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Ministry of Health and Family Welfare
Government of India

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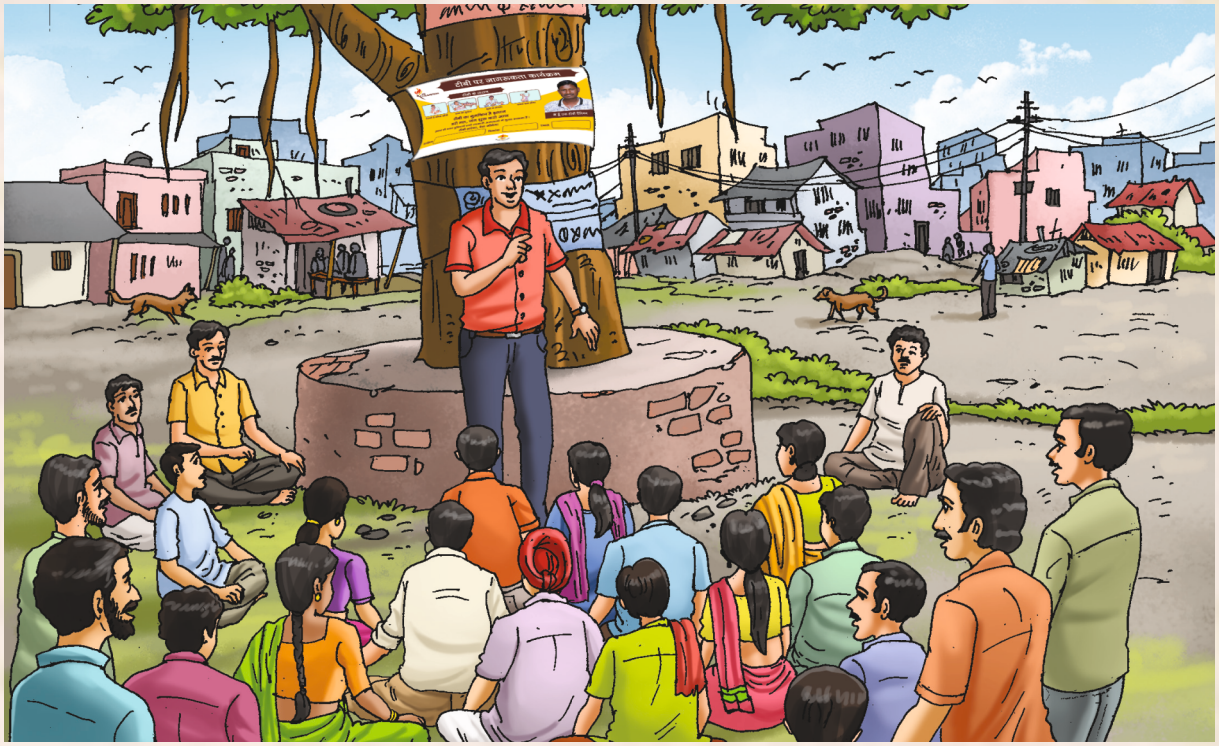

FROM TB SURVIVORS TO TB CHAMPIONS: A TRAINING CURRICULUM

TB CHAMPION

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Central TB Division
Ministry of Health and Family Welfare
Government of India, New Delhi

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CONTENTS

Introduction **13**

Module 1 ..... **15**

TB Science: Getting the basics right 15

Module 2 ..... **24**

TB in India, and the Response 24

- Session 1: Understanding the TB burden 25
- Session 2: Understanding the RNTCP 29
- Session 3: The private sector's role in the TB response 35
- Session 4: A community-led, rights-based approach to TB 39

Module 3 ..... **43**

The TB Care Cascade 43

- Session 1: Our TB Stories 44
- Session 2: Pathways to Cure 46

Module 4 ..... **49**

Effective Advocacy and Communications 49

- Session 1: Introduction to Advocacy 50
- Session 2: Advocating to different stakeholders 54
- Session 3: Using Personal Stories for Advocacy 57
- Session 4: Network Building 62

Module 5 ..... **65**

Providing Psychosocial support to TB-affected communities 65

Module 6 ..... **70**

Building Accountability through Community Monitoring 70

SANJEEVA KUMAR, IAS
Additional Secretary & DG (NACO & RNTCP)
Tele. : 23061066 / 23325331
E-mail : dgnaco@gmail.com
ash-mohfw@nic.in

सत्यमेव जयते

भारत सरकार
स्वास्थ्य और परिवार कल्याण मंत्रालय
निर्माण भवन, नई दिल्ली - 110011
Government of India
Ministry of Health & Family Welfare
Nirman Bhawan, New Delhi - 110011

Dated the 5th July, 2019

MESSAGE

The Revised National TB Control Programme (RNTCP), in accordance with the National Strategic Plan for TB Elimination (2017-2025), has adopted community engagement as a key strategy to reach the unreached. Through community engagement, the RNTCP will work with and through communities to address issues that affect them. Community engagement has been aligned with the thrust areas of the NSP including TB prevention, diagnosis and treatment, especially among vulnerable populations and those who are seeking treatment from the private sector.

TB Survivors and Champions are the torchbearers of this community-led response, which extends person-centred services to affected populations. We have seen that they can be trained through capacity-building workshops to be effective peer educators, offering emotional support to people with TB. TB Champions also have the power to sensitize their communities on TB, reduce stigma and provide real time feedback to the health system. TB Champions are key members of the national, state and district level TB Forums where they will have an opportunity to influence policy level decisions.

To expand this cadre of TB Champions across India, a standardised curriculum has been developed to support TB Survivors to become effective TB Champions. After a pool of TB Champions are created across the country through capacity-building workshops, we anticipate that they will come together to form networks to strengthen and support TB services. More TB Champions will be identified from among priority and vulnerable populations and from remote areas of the country. I am confident that their commitment and enthusiasm will energise the response to TB in India.

(Sanjeeva Kumar)

विकास शील
संयुक्त सचिव
VIKAS SHEEL
Joint Secretary

सत्यमेव जयते

भारत सरकार
स्वास्थ्य एवं परिवार कल्याण मंत्रालय
निर्माण भवन, नई दिल्ली - 110011
Government of India
Ministry of Health & Family Welfare
Nirman Bhavan, New Delhi -110011
Phones : 23061481, 23063506 (T/F)
E-mail : sheelv@nic.in

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MESSAGE

The End TB mission is a priority of the Government of India and we have stepped up our efforts to achieve our TB elimination goal by 2025. However, challenges remain, including reaching the missing million and reaching out to unengaged sectors in the TB response. Trained TB Survivors and Champions have the potential to support the TB programme in mitigating these hurdles.

Many populations are vulnerable to TB for reasons that include poverty, living conditions and occupational hazards. Overcrowding and poor ventilation in houses, malnutrition, smoking, stress, social deprivation and poor social capital mediates the correlation between TB and poverty. Similarly, those employed in industries such as mining, stone crushing, glass and cotton manufacturing, among others are more vulnerable to TB, especially because of their working conditions where they are exposed to hazardous pollutants. An unhealthy workforce affects the productivity of an economy. Under the National Strategic Plan (2017-2025) the RNTCP has already included Active Case Finding among key affected populations and preventing the development of active TB in people in the high-risk groups as two of its priority areas.

Trained TB Survivors can play a key role in the effective implementation of these strategies. The RNTCP will identify and train more TB Champions from among the vulnerable populations. TB Survivors and Champions can become powerful advocates in their communities, especially because they possess an insider's knowledge and understanding of how TB impacts the life of an individual. This training curriculum has been designed to build the knowledge and skills of TB survivors and Champions and support them to become foot soldiers of the End TB mission.

(Vikas Sheel)

Dr. K S SACHDEVA
Dy. Director General
Head, Central TB Division
Project Director, RNTCP

Tel. : 011-2306 3226
011-2306 2980
E-mail : ddgtb@rntcp.org

भारत सरकार
Government of India
स्वास्थ्य एवं परिवार कल्याण मंत्रालय
Ministry of Health & Family Welfare
निर्माण भवन, नई दिल्ली-110108
Nirman Bhavan, New Delhi-110108

MESSAGE

Multi-sectoral coordination and inter-ministerial partnerships along with community engagement are crucial for expediting TB elimination in India. Community engagement forms the cornerstone for the successful implementation of any public health programme. At the centre of India's care and prevention strategy is the person with TB.

The NGO partners of the Revised National Tuberculosis Control Program (RNTCP) have already demonstrated the influence and impact of engaging affected communities in the TB response. After participating in capacity-building workshops and mentorship programmes, TB Survivors and Champions have been providing support to people with TB and their families, conducting sensitization meetings, and advocating with key stakeholders for increased attention to TB. They have also been leading anti-stigma campaigns in their communities.

Trained TB Champions can help in accelerating TB notification through awareness drives in vulnerable areas. They can also improve the overall public awareness on TB, eliminate stigma and remove discrimination around the disease. As advocates, they can engage with local self-governments, educational institutions, youth groups and faith leaders. They can also ensure better service delivery by advocating with RNTCP staff at the ground level.

Moving forward, the RNTCP envisions a large pool of trained TB Survivors and Champions who can complement the key functions of the programme. They will participate in regular support meetings at health facilities, and provide emotional/social support to people with TB. This curriculum has been developed with the inputs of TB Champions themselves and I am confident that it will help expand this cadre across the country and help us work towards our goal of a community-led, person-centred, gender-sensitive, rights-based response to TB.

(Dr Kuldeep Singh Sachdeva)

MESSAGE FROM USAID/INDIA & REACH

India has more than a quarter of the world's burden of TB and drug-resistant TB, and the TB landscape in India is heterogeneous, dynamic and complex. Every year, nearly one million new people with TB go undetected or are not notified to the government programme after diagnosis. Although the introduction of newer treatment regimens and expansion of family DOTS have improved adherence, significant barriers remain to achieve treatment success rates of over 90% among people diagnosed with TB, and particularly drug-resistant TB.

New approaches are needed to ensure that every individual affected by TB can access high-quality, respectful care, and treatment services. Globally, and in India, there is a growing recognition that affected communities, TB survivors and TB Champions must be meaningfully engaged at every point in the care cascade (prevention, diagnosis, treatment and adherence). Engaging communities and families will significantly optimise an individual's chances of being detected early and completing treatment successfully. The active involvement of affected communities can also accelerate rights-based, gender-responsive approaches to TB. India's National Strategic Plan has outlined a range of actions by communities to improve identification of people with symptoms, to support adherence to treatment, and to strengthen grievance redressal mechanisms. TB survivors are enthusiastic and committed to the cause of TB elimination but we must continue to invest in building their capacity and supporting them to become powerful advocates.

Over the last three years, through the TB Call to Action project, REACH and USAID have built the capacity of over 300 TB survivors through capacity-building interventions across six states. These Champions are now actively supporting India's TB response by providing emotional support to people with TB, sensitizing communities, and working to reduce stigma. This curriculum is based on learnings from a series of intensive workshops and is intended to help expand the cadre of TB Champions across India. The process of developing this inclusive curriculum has been participatory, with inputs from members of a working group constituted by the Central TB Division, including Champions themselves.

The development of this curriculum signals the commitment of India's TB programme to engaging communities in a systematic and sustained manner. USAID, as a long-time partner of the Government of India, and REACH remain committed to supporting the RNTCP in its efforts to engage communities, TB survivors and families. Together, and with the active involvement of TB Champions, we can foster a holistic TB response and work to achieve a TB-free India by 2025.

Xerses Sidhwa
Director, Health Office
USAID/India

Dr. Nalini Krishnan
Director
REACH

ACKNOWLEDGEMENTS

'From TB Survivors to TB Champions' is a training curriculum that is intended to be used to train TB survivors to become effective advocates and Champions. This curriculum has been developed in a collaborative manner with inputs from several key stakeholders.

In June 2018, a Working Group was formed to guide the development of the curriculum with the following as members: Dr Devesh Gupta, Central TB Division; Dr Nishant Kumar, DADG, CTD; Dr Sundari Mase, WHO India; Dr Kiran Rade, NPO, WHO India; Blessina Kumar, Global Coalition of TB Activists; Dr Amar Shah, USAID; Brian Holler, USAID; Subrat Mohanty, The Union; Dr Indira Behera, Global Health Strategies; Cedric Fernandes, Touched by TB; Mona Balani, Touched by TB and NCPI+; Sudeshwar Singh, TB Mukt Vahini; Reeta Sahoo, TB Champion; Dr Bhavin Vadera, CTD; Dr Amit Karad, CTD; Chapal Mehra, Survivors against TB; Nandita Venkatesan, TB advocate and Dr Nalini Krishnan, REACH.

The first meeting of the Working Group was held at the TB Association of India premises in New Delhi on 10 August 2018. Following an in-depth discussion, the Working Group members agreed on the need to train TB survivors to be effective advocates and play a meaningful role in the TB response. It was also agreed that a Writing Group would be formed to draft the curriculum.

Accordingly, different sections of the curriculum were drafted by members of the Writing Group including Dr Sundari Mase of WHO India, Dr Amit Karad of CTD, Blessina Kumar of GCTA, Subrat Mohanty from The Union, Cedric Fernandes, TB Champion from Pune, Brian Holler from USAID and Anupama Srinivasan from REACH. Blessina Kumar, Smrity Kumar and Anupama Srinivasan organised the modules and structured the curriculum. Dr Ramya Ananthakrishnan, Dr Pankaj Dhingra and Dr Raghini Ranganathan of REACH provided inputs and edited various versions.

