROCEDURE	DESCRIPTION	LABORATORY TURNAROUND TIME ^b	COMMENTS
Rapid antigen detection tests for TB	Urine-based lateral flow lipoarabinomannan (LF-LAM) assay Based on the detection of mycobacterial LAM antigen in urine. It does not assess drug resistance	30 mins	LF-LAM may be used to assist in the diagnosis of TB in HIV-positive patients with signs and symptoms of TB (pulmonary or extrapulmonary) who have a CD4 cell count less than or equal to 100 cells/ μ L or HIV-positive patients who are seriously ill ^f regardless of CD4 count or with unknown CD4 count Except as described above, LF-LAM should not be used for the diagnosis of TB or as a screening test for TB The test is suitable for use at the point-of-care and has minimal infrastructure or biosafety requirements The commercial example of this test is the Alere Determine™ TB LAM Ag test (Alere Inc, Waltham, USA)

a Tests not recommended by WHO are not included in the Table

b Laboratory turnaround time refers to the time taken from receipt of a specimen at the laboratory to issuing a laboratory test result. The overall turnaround time (from specimen collection to receipt of the result by the clinician) may be much longer and is dependent on a number of factors including speed of referral of specimens to the laboratory and delivery of results to the clinician.

c WHO issued initial policy guidance on DST to second-line drugs in 2008 (WHO/HTM/TB/2008.392; http://whqlibdoc.who.int/hq/2008/WHO_HTM_TB_2008.392_eng.pdf). In 2012, WHO convened an Expert Group to review and update the critical concentrations for both first- and second-line anti-TB drugs. WHO did not proceed with formal policy guidance recommending the revised concentrations because they were based on limited evidence, but issued interim revised critical concentrations for first-line and second-line DST. Emerging evidence suggests that the revised concentrations may require further revision.



d WHO has conditionally recommended selected non-commercial liquid culture systems for detecting TB and for detecting rifampicin resistance as an interim solution pending the development of genotypic or automated liquid culture and DST capacity. These methods include microscopic observation of drug susceptibility (MODS), nitrate reductase assay (NRA) and colorimetric redox indicator (CRI). They are suitable for use at the central level or reference laboratories and require highly trained personnel. However, their use is not intended to replace conventional culture and DST. Their implementation should be phased and include validation against standard methods. Scaling-up the use of CRI, NRA and MODS and decentralizing their use to lower-level laboratories are not recommended (WHO/HTM/TB/2011.9; http://www.who.int/tb/publications/2011/mdr_tb_diagnostics_9789241501620/en/).

e WHO recommends second-line DST for each of the SLIDs and FQs available for use in each NTP.

f “Seriously ill” is defined based on four danger signs: respiratory rate >30/min, temperature >39 °C, heart rate >120/min or inability to walk unaided.

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Session 1.3

Prevention

- Infection control
- Community level prevention – infection control
- Cough etiquette

Duration 1 h

Learning objectives

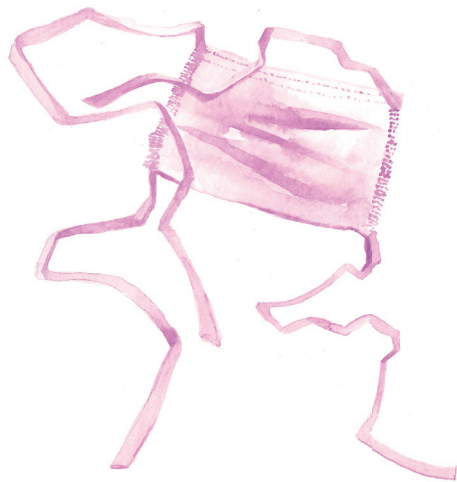
By the end of this session, participants will be able to describe:

- how TB infection can be controlled at personal, family/ community and facility levels
- preventive therapy
- the steps the community and TB survivor groups can take for infection control.

Methodology

Step 1: Discussion (10 mins)

Ask participants to share their experiences and suggestions on existing efforts to control cough infection within the family and from other workplace contacts, and whether or not they have been effective.



Step 2: Slides (15 mins)

Use PowerPoint slides based on the notes provided to explain preventive methods including medical therapy and elaborate on latent TB infection treatment regimens.

Step 3: Group work (30 mins)

- Divide participants into groups and ask them to list out steps that the community can take to ensure airborne infection control at various levels — personal, family, community and facility levels, specifically avoiding stigma for the patient and family.
- Ask representatives from each group to present the key points at the plenary.
- Note these points in separate columns on the flipchart; add new points from each group to the list and indicate points that are repeated.
- Discuss the role of the community in ensuring that these steps are implemented in their respective contexts.

Step 4: Summarize (5 mins)

Review the key points discussed.

Additional resources for facilitators

Prophylaxis/preventive therapy

As there is no widely effective vaccine for TB, using TB drugs to treat latent TB infection (LTBI) is one of the best ways to prevent active TB disease. If active disease has been ruled out, the most common treatment that has traditionally been used for latent TB infection is isoniazid. Isoniazid preventive therapy (IPT) reduces the risk of developing active TB. The standard regimen is 300 mg daily of isoniazid for 6–9 months in adults and adolescents and 5 mg/kg for children. WHO recommends 36 months or more of treatment for people with HIV, including children.

However, evidence now available has shown promising new treatments that are relatively easy to take and at least as effective as INH alone. Most promising of these at this stage is combination of isoniazid + rifapentine once a week for 3 months (total 12 doses).

Various treatment options for management of LTBI are as below:¹⁵

- Isoniazid monotherapy for 6 months is recommended for treatment of LTBI in both adults and children in countries with both high and low TB incidence.
- Rifampicin plus isoniazid daily for 3 months should be offered as an alternative to 6 months of isoniazid monotherapy as preventive treatment for children and adolescents aged <15 years in countries with a high TB incidence.
- Rifapentine and isoniazid weekly for 3 months may be offered as an alternative to 6 months of isoniazid monotherapy as preventive treatment for both adults and children over 2 years of age.
- In settings with high TB incidence and transmission, adults and adolescents living with HIV who have an unknown or a positive TST and are unlikely to have active TB disease should receive at least 36 months of IPT, regardless of whether they are receiving ART or not. IPT should also be given irrespective of the degree of immunosuppression, history of previous TB treatment and pregnancy.
- In selected high-risk household contacts of patients with MDR-TB, preventive treatment may be considered based on individualised risk assessment and a sound clinical justification.

More research is needed both to identify safe and effective treatment options for those infected with DR-TB and to guide follow up in cases where preventive therapy is not initiated.



MODULE 2



Advocacy



Overall objectives of the module

At the end of the day, the individual should be able to:

- understand how to identify and influence advocacy targets
- understand the difference between an advocacy target and an influential person/agency
- understand the importance of engaging “non-traditional” advocacy targets
- be in a position to develop an influencing strategy.

Inform about the day’s plan

- The first session will focus on “what we need to advocate on”
- The second session before lunch will look at “who we need to advocate to”
- The afternoon or the last session will be group work on “how we need to advocate”.

The last two sessions will start off the process of planning for an advocacy campaign.



Session 2.1

Defining advocacy

Duration 90 mins

Training aids/materials required

- LCD projector
- Whiteboard
- Blue tack
- Chart paper
- Markers
- “Pathways to cure” charts with priorities written on Post-its from the previous day.

Learning objective

By the end of this session, participants will be able to define advocacy and start the planning process for advocacy in their respective contexts.

Methodology

Step 1: Welcome and introduction to the session (5 mins)

This session will focus on “what we need to advocate on”.

Step 2: Defining advocacy – brainstorming (10 mins)

- Make 3 columns on the whiteboard. Put headings on each column delineating “What”, “How” and “Who”
- Ask the participants to suggest a word or phrase to describe advocacy, and write the words under different columns. For example:
What: Better drugs, counselling facilities, better care, enhanced domestic funding

How: Protesting, petitioning, spreading the messages, seminars, meetings;

Who: State Health Minister, TB Department Director, drug manufacturers, local leaders, other community groups

- The brainstorming session concludes with the facilitator drawing out the words from the columns to give the following definition:
- Advocacy is work that seeks to change public policies and practices in ways that will have a positive impact on people's lives.¹⁶

Types of advocacy

- **Policy advocacy:** Policy advocacy informs senior politicians and administrators how an issue will affect the country, and outlines actions to take to improve laws and policies.
- **Programme advocacy:** Programme advocacy targets opinion leaders at the community level on the need for local action.
- **Media advocacy:** Media advocacy validates the relevance of a subject, puts issues on the public agenda and encourages the media to cover TB-related topics regularly and in a responsible manner so as to raise awareness of possible solutions and problems.

Facilitator's notes

While several definitions for advocacy exist, this definition fits our need and is in keeping with existing UN advocacy definitions:

“Advocacy denotes activities designed to place TB control high on the political and development agenda, foster political will, increase financial and other resources on a sustainable basis, and hold authorities accountable to ensure that pledges are fulfilled, and results achieved (WHO).”¹⁷

It can be seen that this definition details out the definition arrived at during the brainstorming session earlier.



Advocacy often focuses on influencing policy-makers, funding agencies and international decision-making bodies through a variety of channels — conferences, summits and symposia, celebrity spokespeople, meetings between various levels of government and civil society organizations, news coverage, official memoranda of understanding, parliamentary debates and other political events, partnership meetings, patients’ organizations, press conferences, private physicians, radio and television talk shows and service providers.

Step 3: Stock-taking (1 min)

This is where we introduce a short break before the learning sessions start. A “stretch and sit down” could be suggested. A success story can be mentioned, such as this example from Georgia:

In Georgia, the community members noticed that anti-tuberculosis antibiotics were readily available over the counter, indicating that existing drug regulatory mechanisms were not effective. It also meant that there could be an increase in drug resistance. They community members advocated against this and it led to a meeting between the community and key policy makers including the National TB Programme Manager to discuss the availability of anti-tuberculosis antibiotics without a prescription and the contribution of this practice to drug resistance. Following this meeting, the community members were asked to develop an analytical policy paper describing promising practices of other countries which have faced similar problems and how they have overcome them.

Step 4: Introducing the tools for use in the session (4 mins)

The main tool used during the session will be the “Pathways to cure” exercise conducted in Module 1.

Step 5: Group work (20 mins for group work and 10 mins for presentation)

- Divide the participants into five groups. Participants from the same or nearby geographical areas can be in the same group.
- Ask the participants to prioritize the three biggest barriers to cure for MDR-TB from one column in the “Pathways to cure” chart. This should be written down on Post-it slips.
- The groups can then place the Post-it on a chart paper and defend their advocacy priority choices before the plenary.

Step 6: Group work: advocacy test (10 mins)

Ask the participants to go back to their groups. Each group needs to test their priorities against the following question: “Can this advocacy priority be eliminated or reduced if there are policy or procedural changes?” The priorities that get a “yes” should be written up on separate sheets of chart paper. The groups can share their answers and defend their choices before the plenary.

Step 7: Group work: selecting the advocacy topic (10 mins)

Ask the participants to go back to their groups. Ask each group to consider the question: “Which priority from the ones selected above can be most easily agreed to by a senior government official (less cost to government, easily scalable across the country, less implementation hurdles, greater population impact)?”



Step 8: Presentation (15 mins)

Each group will present their advocacy priorities to the plenary and give the reasons for choosing them. The plenary can then either support their choice or give alternates and come to a common agreement. Each group then takes the agreed priority to work on for the rest of the day.

Step 9: Summarize (5 mins)

Close with a recap of the definition and the key advocacy priorities for MDR-TB for each group.



Session 2.2

Whom do you advocate to?

Duration 90 mins

Training aids/materials required

- Advocacy priority finalized from previous session
- “Pathways to cure” chart
- Flip chart
- Permanent markers

Learning objective

By the end of this session, participants will be able to list the most strategic people or institutions to focus their advocacy initiatives on.

Step 1: Energizer (5 mins)

Choose an appropriate energizer from the options provided in the section “Icebreakers and energizers” to start the session with.

