



Training Curriculum

Strategy to End Stigma and Discrimination Associated with Tuberculosis

Contributions

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Disclaimer

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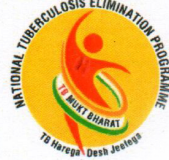
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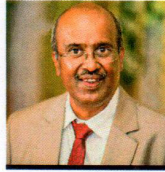
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FOREWORD



The Hon'ble Prime Minister has set an ambitious goal to end TB in India by 2025, five years ahead of the global targets (UNSDG-2030). To achieve this ambitious target all stakeholders must come together to address the challenge of social determinants making communities vulnerable to TB as well as barriers that prevent people affected by TB from accessing TB services available under NTEP.

Stigma is a major deterrent for access to TB services and is a multi-faceted problem that needs immediate attention to mitigate.

The NTEP has put in place a strategy document, 'Strategy to End Stigma and Discrimination Associated with Tuberculosis' developed in collaboration with partners. This strategy document presents a comprehensive approach to addressing stigma and discrimination associated with TB in the community, workplace, and healthcare facilities, and has guidelines for civil society, the private sector, and healthcare facilities to address stigma and discrimination.

This training manual is complementary to the existing strategy document to End Stigma and Discrimination Associated with TB and aids in operationalizing the same. In other words, the module essentially spells out the steps that can be used by all development partners, practitioners or anyone who is working towards addressing stigma and discrimination associated with TB both within the health system and the society.

I would like to congratulate State NTEP team of Karnataka for developing and piloting the training module in partnership with USAID, KHPT and GCTA. I am hopeful that this training manual will support in realising the dream of the TB free India.

(Dr. Rajendra P Joshi)



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MESSAGE



The National Strategic Plan (NSP) for Tuberculosis (2017-25) recognizes the relevance of strengthening social support systems for TB care and community interventions to reduce stigma and discrimination associated with TB in a holistic way. The National Tuberculosis Elimination Program (NTEP) continue to invest in new approaches, tools, interventions and identified the need to strengthen community engagement approaches to ending TB.

We have seen that the community's active participation is required in all the four strategic pillars under NSP (2017-25) - Detect, Treat, Prevent and Build, which will result in early diagnosis of TB, timely initiation of appropriate treatment and linking to all services under NTEP. An aware and active community has the potential to address the underlying factors, especially stigma, that prevent persons from seeking and accessing the healthcare services and benefits provided free of cost by NTEP.

We have developed and shared a strategy document "Strategy to End Stigma and Discrimination Associated with Tuberculosis" with all the stakeholders in 2021. The strategy guide recognizes the extent of the impact of stigma on people with TB, speaks about the various forms that stigma can assume, and also outlines the steps that can be taken to tackle stigma whether in the health care system setting or in the larger society. We see a larger role for communities to create an enabling environment for those persons with TB to make informed choices and decisions without the fear of stigma and discrimination.

This training manual is a supportive guide that will help operationalize our existing stigma mitigation strategy. The manual clearly lists the various steps that can be used by community, nodal agencies of the Government and partners working towards ending TB to address stigma and discrimination associated with TB.

I call upon all State and District NTEP teams and development partners to use this training manual effectively. I would also like to acknowledge the support of the USAID, KHPT and GCTA towards collaboratively developing the manual. I am hopeful that this manual will help the State teams to ensure delivery of Patient Centric TB services.


(Dr. Nishant Kumar)

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Foreword

Since 1998, the United States and India have worked together to combat tuberculosis (TB) through improved person-centred diagnosis, treatment, and prevention, helping treat more than 15 million people with the disease. The U.S. Agency for International Development (USAID), in partnership with local health organizations, supports Prime Minister Modi's goal of TB elimination by improving case detection and treatment success rates, addressing multi-drug resistant TB, and leveraging new partnerships, artificial intelligence, and digital health solutions. TB is a grave public health challenge, with India carrying more than 25 percent of global TB burden.

One of the greatest challenges in achieving a TB-free India is overcoming the stigma associated with the disease. It is well known that the stigma associated with TB acts as a barrier to diagnosis, initiation of treatment, and completion of care. It also prevents people with TB symptoms from accessing health care services. Addressing the delay in diagnosis and ensuring successful treatment outcomes are critical to realizing the goal of ending TB.

In our effort to reduce the stigma and discrimination associated with TB, we must address and seek ways to eliminate the stigma and discrimination associated with TB both within the health system and society writ large.

Through USAID's 'Breaking the Barriers' project, USAID and Karnataka Health Promotion Trust (KHPT) have developed and implemented behaviour change models to increase case notification and improve treatment outcomes in drug-sensitive and drug-resistant TB. This has been done by identifying the behavioral drivers of stigma, dispelling misconceptions about the disease, and humanizing people living with TB.

The training module that has emerged from the "Breaking the Barriers" project and developed in collaboration with GCTA (Global Coalition of TB Advocates), and piloted in partnership with the state of Karnataka will enable partners to address the stigma associated with TB both within the health system and the community. We are also hopeful that this module will support in fulfilling the *TB-Mukt Bharat* vision and improve the health outcomes of the communities.

Sangita Patel

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Foreword

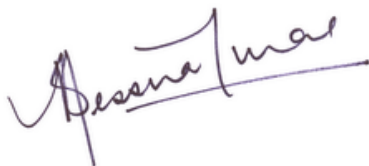
The vision set by the Hon. Prime Minister of a 'TB Mukta Bharat' will remain an unfulfilled dream unless we identify and address barriers to achieving this. Stigma and Discrimination continue to be one of the biggest hurdles and needs to be recognized and addressed at different levels. A people centered rights-based TB response is only possible if people with TB have access to services which are provided respectfully, upholding the dignity of the individuals.

India is one of the first countries to develop the 'National Strategy to eliminate Stigma and Discrimination associated with TB in India' with support from partners and was launched by the Hon. Health Minister on World TB Day 2021.

To support and accelerate the paradigm shift towards a stigma free TB response, we are glad to have had the opportunity to develop the Training Manual based on 'National Strategy to eliminate Stigma and Discrimination associated with TB in India' with support from USAID and KHPT.

Our sincere hope is that this training manual will help different stakeholders in understanding the stigma and discrimination associated with TB and how it affects not only the person with TB but also their families and communities. With this understanding and information we would be better placed to plan and implement stigma reduction strategies that are sustainable and go a long way in achieving the goal of ending TB at the earliest.

TB Harega Desh Jeetega!!
#InvestInCommunities



Blessina Kumar,

The Global Coalition of TB Advocates (GCTA)

Foreword

KHPT is a non-profit organization that has been working for the past two decades in the area of public health with a focus on vulnerable populations across India with strong evidence-based, community centred, and government-integrated approaches. We have been working on TB initiatives for over a decade, implementing person-centric, community-led, and evidence-based innovations to improve health-seeking behaviour among vulnerable populations for successful TB treatment outcomes.

Our experience of working with vulnerable communities tells us that despite several efforts to address the stigma and discrimination associated with the disease, the problem persists and adversely impacts the acceptance of tuberculosis as a curable disease, which in turn deters treatment compliance, leading to higher chances of infection transmission, and loss of human lives.

One of the ways to address this barrier of stigma and discrimination associated with tuberculosis is to spread the right information about TB across masses. At KHPT we did this through our work with local community structures, such as self-help groups, Panchayati Raj Institutions, worker's unions, and health care providers. We need to work with each of the local stakeholders to sensitize them and motivate them to be partners in spreading correct information about tuberculosis across the community, dispelling all myths and misconceptions about the TB and ensuring that persons with TB, their caregivers, and TB survivors can live in an enabling and supportive environment.

We are hopeful that this manual will be a meaningful and practically applicable document for the National TB Elimination Programme (NTEP), and other partners working on strengthening the stigma-free TB response. We are happy to have collaborated with the Global Coalition of TB Advocates (GCTA) to develop the stigma training manual with support from the United States Agency for International Development (USAID).

TB Harega Desh Jeetega!!



Mohan H L

Chief Executive Officer

KHPT, Bangalore

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BACKGROUND



Tuberculosis (TB) is a communicable disease, and one of the top 10 causes of death worldwide. Globally, an estimated 10 million people fell ill with TB in 2020, about 4 million of whom remained undiagnosed or unreported. This resulted in 1.5 million deaths. India carries over a fourth of this burden, averaging an incidence rate of 199 per 100,000 population in 2019. India's National Strategic Plan (NSP) for elimination of TB proposes bold strategies towards the elimination of TB in India by 2025, five years ahead of the global End-TB targets. However, there remain several challenges and barriers in the path towards TB elimination, with some preventing access to quality TB services and care.