We thank and acknowledge the valuable inputs of all the Working and Writing Group members. We thank the REACH team for coordinating and facilitating the development of this curriculum, and for organizing the workshops that provided the basis for the curriculum. Our sincere gratitude to the US Agency for International Development (USAID) and the Health Office team including Xerses Sidhwa, Dr Reuben Swamickan, Dr Amar Shah and Amrita Goswami for their technical inputs and financial support to this process through their development partner, REACH.

This curriculum is dedicated to the resilient and dedicated TB Champions who continue to inspire us with their enthusiasm and commitment to support people with TB.

ABBREVIATIONS

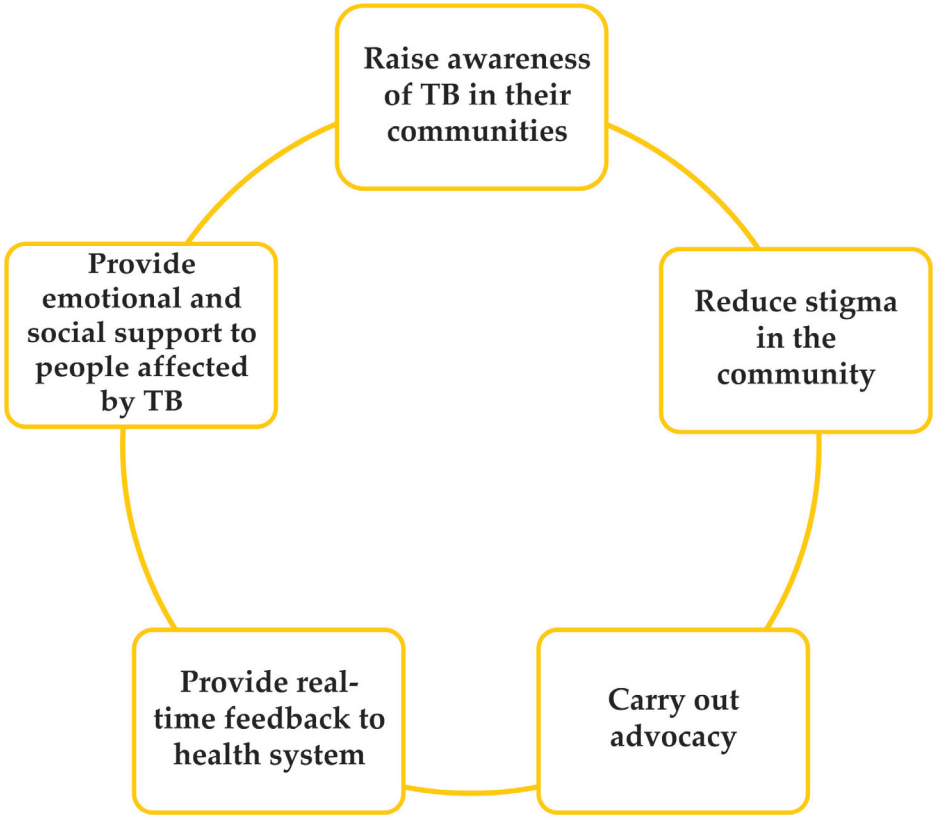
CBNAAT	Cartridge Based Nucleic Acid Amplification test
CSO	Civil Society Organisation
CHC	Community Health Centre
CTD	Central TB Division
DDG	Deputy Director General, TB
DMC	Designated Microscopy Centre
DR-TB	Drug resistant tuberculosis
DS-TB	Drug Sensitive Tuberculosis
DTC	District Tuberculosis Centre
DTO	District Tuberculosis Officer
EPTB	Extra pulmonary Tuberculosis
INH	Isoniazid
IRL	Intermediate Reference Laboratory
LPA	Line Probe Assay
LTBI	Latent TB infection
MDR-TB	Multi Drug Resistant Tuberculosis
MO	Medical Officer
MO-TC	Medical Officer –Tuberculosis Control
MPW	Multi-Purpose Workers
NGO	Non-Governmental Organisation
NHM	National Health Mission
NRHM	National Rural Health Mission
NSP	National Strategic Plan for Tuberculosis Elimination
PHC	Primary Health Centre
PHI	Peripheral Health Institution
PTB	Pulmonary Tuberculosis
RNTCP	Revised National Tuberculosis Control Programme
STDC	State TB Training and Demonstration Centre
STLS	Senior Tuberculosis Laboratory Supervisor
STO	State Tuberculosis Officer
STS	Senior Treatment Supervisor
TB	Tuberculosis
TU	Tuberculosis Unit
USAID	United States Agency for International Development
WHO	World Health Organisation
XDR TB	Extensively Drug Resistant Tuberculosis

INTRODUCTION

The National Strategic Plan for 2017– 25 (NSP) for TB elimination in India proposes transformational changes to how TB is addressed. Globally and in India, there is growing recognition that affected communities – TB survivors, people with TB and their families – must play a greater role in the response to TB. Their potential role as powerful advocates with the capacity to increase visibility for TB, improve public understanding of the disease and destigmatise the TB experience is now evident. TB survivors and Champions (i.e. a trained and committed TB survivor) – can play a long-term in supporting people with TB, sensitising communities, addressing stigma, advocacy and community monitoring. India's experience with HIV and the growth of networks led by affected people across the country has shown us the way. This is also central to the Global End TB Strategy and the UN High Level Meeting Declaration.

The NSP calls for a community-based and person-centred approach to TB as a key strategy to reach the unreached and to support people with TB. As a first step, a National TB Forum, State TB Forums and District TB Forums are being created, with TB survivors and Champions, key decision makers and programme managers as members. At the sub-district and village level, the programme will facilitate the creation of community-led TB forums of TB affected people.

Role of TB Champions



Trained TB Champions are a valuable link for the programme with the community at large. They can not only support people with TB but also help identify people with symptoms of TB and guide them to the nearest facility. By sharing their stories boldly and openly, TB Champions can also reduce stigma in the community and dispel the silence associated with TB.

Through the programme's sustained efforts over the next few years and with the support of all partners, the goal is to ensure that there are at least two TB Champions in each village in India. With an average population of 2,000 per village, a cadre of 13,00,000 TB Champions who support TB services will be created.

Capacity-building of TB survivors

In order to be successful advocates and Champions, TB survivors need training and mentoring. Over the last two years, as part of the TB Call to Action Project supported by USAID, REACH has organised 12 capacity-building workshops and trained over 300 TB survivors. These workshops were organised in partnership with the Central TB Division and the respective State TB Cells of Bihar, Jharkhand, Assam, Odisha, Uttar Pradesh and Chhattisgarh. The objective of these workshops was to identify and engage a pool of TB Champions to engage meaningfully in the TB response. The workshops were structured with an emphasis on participatory learning and a focus on two aspects:

- *Knowledge-building:* Supporting participants to strengthen their understanding of TB and contextualise their personal experiences in the broader state/Indian context, thereby identifying key advocacy focus areas
- *Skills-building:* Helping participants develop advocacy and communication skills, specifically focusing on the ability to tell their stories in an impactful manner and identify and build effective partnerships

Participants were identified through an open call for application, followed by personal interviews. Only TB survivors were eligible to participate in the workshop.

About this curriculum

This curriculum draws on the capacity-building workshops held to date. It is divided into six modules, and some modules are further divided into sessions. The total duration of the curriculum is approximately 20 hours, over three working days. The curriculum is designed to be as participatory as possible, and the majority of sessions are best led by a trained TB Champion, with support from RNTCP and WHO teams. For every module, the objectives of the session and the expected learning outcomes, suggested methods and required materials are outlined. In addition, detailed talking points are provided along with notes for the facilitator. It is expected that the content can be easily adapted to the local context, with relevant data.

TB Science – Getting the basics right

Time Required: 3 hours

Objectives of the Session

- To explain the scientific basics of TB, DR-TB and Latent TB to participants
- To describe diagnosis, treatment and prevention of TB
- To explain TB co-morbidities
- To emphasise that TB has social and economic dimensions, and emotional/ psycho-social support is required

Expected Learning Outcomes

- Participants understand the basics of TB science, including how TB spreads, its diagnosis, treatment, prevention, social determinants and risk factors
- Participants understand drug-resistance, how it develops and how it can be diagnosed, treated, and prevented
- Participants can identify various myths and misconceptions on TB, as well as the correct facts for each
- Participants know all the necessary information about TB to share with their communities

Suggested Methods

- Presentation and discussion
- Short Quizzes/Polling Questions
- Summaries by participants
- Group activities
- Role Play
- Screening of short films

Materials Required

- Presentation with projection facilities
- White board/flip charts with markers
- Small prizes for quizzes
- A4 paper

Session Content

Sub-section 1: What is TB?

- TB is an infectious disease caused by a germ called 'Mycobacterium Tuberculosis'
- TB mostly affects the lungs (causing pulmonary TB) but can also affect other organs, including bones and joints, kidneys, brain, genitals, urinary tract, spine, lymphatic system, intestines, etc. In other words, it could affect all organs except hair and nails
- TB spreads through air. When someone with pulmonary TB coughs, spits or sneezes, droplets of mucous carrying TB germs may be expelled into the air. Anyone who inhales these droplets could develop an active TB infection
- When someone inhales the TB bacteria, it could settle in the lungs and cause pulmonary TB. However, it could also spread to other organs via the blood stream and lymph system and cause an infection in whichever part of the body it settles in
- When TB affects any organ other than the lungs, it is called extra-pulmonary TB
- Many people have already inhaled the TB bacteria and carry it within their bodies, often without their knowledge. All those who inhale the TB bacteria do not become ill with the disease. When someone harbors the bacteria but does not manifest any symptoms of TB, they are said to have Latent TB infection (LTBI). In people who have LTBI, the normal immune system of the body is able to keep the bacteria well under control. An estimated 30 to 40 % of the Indian population has LTBI
- In about 5-10% of the people who harbor the bacteria, the germs multiply and cause TB disease during their lifetime. A person with TB infection can develop TB disease when his or her immunity is lowered
- Malnutrition, diabetes and HIV are some of the risk factors for TB, as they all lower a person's immunity
- Smoking is also a risk factor as it weakens the lungs
- Alcohol use can predispose someone to TB and also interfere with treatment
- Anyone who has evidence of latent TB infection or is in close contact with someone who has pulmonary TB is also at a greater risk of developing TB
- Children can also get TB. TB in children represents about 10 -11% of the total number of people with TB
- TB can affect anyone, although it affects the poor disproportionately
- Under the Revised National TB Control Programme, the Government of India provides free diagnosis and treatment for TB

Sub-section 2: Screening and Diagnosing TB

- The symptoms of pulmonary or lung TB are:
    - Persistent cough for over two weeks
    - Fever, especially in the evening
    - Night Sweats
    - Loss of appetite
    - Loss of weight
    - Blood in the phlegm (haemoptysis)
    - Chest pain
    - Breathlessness
- If someone has had a persistent cough for more than two weeks, it is important to consult a doctor and get tested for TB
- Pulmonary TB is diagnosed by testing the sputum sample by microscopy, any rapid molecular tests such as the Cartridge Based Nucleic Acid Amplification Test or CBNAAT test, or by sputum culture. However, in the case of children who are unable to produce sputum, gastric aspirate/gastric lavage can be alternatively used
- In the case of extra-pulmonary TB, the person will develop symptoms that are specific to the affected area. For example, in the case of intestinal TB, the person may experience diarrhea or in the case of TB of a particular joint, the person may experience pain and swelling of that area. Besides this, fever in the evenings, night sweats, loss of appetite and weight loss are also possible
- Extra-pulmonary TB is ideally diagnosed by examining the affected organ or site, e.g., lymph node or fluid around the lungs. This is done by means of a biopsy or fine needle aspiration of fluid, in which a small bit of the tissue or a sample of fluid is removed through a surgical procedure or needle aspiration and examined under the microscope. Alternatively, the sample can be tested by CBNAAT. The specimen must also be sent for mycobacterial culture and drug sensitivity testing whenever possible. When a biopsy is not feasible, e.g. in the case of the spine, the diagnosis is made with a combination of X-rays, CT or MRI scans and clinical exam
- The Mantoux test is a TB skin test. A substance called purified protein derivative (a preparation of inactivated TB bacterial components) is injected under the skin and if a person reacts to at the site of injection, it indicates the presence of an immune response to TB and, therefore indicates infection with the TB bacteria. However, the Mantoux test cannot be used to determine TB disease but only the immune response to the bacteria. In a country like India, where many people have TB infection (i.e., exposure to and silent infection with the bacteria) but may never develop active TB disease, the Mantoux test cannot tell if someone has TB disease or not, particularly in the case of adults
- Serological or blood tests are very often inaccurate and have been banned by the Government of India and the WHO for diagnosis of TB. In other words, a blood test will not tell someone if they have TB

- Screening is usually the first step in the diagnostic process, and means assessing whether someone has TB symptoms and needs to be referred for diagnosis. Symptom screening and chest X-rays are used to screen for TB

