Global Coalition of TB Advocates

SHORTER ALL-ORAL DR-TB REGIMEN

Training Manual

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BACKGROUND

According to WHO, in 2022, TB claimed 1.1 million lives worldwide and an estimated 10.6 million people fell ill with this disease. Among those affected, 410,000 individuals had drug-resistant TB (DR-TB), underscoring the growing threat this form of TB poses to global public health. The emergence and spread of drug-resistant TB are grave global challenges that demand our urgent attention.

To address the critical issue of DR-TB at a global scale, it is essential to adopt a multifaceted approach. While medical interventions are fundamental, addressing the broader societal and community-related aspects is equally vital in the fight against drug-resistant TB. Communities must be empowered to act as advocates, educators, and support networks for those affected by TB. Moreover, the inclusion of the most vulnerable populations, including marginalized and underserved groups, is crucial as they often bear a disproportionate burden of TB.

The United Nations Sustainable Development Goals (SDGs) and the UN High-Level Meeting (UNHLM) agenda to eliminate TB provide a global framework for tackling the DR-TB crisis. However, the progress in mitigating the threat of DR-TB hinges on recognizing the essential role of TB-affected communities. These communities should be seen as indispensable partners at local, national, and regional levels in the fight against DR-TB, advocating for shorter and more effective treatment regimens and a people-centered, rights-based approach to TB care and prevention.

Drug-resistant TB stands as a formidable global challenge. Addressing this threat requires concerted efforts that go beyond medical treatment, embracing community engagement and partnerships with those most affected. By investing in DR-TB-affected communities and empowering them to lead the charge against this resilient variant of TB, we can make significant strides toward a world free from the grip of TB.

A WORD FOR BPAL REGIMEN

Time and again we have heard from the communities that the pill burden and lack of support is often one of the biggest barriers to completing treatment. All community members with MDR/RR-TB stand to benefit immensely from effective, shorter all oral treatment regimens.

The all-oral, 6-month BPaL/BPaLM regimens comprise 3 to 4 drugs: the new drug pretomanid (developed by the non-profit TB Alliance), used in combination with bedaquiline and linezolid, with or without moxifloxacin. As per the WHO, BPaLM may be used programmatically in place of longer regimens, while moxifloxacin may be dropped in case of known resistance to fluoroquinolones. The effective and quick uptake of these regimens can be a real game changer for many. We must prioritize people getting safer and shorter TB treatments at all levels.

OBJECTIVE OF THE MANUAL

To build treatment literacy, capacitate and enhance advocacy skills of the TB community and other stakeholder to advocate for BPaL/BPaLM.

STRUCTURE OF THE MANUAL

This manual has been designed as a complete package for two days of training. 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

Along with the sessions that they will facilitate, the facilitator(s) are required to read all the topics covered in these modules before training commences in order to have a comprehensive understanding of the scope of each topic and its relevance.

Prior to the training, facilitators will need to 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
- Provide activities that require active participation
- 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 following arrangement, although facilitators may choose to adapt the sequences and timings as per the requirements of the training:

Time
Duration of the session

Material Required
Suggested list of materials to be used during the training

Objective
Desired learning objective to be achieved by participants by the end of the session

Methodology
Step-by-step participatory methods to engage participants in the learning process

Facilitator's Notes
Notes that provide the facilitator with information and tips for facilitating activities

TIPS FOR TRAINERS

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

Most trainings require more than one facilitator. In such cases, it should be ensured that the co-facilitators have read all the training materials in this package and that they feel comfortable with the selected topics from the training manual. A meeting of the facilitators before the training should ideally be conducted to agree on the agenda and to decide who is going to teach which topic. Some facilitators feel more comfortable presenting certain topics than other facilitators and for the benefit of the facilitator and the trainees, this should be taken into consideration.

Understand the profiles of the participants attending the training so that the training can be tailored to suit their needs. 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 there is space for the senior staff to share their experience with the new staff.