Step 2: Advocacy targets (10 mins)

Advocacy targets are the key individuals who are in a position/have the power to bring about changes.

The key targets for advocacy are the so-called duty bearers, those bodies or individuals that represent institutionalised power with the authority to make changes, which gives them the responsibility to ensure that the rights of people affected by TB are protected. The target is the person (or group of people) with the power to respond to your demand and move the political process in relation to your issue.



Advocacy concerning policies and implementation is normally focused on governmental institutions and national parliaments. It may also focus on multilateral institutions and UN agencies.

The identification of your advocacy targets should really be guided by the question “Who has the power to make change happen?”

It is useful to break down this question into more specific questions:

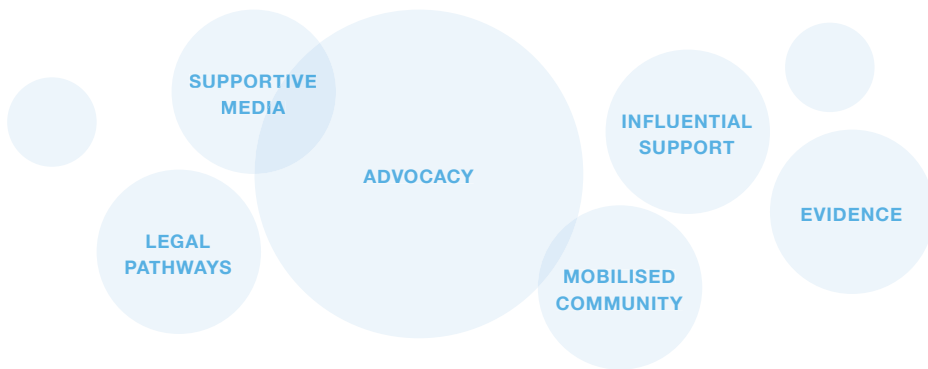
- Who are the decision-makers and which are the institutions that define the policy and practice changes that need to happen?
- At what level are key decisions being made (advisers, chiefs of divisions/departments, ministers, prime ministers, heads of state, parliamentarians, etc.)?
- Through which decision-making process are key decisions being made? Who is consulted in the process? Who has formal and informal power within the process?
- Among the various targets, which individuals have a decisive influence (power to propose or oppose, power of the final say), and which ones are secondary/intermediate targets (consulted in the decision-making process but not the ultimate decision-makers)?
- Of the various targets, which ones are supportive of the changes we would like to see happening (processes, or end goals, or both)? Which ones are opposed to it? Which ones are “swingers” (undecided, may be persuaded to support the changes we would like to see happening)?

Facilitator's note

This diagram represents the many aspects of advocacy. The circles with writing in them are the ones we will focus on in this session. It will help in preparing us to develop a basic advocacy campaign. As we get more experienced, we will realize that there are many more aspects to advocacy and we can slowly fill in the unmarked circles.

Step 3: Group work (50 mins)

Conduct the following exercise to help participants to prioritize the stakeholders on whom the advocacy is to be focused on.



Process¹⁸

- Divide participants into groups
- Select the subject to discuss, e.g. “adherence support for DR-TB patients” or “provision of new drugs for treatment”. Write the subject in the middle of the diagram and draw a circle around it
- Encourage the participants to brainstorm on all the stakeholders or services that are relevant to the subject
- Now rank them according to who is most important and who is least important for fulfilling their request



- From sheets of paper, cut out three circles in different sizes — small, medium and large. Explain to participants that each circle represents one of the stakeholders and that the different sizes of circle show how important they are. For example, a very important stakeholder will have a large circle and a not very important one will have a small circle
- Ask participants to write the name of each stakeholder in either a small, medium or large circle, using the ranking to help them
- Now ask participants to place each of the stakeholder circles on the diagram. Place those closely involved with the issue close to the central subject circle on the diagram, and those not closely involved further away from the centre.
- Where there is close interaction between stakeholders, show this by overlapping circles closely.

Step 4: Discussion (20 mins)

When the activity is complete, discuss what the diagram shows. For instance:

- How many different stakeholders and services are involved with the solution of the problem?
- Which are the most important, and why?
- Which should be more and which should be less important, and why?
- Are there weak or strong relationships between them?
- Which relationships should be stronger?

Record the diagram and responses.

Wrap up (5 mins)

Close the session with a quick review of key points.

Session 2.3

How to advocate — the homework

Duration 180 mins

Training aids/materials required

- Projector
- Laptop with connection to projector
- Flip charts
- Marker pens
- “Pathways to cure” chart
- Copies of Handouts 2.3.1 and 2.3.2

Learning objective

By the end of the session, the participants will be able to develop a draft advocacy plan.

Methodology

Step 1: Gathering evidence (20 mins)

Advocacy requires evidence to support the issues that are being advocated for. Asking five simple questions may identify this evidence:

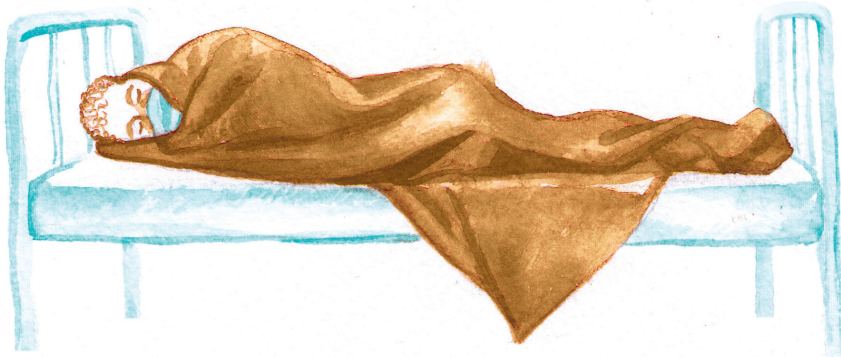
- What is the change we are seeking?
- Why we are seeking this change?
- What benefits will this change bring?
- Have we or other states or countries done something similar, and if so, what are the results?
- Do we have any documentation of this process?



Ask the participants to get back to their groups. Ask the groups to answer these questions in their groups, focused on the priorities that they have chosen.

Step 2: Understanding the legal environment:
group activity (20 mins)

The following or something similar may be stated: “We need to list out what NGOs, citizens, or the media are allowed to do within the boundaries of the law within our respective contexts. We also need to list existing support groups or legal assistance available to advocates or activists. We work within legal boundaries and we should be aware of what we can do.”



Request the groups to think of activities that are allowed and those that are grey areas, where there is no specific legal position. (For example, in some countries people may not be allowed to gather in large numbers at the office of the health department. But gathering in twos and threes is not mentioned. This is a grey area that we can exploit.)

The groups should also be asked to think of agencies that provide legal support, NGOs and lawyers as allies that will support the advocacy plan.

Ask the groups to:

- list out all legally allowed advocacy activities
- list all NGOs that provide legal support.

Step 3: Leveraging the mass media and social media — brainstorming (20 mins)

The following or something similar may be stated: “Let us think of all print and television journalists or media houses who can be considered supportive. Do some of our friends know journalists or have friends in media houses? Can we add that to the resources that we have? And can we also think of media agencies that the targets may be influenced by? How to best use social media for disseminating appropriate messages?”

Each group lists five names for each of the following:

- Media friendly to the community
- Media not friendly to the community
- Names of people who can influence media for the community.

Step 4: Taking stock

Summarize what has been accomplished till now in this session.

Step 5: Types of advocacy (5 mins)

Present the following information with the aid of PowerPoint slides:

- **Confrontational:** Forcing an issue on to the agenda through mass mobilization, the media, etc. This approach can give you a higher profile and greater freedom of action. On the other hand, in many contexts, it can be very counterproductive and can damage future relationships. In some cultures, being openly confrontational is considered completely inappropriate.



- **Cooperative/persuasive:** Presenting evidence in the hope of getting your targets to recognise the merits of your arguments. For example, working with the government to find solutions. This approach will enable you to develop relationships with your targets, gain their trust, allow your direct access and provide more opportunities for working with others.

Step 6: Advocacy tools: brainstorming (20 mins)

Ask the participants to brainstorm a list of advocacy tools. This can be written out on the whiteboard.

Facilitator's note

Advocacy tools could include the following:

- Hold a public panel discussion
- Arrange meetings with advocacy targets
- Arrange a phone call-in. Use a journalist or radio occasionally
- Write letters and emails to decision-makers
- Use social media*
- Use videos
- Organize a media stunt or public protest
- Write a press release

* Social media platforms such as blogs, Twitter, Facebook and WhatsApp can be used to highlight problems, express opinions, share information, provide feedback and advocate for action. This would enable large numbers of people to be reached and information to be widely shared.

Step 7: Developing an advocacy plan: group work (90 mins)

Ask participants to work in groups to develop a draft advocacy plan using the steps outlined in Handout 2.3.1.

A sample is provided below:

Sample advocacy plan

OBJECTIVES	TARGETS	ACTIVITIES
Timing of the diagnostic clinics should be changed to start from 0700 and close at 1900	State Health Dept. Head	Make a petition with 500 signatures of persons affected by TB
		Approach the local clinic in-charge and request for changed timings
		If request is declined, meet with the TB in-charge for the state with the same petition
		Send the petition to the state health department head with a copy to the State Health Minister and WHO Country Office
		Provide evidence of people who had delayed diagnosis because they were not able to access the clinic
		Talk about this with the media and get a TV interview on a local channel.



STEPS	TIMEFRAME	ORGANISING LEAD	COST
Draft a petition and get it edited	10–15 January 2019	Creative TB support group	Free
Request support for the petition from local NGOs	20–30 January 2019	Association of local NGOs	US\$ 100
Ask local community groups and NGOs to sign on the petition	20–30 January 2019	Federation of CSO groups of eastern Gondor	US\$ 100

Facilitator's note

A blank advocacy plan template has been provided at the end of this section. Participants may be provided copies of the template.

Step 8: Wrap up (5 mins)

Get all groups to make a presentation of their plan in 2 mins each. Give feedback time to all groups so that other participants can provide positive or constructive feedback.

Have an energiser that is funny and close the day.





Handout 2.3.1 Advocacy plan

- Name the advocacy target
- Describe the advocacy objective
- Describe the tools being chosen and the rationale.

Example

- Mail-in approach. Get 500 people to mail letters to the Health Secretary in April 2019:
 - Sample template will be distributed electronically to 800 people affected by MDR-TB by 31 March 2019.
 - List of people affected by MDR-TB has been procured from 3 NGOs working on MDR-TB by February 2019.
 - All people on the affected list will be called by phone in the last week of March and requested to send the mail by post in the month of April.
- Follow up: In the event that the mail-in does not have the intended effect, it may need a follow up with a request for meeting the advocacy target. This plan should be incorporated into the advocacy plan from the start and a similar planning detailed, as for example:
 - Send a meeting request to the advocacy target by 30 April 2019.
 - Ask for a meeting for four members of the community selected by the larger group.
 - Give three possible dates and times for the meeting.
 - If no response is received within a week, call the office of the advocacy target and request for an appointment. If put off, make a similar request the next day and the following day onwards for a week or till the appointment is given.

- If no appointment is given after a week of calls, ask a friend to call up the advocacy target's manager and request the manager to put in a word for approving the meeting request.
- If the cooperative advocacy with the manager does not work, plan for a persuasive approach such as media statement or interview. Request a friendly media person to give space for an interview either on TV or in a newspaper that is widely seen or read. Preferably, four people should be interviewed. Make a succinct case including the steps you have taken till now, mail-in and request for interview by mail and/or phone. Highlight the number of deaths or lack of diagnosis, as is the case.
- Make sure that you leave some breathing space so that you can react to new opportunities that arise along the way.
- Resources: List the kind of resources (materials, equipment, food and drink, accommodation, transport, staff and volunteer time, etc.) you think you would need. Also, list where might you find these, e.g. partner organizations, friends and family, etc.
- Kinds of advocacy tools:
 - Hold a public panel discussion
 - Arrange lobbying meetings
 - Arrange a phone call-in. Use a journalist or radio occasionally
 - Write letters and emails to decision-makers
 - Write a petition
 - Use social media
 - Use video
 - Organize a media stunt or public protest
 - Write a press release
- As you make your decisions, ask yourselves:
 - What activities and tactics are most appropriate to reach our targets?
 - Does this activity fit in with the idea of cooperative/persuasive or confrontational?
 - Does it fit in with the advocacy method (public/private)?