Stigma and discrimination are recognized to be among the most common human rights-related barriers hindering the fight against the TB epidemic. In September 2018, Heads of State and Governments at the United Nations High-Level Meeting on TB, and in the resulting Political Declaration on the Fight to End TB, committed to promoting and supporting an end to TB stigma and all forms of discrimination. This commitment demonstrates recognition at the highest level that to end TB, we must end TB stigma.

WHO defines stigma as a mark of shame, disgrace or disapproval that results in an individual being rejected, discriminated against, and excluded from participating in various areas of society. Stigma harms the livelihoods and health of individuals who experience it, and severely hinders TB response. People who fear losing their jobs, loved ones, or being kicked out of school or their homes because of TB are less likely to seek testing and treatment, making an already challenging response even more difficult. The Global Coalition of TB Advocates (GCTA) fervently believes that efforts towards elimination of TB must involve social interventions along with medical and public health interventions. Therefore, GCTA, in collaboration with KHPT, has developed this training manual. It is in complement to the already existing [Strategy to End Stigma and Discrimination Associated with TB](#), developed and published through a collaborative process led by the Central TB Division (CTD), Ministry of Health and Family Welfare, Government of India. This manual is an attempt to unpack the strategy and develop training curricula on ending TB Stigma for community members, frontline health workers and district and state TB officers.

Objectives of the Manual

1 Sensitize state(s)/district(s), TB affected individuals, and other stakeholders on stigma and discrimination, its impact on people affected by TB, and on the reasons it is critical to end stigma to eliminate TB

2 Provide an understanding of the drivers and facilitators of stigma associated with TB

3 Recommend ways to measure stigma related intervention outcomes and impacts at the state/district level

Structure of the Manual

This manual has been designed as a complete package for a one-day training, for a group of 20-25 participants. As an alternative, individual modules addressing a particular thematic area or a combination of selected modules may also be used for specific contexts.

How to Use this Manual

This manual is complementary to CTD, MoHFW, GoI's 'Strategy to End Stigma and Discrimination Associated with TB, thus, the trainer can familiarize themselves with its contents. The facilitator(s) are required to read all the topics covered in these modules before the commencement of the training. This will provide them with a comprehensive understanding of the scope of each topic and its relevance, along with the sessions that they will be facilitating.

Prior to the training, facilitators should consider and discuss how they will use these modules to develop the knowledge and capacity of the participants. The sessions are meant to engage the participants in a participatory learning process based on adult learning principles. Facilitators are encouraged to:

- » Identify participants' needs and what is important to them
- » Provide real-life situations and emphasize the application of learning to real problems

- » Conduct activities that require active participation by trainees
- » Use a variety of training techniques
- » Establish an atmosphere of respect and understanding of differences
- » Provide opportunities for sharing information
- » Discuss and analyze participants' experiences
- » Engage participants as valued resources and encourage them to
- » participate and share their experiences

Each session follows the below stated arrangement, although facilitators may choose to adapt them as per the requirements of the training:



Time

Duration of the session



Materials Required

Materials required during the training, including audio-visual equipment, stationery, handouts, reference materials, pre and post training assessment forms and feedback forms



Objective

Desired learning objectives to be achieved by participants at the end of each session



Methodology

Step-by-step participatory methods that will be employed to engage participants in the learning process



Facilitator's Notes

Notes that provide the facilitator with useful information on the topic of discussion and tips for facilitating activities

Tips for Trainers

Before each day's training, it is recommended that the trainers familiarize themselves with the topics to be covered that day by carefully reading the relevant materials. This will enhance their understanding of the concepts in each slide and their correlation to the accompanying text. Depending on the skills of the trainer and their background, they may wish to include examples or case studies to bring further depth and clarity to the topic being presented.

Most of the trainings require more than one trainer. In such cases, it should be ensured that the co-trainers have read all the training materials in this package and that they feel comfortable facilitating the selected topics from the training manual. Trainers should meet before the training to agree on the agenda and to decide who is going to teach which topic. Some trainers feel more comfortable presenting

certain topics than other trainers. For the benefit of the trainer and the trainees, this should be taken into consideration.

It is important to understand the profile of the participants attending the training in order to tailor the material to suit their requirements. For example, if it is a Hindi-speaking audience, then the training can be conducted in Hindi and the presentations can be translated in Hindi. If the participants are a mix of new and senior staff, then ensure that there is space for the senior staff to share their experience with the new staff.

How to Facilitate

The facilitators should be familiar with participatory forms of learning.

- » They should have the ability to ask exploratory open-ended questions and should make it a point to involve all the participants.
- » The facilitators should be technically competent and be able to answer various intervention-related questions. The topics included may be adapted to suit local needs and priorities.
- » While presenting, it is suggested that the facilitator take center stage and not hide behind a podium or a desk. The facilitator should face the participants when speaking and make eye contact with them. They should speak slowly, clearly and loudly. Use natural gestures and facial expressions, and avoid blocking the participants' view.
- » Involve all participants in discussions. Ask direct questions to the quiet ones and rein in the talkative ones. Move around the room - approach participants to get their attention or response, and use their names.
- » Repeat responses from participants when it is likely that not everyone heard. Respond encouragingly and positively to all answers - correct errors gently. Reinforce participants by thanking them for their comments and praising their good ideas. Respond adequately to questions - offer to seek answers if the answer is not known.
- » Handle incorrect or off-the-subject comments tactfully.
- » During group activities, explain clearly the purpose of the activity, what the participants should do, and the time limit.

Key Things to Remember as a Facilitator

Be flexible. Scheduling may have to change depending on the needs of the participants



Read from the PowerPoint presentation – prepare and use the slides to elaborate on relevant points

Use different teaching methods to enhance participation and retain interest



Make the training a boring experience – intersperse the sessions with energizers/ games

Ensure that teaching materials are ready and available before the beginning of the session



Speak more than the participants – let them brainstorm and discuss

Respect participants' local knowledge



Allow distractions like mobile phones and chatting among participants

Encourage participants to make presentations



Let any one person dominate the discussion

Session 1: Setting the Context



50 minutes



Post-it
Whiteboard
Flip chart

PPT for overview
Pre-training assessment forms
Laptop & LCD projector



By the end of this session, the participants will have introduced themselves to each other and the facilitator

Methodology

1. **Introductions (10 mins):** Conduct a fun ice-breaker activity to get to know your group. This can be replaced with another game for introductions.
 - a. Divide the participants into groups of 4 people each
 - b. Each participant should state her/his name, organization and then, share what their “superpower” is. This can be a special skill, a curious fact about their lives, valuable knowledge they share, etc.
2. **Expectations from the training (10 mins)**
 - a. Each participant is to be given a post-it note
 - b. In one sentence, they should answer “What are your expectations from the training program today?”
 - c. Ask the participants to stick their this post-it on a board. The facilitator can group the answers into major themes or simply read out the post-its
 - d. The expectations that do not match the agenda of the training can be kept under a spot titled “Parking Lot”. You can address this at a later time or state that it is outside the scope of this training
 - e. Be sure to check the expectations board at the end of your training program to see if you have covered them all
3. **From a PPT highlight objectives and overview of training (10 mins)**
 - a. Sensitize stakeholders on stigma and discrimination, its impact on people affected by TB, and on why it is critical to end stigma to eliminate TB
 - b. Provide an understanding of the drivers and facilitators of stigma associated with TB
 - c. Identify and prioritize context specific interventions to end stigma and discrimination in different settings and among specific target audiences

- d. Recommend ways to measure stigma-related intervention outcomes and impact at the national level

4. Ground rules (5 mins)

- a. Interact with participants to list down ground rules to be followed during the training so that there is maximum learning
- b. Note their suggestions on a flip chart and put it up on one side of the hall

5. Pre-Training Self-Assessment (15 minutes)

- a. Request participants to complete a pre-training self-assessment questionnaire
- b. Inform them that a similar post-training assessment will also be administered after the last session of this training
- c. Note that this is not an examination, but conducted to measure the learning and effectiveness of the training

Session 2: Quick Overview of Facts on Tuberculosis



30 minutes



Chocolate, as rewards
Handout A
Laptop & LCD projector

Flip chart
Colour markers



By the end of this session, the participants will have a general overview of Tuberculosis, its transmission, diagnosis and treatment

Methodology

1. Introductions (20 mins)
 - a. Game to achieve a baseline understanding of TB within the participants, and

Refer to Annexure 1 for QUIZ of 16 Questions bank with Answer key
2. Divide the participants into 2 groups to participate in a quiz on TB
3. There'll be 10 questions- 5 to each group.
4. The group with the correct answer gets 10 points. No points for wrong answers.
5. If the question is passed & the other group answers, it gets 5 points.
6. DTO will be the judge and will provide clarifications when required.
7. Award to the winners!