HOW TO FACILITATE

- 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.
- Facilitators should be technically competent to answer intervention-related questions. The topics included may be adapted to suit local needs and priorities
- While presenting, it is suggested to take centre stage – do not hide behind a podium or desk. Face the audience when speaking, not the board or screen. Make eye contact with trainees in all sections of the audience, speak slowly and clearly, and loud enough for everyone to understand and hear. Use natural gestures and facial expressions while avoiding blocking the participants' view
- While discussing, involve all participants. Ask the quiet ones questions. Control the talkative ones. Move around the room - approach people to get their attention or response and use participants' names
- Repeat the participant's responses when it is likely that not everyone heard it. Respond encouragingly to all the answers - correct errors gently. Reinforce participants by thanking them for comments and praising good ideas. Respond adequately to questions - offer to seek answers if not known
- Handle incorrect or off-the-subject comments tactfully
- For group activities, explain clearly the purpose of the activity, what participants have to do, and the time limit

KEY THINGS TO REMEMBER AS A FACILITATOR

Do

- Be flexible. Scheduling may have to change depending on the need of the participants
- Use different teaching methods to enhance participation and retain interest
- Ensure that teaching materials like hand-outs; charts, etc. are available before the beginning of the session
- Respect participants' local knowledge
- Encourage participants to present

Don't

- Read directly from the PowerPoint presentation – instead, use it as cue cards to elaborate on relevant points
- Make it a boring experience for participants – intersperse the sessions with energizers/games
- Speak more than the participants – instead, let the participants brainstorm and discuss
- Let one person dominate discussions
- Allow distractions like cell phones and chatting among participants

SESSION 1

SETTING THE CONTEXT

DURATION

50 mins

MATERIAL REQUIRED

1. Post-it notes
2. Whiteboard
3. Flipchart
4. Session 1 PowerPoint deck
5. Pre-Training Assessment Form (Annexure 1)
6. Laptop
7. LCD Projector

OBJECTIVE

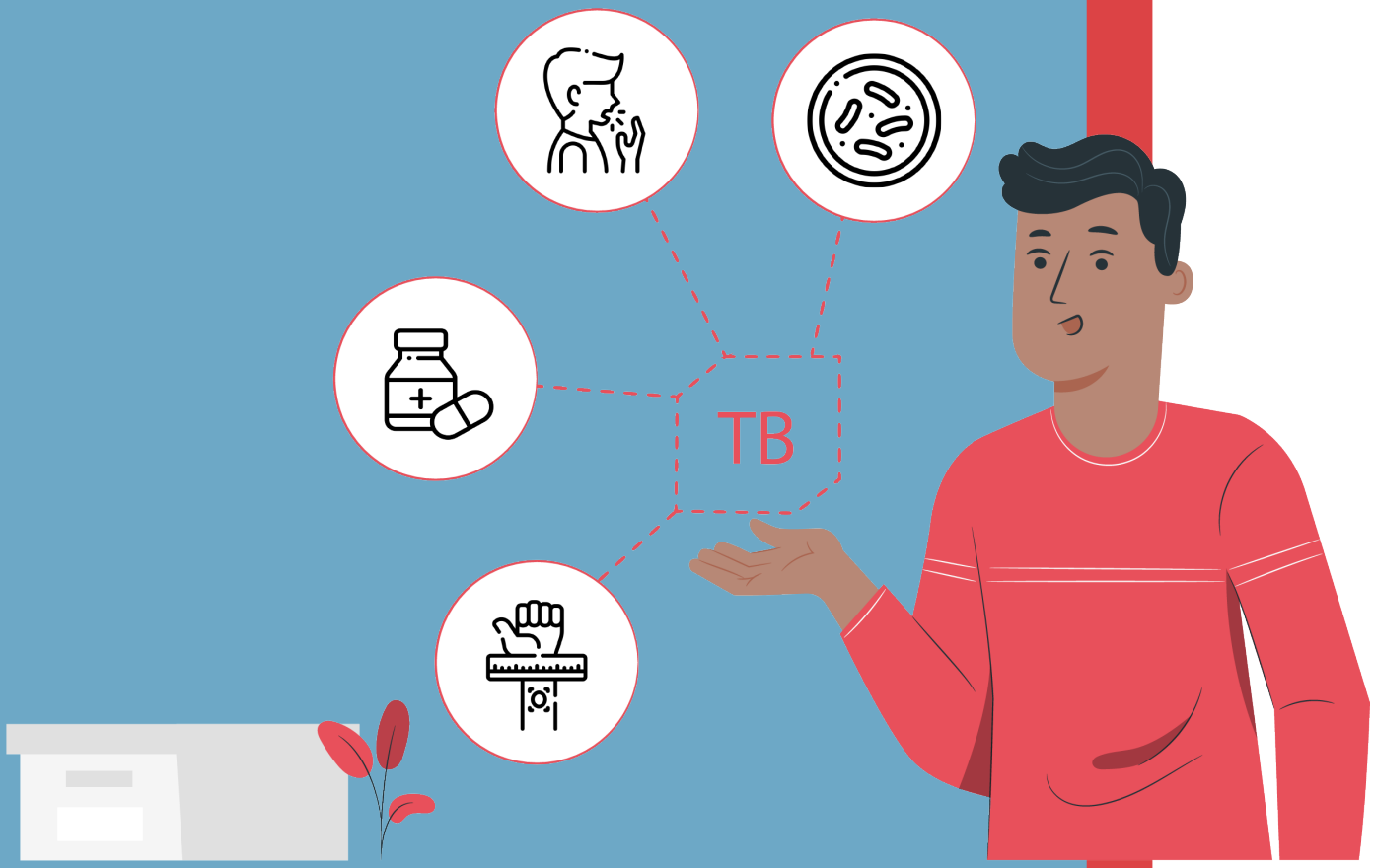
By the end of this session, the participants will have introduced themselves to each other and the facilitator.