- Are we acting safely in the current political environment and national context?
- Are we being realistic about the number of activities and timelines that we are planning?
- When preparing a budget for your project proposal, it is important that you think about:
 - the goals and objectives of your project;
 - which activities contribute most to achieving your project's goals and objectives;
 - what resources you need to implement your activities;
 - what the resources will cost (including your human resources);
 - ensuring that you are allocating sufficient funds to support the resources you have identified;
 - how would the needed funding be mobilized, if not already available.





Handout 2.3.2 Advocacy plan template

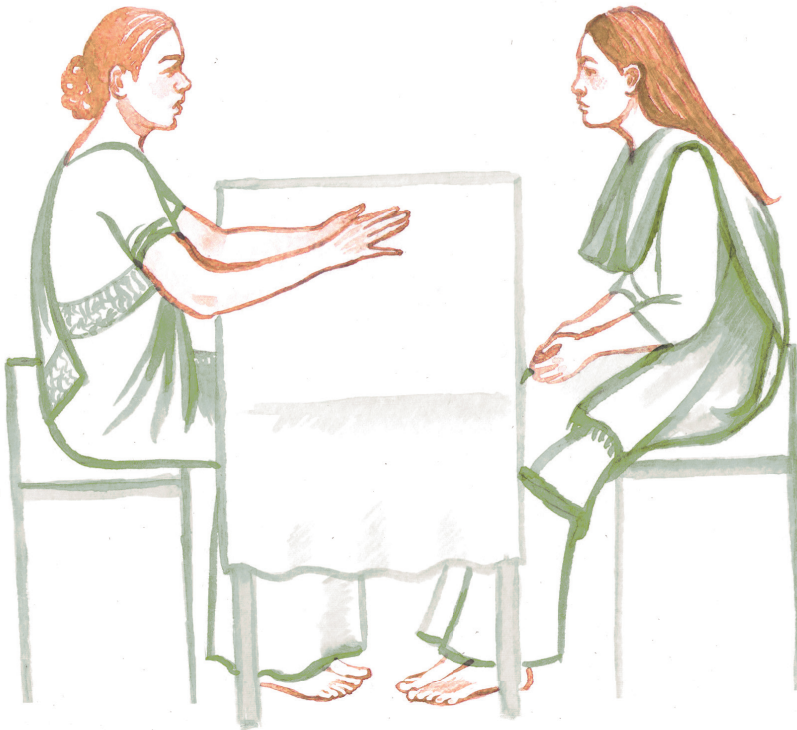
OBJECTIVES	TARGETS	ACTIVITIES	STEPS	TIME-FRAME	ORGANISING LEAD	COST



MODULE 3



Barefoot counselling



Session 3.1

Counselling for DR-TB

Duration 45 mins

Training aids/materials required

- PowerPoint presentation/slides
- LCD projector
- Laptop
- Flipchart/whiteboard
- MPrinted copies of hand-outs

Learning objective

By the end of the session, the participants will be able to understand the need for counselling for DR-TB clients.

Methodology

Step 1: Revisit effect of DR-TB drugs (20 mins)

Use the information provided below in a PowerPoint presentation to frame the context for DR-TB counselling:

- Review the drugs used for DR-TB discussed on Day 1
- Review the side effects of the drugs including the new ones (bedaquiline and delamanid)



Possible ADRs that need monitoring

SER NO.	FUNCTION AFFECTED	EARLY SIGNS AND SYMPTOMS	USUAL OFFENDING AGENTS
1	Gastrointestinal	Nausea, vomiting, gastritis, diarrhoea	Most drugs, especially ethionamide, PAS, pyrazinamide, ethambutol
2	Balance	Giddiness, oversleeping, poor concentration	Amino glycosides, ethionamide, quinolones and/or pyrazinamide
3	Vision	Blurring of vision, disturbance in colour vision	Ethambutol
4	Kidney function	Less than normal urination or total stoppage of urination, puffiness of face, swelling of feet	Kanamycin, amikacin
5	Movement	Joint pains	Pyrazinamide, quinolones
6	Skin reactions	Itching, localised rash Generalized red coloured rash associated with fever and/or mucous membrane involvement	Any of the drugs may give rise to this
7	Liver	Loss of appetite, nausea/vomiting, abdominal discomfort, dark coloured urine, jaundice	Ethionamide, pyrazinamide
8	Neural	Pain and/or tingling sensations in any part of the body, especially in the feet and hands	Linezolid, cycloserine, ethionamide
9	Neural	Convulsions, fits	Quinolones, cycloserine

SER NO.	FUNCTION AFFECTED	EARLY SIGNS AND SYMPTOMS	USUAL OFFENDING AGENTS
10	Mental health	Depression, excessive chatting, unusual violent tendencies, suicidal tendencies	Cycloserine, quinolones, ethionamide
11	Hearing and ear related	Ringing in the ear, deafness, unsteady gait Patient tends to lose balance and fall	Aminoglycoside
12	Thyroid function	Lethargy/tiredness, slowing of activities, puffiness of face, swelling of the thyroid (neck swelling)	PAS, ethionamide
13	Heart	Chest discomfort, palpitation	Bedaquiline, delamanid
14	Joints	Joint pains, specifically small joints like toes	Bedaquiline, delamanid

Facilitator's note

Provide participants with Handout 3.1.1 and Handout 3.1.2.

Step 2: Introduction to counselling (20 mins)

- Invite the participants to sit in a semicircle so that everyone can see each other.
- Introductory exercise: each participant gives out their names with an adjective that they think best describes themselves, e.g. "Rocking Rohan".
- This exercise begins to open up people to look at counselling.
- After the introductions, ask the question "What do you understand by the term counselling?" Note the responses on a whiteboard.
- Agree on the following definition of counselling: "Counselling may be defined as the process of helping other persons help themselves".¹⁹



- Ask the participants if they have ever used counselling and whether they will be willing to share their experiences. Write some of the responses, whether positive or negative, on the whiteboard.
- List out the core ingredients in counselling:
 - Non-judgmental attitude
 - Listening
 - Rapport
 - Collaboration
 - Positive reinforcement
 - Emotional support
 - Confidentiality
- Ask the participants to try and describe what they understand by these terms. Explain why counselling is essential to people on DR-TB drugs (details provided in the section on Additional Resources for Facilitators).

Step 3: Summarize (5–10 mins)

Do a review of the session. Ask the participants to reflect on some of the themes discussed in the module and respond to any queries that might come up.



Handout 3.1.1 Common second-line drugs used for treatment of DR-TB for adults

S NO	DRUGS
1	Bedaquiline (Bdq)
2	Levofloxacin (Lfx)
3	Moxifloxacin (Mfx)
4	Clofazimine (Cfz)
5	Linezolid (Lzd)
6	Cycloserine (Cs)
7	Terizidone (Trd)
8	Ethambutol (E)
9	Delamanid (Dlm)
10	Pyrazinamide (PZA)
11	Amikacin (Am)

(For an exhaustive list of second-line drugs, refer to Table 1.1.)





Handout 3.1.2 Possible ADRs that need monitoring

Possible ADRs that need monitoring

SER. NO.	FUNCTION AFFECTED	EARLY SIGNS AND SYMPTOMS	USUAL OFFENDING AGENTS
1	Gastrointestinal	Nausea, vomiting, gastritis, diarrhoea	Most drugs especially ethionamide, PAS, pyrazinamide, ethambutol
2	Balance	Giddiness, oversleeping, poor concentration	Amino glycosides, ethionamide, quinolones and/or pyrazinamide
3	Vision	Blurring of vision, disturbance in colour vision	Ethambutol
4	Kidney function	Less than normal urination or total stoppage of urination, puffiness of face, swelling of feet	Kanamycin, amikacin
5	Movement	Joint pains	Pyrazinamide, quinolones
6	Skin Reactions	Itching, localised rash Generalized red coloured rash associated with fever and/or mucous membrane involvement	Any of the drugs may give rise to this
7	Liver	Loss of appetite, nausea/vomiting, abdominal discomfort, dark coloured urine, jaundice	Ethionamide, pyrazinamide

SER. NO.	FUNCTION AFFECTED	EARLY SIGNS AND SYMPTOMS	USUAL OFFENDING AGENTS
8	Neural	Pain and/or tingling sensations in any part of the body, especially feet and hands	Linezolid, cycloserine, ethionamide
9	Neural	Convulsions, fits	Quinolones, cycloserine
10	Mental health	Depression, excessive chatting, unusual violent tendencies, suicidal tendencies	Cycloserine, quinolones, ethionamide
11	Hearing and ear related	Ringing in the ear, deafness, unsteady gait Patient tends to lose balance and fall	Aminoglycoside
12	Thyroid function	Lethargy/tiredness, slowing of activities, puffiness of face, swelling of the thyroid (neck swelling)	PAS, ethionamide
13	Heart	Chest discomfort, palpitation	Bedaquiline, delamanid
14	Joints	Joint pains, specifically small joints like toes	Bedaquiline, delamanid



Additional resources for facilitators

Impact of TB²⁰

TB is a chronic and debilitating illness, beyond its medical manifestations and is often accompanied by a myriad of social, psychological, economic and cultural issues.

Psychosocial impact of TB

Highly contagious in enclosed spaces, TB puts an infected person's family and friends at risk. Many people find themselves forced to leave their homes because of the associated stigma. The psychological toll as a result of prolonged medication and toxic side effects is difficult to imagine. Suicidal thoughts, psycho-emotional collapse and serious family or social problems are common consequences of infection as well as treatment.

The effects of TB — coughing, weight loss, debilitating fatigue and fever extend beyond the individual's physical body. Men and women are often isolated and shamed by stigma. Those infected often lose their jobs or drop out of school, leaving them as financially debilitated as they are physically.

Stigma and discrimination are triggered by many forces: lack of understanding of the disease, myths about how TB is transmitted (and can be prevented), lack of access to diagnosis and treatment, immune response to TB and fears relating to illness and death. Lack of knowledge and misconceptions are deep rooted among the affected and infected. Stigma results in part from misinformation and lack of information.

Patients could face the following issues during the course of the infection/disease or treatment:

- Hopelessness and thoughts about abandoning treatment
- Suicidal thoughts or intent
- Stigma and discrimination
- Adverse effects of anti-TB medications
- Problems in the home, with family
- Problems associated with sexual practices
- Economic problems
- Fear of post-treatment relapse
- Fear of transmitting disease to family and friends
- Myths and misconceptions about the disease.

Economic Impact of TB

TB is one of the most disabling diseases in the world today, with high death rates. Although its burden is spread across all age groups, it exacts a very high toll on individuals during their most productive years, i.e. from ages 15 to 44. The impact of TB on families is often economically devastating. The difficulties of taking care of sick individuals usually fall on other family members, putting them at greater risk of infection, lowering their productivity and perpetuating the cycle of poverty.

The emergence and spread of MDR-TB and XDR-TB, now prevalent in many countries worldwide, are confounding the global efforts to halt the spread of TB and are imposing an enormous economic burden on health systems globally. The cost of treating MDR-TB can be 200 times greater than for drug-susceptible TB. Around the world, the economic toll of TB on individuals and public health budgets is significant. TB undermines the capacity of countries to escape poverty and is an enormous drain on the worldwide economy. Because of the long, burdensome, complicated and possibly even fatal course of the disease, TB patients are often no longer able to support themselves and their families financially or help build up the economy of their country.



The average TB patient loses 3 to 4 months of work and upto 30% of yearly household earnings (WHO estimates). In all the 27 countries that have a high burden of MDR-TB, the expenditure for MDR-TB treatment exceeds gross national income per capita.