Session 3: Stigma and its Impact on Persons Affected by TB



70 minutes



Survivor Stories

PPT: quotes of persons affected by TB, types of stigma, causes and consequences of stigma

Flip chart

Markers

Laptop & LCD projector



By the end of this session, the participants will be able to illustrate the causes, actions and consequences of stigma at all levels of society. They will also be able to identify relevant methods to address stigma and discrimination, along with the gender implications of TB stigma

Methodology

1. It Happened to me! (30 minutes)

- a. Introduce the session and inform the participants that this session is about our own experiences of stigma & discrimination.
- b. Start this session by asking the participants what do you understand of the word stigma or of having a finger pointed at you? Give an example, in a family, if two middle aged sisters are there one is married and other is unmarried, who will get more importance and why? So, with the given answers by the participants, the facilitator can explain the meaning of stigma attached to being an unmarried woman and to be marginalized in society. Ask the participant to think of at least one instance in which they felt 'stigmatised or discriminated', i.e., in which they have felt that they have a disadvantage over most people or kept away from others. In case there is a need to elaborate, the facilitator can say: "This is not limited to only your work place or with your colleagues, it may be within your family, your friends, city and state. Anywhere where you felt you were treated as less visible or told to stay away and not be part of regular living activities.
- c. The facilitator can then ask the participants to voluntarily share their experiences.
- d. To begin the discussion, the facilitator can share his /her own experiences.
- e. If participants are not comfortable to share in larger group, they can discuss in pairs.
- f. Also, if any of the pair after sharing between themselves, wish to share with the larger group, they should be allowed to do so.
- g. Facilitator can draw the following on the black/white board if there is need to

further explain stigma & discrimination.

- h. Each of the experiences can be categorized as S & D faced in the family, work, school/college, health facility, cultural event or thoughts about self worth and self stigma based on others behaviours towards you.
 - i. **Stigma refers to a feeling of inferiority raising a question of acceptance by others, while discrimination is the act of non-acceptance and exclusion.**
 - j. Stigma is negatively labelling a person and because of this, the person is not allowed or restricted to do certain activities. It is associated with disfiguring or incurable diseases, in particular, diseases that society perceives to be caused by the violation of social and hygiene norms or that spreads from one person to another. TB is a good example of this type of disease.
 - k. Discrimination leads to the denial and violation of human rights.
 - l. Stigma and discrimination often go hand in hand. A stigmatised group experiences discrimination, while discrimination reinforces stigma. For eg. For a female, widow is stigma and because she is widow, she is not allowed to attend any function is discrimination.
 - m. Marginalisation, Stigma and Discrimination are seen as the greatest hurdles to effective measures of prevention and treatment of TB.
 - n. Stigma and discrimination often results in exclusion of those most in need of care, information and services.
2. Facilitator can narrate a case study to explain the stigma associated with persons with TB and the drivers of that stigma (5 mins)
- a. **Survivor Story 1:** Rameshwari, a 42-year-old female, was diagnosed with TB. When she started her treatment in August 2020, she lived in her marital home and her weight was 33 kgs. Her husband, upon learning of her TB diagnosis, accused her of bringing bad fortune to their house. He was terrified that he might get the infection and would die. He abandoned his wife, asking her for a divorce. By October 2020, when Rameshwari arrived at her parents' home, her weight was 28 kgs. Initially, she refused to continue her treatment and wanted to die. She was provided counselling to help her overcome her trauma. Her maternal family were also counselled and asked to support her in completing her treatment. She also attended Community Support Group meetings regularly, receiving peer support and counselling for treatment adherence. Furthermore, she was provided assistance in getting a decent job through her city's Chamber of Commerce and Industries, and received social entitlements from Women and Child Development schemes. With this support, she completed her treatment successfully.
 - b. **Survivor Story 2:** Raki, a 32 year old transgender person was a popular leader within her community. Despite her health deteriorating she did not get tested for TB or HIV. Her fear of stigma and discrimination made her avoid tests that could confirm her sickness, resulting in delayed testing. This delayed detection of TB & HIV was the cause of her death.

Facilitator's Notes:

Women in India face multiple layers of stigma: that of gender, health conditions, social status based on education, local culture, etc. Their marginalization from health, education and livelihood services further exacerbates their condition in a patriarchal society that violates their human rights.

Stigma, lack of nutrition, below par living conditions, and difficulty accessing health services makes the transgender community more vulnerable to TB. Transpersons afflicted with TB usually have pulmonary TB. Due to severe TB stigma, and the resulting fear of getting thrown out of their family/village/community, they delay testing for TB. The TB stigma faced by transgender persons is so high that they do not even disclose past TB affliction. The layers of stigma of being transgender, HIV positive and TB afflicted makes them avoid government facilities. Even after detecting TB, they can discontinue treatment due to the stigma they face at healthcare facilities.

3. Move on to the PPT with quotes from various categories of people (5 mins)

a. From people with TB

- » “I could not get a loaf of bread from the store near my house because they didn't want to sell it to me... I isolated myself... I could not bring myself to share my pain with my friends... I lost my job and was thrown out of my house...” - a man
- » “At my workplace, people no longer wanted to share my lunchbox; they would avoid me... I induced self-stigma because I was feeling very guilty...” - a woman
- » “My family members keep a distance... Everything is separated... I cook for myself, and wash my own dishes and clothes...” - an older woman
- » “My grandchildren and children are innocent and should not get infected through me...” - an older man
- » “I'm ashamed if I have to wear a mask in public...” - a young woman
- » “I was not certain that I would pull through the long months of treatment...” - a man
- » “I faced so many problems... I lost my job - they told me they didn't need me anymore and that I should rest at home...There was lot of gossip... Even my in-laws reacted meanly... I hated myself...” - a woman

b. From family and co-workers

- » “Our biggest fear was how people would react to our daughter's illness... We avoided telling anyone... We did not want our family to get ostracized, but it's difficult to hide... We did it to protect her...” - a father
- » “I had an effective team member with TB. He hesitated to seek leave. When he did, with great difficulty, I gave him 2 months... But other team members felt I should replace him as it's not OK for him to rejoin...” - a supervisor

- » “My wife (who has TB) is the cause of additional expenditure.” - a husband
 - » “I was so scared when my son was diagnosed with TB. I thought he would die” - a mother
- c. From community members
- » “I have seen how my neighbor, a young boy of 26 years, was kept away by his family, with everything separate...” - a neighbor
 - » “I know a family in my neighborhood whose lives were shattered due to TB. They had no money, and even the children were taken out of school. I definitely do not want this to happen to my family. I am completely staying away from the affected family, so that I do not get TB.” - a neighbor
- d. From healthcare providers
- » “They don’t share the (TB) disease status... they are not asking family members to seek a TB test...” - community care provider
 - » “Patients ask me if they’ll ever be cured. They think that once they are affected, TB will never go away” - a doctor
- e. TB & gender - Conduct a brief discussion on how gender impacts the risk of infection and disease, timely diagnosis, access to treatment, treatment adherence and the need for a gender- based approach to TB. *Please refer to point 6. Some guiding questions for TB and Gender*

5. Choose one of the following two activities

- a. Let’s grow a tree (20 mins)
- » Divide the participants into groups of 6 members each and provide each group with chart paper and markers
 - » Instruct each group to draw a tree and list down the following as different parts of the tree - roots: causes of stigma, trunk and branches: actions of stigma, fruits and flowers: consequences of stigma
 - » Each group is given 2-3 minutes to present key points of their discussions and clearly identifying the causes, actions and consequences of stigma
- b. Stigma balloons (20- mins)
- » Ask participants to share different types of stigma experienced by persons with TB. The facilitator should list the stigma on the whiteboard or flip chart while correcting any misconceptions
 - » Divide the participants into groups of 5-6 members each and provide each group with chart paper and markers
 - » Assign one stigma to each group. Ask them to draw a circle in the center of their chart paper and then write or sketch a symbol of the stigma assigned to them inside the circle
 - » Ask the groups “Why does this happen?” and request them to draw or write the reasons in balloons. For every reason, keep asking “Why is it

so?,” adding further reasons in connecting balloons until they can think of no more reasons

- » The facilitator will move from group to group and ask the participants “What does the diagram say about the root reasons of stigma - cultural & religious beliefs, fears, gender factors, myths, etc.?”
- » Ask the participants to use a different colour pen to add the consequences to each balloon
- » Next, ask the participants to target the root cause (the last of the balloon to the question “Why does this happen?” and list what can be done to prevent the stigma and what resources and support is needed. The points of each group discussion can be saved and utilized in Session 5: Strategic Interventions

6. Move on to the PPT with the definition of stigma and a list of different types of stigma

- a. Take time to explain the different types of stigma. Use the facilitator’s notes to expound further
- b. Ask participants to describe their current thoughts and what they feel needs to change

Facilitator’s Notes:

Stigma is described as a phenomenon whereby an individual with an attribute that is deeply discredited by her/his society is rejected as a result of that attribute. It is a process by which the reaction of others spoils normal identity and which disqualifies the individual from full social acceptance. WHO defines stigma as a mark of shame, disgrace or disapproval which results in an individual being rejected, discriminated against, and excluded from participating in a number of different areas of society.