METHODOLOGY

1. Introductions (10 mins): Conduct an ice breaker to know your group
    a. Each participant will state their name, organization and what their "superpower" is. This can be a special skill, a curious fact about their lives, valuable knowledge they can share, etc.
2. Expectations from the training (10 mins)
    a. Each participant is to be given a post-it note.
    b. They are to answer in one sentence "What are your expectations from the training program?"
    c. They are to stick this post-it on a board and 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 later 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 the expectations.
3. From the PPT, highlight objectives and overview of the training (10 mins)
    a. To gain a basic understanding of drug-resistant tuberculosis.
    b. To learn about the available treatment regimens for drug-resistant tuberculosis.
    c. To learn fundamental advocacy skills to push for the accelerated rollout of BPaLM/ BPaL among relevant stakeholders.
4. Ground rules (5 mins)
    a. Interact with the participants to list down the ground rules to be followed during the training to ensure 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 (10 mins)
    a. Request the 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 in this training.
    c. Note that this is not an examination but conducted to measure the learning and effectiveness of the training.

SESSION 2

TUBERCULOSIS 101



DURATION

1.5 hrs

MATERIAL REQUIRED

1. Chocolates as rewards
2. Handout A: All About Drug-Resistant Tuberculosis (Annexure 2)
3. Laptop
4. LCD Projector
5. Flipchart
6. Coloured Markers
7. Session 2 PowerPoint Deck

OBJECTIVE

To provide an overview of tuberculosis, its transmission, diagnosis and treatment.

METHODOLOGY

1. Introductions (20 mins)
    a. Game to stimulate a mutual understanding of TB within the group and to provide more information as needed. This game is intended to be a quick revision of known facts about TB.
    b. With the aid of the PowerPoint deck, ask the participants to provide the answers to the questions below. The participant with the greatest number of correct answers receives a reward.
        - What causes TB?
        - How does TB spread?
        - What are the risk factors for TB?
        - Name a symptom of TB
        - What is pulmonary TB?
        - What is extrapulmonary TB?
        - Name a part of the body TB cannot affect.
2. With the aid of the PowerPoint deck, discuss TB statistics globally.
3. Discuss the basics of TB prevention, diagnostics, drug susceptible TB, drug resistant TB and adverse drug reactions. Facilitator can also have participants call out responses after passing out Handout A: All about Drug Resistant Tuberculosis at this point (45 mins)
    a. TB Prevention
    b. Diagnostics
    c. Drug Susceptible TB
    d. Drug Resistant TB
    e. Adverse Drug Reaction
4. Facilitator to take time to answer any questions, give out any latest information and encourage discussions about this topic before proceeding (15 mins)

SESSION 3

BPAL/BPALM: SHORTER DR-TB REGIMEN

DURATION

1.5 hrs

MATERIAL REQUIRED

1. Laptop
2. LCD Projector
3. Flipchart
4. Coloured Markers
5. Handout B: Regimen options (Annexure 3)
6. Session 3 PowerPoint Deck

OBJECTIVE

By the end of this session, the participants will get an overview of the shorter DR-TB regimen, its global status and the updated WHO guidelines for BPaL/ BPaLM.