Cultural Impact of TB

Many public health and welfare programmes like the polio eradication programme, AIDS control programme and family welfare programmes have successfully involved cultural and religious leaders as stakeholders in the past. The role of cultural and religious stakeholders could be equally important as that of the policy-makers and health service providers in a disease programme context.

The behaviour change expected among the population certainly needs to consider the cultural and religious values and norms of that particular population, which highly influence their attitudes, perceptions and day-to-day activities. In certain religions, people do not believe in taking treatment for TB and other illness. Infected men and women are often isolated and stigmatized by their own religious people. Lack of knowledge and misconceptions are deep-rooted among the affected and infected within their cultural and religious environment.

The perceived and internalized stigma of the infected individual and the enacted stigma of the community with regard to TB are primarily due to the sociocultural values that contextualize TB as a sick person's disease, hereditary disease or as a punishment for transgressions.

Session 3.2

Counselling information for DR-TB – checklist

Duration 1 h

Training aids and materials

- PowerPoint slides
- Laptop
- LCD projector

Learning objectives

By the end of the session, the participant will be able to describe the stages where counselling is needed for DR-TB and demonstrate the use of checklists for counselling.

Methodology

Step 1: PowerPoint presentations (25 mins)

Use slides to guide this session to explain the checklists to be employed at each stage that may require counselling intervention, based on the suggested content provided in the section below.

Facilitator's note

Counselling will be critical for DR-TB affected persons on the following occasions:

- Pre-diagnostic counselling on suspicion of DR-TB
- Post-diagnostic counselling – results sharing and treatment initiation (if needed)
- Counselling during treatment for treatment adherence
- Post-treatment rehabilitation.



Slides 1 and 2: Pre-diagnosis counselling²¹

Explore reasons for visit and present illness:

- What problems is the person presenting with?
- Recognize, respect and encourage a decision to test

Explore TB knowledge:

- Clarify misconceptions about modes of transmission
- Explain the test and reasons for testing including meaning of a negative or positive result
- Explain the need for diagnostic tests and follow up of results
- Practicalities of test — sample collection, getting results, treatment options, side effects, time taken, distance. Example: sputum test, collection of samples and instructions).

Explore potential test implications:

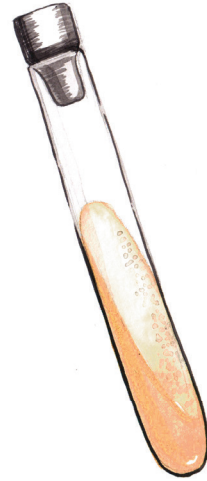
- In relation to a person's life situations such as marriage, pregnancy, family implications, treatment compliance/adherence, employment, immediate travel post diagnostics
- Assess strategies for coping: Social network
- Social support
- Encourage disclosing of test results to other significant family members/partner.

Explain the importance of treating TB (and DR-TB). Introduce the possible side effects:

- Reassurance that TB is curable
- Preventive education
- Cough hygiene
- Immediate steps to prevent possible spread: sleep away, ventilate home, keep away from young children or immune compromised
- Ask if the person would like a counsellor's presence for collection of test results
- Reassure regarding maintenance of confidentiality.

Slide 3: Post-diagnostic counselling: test negative

- Explain meaning and implications of a negative result
- Check back to confirm understanding
- Clarify doubts/misconceptions
- Repeat preventive education:
 - Cough hygiene
 - Healthy lifestyles: cessation of smoking, alcohol use, drug use, nutrition, adequate sleep
 - Appropriate referrals
 - Spread TB prevention message.



Slides 4 and 5: Post diagnostic counselling: test positive

- Let the person affected by TB inform you of the result
- Explore understandings
- Clarify misconceptions
- Empathize and support their emotional situation
- Validate reactions as normal; give adequate time
- Explore whom to inform (disclosure)
- Explore impact on partner, family, friends, employer
- Explore how to break news (offer help and support)
- Explore options of family counselling
- Plan to maximize support and minimize stress
- Assess commitment to, and understanding of precautions
- Explore factors related to general health, nutrition, adequate sleep and exercise
- Consider possible side effects of medication and what to do
- Agree on regular meeting times and emergency support contact
- Provide appropriate brochures for persons affected by TB.



Slide 6: Psychological and emotional support to improve adherence

- Having MDR-TB can be an emotionally devastating experience for persons affected by TB, their family and their social networks
- Considerable stigma is attached to the disease. This may interfere with adherence to therapy
- Socioeconomic problems including hunger, homelessness and unemployment are common among persons affected by MDR-TB. They should be addressed to enable them to adhere to MDR-TB treatment.

Step 2: Adherence counselling (25 mins)

Use the information below, either as slides or in the form of eliciting suggested responses for each possible question from the collective experience of participants. Supplement responses from the information provided below.

Slide 7: Monitoring adherence

ASK	COMMUNICATE
Are you becoming frustrated with the adverse effects?	We can manage your adverse effects if you keep communicating with the clinical and community teams. Many adverse effects improve with time.
Are you feeling better?	Even though you feel better, your MDR-TB is not cured. You must keep taking drugs for the entire treatment period.
Is it convenient for you to take your treatment each day?	We can arrange things so that it is more convenient for you to take treatment. We can give you reimbursement for transportation.
Are you planning to travel soon?	We can make arrangements so that you will not miss any doses.
Are you planning to go back to work?	We can make arrangements so that your treatment is more convenient to your workplace. We can also talk to your employer if you agree.
How is your relationship with your clinical team/community health worker?	If anyone on the clinical or community team is disrespectful, we apologize. Please let us know how we can treat you better.



Slides 8 and 9: Common adherence problems and their solutions

PROBLEMS	POSSIBLE SOLUTIONS
The person affected by TB does not want to take treatment because of adverse effects.	This is the most common reason for loss to follow-up. Treat the adverse effects immediately.
The person affected by TB does not want to take treatment because he/she is feeling better.	Explain “Even though you feel better, you are not cured. There is still MDR-TB in your lungs that will start growing again if you stop treatment.”
The person affected by TB has economic problems that affect his/her ability to be adherent.	Assess basic housing, food and clothing needs and explore ways to address these needs.
The person affected by TB is suffering from alcohol or drug abuse.	Discuss possible alcohol or drug abuse with the family and the person. Refer the person to drug treatment programmes.
The person affected by TB has a bad relationship with the health worker supervising treatment.	Discuss these issues with the community health worker supervising treatment. Change the health worker if these problems cannot be resolved.
The person affected by TB is experiencing isolation, stigma or discrimination.	Educate the family and community. Consider involving community leaders if the person agrees.

Slide 10: Support required by a person affected by MDR-TB



Step 3: Summarize (5–10 mins)

Discuss questions that may come up and close the session by summing up key points from the session.

Session 3.3

Active listening and attending skills

Duration 1 h 30 mins

Training aids/materials required

- Handouts
- Whiteboard/flipchart
- Marker pens

Learning objectives

At the end of the session, participants will be able to demonstrate strategies for active listening and describe its importance in counselling.

Methodology

Step 1: Selective listening skills exercise (15 mins)

Selective listening is the act of hearing and interpreting only parts of a message that seem relevant to you, while ignoring or devaluing the rest. Often, selective listeners will form arguments before they have heard the full story, making them poor listeners.

To confront this in a group environment, the facilitator should compose a list of objects or ideas, all similar in theme, e.g. turkey, lettuce, tomato, mayo, mustard, cheese, etc. These are all sandwich components, and most people will recognize this. The list should be relatively long, maybe 15 to 20 words, and have some repeated words. For example: turkey, lettuce, tomato, mayo, mustard, cheese, ham, lettuce, pickles, onion, olives, lettuce.



The moderator should read this list to the group, and then allot them 30 seconds to write down as many words as they can remember. Most people will remember the word that was repeated the most, and a notable amount will most likely write down words that were obvious, but not actually stated in the list. For example: bread, sandwich, food.

Step 2: Exercises on active listening (35 mins)

- Choose one of the following options:
 - **Option 1.** Pair up participants, and have one person discuss a hobby or passion, while the other person is instructed to ignore what the partner is saying. Discuss the frustration that can come with not feeling heard or acknowledged and review good body language and verbal remarks that a good listener should practice.
 - **Option 2.** In pairs, one participant discusses a type of location they would like to visit, giving only subtle hints as to the specific place. The listener will have to pick up on these subtleties and at the end, recommend somewhere suitable for the speaker based on their explanation. The original speaker will confirm or deny the usefulness of the suggestion, and the two will then discuss ways people can stay alert as a listener, and pick up on the appropriate cues to help them play a more vital role in discussions.
 - **Option 3.** Participants are asked to work in pairs. One person from each pair is asked to step outside. The participants inside the room are asked to think of and share a personal experience that has been difficult for them when their partners return.
- The participants who are outside are asked to seem distracted and not demonstrate active listening skills while their partners are sharing their experience.

- The pairs sit facing each other. Once this is complete, the partners who are seated inside the room are asked to share another personal experience with their partners. This time the participants who are outside are asked to display active listening skills and be with their partners as they hear their experience.
- The partners who shared their experience are asked by the facilitator to share how they felt both times and the difference in how their partners were listening.

Step 3: Interpersonal communication skills (15 mins)

- Ask participants to suggest ways to enhance interpersonal communication. Note responses on whiteboard/flipchart
- Reinforce suggestions by listing “dos and don’ts” from the notes on Interpersonal Communication Skills in the additional resources for facilitators section.

Step 4: SOLER attending skills (10 mins)

Discuss the SOLER attending skills with the participants (distribute Handout 3.2.1)

- **S**quarely face the client
- **O**pen posture
- **L**ean in on occasion
- **E**ye contact
- **R**elaxed and natural behaviour

Step 5: Summarize (5 mins)

- Sum up key points
- Inform participants that these skills would be put to use in the following session.





Handout 3.3.1 SOLER attending skills

Attending skills – SOLER

- **S**quarely face the client
- **O**pen posture
- **L**ean in on occasion
- **E**ye contact
- **R**elaxed and natural behaviour



Additional resources for facilitators

Interpersonal communication skills

The skills involved in good interpersonal communication include:

- listening and understanding
- demonstrating caring, concern and commitment
- problem solving and motivating.

Listening and understanding

Listening and understanding involve more than simply being present while someone is speaking. Active listening means genuinely hearing the other person's words. Often, we think we are listening, but we actually do not pay close attention or do not really hear what the other person is trying to say.

Some key points for improving listening and understanding skills are below.

Dos

- Offer a seat before interacting with the person
- Allow sufficient time for the interaction
- If time is limited, give your full attention during the time you have and the same should be apparent to the person
- Be prompt so the other person does not have to wait a long time for your attention
- Sit with the other person so you are at their level
- Maintain eye contact
- Move your head to indicate you are paying attention
- Apologize for any unforeseen interruptions
- Ask open-ended questions (question that cannot be answered with “yes” or “no”) such as questions that begin with “what”, “why” or “how”. These questions require more than just a few words in the answer
- Periodically summarize what the other person has said to ensure that you have understood; use their own words to repeat the ideas back to them.

Don'ts

- Interrupt while the other person is speaking
- Yell at the other person
- Ask questions that can be answered with just one word; for example, questions that begin with “Do”
- Perform other activities during the meeting
- Ask difficult/embarrassing questions.

Demonstrating caring, concern and commitment

You can demonstrate that you care by expressing your understanding of the feelings and concerns of the other person and by letting them know that you want to help them. You can reflect the other person's emotions back to them with facial expressions that show you are concerned. You can also provide verbal feedback to them to show acknowledgement and recognition of their fears and concerns. Some key points are below.



Dos

- Greet the person
- Say, “Hello, please be seated”
- Address the person by name or appropriate title but always with respect
- Acknowledge and respond to each of their concerns
- Emphasize that your job is to help them
- Ask about family members
- Treat the person with respect
- Smile.



Don'ts

- Minimize or dismiss their concerns
- Put down the other person
- Act superior
- Assume the person knows their way to another person/room/office; give them proper guidance to their next destination.
- Argue with the person.