Sub-section 3: Treating TB

- TB is a curable disease
- The average course of the treatment for drug-sensitive TB is six months. For those with a drug resistant form of TB, the duration of treatment is often longer, up to two years
- Drug-sensitive TB is treated with a combination of drugs (Isoniazid, Rifampicin, Ethambutol and Pyrazinamide)
- In 2017, India shifted from a thrice-weekly regimen to daily fixed dose combinations (FDC) of first – line anti-tuberculosis drugs in appropriate weight bands
- Every person diagnosed with TB in the public sector is assigned a treatment supporter. This person will be responsible for ensuring that the person with TB takes the medicines as required, will update the treatment cards, send reminders to go for regular reviews and generally ensure that the person with TB completes the entire course of treatment
- It is very important to complete the full course of treatment. It is likely that someone with TB will feel better in a few weeks after starting treatment but that does not mean s/he is cured. Anti-TB medicines are strong antibiotics and it is essential to complete the course of medicines to ensure that TB does not recur and that the bacteria does not become resistant to the anti-TB drugs (and cause a more serious complication, i.e., drug-resistant TB)
- TB can easily be treated on an outpatient basis. Only those with severe or complicated TB may require hospitalisation for treatment
- TB treatment is available free of cost at all government centres. However, costs in the private sector vary tremendously – a full course of TB treatment, if bought from a pharmacy, can cost between Rs. 6,000 to Rs. 12,000 for the six months, depending on the drugs prescribed. For drug-resistant TB, the cost may run to lakhs of rupees in the private sector
- All those with TB should be counseled about the possibility of common side effects or adverse drug reactions. The adverse effects could be minor, requiring reassurance and counseling, or major, requiring a change of drugs and could affect the person with TB for a short period or the entire duration of treatment
- The adverse effects could include abdominal discomfort, nausea, vomiting, jaundice, itching, numbness in limbs, joint pain, impaired vision, ringing in ears, dizziness etc.
- A person with TB should seek help from a doctor/care provider if s/he encounters adverse drug reactions and should not take the decision to stop or change the drugs on their own

- A pregnant woman diagnosed with drug-sensitive TB can start on treatment during pregnancy. If she has been diagnosed with TB shortly before delivery, then the baby should be tested for TB

Sub-section 4: Drug-resistance

- Drug resistance means that the TB bacteria have become resistant to one or more specific anti-TB drugs, which are, therefore, no longer effective
- Drug-resistant TB (DR-TB) is harder to treat and requires a longer treatment duration of 18 – 24 months, with less effective and more toxic drugs
- DR-TB can be transmitted from person to person just like drug-sensitive TB (DS-TB); this is called primary DR-TB
- DR-TB can be acquired during treatment of DS-TB; this usually occurs because a person does not take medicines regularly or misses doses or if s/he is given an incorrect prescription or because of malabsorption of medications due to co-morbid conditions such as bowel disease, malnutrition or HIV. They are said to have acquired/secondary DR TB
- When someone with TB develops resistance to two of the most effective drugs used in the treatment (Isoniazid and Rifampicin), with/without resistance to other drugs, the person is said to have Multi-drug resistant TB (MDR-TB)
- The symptoms of MDR-TB are the same as DS-TB – a persistent cough, chest pain, fever, loss of appetite and loss of weight
- Those who come into frequent contact with someone who already has MDR-TB or a person with TB whose treatment has been interrupted are at a higher risk of developing MDR-TB
- MDR-TB is diagnosed by testing the sputum samples for culture and drug sensitivity. However, it takes anywhere from three to six weeks to get results from culture sensitivity tests (which involves growing the TB bacteria from the sputum in a laboratory and testing the bacteria's resistance to anti-TB drugs)
- In recent years, the CBNAAT test has been introduced to diagnose TB and help identify resistance to Rifampicin within a few hours. If a person has bacteria that is resistant to Rifampicin, they are likely to have MDR-TB because Rifampicin resistant almost always occurs along with resistance to Isoniazid (INH)
- In addition, to identify resistance to INH everyone diagnosed with TB on CBNAAT also undergoes LPA (Line Probe Assay)
- Based on the results of CBNAAT and LPA, the person with TB will receive treatment either for DS-TB or DR-TB
- All districts across India have at least one CBNAAT machine and all districts are linked to an IRL (Intermediate Reference Laboratory) in the State for LPA testing
- MDR-TB is curable although the treatment period is considerably longer and often at least two years. However, cure rates are poorer than with DS-TB, at only about 50%

- Recently, two new drugs, Bedaquiline and Delamanid have been conditionally approved by the FDA (Food and Drug Administration) and EMA (European Medicines Agency) for treating MDR-TB and WHO has issued guidelines for their usage. India is currently expanding access to these two new drugs
- XDR-TB is an advanced stage of MDR-TB in which the bacteria, in addition to being resistant to isoniazid and rifampicin, are also resistant to flouroquinolones and injectables, two group of drugs that are used in the treatment of MDR-TB. As a result, treatment options for XDR-TB are limited, highly expensive and have many side effects

Sub-section 5: TB and Co-morbidities

- TB is an opportunistic infection – this means that someone with a weakened immune system is more likely to develop TB than someone with a healthy immune system
- TB is the most common opportunistic infection in people living with HIV. This means that those with HIV are at ten times increased risk of TB and considered vulnerable to TB on account of their lowered immunity
- This co-infection also contributes to the increased mortality, with almost a quarter of deaths among PLHIV due to TB
- The programme mandates that people with HIV should be regularly screened for TB and those with TB and presumptive TB should be tested for HIV
- Similarly, the links between TB and diabetes are also strong. People with diabetes have an increased risk of active TB or TB disease (3-4 times higher than people without diabetes)
- There is evidence to show that diabetes worsens TB treatment outcomes – increased deaths and relapse rates
- For these reasons, it is essential that anyone diagnosed with TB is tested for diabetes regularly and vice-versa
- For the affected individual, managing two infections or two co-morbid conditions can be difficult, and support from families and communities is essential
- Undernutrition and TB are also closely linked. Undernutrition affects a person's immune system and makes them more vulnerable to TB. Undernutrition is the most common risk factor for TB in India. It is estimated that 55% of TB incidence – or newly diagnosed TB – in India is attributable to or because of undernutrition

Sub–section 6: TB Prevention

- The best way to prevent TB is through increased awareness of symptoms, early diagnosis and treatment, treatment adherence and cough etiquette

Contact tracing:

- The programme mandates 'contact tracing', which means that those who live or work in close contact with someone affected by TB must also be tested. This is especially important for household contacts or family members, who share a living space with a person affected by TB
- Some contacts may not have any symptoms while others may have ignored the symptoms. A combination of symptom screening and chest X-rays is used to refer contacts for further diagnostic testing
- Reverse contact tracing should be done for all children with TB, i.e., their parents must be tested for TB to identify the source of infection for the child. This especially includes all household contacts, who share a living space with the child

Treatment of Latent TB Infection or LTBI:

- A person is said to have latent TB if they are infected with the TB bacteria but do not have signs of active TB disease and do not feel ill. However, they could possibly develop TB disease at some point in the future. Approximately 40 % of the Indian population is estimated to be infected with the TB bacteria, but not everyone falls ill and develops the TB disease
- As outlined in the NSP, there was previously no articulated policy for LTBI management except for children less than 6 years of age who are contacts of people with pulmonary TB or PLHIV. It is now envisaged that LTBI diagnosis and treatment will be initially used as a strategy in low prevalence settings identified by the programme

Prevention in Hospital/facility settings:

- The health facility premises should have adequate communication materials displayed for infection control measures such as cough etiquette, disposal of sputum and biomedical waste management
- Those with respiratory symptoms must be fast tracked for medical consultation and testing
- The wards or waiting areas should have adequate cross ventilation
- Masks must be used in high-risk settings

Prevention in Community:

- People with lung TB or any respiratory infection should practice respiratory hygiene and cough etiquette
- There should be no indiscriminate spitting. People with TB, especially in the first few weeks after diagnosis, should cover their nose and mouth while coughing and sneezing
- Those with TB should live or work in rooms which are well-ventilated

- The BCG (Bacille Calmette Guerin) vaccine is currently the only vaccine available for TB. This is a weakened strain of TB that causes the body to build immunity against TB. BCG protects young children from severe forms of TB such as meningitis and disseminated TB. It does not prevent the development of pulmonary TB in children or in adults. BCG also provides a moderate protective effect against leprosy

Sub-section 7: Supporting the person with TB, family and community

- Like other long-drawn out illnesses, TB affects an individual in multiple ways
- Apart from the physical symptoms, TB also has an effect on the earning capacity of an individual and people with TB are often unable to work or support their families
- Those living in poverty are at greater risk, on account of overcrowded homes, poorly-ventilated surroundings or low immunity caused by malnutrition
- People with TB face considerable stigma from their families, providers and communities and can be isolated or ostracised. TB can destroy relationships and impact livelihoods
- TB continues to be associated with various age-old myths and misconceptions that worsen the stigma. For instance, many people believe that TB is hereditary – it is not.
- TB is a gendered disease and affects men and women in different ways
- Men generally face loss of employment and income and struggle to make ends meet, experiencing poverty and occasionally isolation
- A majority of women, on the other hand, are isolated and shamed by their own families, friends and in-laws. Married women are sometimes driven out of their homes. Women are often forced to take their treatment secretly and they live with the constant fear of people around them finding out that they have TB
- People with TB, especially DR-TB, are vulnerable to depression and require counseling and social support
- Family and friends also play an important role at this time. The treatment for TB generally lasts for 6 months or more. During this period, a person with TB needs the support of family, friends, well-wishers and community members
- A good support system can help prevent a person from spiraling into depression and giving up the treatment
- Access to good nutritious food is important during TB treatment. In April 2018, the government initiated the Nikshay Poshan Yojana – a scheme for provision of nutrition support to people with TB. The scheme provides a financial support of Rs. 500/month to each notified person with TB through Direct Benefit Transfer for the duration for which the person is on treatment

Notes for the Facilitator

Setting the context

- The facilitator begins the session by reminding the participants of the importance of understanding all basic information on TB. As TB Champions who will interact with communities, they must be confident that they are sharing accurate information on TB
- The facilitator urges participants to ask questions throughout the session and shares the saying 'there's no such thing as a silly or unnecessary question'

Conveying the key information/messages

- The facilitator begins the session by giving a short overview of the topics to be covered in this session
- S/he divides them into small groups and leads them through a short quiz. This will help the facilitator gauge the level of knowledge about TB and pitch subsequent sessions accordingly
- Each sub-section will have a PowerPoint, but will be interspersed with "knowledge questions". This is important to keep the participants engaged
- The facilitator must remember that as people who have had TB, participants may be familiar with some of the information but not all of it
- The sub-section on supporting the person with TB/their family, in particular, must be crowd-sourced and not be merely didactic, given that participants are likely to have experienced several of the social and economic consequences of TB themselves
- The facilitator can lead participants through a brief exercise in pairs, asking participants to list the support they received/would have liked to receive during their treatment
- The facilitator can also initiate a small group exercise on role play for contact screening
- Short films can be shown wherever relevant and possible

Summarising the session

- The facilitator will provide a short summary of each topic area to consolidate the information learned, at the end of each sub-section
- The facilitator can also call on volunteers to summarise each sub-section before moving on to the next
- The facilitator ends the session by reminding participants that they must keep re-visiting this to strengthen their knowledge as they begin their work as TB Champions

Note: This session is ideally conducted by a technical expert with an experienced TB Champion as a co-facilitator

Module 2
TB in India and the Response

Total number of sessions: 4

Total number of hours: 3 hours, 30 minutes

- Session 1: Understanding the TB burden (1 hour)
- Session 2: Understanding the RNTCP (1 hour)
- Session 3: The private sector's role in the TB response (30 minutes)
- Session 4: A community-led, rights-based approach to TB (1 hour)

About this module

This module is intended to help participants understand the burden of TB in India as well as the current TB response. Through the four sessions in this module, participants will:

- Learn about the TB burden in India and in their state/district
- Understand the basic epidemiological profile of TB and its relevance to their role as TB Champions
- Understand the structure and functioning of the RNTCP at various levels
- Learn about the role and relevance of other key actors in the TB response, including the private healthcare sector and NGOs
- Be introduced to the fundamentals of a community-led response to TB and understand their role as part of this.

The sessions in this module, although technical in parts, are best conducted by trained and experienced TB Champions. Where this is not possible, the sessions may be led by a RNTCP staff member or the WHO Consultant, with the active involvement of TB Champions.