METHODOLOGY

1. The facilitator will start the session by asking the following questions and will note down the responses from the participants (20 mins)
    a. What are the causes of drug resistance?
    b. What are some of the challenges faced by people with MDR/XDR-TB?
    c. How can we address these challenges?
    d. What is BPaL?
    e. Why BPaL?
2. The facilitator explains and summarizes the above discussion through the PowerPoint deck (30 mins)
    a. Introduction: Drug-Resistant TB (DR-TB) is caused when the TB bacteria are resistant to at least one of the first-line TB medications - isoniazid (INH), rifampin (RIF), ethambutol (EMB), and pyrazinamide (PZA).
    b. Causes of drug resistance
        - Mutation in the TB bacteria that makes a drug ineffective
        - Exposure to someone with DR-TB
        - Inadequate or poorly administered treatment regimen allows drug resistant mutants to become the dominant strain - e.g., interruptions or premature discontinuation of treatment, or poor patient adherence
        - Appropriately administered drugs have not achieved necessary drug levels to deal with all population of mycobacteria
        - Weak TB services can lead to delay in detection and effective treatment of drug resistance
    c. What is BPaL/BPaLM
        - BPaL: An all-oral regimen of Bedaquiline (B), Pretomanid (Pa), Linezolid (L)
        - BPaLM: An all-oral regimen of Bedaquiline (B), Pretomanid (Pa), Linezolid (L), Moxifloxacin (M)
    d. BPaL/BPaLM is recommended for people with
        - MDR TB (fluoroquinolone susceptible)
        - Pre-XDR TB
        - Extensive pulmonary TB
        - Extrapulmonary TB, except for TB involving the central nervous system, bones and joints, and disseminated (spread from the lungs to other parts of the body through the blood or lymph system) TB

Facilitator's Note

When initiating the regimen, it is important to ensure that patients have not had previous exposure to bedaquiline, linezolid, pretomanid or delamanid for more than 1-month duration. When exposure is greater than 1 month, these patients may still receive these regimens if resistance to the specific medicines with such exposure has been ruled out.

    e. Distribute Handout B: Regimen Options and discuss in detail the regimen options and factors to be considered for selection of treatment regimens for patients with MDR/RR TB

f. Table showing the difference between the conventional regimen and the shorter regimens

Details	Conventional Regimen	BPaL	BPaLM
Efficacy	~60%	~90%	~90%
Duration	9-18 months	6 months	6 months
Number of Pills	Between 2828 - 4898 pills (depending on body weight and duration)	564 pills	746 pills
Number of Injections	85-130 injections	None	None
Hearing Loss	Yes	No	No
Kidney Failure	Yes	No	No

g. Evidence

There were four arms in the clinical trial Nix and the most favorable result (90.9%) was LZD 600mg for 26 weeks.

Facilitator's Note

BPaL was first studied in the Nix-TB Phase 3 clinical trial, which enrolled people with highly drug-resistant TB in South Africa. It included patients as young as 14 and those who are co-infected with HIV with a CD4 count of 50 or higher. After completing treatment, participants are monitored for two years to ensure they do not relapse. Nix-TB data have demonstrated a successful outcome in 95 of the first 107 patients (90 percent) after six months of treatment with BPaL and six months of post-treatment follow-up. For two patients, treatment was extended to nine months. BPaL has been tested in DR-TB patients co-infected with HIV, including those receiving antiretrovirals (ARVs), and similar outcomes were reported in participants based on HIV status[1].

ZeNix is a successor to the Nix-TB trial and it tested a version of BPaL with a lower dose and shorter duration of linezolid to determine whether the efficacy of BPaL can be maintained while reducing toxicity. ZeNix enrolled participants across 11 sites across Georgia, Moldova, Russia, and South Africa. the treatment regimen remained effective against highly drug-resistant strains of TB with reduced dosage and/or duration of the linezolid component of the regimen. Along with the maintenance of efficacy, there was a decrease in linezolid-associated side effects that accompanied the reduced dosage or duration of linezolid[2].

h. Highly cost-saving
   - Potential health systems savings of USD 740 million per year
   - Potential savings of 40-75% for MDR-TB treatment and up to 90% for pre-XDR-TB treatment
   - Reduction in cost of follow-up due to lower duration

i. Lower pill burden (3-4 pills/day for BPaL/M vs. 13-14 pills/day)

[1] https://www.tballiance.org/portfolio/regimen/bpal
[2] https://www.tballiance.org/portfolio/trial/11883

3. New WHO clinical guidelines
    a. "WHO suggests the use of the 6-month treatment regimen composed of bedaquiline, pretomonid, linezolid (600 mg) and moxifloxacin (BPaLM) rather than 9-month or longer (18-month) regimens in MDR/RR-TB patients."
    b. "...in case of documented resistance to fluoroquinolones, BPaL without moxifloxacin would be initiated or continued."