Problem solving

After listening, understanding and showing that you care, you can then use your knowledge of TB to discuss ways you can work together to find solutions to the problem the other person has with regard to the prevention of TB. Some key points for this are given below.

Dos

- Listen carefully to their point of view
- Paraphrase and summarize frequently to make sure that you understand the problem
- Use non-technical words

- Help them to comply
- Demonstrate that you are concerned about the person
- Convey that you understand their fears and apprehensions
- Make them comfortable
- Identify obstacles to their participation.

Don'ts

- Assume that you know all the answers
- Use technical words
- Treat them as your students
- Tell them to comply
- Assume you know their condition
- Expect compliance without explanation.

Motivating

Finally, you can use all of the knowledge, understanding and trust you've gained during your interaction to continue to motivate each person to maintain involvement in the programme. Here are some of the main points to keep in mind for motivating:

Dos

- Repeat important information in different ways each time you meet
- Emphasize that your job is to help them
- Emphasize that they can lead a perfectly normal life like anyone else
- Use examples from your own experience
- Tell them that this is what you would recommend to your family members
- Compliment the other person on what they have done well
- Recognize their progress
- Emphasize that their welfare is your concern



Don'ts

- Use technical words
- Ignore the efforts the other person has made so far
- Overlook their fear and anxiety
- Ignore or minimize practical barriers
- Criticize their omissions/commissions.

Session 3.4

Supportive counselling

Duration 1 h

Training aids/materials required

- Copies of Handout 3.4.1

Learning objective

At the end of this session, participants will be able to demonstrate basic supportive counselling techniques.

Methodology

Step 1: Peer counselling in practice (35 mins)

- Ask participants to get into pairs. Provide each pair with a scenario from the samples provided at the end of this section (Handout 3.4.1)
- Request one to play the part of the counsellor and the other of the counselee. Let them take 10–15 mins to conduct a counselling session, employing the techniques discussed in the previous session.

Step 2: Reflection (5 mins)

- Request feedback from the participants on the key issues that were discussed, focusing on:
 - what worked well and what did not
 - how many of the “counsellors” felt out of depth and needed help
 - whether any of them had addressed referrals for specific problems



- Discuss the need for referral in case of possible issues they could encounter that would fall beyond the scope of peer counselling. Provide them tips on identifying when to refer people for professional help, for example — potential mental health issues, suicidal ideation, serious unaddressed medical complications, etc.

Step 3: Peer support groups (15 mins)

Discuss the possibilities of forming peer support groups for DR-TB survivors and, if so, what steps could be undertaken.

Some practical steps from the context of other diseases could include the following:

- Elicit opinions on whether a sufficient number of DR-TB survivors and/or activists would be willing to volunteer peer counselling support to other community members requiring support
- Identify common areas of interest
- Identify neutral spaces where they can meet informally
- Recognize strengths or capacities of members according to their interests/abilities
- Select mode of regular communication — meetings, app-based groups, phone calls or other preferred means
- Establish channels for open communication that allow information sharing, peer support, undertaking collective activities and problem-sharing.

Note: If the formation of peer support groups for DR-TB survivors and activists is seen to be a feasible concept, this may be revisited in the course of Module 4

Step 4: Summarize (5 mins)

Close the session by revisiting the key areas discussed.



Handout 3.4.1 Sample scenarios

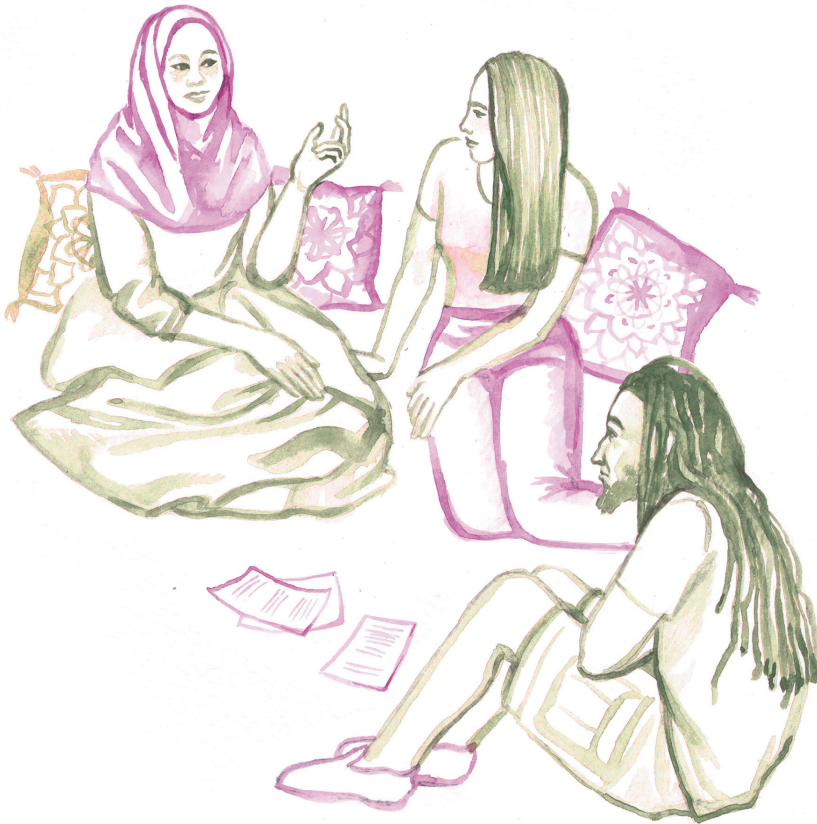
1. Mr H is a 28-year-old married man, and has a 1-year old child. He is the only earning member in the family. Now that he is has been diagnosed with DR-TB, he has also been put on medication. Mr H says that all he wanted was to get cured of DR-TB and get well. But he also reports that each dosage of medication makes him tired and unable to work. This has led him to be absent from work for many days now.
2. Ms G has been married for a year now. She is 23 years old. Her mother-in-law troubles her a lot and keeps belittling her. She never allows her to visit her maternal home. A few weeks ago, Ms G was told at the government hospital that she had DR-TB and must be on medication for many months. Ms G often feel tired and could not do much domestic work. Now her mother-in-law is asking her to go back to her maternal home till she gets cured. This has caused more tension and frequent quarrels.
3. Mr X is 36 years old, a peace loving and quiet person. He is married and has a 10-year-old child. After he started to take DR-TB medication, Mr X's anger is easily triggered and he has become uncharacteristically violent. After he calms down, he regrets his behaviour. As this is happening often, he blames it as a side effect of medications and wants to stop DR-TB medication.
4. A 55-year-old person, diagnosed with MDR-TB, is on a regimen that includes cycloserine and amikacin. Within 1 month of initiation of therapy, the person developed joint pain, restlessness, depression, constipation, insomnia, tinnitus and a decrease in hearing sensation. Very soon the person also developed repeated suicidal thoughts, and his worried wife brought him to the clinic.



MODULE 4



Community feedback systems



Session 4.1

Why community feedback?

Duration 1 h 15 mins

Training aids/materials required

- LCD projector and laptop
- Flipchart/whiteboard
- Coloured whiteboard markers/pens
- Chart paper and coloured pens
- Handout 4.1.1

Learning objectives

By the end of this session, participants will be able to:

- explain the need for community feedback systems for the TB-affected community
- describe priority issues that can be addressed through community engagement.

Methodology

Step 1: Brainstorming (10 mins)

Ask participants to suggest reasons why a robust community feedback system is needed in the context of TB

Supplement responses with possible reasons that could include the following:

- To empower the community on their rights and entitlements to quality health care
- To demand greater accountability from policy-makers and service providers in terms of service delivery



- To promote planning based on locally relevant priorities and issues identified by the community
- To encourage more practical and appropriate ways of improving quality and delivery of services.

Facilitator's note

Explain that as we progress through the day's sessions, we will be exploring examples of community feedback systems that have been successfully implemented in other countries and settings.

Step 2: Understanding the rights and responsibilities of people affected by TB (5 mins)

Provide participants with a copy each of the Patients' Charter for TB Care (Handout 4.1), briefly explaining its contents:

The Patients' Charter for Tuberculosis Care²² (the Charter) outlines the rights and responsibilities of people with TB. It empowers people affected by TB and their communities through this knowledge. Initiated and developed by persons affected by TB from around the world, the Charter makes the relationship with health-care providers a mutually beneficial one.

Step 3: Group exercise (35 mins)

Divide participants into four groups. Each group is assigned two sections each of the Patients' Charter on patients' rights and one each of the patients' responsibilities.

Ask participants to discuss each point assigned to their group and to specify whether community members have full access to these rights and if they can fulfil the responsibilities outlined in the charter.

In case of inadequacies, ask them to specify reasons for the same and suggest how these can be overcome using the following table, for example:

COMPONENT		REASONS FOR INACCESSIBILITY	POSSIBLE SOLUTION/REMEDY
PATIENTS' RIGHTS	PATIENTS' RESPONSIBILITIES		
Care			
Dignity			
	Share information		

Step 4: Presentation of group exercise (20 mins)

One representative/spokesperson from each group presents the key points from the group discussion at the plenary. Questions and comments are invited from other groups.

Step 5: Summarize (5 mins)

Close the session by explaining that this exercise is expected to provide an idea of basic priority issues that need to be addressed through the community engagement and to delineate activities that need to be taken up as part of the planning process.





Handout 4.1.1 The Patients' Charter for tuberculosis care: patients' rights and responsibilities (abridged version)

Patients' rights

You have the right to:

Care	Free and equitable TB quality care meeting the International Standards of Tuberculosis Care (ISTC) Benefit from community-care programmes
Dignity	Be treated with respect and dignity Social support of family, community and national programmes
Information	Information about available care services — be informed about condition and treatment, know drug names, dosage and side-effects Access your medical records in the local language Have peer support and voluntary counselling
Choice	A second medical opinion, with access to medical records Refuse surgery if drug treatment is at all possible Refuse to participate in research studies
Confidence	Have your privacy, culture and religious beliefs respected Keep your health conditions confidential Care in facilities that practice effective infection control
Justice	File a complaint about care, and have a response Appeal unjust decisions to a higher authority Vote for accountable local and national patient representatives

Organization	<ul style="list-style-type: none"> Join or organize peer support groups, clubs and NGOs Participate in policy-making in TB programmes
Security	<ul style="list-style-type: none"> Job security, from diagnosis through to cure Food coupons or supplements if required Access to quality-assured drugs and diagnostics

Patients' responsibilities

You have the responsibility to:

Share information	<ul style="list-style-type: none"> Inform health-care staff all about your condition Tell staff about your contacts with family, friends etc. Inform family and friends and share your TB knowledge
Contribute to community health	<ul style="list-style-type: none"> Encourage others to be tested for TB if they show symptoms Be considerate of care providers and other patients Assist family and neighbours to complete treatment
Follow treatment	<ul style="list-style-type: none"> Follow the prescribed plan of treatment Tell staff of any difficulties with treatment
Show solidarity	<ul style="list-style-type: none"> Show solidarity with all other patients Empower yourself and your community Join the fight against TB in your country



Additional resources for facilitators

The Patients' Charter for Tuberculosis Care²³

The Patients' Charter for Tuberculosis Care (The Charter) outlines the rights and responsibilities of people with TB. It empowers people with the disease and their communities through this knowledge. Initiated and developed by patients from around the world, The Charter makes the relationship with health-care providers a mutually beneficial one.

The Charter sets out ways in which patients, the community, health providers (both private and public) and governments can work as partners in a positive and open relationship with a view to improving TB care and enhancing the effectiveness of the health-care process. It allows for all parties to be held more accountable to each other, fostering mutual interaction and a positive partnership.

The Patients' Charter for Tuberculosis Care practices the principle of Greater Involvement of People with Tuberculosis (GIPT). This affirms that the empowerment of people with the disease is the catalyst for effective collaboration with health providers and authorities and is essential to victory in the fight to stop TB. The Charter, the first global "patient-powered" standard for care, is a cooperative tool, forged from common cause, for the entire TB community.