Internalized or self-stigma - TB-affected individuals may come to absorb or endorse negative stereotypes, and therefore behave or think according to false portrayals and negative messages.

Anticipated or perceived stigma - worry that one will be devalued after a TB diagnosis. This fear, often the result of observing others being stigmatized, is so great that it may delay people from seeking and returning for care, or impact adherence to the prescribed medicines. Whether or not stigma actually occurs, anticipated stigma may with interfere TB care.

Enacted or experienced stigma - - reflects a range of stigmatizing behaviors, messages, and effects that are either directly experienced by persons with TB or by their families and/or that drive others – in particular members of the person’s family, community, health care providers, and people at the person’s workplace – to acts of discrimination, rejection, or isolation in different settings. Enacted and experienced stigma is two sides of the same coin, either seen from the perspective of the stigmatizer (enacted) or the stigmatized person (experienced).

Secondary stigma - refers to the idea that caregivers, friends or family members may expect negative attitudes or rejection because of their association with the disease and/or persons with TB. Furthermore, this may dictate their behaviors or

beliefs, regardless of whether stigmatizing attitudes or reactions actually occur.

Community or public stigma - negative attitudes, beliefs and behaviors held by the wider community, neighbors or co-workers in particular, or the general public. Closely related to anticipated stigma.

Structural stigma - laws, policies, media and institutional architecture that may be stigmatizing or alternatively protective against stigma. This includes societal level conditions, cultural norms and institutional practices that constrain the opportunities, resources and wellbeing of stigmatized populations.

7. Summarize the drivers and facilitators of stigma, consequences of stigma, and the reasons to invest in stigma elimination (10 mins)

a. Drivers and facilitators of stigma

- » **Fear of TB infection:** belief that TB will never be cured, that treatment is long and drawn out, and feeling that it eventually leads to death. A related fear is that TB leads to economic disaster. Some fears are based on or aggravated by myths, such as that TB is a hereditary disease, or a curse
- » **Belief that TB will not affect them:** as TB is believed to be a disease of the very poor, with the image of an “emaciated man with sunken eyes who is coughing blood”, many believe that they or their family members will never get TB
- » **Prejudice about the person with TB:** believing that the disease afflicts those who do ‘bad things’
- » **Belief that it is the societal norm:** doing what others, who stigmatize and discriminate against persons with TB, do

b. Consequences of stigma

- » Low self-esteem
- » Social exclusion
- » Feeling of guilt
- » Isolation
- » Non-disclosure
- » Fewer economic opportunities
- » Reluctant to seek treatment and adhere to treatment
- » Self-stigma
- » Suicidal tendency
- » Negative attitude and behavior

c. Three strategic reasons to invest in stigma elimination

- » Higher acceptance and utilization of NTEP services

- » Reduced catastrophic cost and better use of resource
- » Better realization of India's goal of TB elimination

8. Some guiding questions for TB and gender

- a. Does gender differences have any impact on how TB progresses?
- b. List different gender identities and how these affect TB?

Session 4: Vision, Goal & Objectives of the End Stigma Strategy



90 minutes



Flip chart
PPT: vision & goal, flowchart of stigma-free TB response

Chart paper
Markers
Laptop & LCD projector



By the end of this session, the participants will understand the vision and goal of the end stigma strategy, and the principles behind them

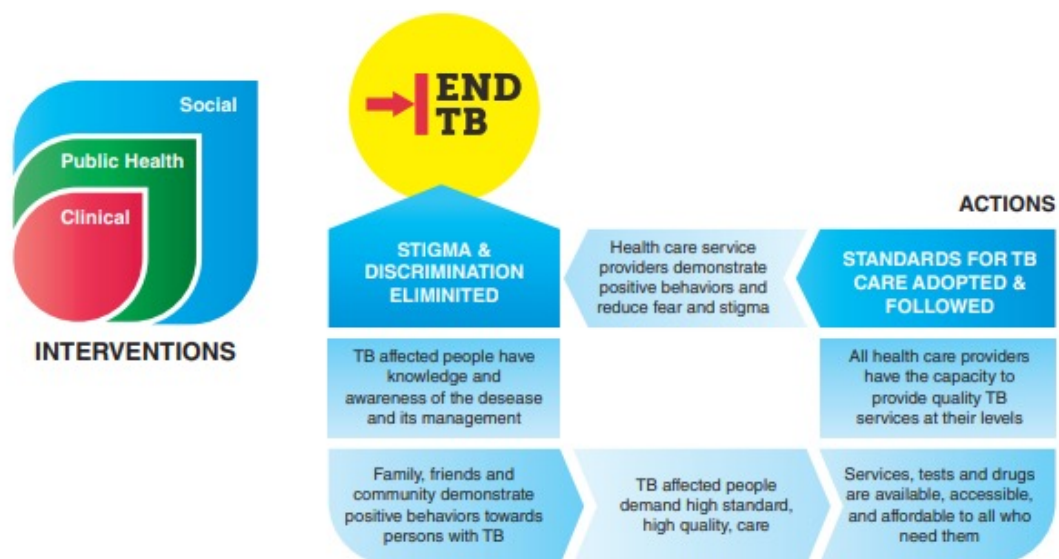
Methodology

1. Ask participants to respond out loud to “What is the need to have a vision and goal to end TB stigma?” Write the answers on the flip chart and circle those that are pertinent (15 mins)
 - a. Supplement answers with
 - » **Advocate for resource** investments to end stigma
 - » **Adopt, build capacity**, and incorporate a cross-cutting strategy for ending stigma and discrimination in all TB interventions with active and informed engagement of persons with or affected by TB
 - » Develop and execute a **communications strategy**
 - » Design and support the **roll out of community-led interventions that mobilize societies to foster non-stigmatizing and non-discriminating behaviours towards persons affected by TB**
2. Project the PPT of the vision and goal for the “End stigma associated with TB” strategy (45mins)
 - a. Vision (PPT): addressing stigma and discrimination with a vision of a stigma-free TB response that enables India’s goal of ending TB, reduces catastrophic costs, and builds higher acceptance and utilization of NTEP services
 - b. Goal (PPT): to end stigma and discrimination faced by persons with or affected by TB, through all stages of the continuum of care
 - c. Group activity: In groups of 5 members each, discuss (PPT): “In light of the vision and goal presentation, what should be the principles and interventions to prevent or remove stigma and discrimination associated with TB?”

Facilitator Notes:

Discussions on persons with TB's immediate needs, creating a sense of security, types of communication, social circle of the affected person, other influencers and their role

- d. Presentation by each group on the topic, with the facilitator asking questions to clarify thinking and reach a conclusion (20mins)
- e. Summarize with this chart on the PPT



A representation of a stigma-free TB response, and its contribution to the elimination of TB

Session 5: Strategic Interventions



60 minutes



PPT: strategic interventions, categories of implementation, audience for intervention and strategic interventions summary

Handout B, C, D, E & F
Chart paper
Markers
Laptop & LCD projector



By the end of this session, the participants will be able to review and discuss recommendations for interventions aimed at influencing or benefiting different target audiences in different settings

Methodology

1. Ask participants to take a moment to review what is being projected. It is clear that a vision and goal should have target audiences in order to draw out specific actions that they can accomplish (15mins)
2. Project over PPT and explain as needed: the strategy is aimed at influencing or benefiting different target audiences in different settings. The interventions are grouped under 3 buckets:
 - a. Advocacy
 - b. Communication
 - c. Community engagement
3. Project over PPT that the above interventions may be implemented in 3 location categories:
 - a. Community
 - b. Workplace
 - c. Health care facilities
4. Project over PPT that the target audience for the interventions are:
 - a. Persons with Tuberculosis
 - b. Inner circle of said persons
 - c. Social circle of said persons
 - d. Community members
 - e. Health care providers