4. Global Status

    As of mid 2023, many countries have already implemented and scaled-up BPaL, such as South Africa, Ukraine, Nigeria, Pakistan, Kyrgyzstan and Tajikistan.

Facilitator's Note

The WHO Consolidated Guidelines on Tuberculosis (TB), Module 4: Treatment - Drug-Resistant Tuberculosis Treatment 2022 update informs health care professionals in Member States on how to improve treatment and care for patients with drug-resistant TB (DR-TB). This document includes two new recommendations – one for the use of a 6-month BPaLM regimen, composed of bedaquiline, pretomanid, linezolid and moxifloxacin in patients with multidrug-resistant or rifampicin resistant TB (MDR/RR-TB) and those with additional resistance to fluoroquinolones (pre-XDR-TB) and another for a 9-month all oral regimen in patients with MDR/RR-TB and in whom resistance to fluoroquinolones has been excluded. In addition, the consolidated guidelines include existing recommendations on treatment regimens for isoniazid-resistant TB, longer all oral regimens, monitoring of treatment response, the timing of antiretroviral therapy (ART) in MDR/RR-TB patients infected with the human immunodeficiency virus (HIV) and the use of surgery for patients receiving MDR-TB treatment[3].

5. Use the PowerPoint Deck to share the experiences of people who have received BPaL

6. Facilitator to take time to answer any questions, give out any latest information and encourage discussions and questions on the latest guidelines (10 mins)

[2] https://www.who.int/publications/i/item/9789240063129

SESSION 4

ADVOCACY AND STAKEHOLDERS

DURATION

2.5 hrs

MATERIAL REQUIRED

1. Laptop
2. LCD Projector
3. Flipchart
4. Coloured Markers
5. Handout C: Advocacy Framework (Annexure 4)
6. Session 4 PowerPoint Deck

OBJECTIVE

By the end of this session, participants will be able to define advocacy, list the steps of advocacy, differentiate between the types of advocacies and describe various advocacy tools.

METHODOLOGY[4]

1. Understanding advocacy (60 mins)
    a. Brainstorming: Ask the participants to take a moment to reflect on the term 'advocacy' and ask them to provide one word each that best defines advocacy. Make a note of the terms that emerge and supplement with the following standard definitions of advocacy:

Facilitator's Note

Advocacy denotes activities designed to place the specific issue response high on the political and development agenda, foster political will and public awareness, increase financial and other resources on a sustainable basis, secure policy or program commitments or changes, and hold authorities accountable to ensure that pledges are fulfilled, and results are achieved.

With the aid of the PowerPoint deck, explain that advocacy often focuses on influencing policymakers, 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.

b. Differentiate between the two main types of advocacy.
    - Reactive advocacy is based on responding to events after they have happened.
    - Proactive advocacy focuses on eliminating problems before they have a chance to appear.

Facilitator's Note

Ask participants for examples from their own experiences on the types of advocacy that they have been involved in or have heard of and identify whether they were reactive or proactive.

c. Advocacy can take on various forms such as:
    - Policy Advocacy: Informs politicians, etc. on 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.

d. Steps of Advocacy: Project or distribute the following suggested framework for advocacy.

Facilitator's Note

An alternative method would be to note the steps incrementally on a flipchart and pause between steps to explain the details given in the next point. The Advocacy Framework may be provided to participants as a handout.

e. Walk the participants through a real-world TB advocacy example, while asking for

[4] All content in this chapter has been adapted from "Transforming the TB responses: capacity building of communities to be change agents" 2019 manual by GCTA

responses regarding each step and how it can be used for TB related advocacy. Take time to brainstorm and process how these steps would apply to them in their work.