Understanding the TB Burden

Time required: 1 hour

Objective of the Session

- To provide basic information about the TB burden, its distribution, mortality and morbidity, outcomes and trends over the years
- To help participants understand the challenges India faces in responding to TB

Expected Learning Outcomes

- Participants have understood the extent and magnitude of the TB burden and its epidemiology
- Participants have understood that TB is not just a medical disease but has many social and economic implications

Suggested Methods

- Presentation and discussion
- Use of infographics, graphs, charts, diagrams etc. in slides
- Crowd-sourcing responses wherever possible to ensure an interactive session
- Adequate time for questions and clarifications

Materials Required

- White board or flip chart
- Presentation + projection facilities

Session Content

Sub-section 1: TB burden

- TB can affect anybody, although it affects the poor disproportionately. Many famous personalities in the past have had TB. Kamala Nehru, Md. Ali Jinnah, S Ramanujan and Amitabh Bachchan all had TB
- In 2017, 100 lakh people were estimated to have developed TB in the world. Of this, 27.4 lakh or 27% are estimated to be from India
- This means out of every four people with TB in the world, one is from India

- India also has a big proportion of MDR-TB in the world. Out of total 5.58 Lakh people with MDR-TB in the world in 2017, 1.35 lakh are estimated to be from India. This means India has almost a quarter of the MDR-TB burden
- As far as mortality is concerned, TB is one of the top 10 causes of death in the world. Here too, India has a large share. In 2017, 13 lakh people with TB died all over the world out of which 4.1 lakh were from India. This means around 1125 people die of TB every day in India
- A comparison of deaths due to TB, HIV and Malaria in India reveals that TB causes far greater number of deaths than either HIV or malaria
- State/district specific data to be included

Sub-section 2: Trend of TB disease over the years

- Why are trends important? They help us understand if our efforts are improving the TB situation in the country
- If we look at the trend over the past years, we find that the incidence of TB (i.e. the number of newly diagnosed people with TB every year) in our country has been decreasing over the years
- In the year 2000, it was 289 per lakh population. In 2017, this has come down to 217.
- The mortality of TB was 56 per lakh per year in 2000 and 31 per lakh per year in 2017. This means that in 2000, for every one lakh people in India, 56 people died of TB. Today, for every one lakh people, 31 people die of TB
- What is notification? This means the number of people with TB reported to the public health system
- The notification of TB has increased from 106 per lakh in 2000 to 133 per lakh in 2017.However, if you compare this to the incidence which is 217 per lakh, we are still missing many people. They could either be getting treatment in the private sector and are not notified, or they may not have been diagnosed with TB at all, and could remain untreated in the community
- Every state and district has a different notification rate
- State/district specific data to be included

Sub-section 3: Treatment outcomes

- TB is a fully curable disease, if diagnosed and treated properly
- The treatment success rate for people with TB enrolled in the national programme (which means those who are declared cured of TB or who have completed the full course of treatment) is 69%

- However, treatment outcomes are poorer among those with drug-resistant TB
- For those who have MDR-TB or Rifampicin resistant TB, the success rate is 46%
- The success rate becomes even lower for those having XDR-TB - around 28 %
- State/district specific data to be included

Sub-section 4: India's Challenges

- The trends show us that there is a decline in TB incidence by 2% every year. However, if we are to reach our target, then this needs to be 10% per year
- There are many challenges that are associated with TB in its diagnosis, treatment, risk factors and comorbidities. TB is also complicated by its social and economic effects
- An important challenge is a delay in getting the right diagnosis. Studies conducted on TB tells us that on an average, there is a delay of two months in the diagnosis of TB. An individual with symptoms is seen by an average of three health care providers before he or she is diagnosed with TB
- Taking medicines for six months is difficult. A person with TB might discontinue medicines because of high cost of medicines, because the symptoms are no longer present, because they experienced side effects or because they did not know about how long they should take medications for
- Co-morbidities like HIV or Diabetes need to be properly addressed and can affect TB outcomes
- Undernutrition or malnutrition is also a factor that increases risk of TB
- TB is associated with stigma at home, in the family, neighbours or at the workplace. This makes management of TB even harder
- There are groups of populations which are more vulnerable to TB such as those living in slums and tribal populations
- Many families are pushed below the poverty line due to catastrophic out-of-pocket expenditure occurring due to TB. This includes costs associated with shopping for a diagnosis (tests, doctor's fee) transport cost and loss of wages
- TB is a social problem and cannot be addressed by health officials alone. Addressing TB needs an inter-sectoral approach. A lot of other sectors need to come together and work with the health department - mines and industries, food and civil supplies, social justice and empowerment, tribal welfare, rural and urban development, woman and child development, environment and forest etc.
- Any state/district specific challenges to be included

Notes for the facilitator

Setting the context:

- This session has lot of technical information and technical jargon. The facilitator must simplify and explain all terms, as many times as required, and must try not to overwhelm the participants with complicated terminology
- The facilitator begins the session by explaining terms such as burden, incidence, mortality etc., as simply as possible
- The facilitator uses overhead projection to explain what is implied in the graphs/charts

Conveying the key information/messages:

- The facilitator then moves on to explain the TB burden in India. The main objective here is to convey the scale and magnitude of the problem
- In the second sub-section, the facilitator introduces the participants to trends, and explains why tracking trends in diseases is important. The facilitator also explains some key concepts like notification.
- In the third sub-section, the facilitator explains the meaning of treatment outcomes, and why this matters
- In the final sub-section, the facilitator asks the participants to name some challenges India could be facing. This part of the session must be crowd-sourced so as to be more interactive
- The facilitator can agree, disagree, clarify and explain the challenges as and when they are named.
- At the end of each sub-section, the facilitator must share state or district specific data and information, based on the training setting. This information must also be added to the slides prior to the training

Summarising the session:

- The facilitator ends the session by asking the group if they have understood the concepts introduced in the session
- The facilitator asks participants to name the top two takeaway messages from the session
- The facilitator urges the participants to focus on understanding their local context – the burden and profile of TB in the areas where they plan to work

Understanding the RNTCP

Time required: One hour

Objectives of the Session

- To introduce the participants to the fundamental tenets of India's National Strategic Plan (NSP).
- To familiarise the participants with the basic structure of the RNTCP from national level to sub district level
- To discuss the need to link people with TB to available social support schemes

Expected Learning Outcomes

- Participants will be familiar with the commitments and strategy of the Government of India for TB elimination, as outlined in the NSP
- Participants have understood the hierarchical structure and functioning of the RNTCP at various levels
- Participants are aware of the appropriate RNTCP facilities and officials that they will have to engage with, while doing their advocacy work or providing support to those affected by TB
- Participants have understood the need for links to social support schemes for people with TB and are equipped to identify schemes relevant to their locations

Suggested Methods

- Presentation and discussion
- Use of infographics, graphs, charts, diagrams etc. in slides
- Crowd-sourcing responses wherever possible to ensure an interactive session
- Adequate time for questions and clarifications

Materials Required

- White board or flip chart
- Presentation + projection facilities

Session Content

Sub-section 1: National Strategic Plan

- The National Strategic Plan for TB is for the period 2017 to 2025 and is an initiative by the Government of India to provide a roadmap for elimination of TB in India by 2025
- The NSP focuses on strengthening existing initiatives and introducing newer initiatives to achieve the goal of TB elimination
- The NSP proposes bold strategies to rapidly reduce the number of TB cases and deaths due to TB by 2025
- It has a vision of a TB-free India with zero deaths due to the disease and no poverty due to TB
- The targets defined in the NSP are:
    - To reduce TB incidence by 80%
    - To reduce deaths due to TB by 90%
    - To ensure that 0% of people with TB incur catastrophic expenditure due to TB
- The NSP has four main pillars –
    - DETECT: Find all people with TB including those seeking care from private providers and those who remain undiagnosed
    - TREAT: Initiate all people diagnosed with TB on appropriate treatment wherever they seek care, with patient-friendly systems and social support
    - PREVENT: Prevent the emergence of TB in vulnerable populations
    - BUILD: Build and strengthen enabling policies

Sub-section 2: India's healthcare structure

- India is a vast country. It has a population of 1.3 billion with 36 states and Union Territories. About 70 percent of our population lives in rural areas. Government facilities providing free care for TB are spread across the country
- The health care of the country is the responsibility of both the state and the central government. Delivering health care is largely the responsibility of the state. The center is responsible for developing guidelines and policies, standards and some amount of funding. In Union Territories, the services are provided by the center
- India's National Health Mission (NHM) has two sub-health missions - National Rural Health Mission(NRHM) and National Urban Health Mission
- As per the NHM, the government facilities which cater to health care are based on population norms:
    - One Community Health Centre per 1,20,000 population. For hilly and tribal/hard-to-reach areas it is one per 80,000 population

- One Primary Health Centre per 30,000 population. For hilly and tribal/ hard-to-reach areas it is one per 20,000 population
- One health sub-centre per 5,000 population. For hilly and tribal/hard-to-reach areas it is one per 3,000 population

- The TB response is led by the Revised National TB Control Programme or RNTCP, within the Ministry of Health and Family Welfare, Govt. of India
- Technical aspects of RNTCP are managed at the Central TB Division under the Ministry of Health and Family Welfare
- Diagnosis and treatment of TB at government health facilities is completely free

Sub-section 3: RNTCP structure

- The structure of RNTCP comprises of five levels, as follows:

- *National:*
  - The Central TB Division (CTD) is a part of the Ministry of Health and Family Welfare (MoHFW) and is responsible for TB care and prevention in the whole country.
  - CTD plans, supervises, monitors and evaluates programme activities throughout the country

- *State:*
  - The State Tuberculosis Officer (STO) based at the State TB Cell is administratively answerable to the State Government and technically follows the instructions of the CTD, and coordinates with CTD and the districts for executing the duties mentioned above. The STO is responsible for planning, training, supervising and monitoring the programme in their respective states
  - The State TB Training and Demonstration Centres (STDCs) assist the State TB Cells in training the health workers in the state on the policies and guidelines of TB, supervising district level programme activities and quality assurance of sputum microscopy

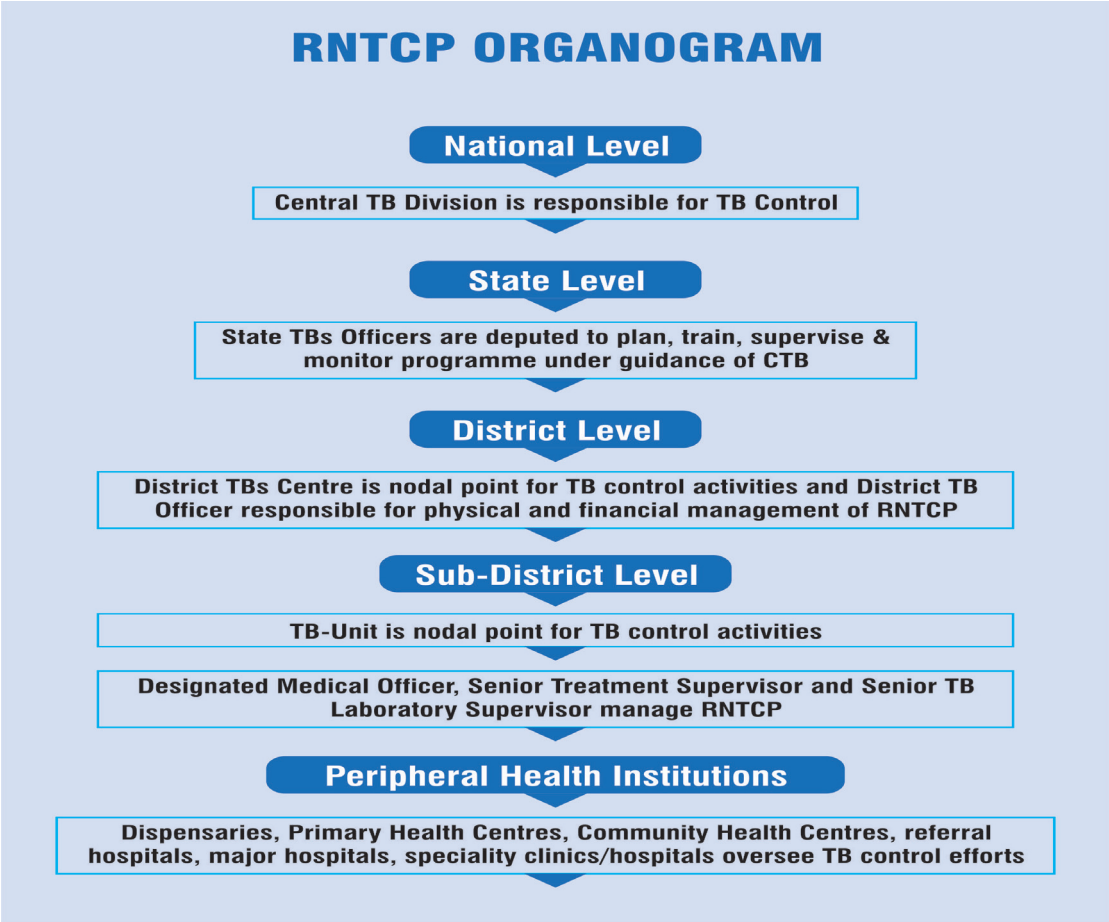
- *District:*
  - The District Tuberculosis Centre (DTC) is the nodal point for TB control activities in the district
  - The District TB Officer (DTO) at the DTC has the overall responsibility of physical and financial management of RNTCP at the district level
  - For each district, there should be a full-time DTO, who is trained in RNTCP at a central level institution, supported by other full-time staff

- *Sub-district:*
  - A Tuberculosis Unit (TU) is the sub-district level unit of the RNTCP
  - The TU covers a population of approximately 2.5 lakhs

- A team, comprising a specifically designated Medical Officer – TB Control (MO-TC), Senior Treatment Supervisor (STS) and Senior Tuberculosis Laboratory Supervisor (STLS), is based in a Community Health Centre (CHC) or Taluk Hospital (TH) or Block Primary Health Centre (BPHC)
- The team of STS and STLS at the TU level are under the administrative supervision of the DTO / MO-TC

- *Designated Microscopy Level:*
  - The TU has one Microscopy Centre for every one Lakh population referred to as the Designated Microscopy Centre (DMC)
  - DMCs are also provided in Medical Colleges, corporate hospitals, ESI, Railways, NGOs, private hospitals, etc., depending upon requirements
  - Every DMC has a lab technician

- *Peripheral Health institution (PHI):*
  - In the context of RNTCP, a PHI has at least a Medical Officer
  - At this level these are dispensaries, PHCs CHCs, referral hospitals major hospitals, specialty clinics TB hospitals or Medical Colleges
  - All health facilities in the private and NGO sector participating in RNTCP are also considered as PHIs
  - Each PHI is required to maintain a record of all people with TB in the TB notification register provided to them



Sub-section 4: Social support schemes and linkages

- Although TB care is free of cost for those registered under RNTCP, there might be some indirect costs that the person has to incur - payments for ancillary drugs, additional diagnostic tests as well as considerable non-medical costs such as expenditure for transport and accommodation
- This is compounded by reduced incomes due to lower productivity or loss of wages
- There will also be intangible costs due to stigma associated with the disease
- For those seeking services in government health facilities, diagnostic tests are available free of cost. For those seeking treatment from the private sector, reimbursements to private labs or providers will be made
- Medicines/drugs are available free of cost under the public sector, and provisions are being made to provide free drugs to all those seeking care in private sector through pharmacists/private providers
- In order to increase treatment adherence and eliminate catastrophic expenditures for people with TB, there are government social support schemes available
    - Linking the Pradhan Mantri Jan Dhan Yojana and Nikshay for direct cash benefits. The programme has adopted a Direct Benefit Transfer (DBT) mechanism to ensure cashless transfer of funds to people with TB
    - Nikshay Poshan Yojana:
        - Nutrition support can help improve the overall nutritional status of people with TB, result in better adherence and treatment outcomes, increased notification and reduced out-of-pocket expenses
        - All notified people with TB, enrolled on or after 1st April 2018, are potential beneficiaries of the scheme
        - Under this scheme Rs. 500/- per month is given to the person with TB till the completion of treatment. The payment is given in instalments
        - The payments will be made direct to the bank account once s/he is notified on Nikshay
    - There are concessions in the railways for travel for people living with TB.
    - For loss of wages, there are linkages to various skill development programmes
    - There are several state specific schemes which must be identified and mapped prior to the session.