- f. Influencers
5. Divide participants into 4 groups and give each the following cases from Annexure 2 and Handout B, C, D, E & F and ask them to brainstorm the following (45mins)
 - a. Discuss each case and with support of the handouts list out the advocacy, community engagement and communication activities that can be done to mitigate the stigma & discrimination
 - b. Each group can present their recommended interventions to the larger group in plenary.
6. The facilitator can note the key interventions that are being shared by the groups. After each presentation, summarize the strategic interventions listed in the Facilitator's Notes via PPT
 - a. Projected on PPT as summary: strategic interventions at community, healthcare and workplace levels
 - b. Close by asking participants of their thoughts and connections with their own presentations
7. Review the discussion points from Session 3

Facilitator's Notes:

1. Summary of Key Community Interventions
 - a. Spread messages to normalize TB among all target audiences
 - b. Encourage communities to promote understanding, empathy, and support to persons with TB and to members of their inner circle
 - c. Disseminate messages that help prevent TB, reduce its spread, encourage early diagnosis, and treatment compliance and completion
 - d. Improve awareness about the symptoms of TB. Inform people on where to seek health care in their vicinity, on what to expect from health care providers, and disseminate messages to reduce fear and stigma
 - e. Where possible, use positive deviants from the target audience to of the same group. TB survivors can play an important role in influencing people, especially those with TB and members of their inner circle
 - f. Strategically engage influencers from political, business/industry, social, and health care arenas to influence communities and people affected by TB, using ways that are mutually beneficial to all concerned
 - g. Invest in 360-degree communication campaigns on stigma prevention and elimination, effectively and efficiently balancing the use of mass-media, mid-media, outreach (inter-personal communication), and digital media; the campaigns focus on offering solutions to problems faced by persons affected by TB

- h. Create treatment support groups locally, to ensure that issues concerning persons with TB and their inner circle are heard and addressed; these support groups include and are preferably facilitated by empowered TB affected persons, or survivors

2. Summary of Key Workplace Interventions

- a. In workplaces where NTEP services are not available, carry out advocacy with workplace managers to provide TB services under the program, including screening, testing, treatment, and post diagnosis care and support
- b. Advocate for a workplace policy against stigma and discrimination, with specific recommendations and actions that comprise of legal measures against discriminatory practices by employers or co-workers, including during the hiring process
- c. Sensitize employers about the impact of TB and TB stigma on workers' productivity and their unique position to support their employees who are affected by TB through early identification, and initiation and completion of treatment
- d. Encourage TB survivors and their networks to share their perspectives and advocate for a TB stigma free work environment
- e. Improve TB awareness among business owners/proprietors and management personnel
- f. Spread messages that normalize TB through amplification of personal TB-related experiences of political leaders, celebrities, and other business leaders
- g. Disseminate messages that prevent TB, its transmission from one person to another, and help contacts of persons with TB to reach out for screening, testing and treatment
- h. Disseminate messages that promote understanding, empathy, and support towards co-workers with TB and their families
- i. Disseminate messages through positive deviants from among co-workers, influencing changes in behavioral norms, or through empowered TB survivors
- j. Establish treatment support groups, preferably facilitated by TB survivors, to encourage the sharing of experiences and addressing issues pertaining to people with TB

3. Summary of Key Health Care Facility Interventions

- a. The rights-based policy against stigma and discrimination issued by the Government of India includes recommendations for health care service providers
- b. Standards for stigma-free TB care are included in the Standards for TB Care in India
- c. Include stigma prevention and elimination, and addressing social issues, in medical education and training programs for health care providers
- d. Awareness of patient rights among health care providers is improved, and stigma is included as a topic in medical conferences

- e. Build capacity of health care providers on use of soft skills, including suitable tone of voice, counseling techniques and avoidance of stigmatizing language and euphemisms.
- f. Encourage health care providers to openly discuss TB with persons with TB and their inner circle
- g. Improve mechanisms to protect health care staff from infection and provide them with timely post-infection support when needed, thus reducing fear among them
- h. Provide communication aids to health care providers, supporting dialogue with persons affected by TB
- i. Encourage communities of health care providers and associations of health care facilities to:
 - » Promote adoption of non-stigmatizing and non-discriminatory language and tone while dealing with people affected by TB
 - » Engage in conversations on stigma with persons affected by TB to help them deal with, or avoid, stigma and discrimination in various settings

Session 6: Monitoring and Evaluation of the End TB Stigma Strategy



90 minutes



Handout G, H, I & J
PPT: Objectives of strategy, theory of change to end TB stigma
Flip chart

Markers
Post-training assessment forms
Laptop & LCD projector



By the end of this session, the participants will understand the need for monitoring and evaluating efforts to end TB stigma. They will be presented with the guidelines and indicators applied to measure input and responses to implementation. The participants will also come up with a list of qualitative and quantitative local indicators to end TB stigma at the block/village/district/state level

Methodology

1. Ask the participants: What is monitoring and evaluation (M&E) and what is the need for it (10 mins)

Facilitator's Notes:

Monitoring and evaluation are both tools that help determine when plans are not working and when circumstances have changed. Monitoring is the periodic assessment of programmed activities to determine whether they are proceeding as planned. Evaluation involves the assessment of the programs towards the achievement of results, milestones, and impact of the outcomes based on the use of performance indicators.

2. Ask the participants how we will perform M&E in this strategy and draw out a few responses from the participants. Capture these responses on the flipchart (10 mins)
 - a. Choose 3 participants and give them a handout each (30 mins)
 - b. Ask the first participant to read *Handout G: High-level National Indicators* aloud
 - » Draw out the participants' understanding of these indicators
 - » Facilitator takes time to go into some detail of this indicator

- c. Ask the second participant to read *Handout H: National and Sub- National Indicators* aloud
 - » Draw out the participants' understanding of these indicators
 - » Facilitator takes time to go into some detail of this indicator
- d. Ask the third participant to read *Handout I: Other Output Indicators Reported by States and Union Territories, and Reported at the National Level* aloud
 - » Draw out the participants' understanding of these indicators
 - » Facilitator takes time to go into some detail of this indicator
3. Facilitator explains each section and ties it to the objectives of the strategy (PPT, 15 mins)
 - a. Advocate for resource investments to end stigma and discrimination associated with TB
 - b. Adopt, build capacity, and implement a cross-cutting and integrated stigma prevention and reduction strategy in all TB care activities, with active participation of TB affected people
 - c. Develop and execute a communications strategy using multiple media and formats, addressing various dimensions of TB-related stigma and discrimination
 - d. Design and support the roll out of community-led interventions that mobilize societies to foster non-stigmatizing and non- discriminating behaviors towards persons with or affected by TB
4. Draw out any questions, comments, confusion among the participants. Take time to discuss and clarify (20 mins)
5. Give Handout J to all participants
6. Post training assessment (15 mins)



Annexure 1

QUIZ of 16 Questions bank with Answer key

Q 1 TB is an infectious disease caused by a germ called

- A. Tuberculosis Bacteria
- B. Mycobacterium Tuberculosis**
- C. TB germ
- D. Koch's Bacteria

Q 2 TB can affect most organs in the body

- A. True**
- B. Somewhat true
- C. False
- D. Somewhat false

Q 3 TB affects only people who are poor

- A. True
- B. Somewhat true
- C. False**
- D. Somewhat false

Q 4 This is not a symptom of Pulmonary TB

- A. Persistent cough
- B. Hair fall**
- C. Blood in the phlegm (haemoptysis)
- D. Loss of weight
- E. Breathlessness
- F. Fever
- G. Chest pain
- H. Loss of appetite

Q 5 Extra-pulmonary TB can be accurately diagnosed through sputum test

- A. True
- B. Somewhat true
- C. False**
- D. Somewhat false

Q 6 TB is a curable disease

- A. True**
- B. Somewhat true
- C. False
- D. Somewhat false

Q 7 TB treatment is

- A. Free**
- B. a combination of drugs**
- C. 6 months for drug-sensitive TB and 24 months or 2 years for drug-resistant TB**
- D. Easily given on out patient basis**

Q 8 Drug resistance means

- A. The person with TB is also a drug (narcotics) user
- B. The person's religion objects to TB medicine
- C. TB medicines are not able to kill the TB bacteria in a person.**
- D. All the above

Q 9 TB affects an individual's bodily health only

- A. True
- B. Somewhat true
- C. False**
- D. Somewhat false

Q 10 Psychosocial support to a PwTB can be given by

- A. Counsellor**
- B. Family**
- C. Friend**
- D. Community member**

Q 11 If TB treatment is completed appropriately the person cannot get the infection again