Patients' rights

Care

- The right to free and equitable access to TB care from diagnosis through treatment completion regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture, or having another illness

- The right to receive medical advice and treatment which fully meets the new International Standards for Tuberculosis Care (ISTC), centring on patient needs, including those with MDR-TB or TB–HIV co-infections and preventative treatment for young children and others considered to be at high risk
- The right to benefit from proactive health sector community outreach, education and prevention campaigns as part of comprehensive care programmes

Dignity

- The right to be treated with respect and dignity, including the delivery of services without stigma, prejudice or discrimination by health providers and authorities
- The right to quality health care in a dignified environment, with moral support from family, friends, and the community



Information

- The right to information about what health-care services are available for TB and what responsibilities, engagements, and direct or indirect costs are involved
- The right to receive a timely, concise and clear description of the medical condition, with diagnosis, prognosis (an opinion as to the likely future course of the illness) and treatment proposed, with communication of common risks and appropriate alternatives
- The right to know the names and dosages of any medication or intervention to be prescribed, its normal actions and potential side-effects and its possible impact on other conditions or treatments



- The right of access to medical information that relates to the patient's condition and treatment and to a copy of the medical record if requested by the patient or a person authorized by the patient
- The right to meet, share experiences with peers and other patients and to voluntary counselling at any time from diagnosis through treatment completion

Choice

- The right to a second medical opinion, with access to previous medical records
- The right to accept or refuse surgical interventions if chemotherapy is possible and to be informed of the likely medical and statutory consequences within the context of a communicable disease
- The right to choose whether or not to take part in research programmes without compromising care

Confidence

- The right to have personal privacy, dignity, religious beliefs and culture respected
- The right to have information relating to the medical condition kept confidential and released to other authorities contingent upon the patient's consent

Justice

- The right to make a complaint through channels provided for this purpose by the health authority and to have any complaint dealt with promptly and fairly
- The right to appeal to a higher authority if the above is not respected and to be informed in writing of the outcome

Organization

- The right to join, or to establish, organizations of people with or affected by TB and to seek support for the development of these clubs and community-based associations through health providers, authorities and civil society
- The right to participate as stakeholders in the development, implementation, monitoring and evaluation of TB policies and programmes with local, national and international health authorities

Security

- The right to job security after diagnosis or appropriate rehabilitation upon completion of treatment
- The right to nutritional security or food supplements if needed to meet treatment requirements

Patients' responsibilities

Share Information

- The responsibility to provide the health-care giver as much information as possible about present health, past illnesses, any allergies and any other relevant details
- The responsibility to provide information to the health provider about contacts with immediate family, friends and others who may be vulnerable to TB or may have been infected by contact

Follow treatment

- The responsibility to follow the prescribed and agreed treatment plan and to conscientiously comply with the instructions given to protect the patient's health and that of others
- The responsibility to inform the health provider of any difficulties or problems with following treatment, or if any part of the treatment is not clearly understood



Contribute to community health

- The responsibility to contribute to community well-being by encouraging others to seek medical advice if they exhibit symptoms of TB
- The responsibility to show consideration for the rights of other patients and health-care providers, understanding that this is the dignified basis and respectful foundation of the TB community

Show solidarity

- The moral responsibility of showing solidarity with other patients, marching together towards cure
- The moral responsibility to share information and knowledge gained during treatment and to pass this expertise to others in the community, making empowerment contagious
- The moral responsibility to join in efforts to make the community TB free

Session 4.2

Mapping existing systems

Duration 1 h 30 mins

Training aids/materials required

- LCD projector and laptop
- Flipchart/whiteboard
- Coloured whiteboard markers/pens
- Chart paper and coloured pens

Learning objectives

At the end of this session, participants will be able to illustrate existing systems of service delivery and identify barriers thereof.

Methodology

Step 1: Building on what we know (10 mins)

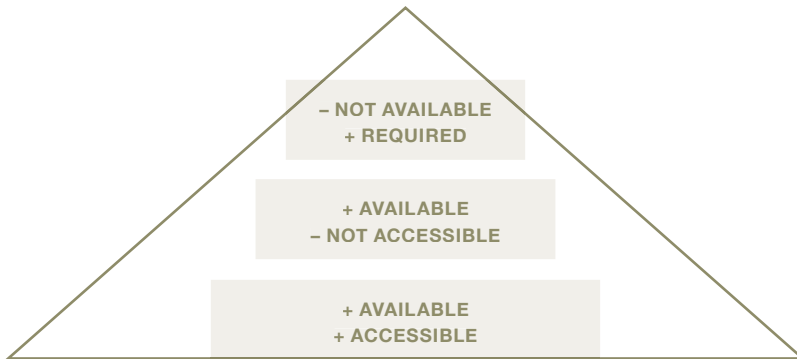
Refer back to issues highlighted in preceding sessions/modules that may be summarized in this exercise. Request participants to reflect on the community's current needs in terms of enhanced access to services and also on services that they would benefit from in the future.

Step 2: Group exercise (45 mins)

Ask participants to work in four groups using the following diagram to identify TB-related services, interventions and platforms in their respective contexts.



Tuberculosis-related inventions / services / structures / platforms



List suggestions of how the currently unavailable and inaccessible areas can be addressed:

- At the base of the pyramid, participants list the services that are available and are easily accessed by the community.
- In the second level, they list services that are available but not easily accessed. Participants should also be asked to discuss why these services are not being accessed.
- At the top of the pyramid, they list services that are required but not available or accessible. Possible reasons are also to be discussed.
- Ask participants to discuss how overall services can be improved with the community's proactive engagement at all levels, and how the aspirational goals at the top of the pyramid can be made possible over time.

Step 3: Presentation of group work (30 mins)

Representatives from each group present their diagrams and group members supplement points. Other groups are invited to comment.

Facilitator's note

It is important to note which section of the pyramid contains the bulk of points in each of the groups' presentations. This basic situational analysis could point to areas that need more intensive focus for the planning process described in the final session.

Step 3: Summarize (5 mins)

Explain that this exercise is one that can be used in order to elicit basic information from the community about existing services, barriers and the potential for the community to come together to promote enhanced services.

Additional resources for facilitators

Guidance for civil society organizations (CSOs)/NGOs²⁴

Asking how community experiences of TB services can help to:

- identify gaps in services
- plan how to help people overcome any barriers
- advocate with health workers and managers to improve access to services.

The main information that an NGO/CSO will need from a situation analysis will be about the TB services and health infrastructure currently available to their community. This will help to understand where the services are and how people can use them. It will show whether there are any gaps or barriers that prevent people from accessing TB services. It should also make clear where and how people can be referred from the community to TB services.



The situation analysis should include all the places in which community-based TB activities can happen and where the health system provides TB services, for example in:

- community meeting places
- local dispensaries or health posts
- health centres used by the community
- health facilities with TB laboratory and X-ray services
- TB clinics with diagnosis and treatment facilities
- referral centres for specialist TB care, such as for MDR-TB and XDR-TB.

Session 4.3

Global examples of community feedback systems

Duration 1 h 15 mins

Training aids/materials required

- LCD projector and laptop
- Flipchart/whiteboard
- Coloured whiteboard markers/pens
- Chart paper and coloured pens

Learning objective

By the end of this session, participants will be able to differentiate between the different models of community feedback and monitoring employed in various global contexts in order to adopt or adapt the most appropriate model/s.

Methodology

Step 1: Exploring existing knowledge base (10 mins)

Ask participants to suggest examples of community feedback and monitoring systems that they know of. These could include illustrations from other sectors besides health or TB. List the responses on a flipchart or whiteboard. Invite brief descriptions of each example, if possible.



Step 2: Describing existing approaches (15 mins)

Describe the basic approaches for community monitoring and feedback employed in different contexts. Most of the examples fall into broadly two categories:

1. **Government-led/provider-initiated monitoring mechanisms.**
These are systems built into the national programme for feedback or reporting of grievances by the community, as well as local mechanisms constituted to monitor service delivery. These could include coordination between local health services and community representatives.
2. **Community-led monitoring/feedback systems.** These could imply either informal monitoring and feedback systems on service delivery led by the community, or more structured assessments of health facilities by trained community members and feed-back during regular meetings with national/sub-national programme managers and other stakeholders.

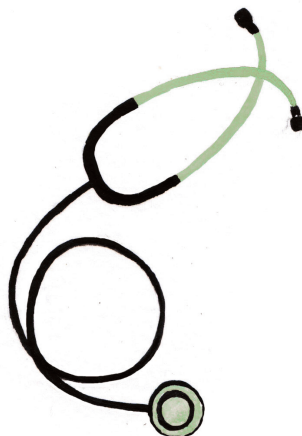
Facilitator's note

Please see section on additional resources for facilitators

Step 3: Discussion (20 mins)

Open discussions on:

- advantages and disadvantages of these approaches
- which, if any, of these approaches could be adopted or adapted by the community to address existing needs and future stages of progress
- comments and suggestions from participants.



Step 4: Back to basics (25 mins)

Facilitator's note

If participants are already part of well-established community groups, this step may be used as a brief checklist. However, if participants indicate that they are still in the nascent stages of coming together as a community, the process outlined below may be discussed in more detail.

Steps to facilitate basic community feedback mechanisms

1. Decide on what kind of information needs to be collected from the community. This could be in the form of qualitative information or basic quantitative information drawn from the barriers or issues identified in preceding sessions.
2. Identify key community representatives who are willing to be part of this process.
3. Collect the information you need using a range of methods such as informal and semi-structured interviews with individuals or small groups and other participatory approaches. A checklist may be used if monitoring services are available at a health-facility.
4. Analyse the information and consolidate agreed priority themes and issues such as:
 - what is happening on TB in the target communities
 - gaps in services and NGOs/CSOs that are not active on TB but could be engaged
 - important barriers that prevent people from using TB services or from completing their TB treatment
 - suggestions for removing these barriers.



5. Establish a mode of regular communication or meetings to discuss plans to address these issues and to ensure consistent updates on progress.
6. Ensure meaningful participation at larger platforms such as national/state/district level TB forums, as well as coordination meetings with local health providers and the National Tuberculosis Programme (NTP). Present updated information in a format that will help them to clearly understand the issues and advocate for action. Feedback supported by evidence and actual data is likely to have a greater impact.
7. Network with national and international networks, agencies and organizations on issues of common interest.
8. Explore available avenues for capacity-building of community members on an ongoing basis.

Step 5: Summarize (5 mins)

Reinforce key points discussed in this session, stressing that these are crucial building blocks for the action plans that will be developed in the final session.

Additional resources for facilitators

Approaches to community feedback and monitoring

A. Government led/provider initiated monitoring mechanisms

These are systems built into the national programme for feedback or reporting of grievances by the community, as well as local mechanisms constituted to monitor service delivery that could include coordination between local health services and community representatives. Examples include formation of committees at

community and health service levels, setting up NGO coordinating bodies (NCBs), community score cards, facility level score cards, district/state level coordination committees and the use of digital technology.

Examples

1. Coordination meetings

Periodic coordination meetings are called by the NTP at national and state levels to discuss feedback on quality of service, validate data and programming. In some countries, TB forums have been established at district, state and national levels in which representation from the community and civil society organizations is ensured. Local level coordination meetings between various local health services, stakeholders and community representatives are also held.

Note: NTPs operate at national, regional/provincial, district and health facility levels. At national level, the NTP is responsible for TB strategy, policy and overall programme management. Depending on the country context, TB service delivery may be managed by a regional or provincial TB coordinator. The NTP basic management unit (BMU) is at district or equivalent level. It is responsible for all TB public health programmes in its area, including training, supervision, drug supply and monitoring. Services are usually provided by hospitals and clinics. At local level, TB services are usually provided through health centres, health clinics and health posts. These are usually part of the public health system. Services may also be provided by not-for-profit NGOs or faith-based organizations (FBOs) and private practitioners.