Notes for the Facilitator

Setting the context:

- The facilitator begins the session by reminding participants that they were introduced to the scale of the TB problem in the previous session. This session will focus on India's response and how we are addressing the many challenges
- The facilitator reminds the participants that India provides access to free diagnosis and treatment for TB through a vast public health system. Understanding the TB system is very important for the TB Champions
- The facilitator asks participants to name the different cadres of healthcare workers and providers they are aware of and have interacted with during the course of their illness

Conveying the key information/messages:

- The facilitator briefly explains the basic tenets of the NSP to participants, and gives examples of how policies affects them at the district or sub-district level
- The facilitator moves on to explaining the structure of the RNTCP at various levels, ensuring that s/he crowd-sources what the participants already know, at different points through the session
- The facilitator can use a white board or flip charts to draw the structure, as s/he is explaining it, in addition to the diagram on the PPT
- Once the facilitator is confident that participants have understood the structure, s/he moves on to explaining the need for social support schemes for those affected by TB

Summarising the session:

- The facilitator asks participants to take a sheet of paper and quickly draw the RNTCP structure wherever they live, along with names of the key RNTCP staff they will find at the facilities
- The facilitator reminds participants of the need to introduce themselves to key RNTCP staff, and to work closely with them in their capacity as TB Champions
- The facilitator tells participants that this relationship is key to achieving their goals as TB Champions
- The facilitator urges participants to find out more about the schemes relevant to their state. Based on this, they could advocate for new schemes and simultaneously work to ensure that those affected by TB are aware of the existing schemes and how best to access them
- The facilitator ends the session by asking participants to name the top two takeaway messages from the session

The private sector's role

Time Required: 30 mins

Objectives of the session

- To introduce participants to a key actor in the TB response – the private health care sector
- To provide participants with an overview of the role of the private health care sector and private providers in TB care

Expected learning outcomes

- Participants have a clear understanding of the role of the private sector and providers in the TB response
- Participants recognize that irrespective of where someone seeks diagnosis or treatment for TB, they are entitled to the highest quality care possible
- Participants will be able to provide any necessary guidance to people with TB who are accessing services from the private sector and help them get access to benefits that are available

Suggested Methods

- Presentation and discussion

Materials Required

- White board or flip chart
- Presentation + projection facilities

Session Content

Sub-section 1: The private sector and TB

- About 80% of the Indian population seek care in private hospitals and clinics
- The private sector is vast and heterogeneous and includes stand-alone private practitioners, clinics and nursing homes, NGO-run hospitals and large corporate hospitals. It also includes those practicing Indian systems of medicine, traditional healers, paramedics and pharmacists or chemists

- Recognizing a person's right to seek treatment wherever s/he wants to and his/her right to quality health care, the government has defined Standards of TB Care in India (STCI), meant to be followed by both the public and private sector
- There are provisions within the RNTCP for people with TB who prefer to seek care from the private sector
- The Government has banned serological or blood tests for diagnosis of TB – this extends to laboratories in the private sector
- Private sector labs can be engaged to display information on TB, to link people diagnosed with TB to treatment support and for notification
- Private pharmacists and chemists are a vital link to the community and can act as treatment supporters, refer those with symptoms and display information on TB
- All TB drugs have been put under Schedule H1 of the Drugs and Cosmetics Act 1945. This means that the drugs cannot be sold without a doctor's prescription and pharmacists have to keep a record of the doctor and client details along with the sale of all anti-TB drugs through their outlet

Sub-section 2: About private sector engagement

- Private sector engagement is intended to ensure that every person with TB receives the highest standards and quality of care, irrespective of where they seek services
- Private sector engagement is aimed at ensuring that:
  - All those with TB are notified and receive quality care
  - There are linkages for access to free, quality diagnosis and free drugs
  - There is psycho-social support to all persons with TB
  - Out-of-pocket expenditures are reduced
- The following arrangements are in place for those seeking care from the private sector:
  - Provision of CBNAAT testing services to those seeking care from private doctors
  - Establishment of clinical sample transportation from private health facilities to CBNAAT sites for free testing
  - Provision of daily regimen using Fixed Dose Combination (FDC) anti-TB drugs to those with TB who are on treatment in the private sector
  - Provision of ICT adherence, counselling, follow up and screening for comorbidities
- There are three options to link a person with TB who is getting treated in the private sector with free anti-TB drugs from the RNTCP:
  - Refer those diagnosed with TB to a public health facility

- Stocking and dispensing of drugs at private practitioners' health facilities
- Stocking and dispensing of drugs at pharmacies

- People with TB getting treated in the private sector are also eligible to receive Rs 500/month for the duration of TB treatment through the Nikshay Poshan Yojana
- In addition, the programme offers the following incentives to private providers for notifications and to treatment supporters for supporting people with TB:
  - Newly diagnosed Person with TB : Rs 500/- at notification and Rs 500/- at completion of treatment
  - Previously Treated Person with TB : Rs 500/- at notification and Rs 1000/- at completion of treatment
  - Drug Resistant Person with TB: Rs 500/- at notification, Rs 1500 to treatment supporter on completion of Intensive phase and Rs 3000 to treatment supporter on completion of treatment

Sub-section 3: Notification

- It is now mandatory for private providers to notify all people with TB under their care/treatment. This information is critical for the government to understand the real burden of disease and ensure access to public sector schemes and benefits for those seeking care in the private sector
- Public health actions will also be taken following notifications from the private sector. This implies that there could be home visits, counselling of people with TB and their family members, treatment adherence and follow up support, contact tracing, access to HIV testing etc
- All notifications are to be done through Nikshay, an online portal for entering all the records of people with TB. Private providers are required to register themselves on Nikshay.
- In order for a private health facility to begin notifying, the first step is to complete a one-time facility registration
- Private providers can notify in several ways, besides notifying on the Nikshay portal directly:
  - Submission of soft copy of reporting by email or WhatsApp
  - Submission of hard copy of reporting by post, courier or hand
  - Submission by using authorised mobile numbers by call to 1800 11666
  - Direct online transmission from laboratory or hospital MIS to Nikshay

Notes for the Facilitator

Setting the context:

- The facilitator begins the session by emphasizing the importance of the private sector for TB, and therefore the importance of working with private providers
- The facilitator asks the participants to share, briefly, any experiences they may have had with the private sector
- The facilitator explains that every individual has the right to seek the provider of their choice, in either the public or private sector. However, irrespective of where they go, they should have access to the highest quality of diagnosis and treatment for TB
- The facilitator is careful to keep his language simple and to explain any jargon or scientific terminology that is used

Conveying the key information/messages:

- The facilitator explains the key actors in the heterogeneous private healthcare sector in India, and emphasises that this includes non-allopathic providers as well
- The facilitator goes on to explain that India cannot achieve its TB elimination targets without engaging the private sector
- The facilitator reminds participants that it is assumed that a majority of the 'missing' people with TB are seeking care in the private sector, or remain undiagnosed in the community
- At the core of private sector engagement is ensuring that those seeking care in the private sector have access to all or as many of the benefits in the public sector as possible, including diagnostics, treatment and other services
- The facilitator describes the different benefits that are available to those seeking care in the private sector
- The facilitator also explains the incentives that private providers are eligible for
- Finally, the facilitator explains the concept and importance of notification to the participants

Summarising the session:

- The facilitator asks participants to summarise the top takeaway messages from the session
- The facilitator ends the session by asking participants to identify some key private providers that they may be interested in engaging with, in their respective areas

A community-led, rights-based approach to TB

Time Required: One hour

Objectives of the Session

- To explain the principles of a community-led, rights-based approach to TB as well as the need for such an approach
- To discuss the critical role TB Champions can play in the implementation of such an approach
- To outline the different ways in which TB Champions can support the TB response

Expected Learning Outcomes

- Participants have a clear understanding of what a community-led, rights-based approach means, and why it is necessary
- Participants are able to articulate the components of a community-led approach in the TB programme
- Participants have understood their role and that they are an integral part of such an approach

Suggested Methods

- Presentation and Discussion

Materials Required

- Presentation and projection facilities

Session Content

Sub-section 1: About community mobilisation and engagement

- Community engagement is defined as the process of working collaboratively with and through communities to address issues affecting their well-being
- The term 'community' is widely interpreted in many ways. For our understanding, 'community' is used to refer to a group of people, defined by some common characteristics

- The phrase 'affected community' is specifically used to refer to those who have been directly affected by a disease. This could include, for example, someone being treated for TB or their family or someone living with HIV as well as his/her family
- Empowering communities is key to a robust and sustained community engagement programme – communities need the right information in order to participate in the TB response
- The involvement of communities can:
    - Promote engagement with policymakers and implementers to ensure justice and rights and safeguard the dignity of people with TB
    - Supplement and complement government initiatives to enforce person-centred laws, policies and programmes
    - Help reduce stigma and discrimination and ensure social security of people with TB, survivors and their families
    - Increase the social acceptance of those affected by TB
    - Break down the barriers/silence around issues of people living with TB, and their families and communities
    - Bring the perspective of affected populations and people living with disease to the TB response

Sub-section 2: Components of Community engagement under RNTCP

The scope of community engagement will evolve over a period of time under RNTCP. Under the RNTCP, the following community engagement interventions are proposed or underway:

- At the institutional level, for a community-led response to TB, the programme has established National and State TB Forums. District TB Forums are currently being established. These forums include persons with TB and TB-affected communities along with decision-makers and programme managers
- The creation of these Forums creates a seat at the table and encourages active participation by community actors at all levels
- These Forums are expected to advice the programme on:
    - Ways to engage communities meaningfully
    - Increase community participation in the TB programme
- Creation and building of a cadre of TB champions through capacity-building workshops
- Supporting the formation and functioning of survivor-led networks at various levels
- Developing and implementing a rigorous community monitoring system

- Sensitising Village Health Sanitation and Nutrition Committees, PRIs and other community structures to engage them in the TB response

Sub-section 3: A Rights-based approach to TB

- By putting communities at the centre, a rights-based approach to TB becomes possible
- This means that communities must be aware of and be able to assert their rights
- This includes, for example, the right to health, the right to access free services in the public system, the right to be free of discrimination
- Empowering communities to demand their rights can help improve the quality of services in the public and private sector

Sub-section 4: Role of TB Champions

TB survivors and Champions are an integral component of the TB response, and can play a critical role in five key areas:

- Provide emotional and social support to those with TB and their families through referrals, treatment adherence support, stigma reduction support, social support for access to schemes and benefits etc.
- Improve awareness and understanding of TB and its prevention through community sensitisation
- Reduce stigma in the community by speaking up boldly and freely about how TB impacted their lives
- Advocate with key stakeholders including health officials, bureaucrats, elected representatives and the media
- Provide real-time feedback to the programme and providers about TB care services to enhance quality of services and mitigate any service-delivery issues
- Please refer to the diagram in the introduction section of this curriculum

Notes for the facilitator

Setting the context

- The facilitator begins the session by asking participants what they understand by the term 'community' and 'community engagement'. The facilitator gradually builds the meaning of these two terms by drawing inputs from the participants and simultaneously clarifying any questions

Conveying the key information/messages

- The facilitator again crowd-sources what involving communities can achieve. It is likely that participants will be able to articulate several of these points. The facilitator can add on those that have not been mentioned
- The facilitator then moves on to discussing the different community engagement components under the RNTCP. It is important to mention that several of these are underway/ongoing and can be strengthened by the active participation of the participants
- The TB Forums, for example, are an opportunity for the participants, and the facilitator must encourage participants to find out about forums in their districts/states
- The facilitator must emphasis that this workshop, that they are participating in, is one of the critical components of a robust community-led approach, and that it is the first step towards a sustained involvement of TB Champions
- The facilitator then explains the basic meaning of a rights-based approach. This is a complex area, and the facilitator can choose to get into as much detail as possible. Here, it is important to mention that a charter, outlining rights and responsibilities, was developed by Project Axshya and has been introduced across the country (Annexure 1). The facilitator shares the saying 'Nothing for us, without us'
- In the final part of the session, the facilitator focuses on the role of TB Champions, going forward after this workshop. The facilitator can again crowd-source this and ask the participants how they think they can support the TB response and finally share the five identified aspects of a TB Champion's role

Summarising the session

- The facilitator must ensure that participants understand that they are an integral part of the community engagement being described in this session
- It is their participation and active involvement that can strengthen the shift towards a community-led response
- The facilitator can end the session by asking participants to name their top takeaway messages from the session

Module 3
The TB Care Cascade

Total number of sessions: 2

Total number of hours: 3.5 hours

- Session 1: Our TB Stories (1 hour, 30 mins)
- Session 2: Pathways to Cure (2 hours)

About this module

This module is primarily interactive and intended to help participants to:

- Share their personal experiences of TB and how it has impacted their lives
- Work together to understand and identify the potential barriers for those affected by TB through the care cascade
- Translate these barriers into advocacy opportunities

The sessions in this module are ideally facilitated by TB survivors/Champions themselves.