- A. True
- B. Somewhat true
- C. False**
- D. Somewhat false

Q 12 People living with HIV are up to 20 times more likely to fall ill with TB

- A. True**
- B. Somewhat true
- C. False
- D. Somewhat false

Q 13 The symptoms of MDR-TB are not the same as those of "ordinary TB"

- A. True
- B. Somewhat true
- C. False**
- D. Somewhat false

Q 14 In 2012 & 2014 Two drugs were approved for treating MDR-TB by FDA & EMA with guidelines by WHO

- A. Pyrazinamide (PZA), and Ethambutol (EMB)
- B. Bedaquiline and Delamanid**
- C. Rifampin (RIF) and Isoniazid (INH)
- D. Moxifloxacin and Isoniazid (INH)

Q 15 Isolation of PwTB from family is not essential in TB treatment

- A. True**
- B. Somewhat true
- C. False
- D. Somewhat false

Q 16 TB treatment Supporter Scheme under NTEP in India is called

- A. Ayushman Bharat Pradhan Mantri Jan Arogya Yojana
- B. Mission Indradhanush
- C. Nikshay**
- D. All the above



Annexure 2

Case stories for session 5 Strategic Interventions

- 1 Nusrat is 18 years old and lives in a slum in Hyderabad, Telangana. She is an intermediate student. She was suffering with fever and regular cough and she went to hospital for a test. She was given medicine for cough and fever. But she didn't get cured. Later with the advice of a community leader, she went to the government hospital and was diagnosed with Pulmonary TB in April, 2022.

Though she was encouraged to take her treatment, she faced stigma and started losing her confidence. Her friends at college started maintaining distance from her as they came to know about her status. They advised her to eat separately during lunch time. She was disappointed and psychologically disturbed for a quite some time. At times she avoided going to classes and missed important lectures, for this her teachers scolded her.

Discuss:

- I. What is the problem/s that Nusrat faces?
 - II. What are your recommended advocacy interventions that can mitigate the S & D faced by students and who do you think can be influenced ?
 - III. What are your recommended community engagement interventions that can mitigate the S & D faced by students and who do you think can be influenced?
 - IV. What are your recommended communication activities that can mitigate the S & D faced by students and who do you think can be influenced ?
- 2 Raki (32), was known as Jindal Rani, she controlled the TG community of Bellary district. She was a Guru and she was a leader of her community. She was very popular among the TG and sexworkers community in Bellary. She was not comfortable to go to the health facilities for HIV tests so she never knew why she fell very ill. , while her health deteriorated she was taken to emergency services to a hospital and was detected with co infection of HIV & TB. The delayed detection of TB and HIV caused her death. Her friends said, as a Guru she was powerful, had authority in her community but scared of the stigma and discrimination she would face in the health centre so she avoided test and confirming the sickness. Discuss:
 - I. Why was Raki scared of accessing health services ?
 - II. What are your recommended advocacy interventions that can mitigate the S & D faced by transgender persons in health facilities and who do you think can be influenced ?
 - III. What are your recommended community engagement interventions that can mitigate the S & D faced by transgender persons in health facilities and motivate them to seek services ? And who can be involved in these interventions?
 - IV. What are your recommended communication activities for health care providers that can mitigate the S & D faced by trans persons in health facilities?
 - 3 Laxman lived in the outskirts of the village with his family of two children, wife and aged parents as he belonged to the dalit community. He was the sole bread winner for the family but when he was diagnosed with TB he had to give up his job as his employers said he was too weak to work. His coworkers too agreed

with the employers as they feared that they too would get TB and had already started to keep distance from Laxman during work and lunch break. As an informal worker Laxman had no support and became jobless, taking his whole family into crisis. Discuss:

- I. What type of S & D did Laxman experience ?
 - II. What are your recommended advocacy interventions that can mitigate the S & D faced by PwT in their work place and who do you think can be influenced?
 - III. What are your recommended community engagement interventions that can mitigate the S & D faced by PwT in their work environment and who can be involved in these interventions?
 - IV. What are your recommended communication activities that can mitigate the S & D faced by PwT in their work place and who do you think can be influenced ?
4. Gangawati was a mother of two little children when she was diagnosed with TB at the age of 35. When she started her treatment, she lived in her marital home but because the neighbours started avoiding interactions with them it angered her husband. He accused her of bringing bad fortune to their family and asked her to leave. She had to leave her children and went to stay in her maternal house. Here too her parents were ashamed to tell the relatives that their daughter was thrown out of her husband's house and kept taunting her. She was ill and felt all the more miserable which did not motivate her to adhere to the TB treatment regimen.

Discuss:

- I. What S& D did Gangawati face?
- II. What are your recommended advocacy interventions that can mitigate the S & D faced by PwT in the family & community and who are the leaders or influencers who can be approached ?
- III. What are your recommended community engagement interventions that can mitigate the S & D faced by PwT in the communities they live in ?
- IV. What are your recommended communication activities that can be carried out in the community to mitigate the S & D faced by PwT ?



HANDOUTS



Handout A: All About Tuberculosis

1. What is TB? How does it spread?

- » 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
- » When TB affects any organ other than the lungs, it is called extra- pulmonary TB.
- » TB spreads through the 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
- » TB can affect people of any age group or economic strata
- » Since TB is an airborne disease, anyone who inhales the bacteria can get infected with TB
- » When someone inhales the TB bacteria, it can settle in their 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
- » Many of us have already inhaled the TB bacteria and carry it within our bodies, often without our knowledge. All of us who inhale the TB bacteria do not become ill with the disease. In most people, the normal immune system of the body is able to keep the bacteria well under control. In about 10% of the people who harbour the bacteria, the germs multiply and cause TB disease
- » A person with TB infection usually develops TB disease when his or her immunity is lowered
- » Poor nutrition, 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
- » Anyone in close contact with someone who has pulmonary TB is at a greater risk of developing TB

2. Diagnosing TB

- » The symptoms of pulmonary or lung TB may include
 - Persistent cough
 - Cough of any duration in people who are living with HIV (PLHIV)

- Blood in the phlegm (haemoptysis)
- Fever
- Chest pain
- Loss of appetite
- Loss of weight
- Breathlessness
- In children, specific symptoms such as falling off growth curve, reduced playfulness

Latent TB Infection (LTBI) and TB disease

- » If someone has had a persistent cough, it is important to consult a doctor and get tested for TB
- » Pulmonary TB is diagnosed by testing the sputum sample by microscope, any rapid molecular tests such as Cartridge Based Nucleic Acid Amplification Test (CBNAAT) or by sputum culture
- » In the case of extra-pulmonary TB, the person will develop symptoms that are specific to the affected area. For example, in a case of intestinal TB, the person may experience diarrhoea or in the case of TB of a particular joint, the person may experience pain and swelling in that area. Besides this, fever, loss of appetite and weight loss is also possible
- » Extra-pulmonary TB is ideally diagnosed by examining the affected organ or site. This is done through a biopsy, in which a small bit of tissue or fluid from the affected part is removed through a surgical procedure and examined under a microscope. Alternatively, the sample can be tested by CBNAAT. When a biopsy is not feasible, for instance in the case of the spine, the diagnosis is made with a combination of X-rays, CT or MRI scans and symptoms. A genotypic test would be the preferred test over microscopy, especially in PLHIV and children
- » Serological tests (blood tests) are very often inaccurate and have been banned by WHO for the diagnosis of TB. In other words, a blood test will not tell someone if they have latent TB infection or TB disease
- » The Mantoux test is a skin test. It checks to see if the immune system of the body recognizes TB, which is a sign that someone may have TB in the system. However, the Mantoux test cannot be used to determine active TB disease but only the presence of the bacteria in the system. A Mantoux test cannot definitively tell if someone has TB disease or not, particularly in the case of adults. However, in children, the Mantoux test is often used to diagnose TB disease
- » Screening is sometimes done prior to referring an individual for diagnosis. Screening means assessing whether someone is vulnerable to the disease and needs to be referred for diagnosis. Symptom screening, for example, means assessing whether a person has any of the TB symptoms and is often used as a tool for finding missed people with TB