2. NGO coordinating bodies

Government programmes can link with NGOs/CSOs for specific health approaches through an NGO coordinating body (NCB) that brings NGOs together as a coalition or network. This should be set up and independently managed by the NGOs/CSOs, who can then not only more systematically engage in partnership with government but also act as advocates. The NCB can act as an umbrella body for NGOs/CSOs to develop a working relationship and engage with the NTP, health providers and each other. It can provide the NTP with a clear contact point for active and systematic collaboration and for hearing about the needs, constraints and lessons learnt by NGOs/CSOs in planning, resourcing and implementing community-based TB activities. The NCB is also a structure that can serve to attract more and more NGOs and CSOs that have not been aware of or been involved in TB activities on a continuing basis. This has the potential to extend TB activities to more communities and to neglected parts of the population.

3. Community scorecards

The Community scorecard is a 2-way and ongoing participatory tool for assessment, planning, monitoring and evaluation of services. It is easy to use and can be adapted into any sector where there is a service delivery scenario. The community scorecard brings together the demand side (service user) and the supply side (service provider) of a particular service or programme to jointly analyse issues underlying service delivery problems and find a common and shared way of addressing those issues. It is an exciting way to increase participation, accountability and transparency between service users, providers and decision-makers. It is a participatory tool that:

- is conducted at micro/local level and uses the community as the unit of analysis;
- generates information through focus group interactions and enables maximum participation of the local community;
- provides immediate feedback to service providers and emphasizes immediate response and joint decision-making; and
- allows for mutual dialogue between users and providers and can be followed by joint monitoring.

The Community scorecard is meant for use by government institutions at various levels from central ministries to local assemblies, district staff and government agencies; NGOs (national and international) operating in various sectors such as health, agriculture, education, governance, gender and rights; community-based structures such as health centre committees and village development committees; community-based organizations such as women's groups and home-based care groups; and community committees whose responsibility it is to represent their constituents in the community, e.g. village health committees, village development committees, village AIDS committees, etc.²⁶

4. QUOTE TB Light

QUOTE TB is a tool that is meant for use as part of regular NTP supervision activities. It is an instrument to measure the needs and perceived quality of services from the perspective of persons affected by TB. It is also a management tool to help NTPs, health facilities and their partners assess the quality of TB services, based on feedback received from the community. The tool focuses on nine dimensions of quality TB care. It consists of a TB patient focus group discussion guide, standardized TB patient questionnaire and quality impact scoring sheet.



5. Community Action for Health

The Community Action for Health, earlier known as Community Based Monitoring and Planning, is a key strategy of the National Health Mission (NHM), which places people at the centre of the process of ensuring that the health needs and rights of the community are being fulfilled. It allows them to actively and regularly monitor the progress of the NHM interventions in their areas. It also results in communities participating and contributing to strengthening health services. The process involves strengthening of Village Health, Sanitation and Nutrition Committees (VHSNCs), Rogi Kalyan Samitis (RKSs) and Planning and Monitoring Committees (PMCs) at the primary health care (PHC), block, district and state levels; creating community awareness on NHM entitlements, roles and responsibilities of the service providers; training of VHSNC, RKS and PMC members; undertaking community level enquiries to assess availability, range and quality of health services; developing village and facility level reports to reflect the status of health services; organizing jan samvad (public dialogue) for advocacy with health providers and managers to highlight gaps and find solutions; and corrective action and planning to address the emerging issues and gaps.²⁷

6. Digital technology

This encompasses smart phone based applications and other digital media that aim to enable community groups to monitor access to HIV prevention and treatment and provide feedback on the quality of those services. The updated TB treatment guidelines for drug-susceptible TB published by WHO in April 2017 include, for the first time, evidence-based recommendations related to the use of digital technologies. These include short message service (SMS, mobile phone texting), video-supported TB treatment and electronic medication monitors. Although data on the impact of these

interventions on improving treatment outcomes of persons affected by TB and reducing costs to health services remain limited, several studies that are expected to improve the quality of the evidence and provide more information on their performance in different settings are now underway. Digital technologies are being used in a variety of ways in TB care. Some interventions are pilot projects whereas others are implemented on a much larger scale.²⁸

B. Community-led monitoring/feedback systems

These could imply informal monitoring and feedback systems on service delivery led by the community, or more structured assessments of health facilities by trained community members.

Examples include establishing support groups of people affected by TB, informal groups that communicate via social media to address stock-outs, human rights violations, stigma and discrimination, etc.

Examples

1. Networks of PLHIV and key populations

Community networks of PLHIV and key populations such as people who use drugs, men who have sex with men, sex workers and transgender people at regional, national, state and district levels are often the driving force behind empowering communities.

At the international level, the Global Network of People Living with HIV (GNP+) advocates to improve the quality of life of PLHIV. As a network of networks, GNP+ is driven by the needs of PLHIV worldwide. GNP+ works with independent and autonomous regional and national networks of PLHIV in all continents. GNP+ has created different evidence gathering tools to support networks of PLHIV and HIV community activists in their advocacy. The tools use the methodology of learning-by-doing, empowering PLHIV with knowledge and skills and



building the capacity of GNP+ partners. GNP+ uses the power of evidence-based advocacy to improve the HIV response and the lives of PLHIV. In different countries, the tools have been instrumental to policy change.

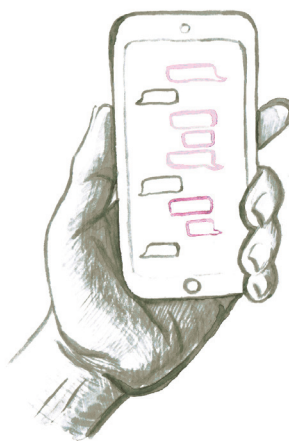
2. HIV Stigma Index²⁹

The PLHIV Stigma Index is the world's largest social research project implemented by PLHIV themselves. Since the project began in 2008 it has been implemented in over 70 countries and translated into 54 languages. More than 1600 PLHIV have been trained as interviewers and over 100 000 PLHIV have been interviewed.

The Stigma Index provides a tool that measures and detects changing trends in stigma and discrimination experienced by PLHIV. The Stigma Index operationalizes the Greater Involvement of People Living with HIV/AIDS (GIPA) principle, while building an evidence base and increasing advocacy. It aims to address stigma relating to HIV while also advocating on the key barriers and issues perpetuating stigma – a major obstacle to HIV treatment, prevention, care and support. The Index helps to improve workplace policies, informs debates about the criminalization of HIV transmission and promotes the realization of human rights.

3. Social media platforms

Community feedback via social media (Facebook, WhatsApp, other chat groups) is becoming an increasingly popular method for community members to express opinions, share information, provide feedback and take action when appropriate. While mostly informal, priority discussion topics include treatment issues,



stock-outs of essential medications, emergency cases, reporting incidents of stigma and discrimination, news and updates.

4. Client satisfaction surveys

These online applications are used to monitor quality of services in communities via client satisfaction surveys.

What do NGOs/CSOs need in order to work effectively on TB?³⁰

Reaching more people with community-based TB activities requires NGOs/CSOs to identify and provide a set of TB services and to collaborate with the NTP and the health system. Larger NGOs may already have sufficient funding and other support that enables them to integrate community-based TB activities into their existing portfolio of work. Some smaller organizations may not have enough resources or capacity to do this. However, they may have the potential to develop their capacity if they are strengthened. The resources and support especially needed are:

- **Funding** to ensure their stability as organizations (core funding) while they implement their activities
- **Technical support, mentoring and resources** to assist them in delivering services, documenting activities and engaging in advocacy
- **Training and capacity-building** for running their organization or group and for implementing their TB activities, including mentorship and technical support
- **Linkages and partnerships** to support their contributions to community health, including with other NGOs, national programmes such as the NTP and providers of funding, training and mentoring and technical resources.



Session 4.4

Getting to where we want to be

Duration 1 h 30 mins

Training aids/materials required

- LCD projector and laptop
- Flipchart/whiteboard
- Coloured whiteboard markers/pens
- Chart paper and coloured pens
- Copies of Handout 4.4.1

Learning objective

By the end of this session, participants will be able to develop community-centred action plans.

Methodology

Step 1: Putting it together (5–10 mins)

Ask participants to reflect on key areas that have been discussed over the course of various sessions in the workshop that can be related to their respective contexts. These may be in the form of issues prioritized, barriers identified and measures that can either be explored or incorporated into their future course of action.

Step 2: Prioritizing issues and objectives (15 mins)

Facilitator's note

Before starting on the group exercise, consider the composition of the participants. If they all share the same or similar geographical/situational contexts, they may be asked to work in larger groups. However, if the representation is from diverse contexts, individual sheets of the action plan template (Handout 4.2) may be distributed.

- Participants are asked to list the most critical objectives that they need to take up as a community. These are further prioritized in order of importance.
- Inform participants that these may be addressed as the objectives that will go into their action plans.

Step 3: Draft action plans (45 mins)

- Provide participants with copies of the action plan template (Handout 4.4.1)
- Explain what needs to go in to each column. For example:
 - **Objectives:** What is it that they want to achieve?
 - **Activities:** What will they do in order to achieve the objectives?
 - **Person/s responsible:** Who will take up the assigned responsibilities for the activities?
 - **Potential allies:** Are there other community groups, health-care service providers, stakeholders or CSOs that they can partner with?
 - **Timelines:** When will these activities take place?
 - **Resources required:** What will they require in order to carry out their activities?

Note: Resources do not necessarily mean only financial resources. They can include human resources, time or concepts.



Step 4: Presentation of group work (15 mins)

Facilitator's note

If participants are working in larger groups of three or four, each group can be asked to present their action plans at the plenary. However, if they are working individually, the facilitator may call for three or four volunteers to share the action plans that they have drafted.

Facilitate discussion on the draft action plans and focus on whether the objectives and activities indicate a movement towards enhanced community involvement in feedback/monitoring to improve adequacy of service provision in the context of DR-TB management.

Step 5: Summarize and close (5 mins)

Close the session by asking participants to reflect on how best they could take forward the action plans in their respective contexts.



Handout 4.4.1 Action plan template

OBJECTIVES	ACTIVITIES	PERSON(S) RESPONSIBLE	POTENTIAL ALLIES	TIMELINES	RESOURCES REQUIRED



Additional resources for facilitators

Writing objectives³¹

- Discuss the meaning of the word “objective” (a statement about specific activities of a project and what it will achieve through these activities)
- Explain how objective writing helps to answer the following questions:
 - What will change as a result of the activity?
 - Who will be most involved in the activity? Who will benefit most from these changes?
 - How much will the activity change a problem?
 - When will the activity be completed?
 - Where will the activity take place?
 - Take one problem at a time. Using the questions outlined above, decide on an objective that would address the problem.
- Explain that objectives should be SMART: specific, measurable, achievable, relevant and time-bound:
 - Specific — an objective should say exactly what will be achieved, with who, how, when and where
 - Measurable — so that you are able to tell exactly when the objective is achieved
 - Achievable — it must be realistic given the circumstances you are working in and time you have available
 - Relevant — it must relate to the problem being addressed
 - Time-bound — it must be achieved by a certain date and not go on and on.



Suggested reading material

1. World Health Organization (2013). Engage-TB: integrating community-based tuberculosis activities into the work of nongovernmental and other civil society organizations: implementation manual. Geneva: World Health Organization; 2013.
2. The People Living with HIV Stigma Index (<http://www.stigmaindex.org/>, accessed 16 March 2019).
3. Community Action for Health (<http://nrhmcommunityaction.org/about/>, accessed 16 March 2019).
4. CARE Malawi. “The Community Score Card (CSC): A generic guide for implementing CARE’s CSC process to improve quality of services.” Cooperative for Assistance and Relief Everywhere, Inc.; 2013 (https://www.care.org/sites/default/files/documents/FP-2013-CARE_CommunityScoreCardToolkit.pdf, Accessed 16 March 2019).
5. Barriers to access — TB Alert (<https://www.tbalert.org/about-tb/global-tb-challenges/barriers-to-accessing-treatment/>, accessed 16 March 2019).
6. World Care Council. The Patient’s charter for tuberculosis care. 2006 (http://www.who.int/tb/publications/2006/istc_charter.pdf, accessed 16 March 2019).