- Select an issue or problem you want to address
  - » Prioritize the most urgent issue requiring advocacy for which you have the appropriate resources and knowledge.
  - » Discuss why you want to take up the issue and what you hope to achieve.
- Analyse and research the issue/problem
  - » Gather as much information about the issue as possible.
  - » What are the key areas you want to focus on? Are there existing advocacy efforts to address these? How much documented evidence is available?
  - » What kind of evidence can be used for advocacy? Photographs, testimonies, official records, correspondence, etc.
  - » How can these be used?
- Develop specific objectives for your advocacy work
  - » Objectives should be clear and focused.
  - » Should be a specific statement that clearly describes results that will be pursued within a specific period (specific, measurable, achievable, realistic and time-bound).
- Identify your targets
  - » Primary target audience includes decision makers who have the authority to bring about desired change.
  - » Secondary target audience includes persons who have access to and can influence primary target audience – like other policy makers, community leaders, friends, relatives, media, religious leaders, etc.
  - » Identify individuals in the target audience and their positions – determining whether they support, oppose or are neutral to the advocacy issue.
- Identify your resources
  - » Resources can include people and funds – not all advocacy initiatives require funding.
  - » What are the internal resources you have? Can you also access external resources?
- Identify your allies
  - » Potential allies may include other organisations or community groups.
  - » Building a wide support base is essential, as is working in collaboration with other partners – can help pulling together resources, approaching decision makers and rallying supporters.
- Create an action plan
  - » Put together an action plan to guide the advocacy process. This should include details of activities, timelines and allocation of responsibilities.
- Implement, monitor and evaluate
  - » Build in monitoring and evaluation as an ongoing component to the advocacy strategy.
  - » Periodically review each step in your plan and determine whether it was implemented effectively, or if course corrections are required.

2. Introduction to advocacy tools (30 mins)
    a. Take the participants through the various tools of advocacy.
        - 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 information from various sources and develops it into policy options that 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 decision-makers who have the power to make desired changes 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 unity and commonality of purpose are key to the success of advocacy work.

Facilitator's Note

These can translate into actions that the community could take up, such as

- Hold a public panel discussion
- Arrange face-to-face meetings with advocacy targets
- Arrange a formal phone call with specific asks
- Write letters and emails to decision-makers
- Write op-eds or letters to the editor
- Write a petition
- Use social media platforms such as blogs, Twitter, Facebook and WhatsApp
- Use audio-visual media
- Organize a media stunt or public protest
- Write a press release
- Organize rallies
- Hold a press conference
- Participate in relevant networks, meetings and moments

Provide a few tips on what should be kept in mind while developing advocacy strategies or conducting advocacy initiatives.

- 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 are often preceded by numerous failures. It is important not to give up, but to learn from our mistakes and 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 policymakers, funders and decision-makers through a variety of channels. It seeks to ensure that governments are committed to implementing TB policies and activities.
- 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.

3. Stakeholder analysis (60 mins)

   Understanding our stakeholders. Facilitate an open discussion about the different kinds of people and institutions that the community of people affected by TB can and should work with when engaging in advocacy, based on the following discussion points:

   a. Who are stakeholders?
   b. What is the objective of stakeholder analysis?
   c. Divide participants into groups consisting of 6-7 members in each group. Provide each group with a flipchart and permanent markers.
   d. Group members are asked to first list all relevant stakeholders and then come to a consensus on assigning each of the stakeholders to the appropriate levels in the pyramid according to the following sequence:
      - Bottom Level: least influential
      - Mid-Level: fairly influential
      - Top Level: most influential

      As participants complete this analysis, have them speak to their rationale for categorizing stakeholders' level of influence.
   e. Revisit the advocacy tools described in the previous session and ask participants to discuss which advocacy tools and actions can be effective for different levels of stakeholders identified. The following template may be used as an example:
      - Key stakeholders
      - Appropriate tools and actions
      - Key messages
   f. Ask one spokesperson from each group to present a brief report on the group work to the larger group. Do ask participants to comment on the presentations made by other groups.
   g. Summarize the session with questions and responses and any further clarifications.

SESSION 5

COMMUNICATION AND TOOLS

DURATION

1.5 hrs

MATERIAL REQUIRED

1. Laptop
2. LCD Projector
3. Flipchart
4. Coloured Markers
5. Post-its
6. Handout D: Communications and Developing Skills for Social Media (Annexure 5)
7. Handout E: Social Media Advocacy and Essential Skills for Success (Annexure 6)
8. Reward for winners
9. Session 5 PowerPoint Deck

OBJECTIVE

By the end of this session, participants will be able to describe how the digital space can be used for advocacy.

METHODOLOGY

1. Understanding communications (10 mins)
    a. Brainstorming: Ask participants to suggest words that come to mind when we think of communication. Note these on a flipchart to demonstrate the range of perspectives to communication.
    b. Share the following points via a talk or PowerPoint deck: being able to communicate effectively is a critically important life skill. 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)
        - Visual (using logos, maps, charts or graphs)
        - Non-verbal (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.