3. Treating TB

- » TB is a curable disease
- » The course of TB treatment is 6 months for drug-sensitive TB and 24 months or 2 years for drug-resistant TB
- » TB is treated with a combination of drugs (HREZ-Isoniazid, Rifampicin, Ethambutol and Pyrazinamide). These drugs are given daily and sometimes as fixed dosed combinations (FDC)
- » Every person diagnosed with TB is assigned a treatment supporter (follow national TB guidelines in country) who will be responsible for ensuring that medicines are taken as required, updating the treatment cards, reminders to go for reviews on time, follow-up if there are any side effects and ensuring that the entire course of treatment is completed
- » Nikshay is the Treatment Supporter Scheme under NTEP in India. A staff/ Treatment Supporter can be any personnel from Medical Officer to MPWs and community volunteers who will be working with the program, including personnel from partner organizations and JEET, and informants.
- » 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 they are cured. Anti-TB medicines are strong antibiotics and it is essential to complete the course of medicines to ensure that one does not have a recurrence of TB and that the body 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 severe cases and complicated TB treatment require hospitalisation
- » TB treatment is available free of cost at all government centres.
- » However, costs in the private sector vary tremendously
- » For most people TB treatment is safe and does not cause side effects. However, some people may develop side effects and they should be evaluated by the doctor and offered testing to see if one of the TB medicines is the cause of the problem
- » Some side effects with TB treatment include vomiting, nausea, problems with the liver, and problems with the nerves in the hands or feet. Early identification of these side effects is important to make sure they do not cause permanent damage. People on TB treatment experiencing side effects should talk to their doctors right away

Possible Adverse Drug Reactions (ADR) that need monitoring			
	Adverse Drug Reaction	Early Signs and Symptoms	Usual Offending Agents
1	Gastro Intestinal Symptoms	Nausea, vomiting, gastritis, diarrhoea	Most drugs, especially Ethionamide/PAS/Pyrazinamide/Ethambutol
2	Giddiness	Giddiness, oversleeping, poor concentration	Amino glycosides, Ethionamide, Quinolones and/or Pyrazinamide
3	Ocular Toxicity	Blurring of vision, disturbance in color vision	Ethambutol
4	Renal Toxicity	Less than normal urination, total stoppage of urination, puffiness of face, swelling of feet	Kanamycin
5	Arthralgia	Joint pains	Pyrazinamide, Quinolones
6	Cutaneous (skin) Reactions	Itching, localised rash, generalized erythematous rash associated with fever and/or mucous membrane involvement	Any of the drugs may give rise to this
7	Hepatitis	Loss of appetite, nausea/vomiting, abdominal discomfort, dark coloured urine, jaundice	Ethionamide, Pyrazinamide
8	Peripheral Neuropathy	Pain and/or tingling sensations, especially in feet and hands	Cycloserine, Ethionamide
9	Seizures	Convulsions, fits	Quinolones, Cycloserine
10	Psychiatric disturbances	Depression, excessive chatting, unusual violent tendencies, suicidal tendencies	Cycloserine, Quinolones, Ethionamide
11	Vestibulo-Auditory disturbances	Ringling in the ear, deafness, unsteady gait, tendency to lose balance and fall	Aminoglycoside
12	Hypothyroidism	Lethargy/tiredness, slowing of activities, puffiness of face, swelling of the thyroid (neck swelling)	PAS Ethionamide

4. Drug-resistance

- » Drug resistance means that the TB medicines are not able to kill the TB bacteria in a person. The bacteria have become resistant to specific drugs, which are therefore no longer effective
- » When someone with TB develops resistance to two of the most important drugs used in the treatment, Isoniazid and Rifampicin, the person is said to have MDR-TB
- » Drug-resistant forms of TB spread through the air just like other forms of TB
- » In some cases, people get MDR-TB by inhaling MDR-TB infected droplets
- » The symptoms of MDR-TB are the same as those of “ordinary TB” – a persistent cough, chest pain, fever, loss of appetite and weight loss
- » 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 CBNAAT, LPA, MGIT and conventional culture methods. However, it takes anywhere from three to twelve weeks to get results from culture tests
- » In 2012 and 2014, two new drugs: Bedaquiline and Delamanid , were 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
- » 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 two of the most potent drugs used to treat MDR-TB i.e, fluoroquinolones and the injectables. Since someone with XDR-TB is resistant to most of the core drugs used to treat TB, treatment options are limited, highly expensive and have many side effects
- » Everyone has a right to the best possible treatment free of charge and people also have a right to know about the side effects before starting on treatment (people-centered, rights-based TB response)

5. TB and co-infections

- » People living with HIV are up to 20 times more likely to fall ill with TB. TB is the most common opportunistic infection for people living with HIV. This means that those with HIV are considered vulnerable to TB on account of their lowered immunity
- » This co-infection also contributes to increased mortality, with over a quarter of the deaths among PLHIV resulting from TB
- » The programme mandates that PLHIV should be regularly tested for TB and all people diagnosed with TB should be tested for HIV
- » People with diabetes have an increased risk of active TB or TB disease (2-3 times higher than people without diabetes). It is essential that anyone diagnosed with TB is tested for diabetes regularly and vice- versa

- » There is some preliminary evidence to show that diabetes worsens TB treatment outcomes – increased deaths and relapse rates
- » For the affected individual, managing two infections can be difficult, and support from families and communities is essential

6. Support required

- » Like other long drawn-out illnesses, TB affects an individual in multiple ways. Apart from the physical symptoms, TB also influences the earning capacity of an individual and patients are often not able to support their family
- » People affected by TB face a certain amount of stigma and risk being isolated or ostracised. Everyone should have access to diagnostics and treatment for free
- » Psycho-social support
 - Counselling: Peer-counselling from TB survivors and/or people affected by TB can be very effective in providing support. Channels for open communication that allow information sharing, peer support, undertaking collective activities and problem-sharing should be established. This can be through meetings, app-based groups, phone calls or other preferred means. Peer counsellors need to keep in mind that issues that fall beyond their scope should be referred to professional counsellors and experts (for example: potential mental health issues, suicidal ideation, serious unaddressed medical complications, etc.)
 - Social support: During the course of the treatment, persons affected by TB need the support of family, friends, well-wishers and community members. A good support system can help prevent the patient from spiralling into depression and giving up the treatment. To avoid catastrophic costs, adequate financial support is essential for people who are diagnosed and on treatment for TB
- » Access to nutritious food is also important during TB treatment




Handout B

Location	Strategic Interventions		
	Advocacy	Communications	Community Engagement
In the community			
At the workplace			
At the healthcare facility			



Handout C

Target Audience	Impact Desired
	<ul style="list-style-type: none">» Diagnosis» Treatment» Post-treatment



Handout D: Advocacy

1. Advocacy Basics

- » Advocacy denotes activities designed to place the TB response high on the political and development agenda, foster political will, increase financial and other resources on a sustainable basis, and hold authorities accountable to ensure that pledges are fulfilled, and results are achieved
- » Advocacy often focuses on influencing policy-makers, funding agencies and international decision making bodies through a variety of channels: conferences, summits and symposia, celebrity spokespeople, meetings between various levels of government and civil society organizations, news coverage, official memoranda of understanding, parliamentary debates and other political events, partnership meetings, patients' organizations, press conferences, private physicians, radio and television talk shows, service providers
- » While several definitions for advocacy exist, this definition fits our need and is in keeping with existing UN advocacy definitions. Advocacy denotes activities designed to place the TB response high on the political and development agenda, foster political will, increase financial and other resources on a sustainable basis, and hold authorities accountable to ensure that pledges are fulfilled, and results are achieved
- » Advocacy is a process to bring about change in the policies, laws and
- » practices of influential individuals, groups and institutions
- » 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 an organization in terms of its social power and technical capacity
- » Advocacy combines various complementary initiatives in order to achieve an objective. Advocacy influences policy-makers, funders and decision-makers; variety of channels

2. Types of Advocacy

- » Reactive: Reactive advocacy is based on responding to events after they have happened
- » Proactive: A proactive approach focuses on eliminating problems before they have a chance to appear

3. Forms of Advocacy

- » Policy Advocacy: Informs politicians, etc. how an issue will affect the country; requests specific actions to improve laws and policies
- » Program Advocacy: Targets opinion leaders at the national/community level 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

4. Possible Advocacy Tools

- » Information: Gathering, managing and disseminating information lays the basis for determining the direction of an advocacy campaign. Research is one way of gathering information
- » Research: Conducting research and policy analysis uses the information from various sources and develops it into policy options which become the key content of an advocacy campaign
- » Media: Various media are used to communicate the campaign's message(s) to the different stakeholders
- » Social Mobilization: Mobilizing the broadest possible support from a range of stakeholders, including the public at large, is essential to building the influence of the campaign
- » Influencing: Convincing the decision-makers who have the power to make the desired change involves a set of special knowledge and skills.
- » Litigation: Sometimes, using the court system to challenge a policy or law can reinforce an advocacy campaign
- » Networks, Alliances and Coalitions: Sharing of information and resources, and strength in commonality of purpose are key to the success of advocacy work.
- » In relation to TB, it could for example be: (a) a coalition of civil society organisations (CSOs) holding a press conference or jointly signing an open letter; (b) a meeting with a country's President; (c) a drama 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 our own selves