References

1. WHO Global TB report 2018. Geneva: World Health Organization; 2018.
2. Lorent N, Choun K, Thai S, Kim T, Huy S, Pe R et al. Community-Based Active Tuberculosis Case Finding in Poor Urban Settlements of Phnom Penh, Cambodia: A Feasible and Effective Strategy. 2014. PLoS ONE 9(3): e92754 (<https://doi.org/10.1371/journal.pone.0092754>, accessed 17 March 2019).
3. Arshad A, Salam RA, Lassi ZS, Das JK, Naqvi I, Bhutta ZA. Community based interventions for the prevention and control of tuberculosis. *Infectious Diseases of Poverty*. 2014;3–27 (<https://doi.org/10.1186/2049-9957-3-27>, accessed 17 March 2019).
4. Tuberculosis. Geneva: World Health Organization; 2018 (<http://www.who.int/news-room/fact-sheets/detail/tuberculosis>, accessed 10 January 2019).
5. <https://medical-dictionary.thefreedictionary.com/surrogate+marker> An indirect indicator of a disease state or of its response to therapy. Such markers often include laboratory tests thought to represent clinical progress accurately. <http://www.tbonline.info/learn/>
6. Automated real-time nucleic acid amplification technology for rapid and simultaneous detection of tuberculosis and rifampicin resistance: Xpert MTB/RIF system for the diagnosis of pulmonary and extrapulmonary TB in adults and children: policy update. Geneva: World Health Organization; 2013.
7. WHO treatment guidelines for isoniazid-resistant tuberculosis: Supplement to the WHO treatment guidelines for drug-resistant tuberculosis. WHO/CDS/TB/2018.7. Geneva: World Health Organization; 2018.

8. Definitions and reporting framework for tuberculosis – 2013 revision. WHO/HTM/TB/2013.2. Geneva: World Health Organization; 2013.
9. WHO treatment guidelines for drug-resistant tuberculosis, 2016 update. Geneva: World Health Organization; 2016.
10. WHO consolidated guidelines on drug-resistant tuberculosis treatment. Geneva: World Health Organisation; 2019
11. Tuberculosis. TB Publications. Geneva: World Health Organization; 2018 (www.who.int/tb/publications, accessed 17 March 2019).
12. Longer MDR-TB regimens usually last 18–20 months and may be standardized or individualized. These regimens are usually designed to include at least five medicines considered to be effective.
13. The position of delamanid will be re-assessed once individual patient data from Otsuka trial 213 has been reviewed; these data were not available for the evidence assessment outlined above.
14. GLI Practical Guide to TB Laboratory Strengthening. Global Laboratory Initiative; 2017.
15. Latent tuberculosis infection: updated and consolidated guidelines for programmatic management. Geneva: World Health Organization; 2018.
16. Advocacy Strategy Toolkit (http://www.unaids.org/sites/default/files/media_asset/advocacy_toolkit_en_0.pdf, accessed 17 March 2019).
17. TB/HIV Monitoring & Advocacy: Experiences & Leadership by AIDS Activists, Compiled by Public Health Watch (PHW) and Treatment Action Group (TAG). Quote from Tamari Trapaidze.
18. Adapted from: Tools Together Now! – 100 participatory tools to mobilize communities for HIV/AIDS. International HIV/AIDS Alliance; 2006 (https://www.aidsalliance.org/assets/000/000/370/229-Tools-together-now_original.pdf?1405520036)

19. Vihaan Care and Support Programme – Counselling module; pg. 64
20. Adapted from: Building Counselling Skills for DR TB Counsellors, Training Manual. Central TB Division, Directorate General of Health Services, Ministry of Health & Family Welfare, Nirman Bhavan, New Delhi
21. All slides on Counselling are adapted from “Building Counselling Skills for DR-TB Counsellors”
22. The Patients’ Charter for Tuberculosis Care – Patients Rights and Responsibilities. San Francisco: National Tuberculosis Center; 2006 (https://www.who.int/tb/publications/2006/patients_charter.pdf, accessed 17 March 2019).
23. World Care Council. Patient’s charter for tuberculosis care. 2006 (http://www.who.int/tb/publications/2006/istc_charter.pdf)
24. Engage-TB: integrating community-based tuberculosis activities into the work of nongovernmental and other civil society organizations: implementation manual. Geneva: World Health Organization; 2013.
25. Adapted from Engage-TB: integrating community-based tuberculosis activities into the work of nongovernmental and other civil society organizations: implementation manual
26. The Community Score Card (CSC): A generic guide for implementing CARE’s CSC process to improve quality of services – Toolkit. Cooperative for Assistance and Relief Everywhere, Inc.; 2013 (https://www.care.org/sites/default/files/documents/FP-2013-CARE_CommunityScoreCardToolkit.pdf, accessed 17 March 2019).
27. Community action for Health. New Delhi: National Health Mission (<http://nrhmcommunityaction.org/about/>, accessed 17 March 2019).
28. Global Tuberculosis Report 2017. Geneva: World Health Organization; 2017. License: CC BY-NC-SA 3.0 IGO.

29. The People Living with HIV Stigma Index (<http://www.stigmaindex.org/>, accessed 17 March 2019).
30. Engage-TB Approach – Implementation Manual: integrating community-based tuberculosis activities into the work of nongovernmental and other civil society organizations. Geneva: World Health Organization; 2013.
31. Adapted from: Tools Together Now! – 100 participatory tools to mobilize communities for HIV/AIDS. International HIV/AIDS Alliance; 2006 (https://www.aidsalliance.org/assets/000/000/370/229-Tools-together-now_original.pdf?1405520036)

Annexes

Annex 1: Pre and post-test questionnaire

1. TB is cause by a virus and is spread through contaminated water.
a) True b) False

2. People living with HIV are less likely to develop TB disease than people without HIV
a) True b) False

3. MDR TB is caused by bacteria that do not respond to isoniazid and rifampicin
a) True b) False

4. Drug resistance can arise when:
a) Medicines are sub-standard
b) Doses are missed
c) Treatment is interrupted
d) Treatment regimens are inappropriately designed or dosed
e) All of the above

5. Delamanid is widely accessible to patients worldwide.
a) True b) False

6. Listening is not a skill a person has to learn, we are all born with it.
a) True b) False

7. Once you are on DR TB medication you will get well without any trouble.
a) True b) False
8. Family and friends are crucial to recovery for a person affected by DR TB
a) True b) False c) Maybe
9. Counselling is a very important part of DR TB treatment
a) True b) False
10. Many working with people affected by DR TB tend to lose their jobs.
a) True b) False
11. If someone informs you of their TB test result, you can tell others about it.
a) True b) False
12. A busy counsellor can listen to the person affected with TB while typing on the computer.
a) True b) False
13. A counsellor is allowed to argue with a client about medical facts.
a) True b) False
14. Repeating the same information can make the client get upset with the counsellor.
a) True b) False
15. Peer counselling is an activity for trained counsellors.
a) True b) False

16. Advocacy is defined as “informing the policy maker of the difficulties faced by the community”.
- a) True b) False
17. Advocacy activity is expensive.
- a) True b) False
18. Advocacy requires extensive knowledge of media.
- a) True b) False
19. Advocacy is an activity for large NGOs.
- a) True b) False
20. Advocacy is an illegal activity in most countries.
- a) True b) False
21. Knowing politicians is necessary for any advocacy activity.
- a) True b) False
22. Street protests are not advocacy.
- a) True b) False
23. Good advocacy requires evidence collection to support your point.
- a) True b) False
24. Planning is not necessary for community advocacy.
- a) True b) False
25. Twitter is not a real advocacy tool.
- a) True b) False

26. Community feedback systems cannot be used to demand greater accountability from policy makers and service providers in terms of service delivery
 a) True b) False
27. The Patients' Charter for Tuberculosis Care has been developed exclusively by healthcare professionals.
 a) True b) False
28. Existing systems of service delivery for tuberculosis are not uniformly accessible for all community members.
 a) True b) False
29. Community feedback systems can be:
 a) Government/provider-led b) Community-led
 c) Both of the above
30. The community can themselves develop and implement action plans that will improve adequacy of services in the context of DR TB management
 a) True b) False

Answer codes

1 – b	6 – a	11 – b	16 – b	21 – b	26 – b
2 – b	7 – b	12 – b	17 – b	22 – b	27 – b
3 – a	8 – a	13 – b	18 – b	23 – a	28 – a
4 – e	9 – a	14 – b	19 – b	24 – b	29 – c
5 – b	10 – a	15 – b	20 – b	25 – b	30 – a

Annex 2: Feedback forms

Feedback form Day 1

SESSIONS	FEEDBACK PLEASE PLACE CHECK MARK (✓)			REMARKS
	GOOD	FAIR	POOR	
Introductory session				
Session 1.1 Basics of TB				
Session 1.2 Drug resistant TB				
Session 1.3 Prevention				

1. What did you learn during today's sessions that you anticipate using in your work?
2. Was there anything you did not like during today's sessions? Please provide specific examples.
3. Please provide any other comments or suggestions

Thank you.

Feedback form Day 2

SESSIONS	FEEDBACK			REMARKS
	PLEASE PLACE CHECK MARK (✓)			
	GOOD	FAIR	POOR	
Session 2.1 Defining advocacy				
Session 2.2 Whom do you advocate to?				
Session 2.3 How to advocate — the homework				

1. What did you learn during today's sessions that you anticipate using in your work?
2. Was there anything you did not like during today's sessions? Please provide specific examples.
3. Please provide any other comments or suggestions

Thank you.

Feedback form Day 3

SESSIONS	FEEDBACK PLEASE PLACE CHECK MARK (✓)			REMARKS
	GOOD	FAIR	POOR	
Session 3.1 Counselling for DR-TB				
Session 3.2 Counselling information for DR-TB: checklist				
Session 3.3 Active listening and attending skills				
Session 3.4 Supportive counselling				

1. What did you learn during today's sessions that you anticipate using in your work?
2. Was there anything you did not like during today's sessions? Please provide specific examples.
3. Please provide any other comments or suggestions

Thank you.

Feedback form Day 4

SESSIONS	FEEDBACK			REMARKS
	PLEASE PLACE CHECK MARK (✓)			
	GOOD	FAIR	POOR	
Session 4.1 Why community feedback?				
Session 4.2 Mapping existing systems				
Session 4.3 Global examples of community feedback systems				
Session 4.4 Getting to where we want to be				

1. What did you learn during today's sessions that you anticipate using in your work?
2. Was there anything you did not like during today's sessions? Please provide specific examples.
3. Please provide any other comments or suggestions

Thank you.

Annex 3: Icebreakers and energizers

The interview game

Break the group into two-person teams (have them pick a partner that they know the least about). Have them interview each other for about 5 mins. They need to learn about what each other likes about their job, past jobs, family life, hobbies, favourite sport, etc. After the interviews, reassemble the group and have each team introduce their team member to the group. This exercise helps them to learn about each other.

Three in common game

Break the group into threes. Their objective is for each group to find three things they have in common, but not normal things like age, sex or hair colour. It must be three uncommon things. After letting the groups converse for 10–15 mins, they (as a group) must tell the rest of the groups the three things they have in common.

Out on the town game

If you need a quick energizer, ask everyone to pantomime something they did the night before. Individuals or groups can act out a movie they went to, describe a meal they ate, or recreate a scene witnessed at a bar.

Quick change artist game

Pair off into partners facing each other. Each player is to observe his or her partner's appearance. Then the players turn around back-to-back and make two or more changes in their dress, hair accessories, etc. When they face each other again, each partner must identify the changes made by his or her partner. This can be repeated several times by changing partners and increasing the number of changes made.

Sunshine cards game

Everyone writes their name in the centre of a piece of paper and draws a sun around their name. Pass your paper around to the person on your right. That person will write something positive about you and they do not have to sign their name. Continue to pass your name around until everyone has written something on all the papers.



Illustrations by Paulina Siniatkina