Our TB stories

Time Required: 1 hour 30 mins

Objectives of the Session

- To encourage participants to share their TB stories by creating a safe, conducive environment
- To build solidarity among the participants based on their common identity
- To enable participants to understand the power of their stories and the opportunity it presents for advocacy

Expected Learning Outcomes

- Participants have opened up and share their personal stories with each other
- Participants have had an opportunity to hear how TB has affected the lives of others
- Participants have understood the many dimensions of how TB impacts people

Materials Required

- Seating arrangement in a circle. It can be the floor, chairs etc.
- A calm environment with as little disturbance as possible – phones on silent

Suggested Methods

The participants sit in a circle, either in chairs or on the floor on mats, based on the location. Participants take it in turns to share their personal stories of how TB impacted their lives. Some participants may also share how they responded or handled the situation.

This session is ideally facilitated by a TB survivor and Champion, who begins the session by sharing his/her story.

The facilitator ensures that there is no disturbance and only the participants and facilitator/s are present for the session. The facilitator makes it very clear that this is voluntary and not everyone needs to share their stories. There should be no pressure on the participants to share. A non-judgmental environment is created and participants are assured of confidentiality.

Session Content

There is no specific prescribed content for this session.

This is a session that gives space to people who survived TB to share their story freely without instruction or coaching. In the context of TB, where the human side of the disease is often unknown and unattended to, this space provides a unique opportunity for people to talk openly and without restrictions about their very personal experiences.

An affirmative and positive outcome of this session should be the sense of empathy, solidarity, cohesion and unity among the group, which could lead to many positive outcomes

Usually for many in the group it is the first time they have the opportunity to openly share their experiences and to hear how TB had affected the lives of others.

Notes for the facilitator

- The facilitator introduces the session and its objectives and invites participants to join in
- This session is likely to be an emotional experience and requires the facilitator to be extremely sensitive and gently guide the flow
- It is recommended to keep adequate time – once the participants start sharing it is not recommended to interrupt or stop them midway. The assumption for 90 minutes is that approximately 20 participants will share their stories and speak for five minutes each
- The facilitator closes the session at the appropriate moment, thanking the participants for sharing their stories
- S/he reminds them that stories are powerful and used in the right manner, can become excellent advocacy tools

Pathways to Cure

Time Required: 2 hours

20 minutes: Introduction (including dividing into groups)

60 minutes: Group work

40 minutes: Reporting back, sharing and discussion

Objectives of the Session

- To enable TB Champions to draw on their experiences with TB to identify potential barriers through the care cascade
- To work as a group to understand that it is not just an individual problem
- To help participants reflect on their experiences and identify barriers as a basis for advocacy

Expected Learning Outcomes

- Participants have understood the TB Care Cascade and the seven stages
- Participants have identified the barriers they experienced at every stage
- Participants have learnt about the barriers that others experienced at the different stages
- Participants have begun to understand the commonalities and differences in their TB experiences

Materials Required

- Chart papers, minimum 10, colourful ones are preferred
- Markers/sketch pens
- Post it notes
- Tables for group work

Suggested Methods

This session is intended to be facilitated group work and can be done in two different ways, depending on the time available and the number of participants.

Option 1:

A total of 30-35 participants are divided into seven small groups of 4-5 each. Each group is assigned one of the seven stages and given a chart paper with the name of the stage written on it. Working together, and with inputs from the facilitators, each group identifies barriers for the stage they are assigned. Each of the seven groups report back to the larger group.

Option 2:

A total of 30 participants can be divided into five groups of six people each. Each group can be given seven chart papers, with the names of each stage written on them. Working together, and with inputs from the facilitators, each group identifies barriers for each stage. The facilitators can invite groups to report back on one or two stages each, randomly, ensuring that all seven stages are covered. This is the preferred option

Participants are free to give inputs to the other stages as well.

Participants can use post-it notes to write barriers and these can be stuck onto the chart papers.

Session Content

'Pathways to Cure' is a group exercise that enables participants to identify the challenges and barriers in health and community settings that can threaten the pathway to cure for a person with TB. Encouraged to draw from their personal stories, (Module 3, session 1) participants are stimulated to think about it in a more structured way, using the framework of the TB care cascade to identify problems that impacted or could have more seriously impacted their lives . The barriers or challenges can be identified in seven stages which may be defined on colourful chart papers that are displayed along a long wall or on tables.

The seven stages are:

- Developing symptoms
- Seeking care
- Getting a diagnosis
- Starting treatment
- Completing treatment
- Getting cured
- Getting back on track

The table below is an example of some barriers participants could identify:

BARRIERS AT THE INDIVIDUAL/COMMUNITY LEVEL

DEVELOPING SYMPTOMS	SEEKING CARE	GETTING A DIAGNOSIS	STARTING TREATMENT	COMPLETING TREATMENT	GETTING CURED	GETTING BACK ON TRACK
• Poor understanding of TB • Lack of support from family • Superstitious or religious beliefs • Tendency to self-medicate • Opioid use	• Lack of clear information • Poor health-seeking behaviour (health often not a priority) • Fear of stigma • Lack of support from family • Financial restrictions	• Financial restrictions • Tendency to seek care in a private facility • Difficulty in producing sputum	• Lack of counseling • Fear of side effects • Forgetting to take medication • Difficulty swallowing all the pills	• Poor nutritional status • Inability to support treatment financially • Loss of employment • Migration	• Unhealthy lifestyle • No motivation to complete treatment	• No employment • No social security • No support group • Poverty

BARRIERS AT EVERY STAGE
*Lack of clear information *Stigma and discrimination *Fear of losing family/partner/friends/jobs

The participants can work together to analyse and group the problems under challenges faced in both health system and community settings. Too often, discussions on TB focus on the individual and system-related challenges in isolation and in so doing ignores the experience and overall needs of people with TB. By thinking and analyzing the different stages in a structured way, it is possible to think about the experience in a comprehensive holistic manner, reflective of the entire experience of TB and the need to be supported in both the health and community settings.

Notes for the facilitator

Setting the context:

- The facilitator begins by dividing the participants into small groups, preferably through a fun activity or game
- The facilitator explains the objectives and structure of the session
- The participants begin their group work
- The facilitator, with another colleague if possible, wanders around the room, providing inputs to all the groups and answering any questions

Conveying the key information/messages:

- The facilitator can give examples but preferably does not guide the participants
    - For example, participants could have questions about when one stage ends and another begins
    - Or participants could ask which stage to include stigma at, considering its a cross-cutting barrier
- The facilitator should encourage groups to select a leader at the beginning, who will be responsible for reporting back
- The facilitator should keep a close watch on any particularly silent groups and provide them with any additional guidance if necessary

Summarising the session:

- Once the participants have completed their discussions, the facilitator invites them to share with the larger group. Alternatively, the full group could walk around the room, examining and discussing the different chart papers
- The facilitator ends the session by thanking the participants for introspecting on their TB experience and suggests that each of these barriers could be potential advocacy opportunities. This will be discussed in subsequent sessions

Module 4
Effective Advocacy & Communications

Total number of sessions: 4

Total number of hours: 6 hours

- Session 1: Introduction to Advocacy (1 hour)
- Session 2: Advocating to different stakeholders (2 hours)
- Session 3: Using Personal Stories for Advocacy (1.5 hours)
- Session 4: Network Building (1.5 hours)

About this module

This module is a quick but thorough introduction to the principles of effective advocacy and is intended to help participants to:

- Understand the fundamental principles of advocacy
- Understand why advocacy is necessary for TB
- Learn some advocacy tools they can use
- Understand the need for different strategies for different stakeholders
- Learn and practice telling their personal stories to different audiences
- Understand the power of networks of TB Champions and the need for establishing, building and sustaining such networks

The sessions in this module, particularly 3 and 4, are ideally facilitated by TB survivors/Champions themselves.

Introduction to Advocacy

Objectives of the Session

- To enable TB Champions to understand the importance of advocacy in the TB response
- To help participants understand how advocacy can be an effective tool in bringing about positive change
- To build the capacity of TB Champions by introducing advocacy strategies and tools that they can effectively use in their work

Expected Learning Outcomes

- Participants will be able to explain the meaning of advocacy and its basic principles
- Participants will be able to make their advocacy and implementation plans to address barriers and challenges in access to TB services
- Participants will be able to identify barriers and convert them into their advocacy priorities

Suggested Methods

- Presentation and Discussion
- Role play and games

Materials Required

- Presentation with slides and projection facilities
- Flip-charts

Session Content

Sub-section 1: What is advocacy?

- Advocacy is the act of speaking on behalf of or in support of another person, idea or issue
- Advocacy is a process of change - a series of activities linked to a defined goal – and not just a one-off event
- Advocacy consists of more than one strategy or activity. It entails the implementation of various strategies and activities over time, with creativity and persistence

- Advocacy victories often are preceded by numerous failures. It is important not to give up, but to learn from our mistakes and to continually strengthen our efforts.
- Advocacy combines various complementary initiatives in order to achieve an objective. Advocacy influences policy-makers, funders and decision-makers. It seeks to ensure that governments are committed to implementing TB policies and activities
- Advocacy can take many forms. In relation to TB, it could for example be:
  - a coalition of civil society organisations (CSOs) holding a press conference or jointly signing an open letter
  - a meeting with a country's President
  - or a play about rights performed for key decision-makers by actors living with TB
- Advocacy can be written, spoken, sung or acted. It can also vary in the time it takes – from a few minutes to several years. We can do advocacy on our own or with others. It is possible to advocate for other people or for ourselves

Sub-section 2: How advocacy complements and enhances other TB work

- Advocacy is only one approach to influencing TB prevention, care, impact and policy work. Other approaches include community mobilisation, education, public health measures, good medical services and community support
- By gaining the support of people in power and changing the social environment in which this work takes place, advocacy can enhance these other approaches, making them more effective. Almost all non-government organisations (NGOs) have experience of doing advocacy – even if they do not realise it, or do not use the word 'advocacy'

Sub-section 3: Identifying Advocacy opportunities

- To effectively identify opportunities, advocates need to understand the usual rules and procedures a country uses to make programme and policy decisions
- These may be at the national level, where discussions are focused on broad policy issues and official national policies, or at the operational level, where specific resource allocation and service delivery guidelines are formulated
- They can be 'reactive', which requires moving fast when a local, national or international event provides an opportunity for TB advocacy
- Or they may be 'proactive', which requires a strategy and planning for the future in order to have maximum impact in what you are saying and on the people you are trying to influence

Sub-section 4: Doing Advocacy - Key steps

- Identify issues or challenges in the TB response (like in the Pathways exercise, for example)
- Select an issue or problem you wish to address
- Gather available information about the issue
- Analyse the problem and potential solutions
- Develop specific objectives for your advocacy work
- Identify your targets (whom will you influence?)
- Identify your resources (what funds will you need? What other resources do you have?)
- Identify your allies (who will you work with?)
- Create an advocacy plan with specific goals, outcomes, dates and responsibilities
- Implement, monitor and evaluate your work (ongoing, and amend it as you go along)

Sub-section 5: Qualities of an effective advocate

- Deep knowledge and understanding of topic, issue, subject
- Effective communication skills
- Negotiation and persuasion skills
- Confidence and conviction

Examples of good, effective advocacy
(to be identified by facilitator as relevant in the local context)

Notes for the facilitator

Setting the context:

- The facilitator begins the session by preferably briefly sharing his own advocacy experience. S/he goes on to explain that this will be a session with a formal presentation. Participants will have an opportunity to ask questions at the end or at any point during the session

Conveying the key messages/information:

- The facilitator begins the session by asking the group if anyone can explain the meaning of advocacy. Depending on the responses, the facilitator builds the meaning using flip charts

- The facilitator then explains how advocacy fits into and complements a holistic public health response in other ways, the need for advocacy. The facilitator could ask the participants why TB needs advocacy and note down the responses
- The facilitator goes on to explain how advocacy opportunities can be identified
- The facilitator then outlines the various steps in doing advocacy. This could be a crowd-sourced activity
- The facilitator identifies the qualities of a good advocate. Again, this could be crowd-sourced so as to make it more interactive

Summarising the session:

- The facilitator ends the session by giving some examples (preferably India, preferably public health) of what effective advocacy achieved

The contents of this session are adapted from various advocacy toolkits and guides.