Handout E: Communication

1. Communication Basics

- » Communicating effectively is the most important of all life skills
- » Communication is simply the act of transferring information from one place to another, whether this be:
 - Vocally/verbally (using voice)
 - Written (using printed or digital media such as books, magazines, websites or emails)
 - Visually (using logos, maps, charts or graphs)
 - Non-verbally (using body language, gestures and the tone and pitch of voice)
- » How well this information can be transmitted and received is a measure of how good our communication skills are
- » Communication is the process of imparting or interchanging of thoughts, opinions, or information by speech, writing, or signs
- » Principles of Effective Communication for Health
 - Accessible - Map your stakeholders and tailor your communication channels to fit them
 - Actionable - Messages should encourage decision-makers to take the recommended steps
 - Credible - The action-makers should perceive your information to be credible. Use data points from reliable resources only
 - Relevant - Communicate to help audiences to see the health information, advice or guidance as applicable to them, their families, or others they care about
 - Timely - Communicate the right information at the right time
 - Understandable - Communicate without jargon

2. Possible Methods

- » Spread the message “Anyone can get TB” through amplification of personal TB related experiences of political leaders, celebrities, and community leaders at appropriate levels (local, state, national, others)
- » Disseminate messages that encourage community influencers to reassure persons with TB and their inner circle that they will be supported in overcoming barriers to access quality TB care services
- » Use all mediums of communication



Handout F: Community Engagement

1. Community Engagement Basics

- » The term “community” is widely interpreted in many ways. For our understanding, it 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 living with TB as well as their family
- » Inadequately served populations refer to people who are vulnerable, underserved or at-risk of TB infection and illness. This could include people living with HIV, people who use drugs, people who have increased exposure to TB due to where they live or work, people who have limited access to quality TB services, and people at increased risk of TB because of biological or behavioral factors that compromise their immune function
- » Community engagement is defined as the process of working collaboratively with and through communities to address issues affecting their well-being
- » 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.

2. The involvement of communities can:

- » Ensure engagement with policymakers and implementers to ensure justice, rights and dignity of persons with TB for effective service delivery
- » Supplement and complement government initiatives to enforce persons with TB friendly law, policy and programs
- » Help reduce stigma and discrimination and ensure social security of persons with TB, survivors and their families
- » Increase the social acceptance of those affected by these diseases
- » Break down the barriers/silence around issues of people living with TB
- » Bring the perspective of affected populations and people living with disease to the programmes



Handout G: High-level National Indicators

- A. Resources invested to end stigma and discrimination associated with TB
- B. Adoption and implementation of a stigma prevention and reduction strategy in TB care activities, with active participation of TB affected people
- C. States and partners supported for the development of local strategies and operational guidelines for advocacy, communications, and community engagement, to end TB associated stigma and discrimination



Handout H: National and Sub-National Indicators

- A. Advocacy actions undertaken to improve resource allocation and effort to end TB associated stigma and discrimination; segregated by level of action
- B. Communication messages and posts that are aimed at preventing, ending, and mitigating TB associated stigma and discrimination; segregated by route of messaging – mass media, social media, print, out-of-home (posters, hoardings), and other
- C. Community engagement activities that solely or inclusively address TB associated stigma and discrimination; segregated by type of activity, and level



Handout I: Other Output Indicators Reported by States and Union Territories, and Monitored at the National Level

- A. TB affected persons recruited, and sensitized or trained, to support the NTEP's efforts to end stigma and eliminate TB; disaggregated by gender, and level or recruitment and sensitization/training
- B. Sensitization/training modules developed for capacity building in stigma mitigation; disaggregated by target audience, and level
- C. Research activities concerning stigma and discrimination associated with TB, and addressing where in the continuum of care to focus, and on how to act; segregated by type of stakeholder conducting the research, and level




Handout J: Stigma Free Language Guide

1. Ground Realities Highlight Challenges for Accessing Care

- » The GCTA conducted trainings across the globe with 250 affected community members. With every training we heard communities listing stigma as one of the top barriers. There are several levels at which stigma needs to be addressed, along with multistakeholder involvement and several creative interventions led by the affected community. One of these is the use of language that is non-stigmatizing and non-discriminatory. Words matter!

2. Terms not to use

Use instead

- » **TB contact**  **contact person**
(The term does not have strong negative connotations, but it is not person-centered)
- » **defaulter** **loss to follow-up**
(Historically, the word default(er) unnecessarily and unfairly places the blame on the person receiving the treatment)
- » **he/his, she/her** **they/them**
(Gender-sensitive language does not presume a binary opposition such as male/female)
- » **suspect** **person with presumed TB**
(A person who presents with symptoms or signs suggestive of TB. The term suspect is generally used in a criminal law context to indicate a person who is suspected of committing an offense. The term person with presumed TB removes that negative association)
- » **TB control** **TB prevention and care**
(This term's use is no longer recommended by the WHO because it is not people-centred and ignores the contribution of communities and people affected by TB)

3. These terms have use when discussing certain aspects of TB care. Use carefully

- » **presumed/presumptive**
Places emphasis on the disease and not the person. Can be rephrased to focus on the person
- » **burden**
It should be stressed that it is the disease and not the people affected by the disease that burden a country, a region or the world

- » case finding/case detection

Identification of newly developed TB in an active systematic way or through an inactive identification of new TB by virtue of action taken by the person experiencing symptoms

- » adherent/nonadherent

This term unfairly assigns singular responsibility for treatment completion on the person

- » risk groups

When discussing an individual or group, it is best to say key and vulnerable populations

- » sputum or smear negative/positive

The preferred term is bacteriologically positive/negative

- » patient/TB patient

Person on treatment, person receiving health care and, in some countries, client are preferable terms and phrases



Pre and Post Assessment Questionnaire

1. TB affects only the lungs.
 - a. True
 - b. False
2. TB is the most common opportunistic infection for people living with HIV.
 - a. True
 - b. False
3. Stigma is caused by lack of education on TB and its modes of transmission.
 - d. True
 - b. False
4. The vision for the 'End stigma associated with TB' strategy is
 - a. addressing stigma and discrimination
 - b. ending TB
 - c. a stigma-free TB response
 - d. utilization of NTEP services
5. The following are avenues to engage with audiences that can impact decisions for change:
 - a. Communication
 - b. Bank loans
 - c. Signing files
 - d. Advocacy
6. Reactive advocacy is the only kind of advocacy that works.
 - a. True
 - b. False
7. Stakeholders can refer to both individuals and institutions.
 - a. True
 - b. False
8. One indicator of the program achieving results is
 - a. resources allocated to end stigma
 - b. more PowerPoint presentations
 - c. food distribution
9. Inner circle of those affected with TB are
 - a. a close-knit club
 - b. people who are emotionally, financially or otherwise invested in persons with TB
 - c. public and private providers of healthcare
10. The final outcome of the theory of change to end TB stigma is
 - a. to ensure education for all suffering due to TB
 - b. to ensure toilets for all suffering due to TB
 - c. to ensure zero deaths, disease and suffering due to TB

Answers to Pre and Post Assessment Questionnaire

1. False
2. True
3. True
4. All of the choices mentioned
5. Communication and Advocacy
6. False
7. True
8. Resources allocated to end stigma
9. People who are emotionally, financially or otherwise invested in persons with TB
10. to ensure zero deaths, disease and suffering due to TB



Feedback Form

Sessions	Excellent	Good	Fair	Poor	Remarks
Session 1					
Session 2					
Session 3					
Session 4					
Session 5					
Session 6					

1. What did you learn during today's sessions that you anticipate using in your work?

2. Was there anything you did not like during today's sessions? Please provide specific examples.

3. Please provide any other comments or suggestions.

Thank you!



Evaluation Form

	Strongly Disagree	Disagree	Agree	Strongly Agree
This course has provided me with new insights and knowledge about various issues related to ending TB stigma				
I feel better informed to address TB stigma				
I believe this course is very useful in my work environment				
I have learned new information and skills that I feel I will be able to pass onto others				

Do you have any comments on:

Trainers?

Training Methods?

Venue, accommodation, food? (where applicable)

What information was missing from this training that you think is important?

Do you have any other suggestions or remarks?