2. Game: 'jump and earn' (10 mins)

    Ask the participants to line up on one end of the room and proceed to ask them true or false questions about social media platforms and ask them to jump towards the right if they think the answer is true and jump towards to left if the answer is false. Audio-visual aids maybe used to make the game more interesting. Allocate points for every correct answer and hand out a prize at the end of the game.
    a. Social media is difficult to handle (everyone gets a point for whichever answer they provide)
    b. Twitter is a micro-blogging platform (true)
    c. Facebook page and Facebook group are the same thing (false)
    d. A tweet can have a maximum of 500 characters (false)
    e. It is okay to not have frequent and periodic activity on a social media page (false)
    f. While a tweet can be edited after a post, a Facebook post cannot be (false)
    g. More women use Facebook compared to men (true)
    h. Facebook caters to a larger market than twitter (true)
    i. Facebook is more popular with middle aged adults (true)
    j. Social media does not have to be engaged for advocacy (everyone gets a point for whichever answer they provide)

3. Build on this knowledge (30 mins)

    Begin by introducing why social media can be a best buy for advocacy.
    a. What is social media advocacy and how can it help you?
        - Social media advocacy is most simply defined as leveraging your relationships with people who are supporters of your cause through social media so that they help you by sharing their enthusiasm for your company.
        - In most cases, this includes your customers, influencers, and employees.
    b. Design a social media advocacy strategy in line with goals.
        - Your social media advocacy plan should support your larger strategic objectives.

- The more specific and concrete your goals, the more you can create a social media advocacy strategy that results in the right people viewing and sharing your content.

c. How to create a social media advocacy program that will work for you?
   - Know your audience
     - » Know your demographics – age/gender/language preferred, etc.
     - » What do the audiences love/like?
     - » What are the audience members passionate about?
     - » Remember - you can't provide meaningful content to your audience if you don't know what they care about.
   - To understand your audience better, you must look no further than your own social media
     - » What posts do people respond to and comment on?
     - » What kind of posts are met with silence?
     - » Think like a detective and make a list of what's working and what is not.
   - Don't ignore your employees when identifying social media advocates
   - Build a relationship with your advocates
     - » It's vital to nurture the relationship you have with your advocates and show your appreciation for them.
     - » Use a monitoring system to reach out and identify who is sharing your content and thank them or tag them when they've shared content, participated in your groups or engaged in your live videos.
   - Reward your social media advocates in a creative way
     - » If you are looking for ways to incentivize your advocates to share your content, consider offering rewards that they will appreciate such as access to webinars or training on a skill.
   - Give your audience a story to tell, and help them tell it
     - » Create a campaign that is humorous, useful, touches the heart, or is otherwise memorable. Your content needs to stand out and inspire.
     - » Ask yourself: what is the remarkable part of this story that would make someone turn to the person standing next to them and tell it?
   - Decide how you will measure the success of your social media advocacy
     - » Your social advocacy program should be something you continually watch and measure to determine success
     - » Decide what metrics you will track early on in your planning (e.g. reach or engagement metrics)
     - » Take notes of who and what is making your program most successful based on the metrics you decide to track
     - » The more you can learn from monitoring your social advocacy program, the better you can plan

4. Further, discuss the basics of choosing and using any social media platform with the aid of Handout D
   a. With the aid of the PowerPoint deck, discuss the primary options for social media advocacy.

- Twitter
  - » A platform to share your thoughts with followers in 280 characters or less
  - » You can tweet at (@) people/groups; use hashtags (#) to create or join a movement referencing certain subject matter and follow other people/groups to get different viewpoints, learn something new, and follow breaking news and what others are doing; and retweet the posts of others to share the idea or news with your followers
  - » The more often you tweet and explore on twitter, the more your follower base and subject matter will grow—getting your word out to a greater volume of people
- Facebook
  - » A platform to share your thoughts with friends and followers. Also has a "group platform" that many organizations use to communicate with other group members or grow support for a certain movement
  - » You can post status updates, links, announcements, photos, documents, etc.
  - » Has a similar hashtag system to twitter, allowing you to create or join a movement involving certain subject matter
  - » Has more active users than any other platform
- Instagram and YouTube
  - » Good resources for sharing videos and photos
- WhatsApp
  - » Great way to stay connected with immediate peer group & your community
  - » Effective platform for real-time communication
  - » You can also use this platform to talk to people about stigma elimination