Advocating to different stakeholders

Objectives of the Session

- To enable TB Champions to know the key stakeholders they can advocate to
- To help participants understand that different advocacy strategies and tools are required for different stakeholders

Expected Learning Outcomes

- Participants will be able to name the key stakeholders for effective advocacy as well as the different kinds of advocacy
- Participants will be able to identify some key advocacy strategies and tools
- Participants will have had an opportunity to practice some of these tools

Suggested Methods

- Discussion, Role-play and Group work

Materials Required

- Presentation with slides and projection facilities
- Flip-charts
- Any other props required for role-play, can be generated by participants

Session Content

Sub-section 1: Different kinds of advocacy

Some kinds of advocay include:

- Policy advocacy: Informs politicians, elected representatives, etc. how an issue will affect the country; requests specific actions to improve laws and policies
- Programme advocacy: Focuses on programme implementers at various levels to take action
- Media advocacy: Validates the relevance of a subject; puts issues on the public agenda, prompts the media to cover TB-related topics

Sub-section 2: Some advocacy tools and techniques

- Parliamentary debates
- Political events

- Community meetings
- Petitions
- Letter writing campaigns
- Using social media
- Personal stories
- Working with the media

Sub-section 3: Key messages

- Advocacy should support the overall TB strategy
- Activities should be tailored to specific challenges and achievable results
- Planning is critical to success
- Build relationships over time to strengthen your ability to influence
- Use current priorities to your advantage
- Focus your work on the places where you will see the most benefit for your efforts
- Extend your reach. Partner with key organisations that have large networks or are invested in your cause

Notes for the facilitator

- The facilitator begins the session by saying that participants will now have an opportunity to practice what they learnt in the previous session
- As a first step, each participant will be asked to map the key stakeholders in his or her area using a standard template
- The facilitator will then lead an open discussion of the different kinds of people TB Champions can and should work with
- For the second exercise, the facilitator divides participants into groups of no more than 7-8 at the maximum
- Each group is assigned a different kind of advocacy – policy, programme, media
- Each group is asked to come up with an advocacy campaign
- The facilitator also asks the participants to first identify the issue(s) they wanted to advocate on/for, based on the pathways exercise
- Each group then works on developing their campaign ideas. For example, one group could prepare and present a pitch to an MLA for a DMC in their area. Another group could present a mock press conference on a TB issue in their community. A third group could draft a letter to the programme with information from the field and a request to take action

- The facilitator provides inputs where required and encourages the participants to be as innovative and creative as possible
- The three groups 'perform' and get feedback from their peers
- The facilitator asks the groups to identify what they enjoyed about the process and what they found challenging
- The facilitator ends the session by reminding participants that advocacy is a long process and requires patience

Using Personal Stories for Advocacy

Time Required: 1.5 hours

45 minutes: Presentation and discussion

20 minutes: Individual work

25 minutes: Sharing of stories (in small groups or to the larger group)

Objectives of the Session:

- To describe the importance of communication and story-telling for effective advocacy
- To provide TB Champions with the knowledge and skills required to tell their personal stories effectively for different audiences

Expected Learning Outcomes:

- Participants will have a clear understanding of the basics of effective story-telling
- Participants will understand the elements of a good story
- Participants will learn how to use their own personal story of the TB journey as an advocacy tool

Suggested Methods:

- Presentation and projection facilities
- Open discussion
- Practice sessions in small groups for peer feedback

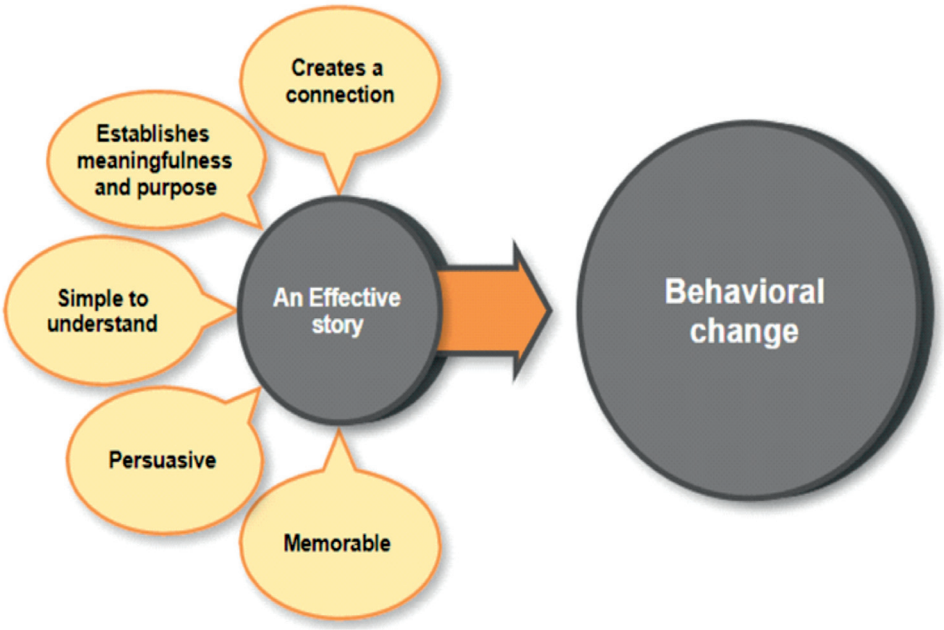
Materials Required

- Presentation with slides
- A4 size individual sheets
- Pens
- Flip chart
- Short videos of personal stories by TB Champions

Session Content:

- Why is personal storytelling important for advocacy? Why should TB survivors share their stories?
  - Can convey a wealth of information and high level of detail
  - Provides context, yet is personal
  - Helps listener connect and identify with an issue/situation
  - Listener learns
  - So does the storyteller

- Good stories can trigger behavior change



- What are the elements of a good story?
  - About something that really happened to you
    - "When I was ..."
    - "My colleague or friend told me about when she/he ..."
  - Told from your perspective
  - Describes something at a specific time and location
    - "Last year when I was working on / helping someone ..."
    - "When…."

- Good stories have a 'story spine'. It builds tension for the reader/listener and takes her/him to a logical outcome/conclusion

What are some ground rules for effective story-telling?

- Keep it simple and personal
  - The focus should be on the TB Champion's story, not the burden of TB in India or what happened to other people
- Know your audience and learn to tell the same story in different ways for different people
  - For example, a TB Champion who meets an MLA must highlight policy-level issues
  - A TB Champion who meets a programme manager must identify ground-level issues that need to be resolved
  - A TB Champion who speaks to other survivors must inspire and motivate them
  - All of these can be based on the same personal story, by just drawing on different elements

- Know which details to include, which ones are not relevant and keep it short
  - The TB Champion must identify the important message s/he wants to convey - is it diagnostic delays, inaccessibility of services, adverse effects, stigma, loss of wages, costs, etc.
  - Every detail of a personal story is vital for the storyteller, but not necessarily the audience
  - The diagnostic pathway the TB Champion experienced may, for example, be relevant for a certain audience but not all
- Understand that a powerful story need not be a sad story - your aim is not to make listeners cry
  - Personal stories should not evoke pity in the listener instead it should galvanise them to action
- Accepting that some details may be too personal to share
  - But be honest about it and acknowledge that it is too painful to share some information related to how TB impacted the person's life

Group Activity:

Following the presentation, the participants take 10 minutes to write their personal stories of how TB affected their lives, assuming the following:

- They have 2 minutes to tell someone their story and it must be as powerful as possible
- They follow the story spine method
- They can write/speak in any language they are comfortable with

They will then divide into small groups of 4-5 and practice telling each other the stories. Each person should get at least one opportunity to share their story, based on what they have written.

Time permitting, 2-3 volunteers can be invited to share their stories to the larger group, and receive feedback from their peers

Notes for the facilitator

Setting the context:

- The facilitator begins the session by asking the group why personal stories are important for advocacy. The responses can be written on a flip chart and reviewed with the first slide of the presentation
- The facilitator makes the case for effective storytelling and its potential impact on listeners, conveying that there is no substitute for honest, emotional storytelling

- The facilitator shows 2-3 short videos featuring TB Champions as examples of good storytelling

Conveying key messages/information:

- The facilitator crowdsources the elements of a good story and then shares the relevant slides
- The facilitator explains the concept of the story spine with an example (not necessarily related to TB)
- The facilitator then leads a discussion on the ground rules for effective storytelling, preferably with examples for each rule. The facilitator will explain that these are not meant to be prescriptive as much as suggestive and that individual personalities must shine through personal stories
- The facilitator reminds participants that body language and expressions are as important as what they are saying
- After the discussion, the facilitator asks each participant to take 10 minutes to write their individual stories on paper
- The facilitator encourages participants to work in the language they are comfortable in
    - Depending on the group's literacy levels, this can be converted into an exercise in pairs
- As a final exercise, the facilitator divides the participants into groups of 4-5. In these groups, each participant can share their story at least once and get feedback from their peers
- The facilitator invites 2-3 volunteers to come share their stories in front of the larger group and get feedback. Alternatively, the facilitator can call on a participant s/he knows is likely to be eager/confident to share and will be a good example for the others to emulate

Summarising the session:

- The session concludes with a quick summary of the importance of storytelling and a plea to all TB Champions to share their stories boldly and openly, without fear of judgement or stigma

Important: the facilitator's role is to be encouraging and create a safe space where participants feel comfortable sharing their stories. The facilitator must not give highly critical feedback openly nor discourage any participant from sharing any aspects of their stories. Finally, the facilitator must encourage as many participants to participate in this session as possible but not compel those who may be reticent for various reasons.

Network-building

Time Required: 1 hour, 30 minutes

Objectives of the Session

- To understand the significance and potential of networks as a means of advocacy and community strengthening
- To describe the processes that can be adopted for effective network-building
- To provide participants with the knowledge and skills required to build a strong network

Expected Learning Outcomes

- Participants clearly understand the power of networks, and their role in building them
- Participants are equipped with the preliminary knowledge and skills required to build a strong network

Note: in settings where networks already exist, the session can focus on network-strengthening and bringing together existing members with potential new members.

Suggested Methods

- Presentation
- Open discussion
- Small Group activity

Materials Required

- PPT
- Chart Papers
- Markers
- Double sided tape

Session Content:

- Why is network-building important?
  - Brings together people with a common goal and motive
  - One of the most effective ways for rights-based advocacy
  - Effective tool for affirmative and protective policy and legislative level changes

- Strengthens community monitoring systems for real time impact

- What are the areas in which the network can work?
  - Supporting people with TB: To support people with TB through psycho-social support, stigma mitigation etc.
  - Community mobilisation and awareness: To sensitise communities about the basics of TB and where to seek TB services
  - Advocacy: To advocate with multiple stakeholders including government officials, policy makers, private sector, on various issues related to TB
  - Stigma reduction: To address the issues of TB-related stigma at various levels including families, workplaces and communities

- What are the processes adopted for network formation?
  - The first step is a recognition by the group or potential members of the need for a network
  - Once this decision has been taken, members should discuss and agree on the objective of a network, and what they hope to achieve
  - They can identify the geographies they plan to work in as well as how the network will expand. The criteria for membership should be discussed (e.g.: only survivors, those currently on treatment, family members, TB-affected communities, etc.)
  - Leadership is critical and the network should identify its leader(s) at the earliest possible opportunity
  - At the next stage, the network should develop a road map and work-plan, and also put in place governance mechanisms
  - The network members should take a decision on registration of the network and their legal status
  - Do the members want to go in for registration? If so, legal provisions under the Indian system for registration must be discussed
  - Networks can also choose to come together and function informally

Network-building should also focus on reaching out to and bringing in people who are affected by TB to the group. Discuss how this outreach can be done, what material would be needed to sensitise potential network members and how they will be enrolled in the network.

Here, it is important to provide examples of successful networks, preferably working on health issues, and from a similar geography. It would also be good to invite founders or members of existing networks to talk about the opportunities and challenges in network-building.

Group Activity:

Following the presentation and discussion on thematic areas of engagement, the participants are divided into four small groups. Each group gets a thematic area to discuss (Advocacy, community awareness, supporting people with TB, stigma reduction).

The participants have 30 minutes to discuss the various activities that can be undertaken under the various thematic areas. Each group gets 5 minutes to make a presentation. The objective of this exercise is for participants to suggest what networks can do, vis-à-vis, what individuals can achieve. The presentations and suggested activities must focus on the power of the collective.

Notes for the Facilitator

- This session is ideally led or facilitated by a founder member of an existing network
- The facilitator begins the session by asking the group to provide the first word that comes to their mind when they think of networks. These responses are listed on a flip chart
- The facilitator crowdsources the reasons for a network and then shares the relevant slides
- Networks are an important tool for advocacy. The facilitator must amplify this in the presentation and provide examples of existing networks
- The facilitator must also emphasise the importance of building partnerships with others working on TB, to leverage and share resources whenever possible
- The facilitator can show short videos of the work of networks to provide an idea of the kind of thematic areas that the network can work in
- The facilitator leads the participants through the short group exercise described above
- If time permits, the facilitator can also introduce other team-building exercises
- The session concludes with a quick summary of the important points of the session
- The facilitator, after the session, asks the participants if they want to form a network in their state/ district (If the network is not already formed). If the network is already in existence, the facilitator informs participants about the network and its work

Providing Psychosocial Support to TB-affected communities

Time Required: 2 hours

Objectives of the Session

- To ensure TB Champions understand why and how peer support can be effective in helping overcome psychosocial issues associated with TB and completion of treatment
- To empower TB Champions to use best practices in providing psychosocial support and know when to refer individuals to others for further assistance

Expected Learning Outcomes

- Participants will be able to articulate the major psychological and social issues people affected by TB, their family and friends commonly face
- Participants will implement productive listening and counselling techniques to address psychosocial issues
- Participants will clearly understand their role and limitations in providing this support and will know when and where to refer individuals for further assistance

Suggested Methods

- Presentation
- Discussion
- Role Playing

Materials Required

- Presentation + projection
- White board/flip-charts

Session Content

Sub-section 1: Why psycho-social support matters

- TB is a disease that affects both the physical and emotional health of an individual. A person may be on treatment for TB but not necessarily receiving emotional or psycho-social support. TB Champions can fill this important role
- *Psycho-social health* is the mental, emotional, social, and spiritual dimensions of what it means to be healthy. Psychosocial health is the result of complex interaction between a person's own psychology and how they perceive and interact with others[i]

- If a person is psychosocially healthy, they are better equipped to deal with the problems associated with TB, more likely to successfully complete treatment, and more likely to have better health outcomes
- TB Champions, in their capacity as survivors, are peers and can provide valuable support to those with TB and their families. *Peer-support* is the process of giving and receiving encouragement and assistance to achieve long-term recovery. Peers offer emotional support, share knowledge, teach skills, provide practical assistance, and connect people with resources, opportunities, communities of support, and other people[ii]
- A TB Champion can use her or his lived experience of recovery from TB, plus skills learned in formal training, to provide support to promote adherence, mind-body recovery, and resilience to deal with the disease

Sub-section 2: What can peer counselors (TB Champions) do?

- They provide compassionate listening, and a positive vision of the future. Additionally, they can work with individuals in problem solving, and developing achievable action plans. They can play an important role in supporting people in self-managing TB and working towards whole health goals. They are uniquely qualified to assist others in connecting with their communities, strengthening supportive relationships, accessing formal and informal resources, and working with cultural humility to support people across a wide range of people[iii]
- Can take many forms: One-on-one, in a group, over the phone, via WhatsApp or SMS, online
- TB Champions can offer different kinds of support:
  - Emotional - Demonstrate empathy, caring, or concern to bolster the person's self-esteem and confidence
  - Instrumental - Share knowledge and information
  - Affiliation - Provide assistance to help others accomplish tasks (e.g. make daily plans, provide referrals, enrollment in programme, etc.)
- What does a TB champion do and not do?

What a TB Champion Is/Does	Is Not/Does Not
A person who has been affected by TB	A medical professional
Shares lived experience	Gives professional advice
A role model	An authority figure
Sees the person as a whole person in the context of the person's roles, family, community	Sees the person as a case or diagnosis
Motivates through hope and inspiration	Motivates through fear of negative consequences
Teaches how to acquire needed resources	Gives resources and money to the person
Uses language based on common experiences	Uses clinical language
Helps the person find professional services from doctors, psychologists, lawyers	Provides professional services
Helps to set personal goals	Mandates tasks and behavior

- A TB Champion can continue to be in touch with the person who has TB. This would signal continued commitment and help to build better trust. When the person with TB is feeling better, and is nearing the end of the treatment, the TB champion could tell him/her about the kind of work s/he does and encourage the person with TB to take up similar work or join the network of TB Champions

Sub-section 3: Skills required to provide psycho-social support

- *Non-judgement:* The most important attribute of a good TB counselor is not questioning or criticizing someone who is facing the significant challenges posed by a TB diagnosis of themselves or a loved one. Everyone's problems and processing of an illness is different. It is important not only to avoid judgmental statements, but also to avoid judgmental questions and tones
- *Active listening* builds trust and rapport. An active listener will use open-ended questions, reflect feelings, and provide affirmations while avoiding communication roadblocks
    - Facilitator will give closed or judgement-loaded questions and trainees will need to restate them to be active listening questions
- *Positivity:* It is important to provide empathy, but never criticise someone or their family or friends. Use questions and your own story to help guide them to positive solutions
- *Storytelling:* Through stories, peer supporters can reveal their vulnerabilities and strengths and reinforce their peer identity. In the process of sharing their lived experiences, peer supporters can model positive behaviors which can stimulate problem-solving and motivate peers in their own self-care. The only caveat is to balance storytelling against oversharing; that is, watching for peer supporters with strong personalities that may dominate conversations with their own stories[iv]

Sub-section 4: Stigma and Discrimination

- *Stigma* is a negative judgement or label people place on a person or a group of people because of a characteristic, like TB diagnosis[v]
- What are other things people are stigmatised for?
    - Answers could include: caste, race, religion, age, socioeconomic status, gender, sexual orientation, education, disease, place of origin, nature of work
- *Discrimination* is when a person is treated less favorably as a result of their condition or characteristic[vi]
- What are some of the stigmatizing thoughts people have about someone with TB?"
    - Answers could include: Poor, dirty, alcoholic, unemployed, hereditary issue, bad family, occupation
- What are some ways in which people with TB are discriminated against?

  - Answers could include: lose or cannot get job, shunned by family and friends, cannot get married, receives poor medical treatment

- People who face unaddressed stigma and discrimination develop poorer psychosocial health, and are less likely to recover from disease
- Also, when people do not seek treatment because of stigma, they are more likely to transmit the disease to their family and friends

Group Activity

- The facilitator will call on two volunteers who will roleplay a first interaction between a TB Champion and a person on treatment. This conversation can last for approximately five to ten minutes, but could be longer
- The objective of the roleplay is to understand what the TB Champion must convey in this first conversation, irrespective of whether it is in person or on the phone – it is important that the person with TB clearly understands the TB Champion's role and how s/he can help
- The TB Champion must clearly describe how s/he will support the person with TB over the next few weeks or months as well as the proposed frequency of their interactions
- The person with TB must be given an opportunity to ask questions and seek clarifications
- After the roleplay, the facilitator will lead a brief discussion on the conversation. Although some criticism can be levied, try to keep the feedback mostly positive
- Have all participants pair off and act out a first interaction – each participant must have the opportunity to enact both roles (once as a newly diagnosed person with TB and once as the TB Champion)
- After the paired exercise, ask the group what they found challenging and what they thought a good counselor would require. Have the group brainstorm solutions to difficult situations that were shared

Notes for the facilitator

Setting the context

- The facilitator will begin the session by reminding participants that this is a core support that they can provide to those affected by TB
- The facilitator will define some key terms such as "psychosocial health" and "peer support"
- The facilitator will ask the participants to give responses to this question: *"Why is a TB Champion best placed to provide psychosocial support?"*. All the responses should be written on a board or flip charts

Conveying the key information/messages

- The facilitator leads the participants through a discussion on how a TB Champion can provide support to people with TB and their families
- The facilitator will also clarify what the TB Champion cannot and should not do. For example, the TB Champion is not a replacement for the doctor or a trained counsellor to treat depression or hallucinations
- The facilitator can include many small activities in this session, including:
    - Write all the points in the table above (what TB Champions can/cannot do) and have the participants place them under the correct heads
    - Another option would be to write them out, line by line and ask why each is in their respective column
    - The facilitator can give judgement-loaded questions and ask participants to restate them to be neutral questions. For e.g.: you should not have gone from one doctor to another, wasting your time and delaying your diagnosis. This is an example of a judgement-loaded question
- The facilitator will state that two of the major issues that affect someone with TB are stigma and discrimination. The facilitator will then define stigma and discrimination:
- The facilitator can then develop two lists or discuss the ways in which people with TB are stigmatised and discriminated against
- The facilitator then conducts the activity described above and ensures that all participants have sufficient time to do this roleplay exercise

Summarising the session

- The facilitator leads participants through a joint analysis of the role-play, what they found challenging and what worked for them
- The facilitator concludes the module with a review of the key terminology, and asks participants to name their top two takeaways from the session
- The facilitator encourages TB Champions to include the skills of effective communication into their everyday life

[1] Donatelle, R. J., & Davis, L. G. (2011). Health: the basics. Benjamin Cummings.

[1] Mead, S. Defining Peer Support. (2003). Retrieved from http://www.mentalhealthpeers.com/pdfs/DefiningPeerSupport.pdf

[1]Hendry, P., Hill, T., Rosenthal, H. Peer Services Toolkit: A Guide to Advancing and Implementing Peer-run Behavioral Health Services. ACMHA: The College for Behavioral Health Leadership and Optum, 2014.

[1]http://peersforprogress.org/pfp_blog/fundamentals-of-good-peer-support-strengthening-communication-skills/

[1]Baral, S. C., Karki, D. K., & Newell, J. N. (2007). Causes of stigma and discrimination associated with tuberculosis in Nepal: a qualitative study. BMC Public Health, 7(1), 211.

[1]Baral et al, (2007).

Building accountability through community monitoring

Time Required: 1 hour

Objectives of the Session

- To help participants describe the need for community feedback and monitoring
- To enable participants to identify and prioritise issues that need to be addressed through community monitoring

Expected Learning Outcomes

- Participants are able to articulate the need for community monitoring
- Participants are clear about their role in this process and how they can get involved

Suggested Methods

- Brainstorming
- Presentation
- Group Discussion

Materials Required

- Presentation + projection
- White board/flip-charts

Session Content

Sub-section 1: About community monitoring

- Community monitoring is an integral part of a community-based response to TB
- Community monitoring – monitoring and feedback by communities served by a programme – can provide valuable, real-time, from-the-field information that may otherwise not be available.
- In other words, community monitoring connects service providers with service-users
- What are some examples of situations where community monitoring has proven useful?

- There are many examples of community monitoring from different countries
- Community monitoring should be conducted in an environment of trust and with a shared vision of ending TB
- Community monitoring seeks to constantly ask – how can we further improve and ensure that TB-affected communities can access the highest quality of services possible?
- Community monitoring efforts can be directed at the public and private systems
- An effective and robust community monitoring system can not only ensure the direct flow of information but also help create an environment conducive to real-time problem solving
- Community monitoring can bring to the attention of the officials the deficiencies or lack of manpower / logistics such as reagents/drugs or other qualitative aspects of services
- Community monitoring is not mere fault-finding but should also provide positive feedback and express appreciation when the availability or quality of services has improved

Sub-section 2: Community monitoring mechanisms

- The RNTCP has mechanisms built into the programme for feedback or reporting of grievances by those with TB and their families. This may be a mobile telephone number to which a call maybe made, or a register where your grievance may be recorded or a box into which it may be deposited
- *Community Score cards:* This is a mechanism through which citizens monitor the quality of community based public services. It provides the opportunity for citizens to analyse any particular service they have received based on their personal feelings, to express dissatisfaction or to provide encouragement for good work. It also further suggests measures to be taken if flaws still remain[1]
- *QUOTE TB Light:* QUOTE TB is a tool that is meant for use as part of regular programme supervision activities. It is an instrument to measure the needs and perceived quality of services from the perspective of the person with TB. It is also a management tool to help programme managers, health facilities, and their partners to assess the quality of TB services based on feedback. The tool focuses on nine dimensions of quality TB care. It consists of a focus group discussion guide, standardised questionnaire, and quality impact scoring sheet[2]
- *Community Action for Health:* The Community Action for Health, earlier known as Community Based Monitoring and Planning (CBMP), 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[3]

- *Use of Digital technology:* TB Mitra is a free-to-use mobile-phone based application that enables users to report any issues they face at any stage during the diagnosis and treatment process. This has been developed by REACH with support from USAID. Through this application, users can learn about TB, know where to go for services and provide feedback on TB services. This is currently being tested
- *Direct outreach:* TB Champions, those on treatment and members of networks can directly provide feedback on TB services to the relevant officials. Relaying feedback as a network may be more effective in certain situations

Notes for the facilitator

- The facilitator begins the session by crowd-sourcing the meaning of community monitoring
- S/he then asks participants why community monitoring is necessary, and what the role of TB Champions is in this process
- The facilitator shares that the aim of community monitoring is not to find fault but identify areas for improvement
- The facilitator gives examples of different community-monitoring mechanisms to participants
- The facilitator ends the session by asking participants if they can think of any other ways to provide feedback, and to name their main takeaway from the session

[1] http://blogs.worldbank.org/category/tags/community-score-card

[2] https://www.challengetb.org/publications/tools/ua/Quote_TB_Light.pdf

[3] https://nrhmcommunityaction.org/about/

CLOSING SESSION

The final session of the workshop can be for participants to develop and share their TB work-plans for peer review. These plans can focus on supporting people with TB, advocacy and community sensitisation, according to where the TB Champion lives and intends to work. These work-plans can have specific targets, to motivate Champions to work towards them from the beginning.

The workshop can end with a brief valedictory session, chaired by an elected representative, a senior health official or a key influencer such as a prominent TB Champion or a journalist etc. Participants must be given certificates and their active engagement over three days appreciated.

Annexure 1
Patient's charter for Tuberculosis Care

Patients' Rights
You have the right to:

Care

- The right to free and equitable access to tuberculosis 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, centering on patient needs, including those with multidrug-resistant tuberculosis (MDR-TB) or tuberculosis-human immunodeficiency virus (HIV) coinfections 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 programs

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 healthcare in a dignified environment, with moral support from family, friends, and the community Information
- The right to information about what healthcare services are available for tuberculosis 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 which relates to the patient's condition and treatment and to a copy of the medical record if requested by the patient or a person authorised by the patient
- The right to meet, share experiences with peers and other patients and to voluntary counseling 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 programs 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

Organisation

- The right to join, or to establish, organisations of people with or affected by tuberculosis and to seek support for the development of these clubs and community-based associations through the health providers, authorities, and civil society
- The right to participate as "stakeholders" in the development, implementation, monitoring, and evaluation of tuberculosis policies and programs 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
You have the responsibility to:

Share Information

- The responsibility to provide the healthcare 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 tuberculosis 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 the symptoms of tuberculosis
- The responsibility to show consideration for the rights of other patients and healthcare providers, understanding that this is the dignified basis and respectful foundation of the tuberculosis 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 tuberculosis free

"Just like I was cured, I want others to be cured too. I have already started identifying TB-affected people in my Panchayat"
- Nirmal Kerketta, TB Champion, Jharkhand

"I have won the battle against TB. Now it's your turn to take on the fight. Let us work together to eliminate TB"
- Suneeta Kumari, TB Champion, Uttar Pradesh

"Stay confident and fight against TB. Be a role model for others...TB Champions like us can inspire and motivate people affected by TB"
- Mala Nayak, TB Champion, Assam

"I am determined to create awareness about TB among women in my village so that they do not face the problem of late detection like I did"
- Vimla Vako, TB Champion, Chhattisgarh

Central TB Division
Ministry of Health and Family Welfare,
Nirman Bhavan, New Delhi - 110108
www.tbcindia.gov.in