5. Address any questions, stray comments, and dialogue. Pass out handout E
6. Storytelling
   a. The power of storytelling
      - Stories have a transformative power to allow us to see the world in a different way
      - It gives us an opportunity to learn from another person's experience and it can shape, strengthen or challenge our opinions and values
      - Stories emotionalize information
   b. Connect to information
      - Find the emotional core of your message
      - Emotion combined with information becomes memorable and actionable
   c. Be authentic
      - Rather than focusing on what you want to get out of telling the story, shift your focus on how you will serve your audience.
   d. Give the participants 10 minutes to come up with a 1-minute story about themselves and their experience with tuberculosis for social media. Each participant must present their story at the end of the 10 minutes. Then, based on feedback, the participants will tweak their story and post it to a social media platform of their choice.
7. Address any questions, stray comments and dialogue. End the session by summarizing key points

SESSION 6

COMMUNITY LED MONITORING

DURATION

60 mins

MATERIAL REQUIRED

1. Laptop
2. LCD Projector
3. Flipchart
4. Coloured Markers
5. Session 6 PowerPoint Deck
6. Post Training Assessment Form (Annexure 1)

OBJECTIVE

By the end of this session, participants will be able to define and explain CLM (Community Led Monitoring)

METHODOLOGY

1. The facilitator will start the session by asking the following and note down the responses from the participants (20 mins)
    a. What is CLM?
    b. Why CLM?
    c. How to conduct CLM?
    d. Where to conduct CLM?
2. Use the PowerPoint deck to explain and summarize the above discussion
    a. What is CLM?
        - Monitoring of services BY communities, where they are the end-user.
        - Monitoring is routine
        - Monitoring is of indicators that are relevant to that community in order to improve services (quality, type of service etc.).
        - Monitoring provides an evidence-informed platform for the all-too-often missing voice in the response to advocate for change.
        - CLM is a process where communities take the lead to routinely monitor issues that matter to them. Communities then work alongside policymakers to co-create solutions to the problems they have identified. When problems uncovered through CLM aren't resolved, communities escalate with evidence-based advocacy and campaigning until they achieve implementation of corrective actions by duty bearers
    b. CLM is not
        - Monitoring people by governments or any other group
        - Providers carrying out monitoring projects with the recipients of care
        - A parallel M & E system to the routine government monitoring and evaluation
        - Communities covering data collection gaps for donor M&E
        - Only data collection
        - A snapshot of data to understand recipient of care experiences
        - A quality improvement initiative

Facilitator's Note

CLM is focused on fact-finding, not fault-finding – building trusting and effective relationships for meaningful change is fundamental to the ethos of CLM. It is a powerful model for improving the quality of healthcare services, by empowering communities with data to advocate for change. What differentiates CLM from typical efforts to improve health service quality is its accountability function: CLM is developed by and for communities using the services being monitored in order to uncover and correct problems undermining access to quality health services. In the CLM model, service users and directly impacted communities lead a systematic data collection effort, in which the community itself decides which issues should be tracked, creates indicators, and collects facility- and community-level data. These data are then analyzed and used to support advocacy directed at government and donors, with the aim of improving accountability and improving the quality of healthcare services[5].

[5] http://clm.itpcglobal.org/

c. Key methods or approaches
    - Mixed method design - Qualitative and Quantitative
        - » Increasingly being applied in community-led monitoring
    - Mixed methods design is when a CLM implementer collects qualitative and quantitative data, analyze it, integrates the findings, and draws conclusions
        - » A key component of mixed methods design is the integration of the quantitative and qualitative findings/results in drawing conclusion about an issue or problem

Facilitator's Note

There are numerous ways that the community can monitor services. This enables communities to have agency in following up different services, their access and other ground realities.

One Impact: a digital tool developed by Stop TB Partnership enables people with TB to connect with peers, access TB services and information, and report problems faced while on TB treatment. It also enables national TB programs and other health frameworks to gain access to reliable data that helps them understand the needs and concerns of people affected by TB, which in turn informs service delivery and improves the national TB response. However, in countries where a large portion of the population does not own a smartphone, the use of One Impact becomes a challenge.

Community Treatment Observatory (CTO): a structured system designed to regularly gather and analyze data related to healthcare services, particularly focusing on the treatment and care of specific health conditions within a community, is another method that can be used to collect qualitative and quantitative data. The GCTA conducted the first CTO for TB in 2020 by training community members to collect data. The addition of the human element in CTO allows the trained community members feel they are part of the solution by gathering comprehensive data and suggesting ways to address challenges highlighted through this method.

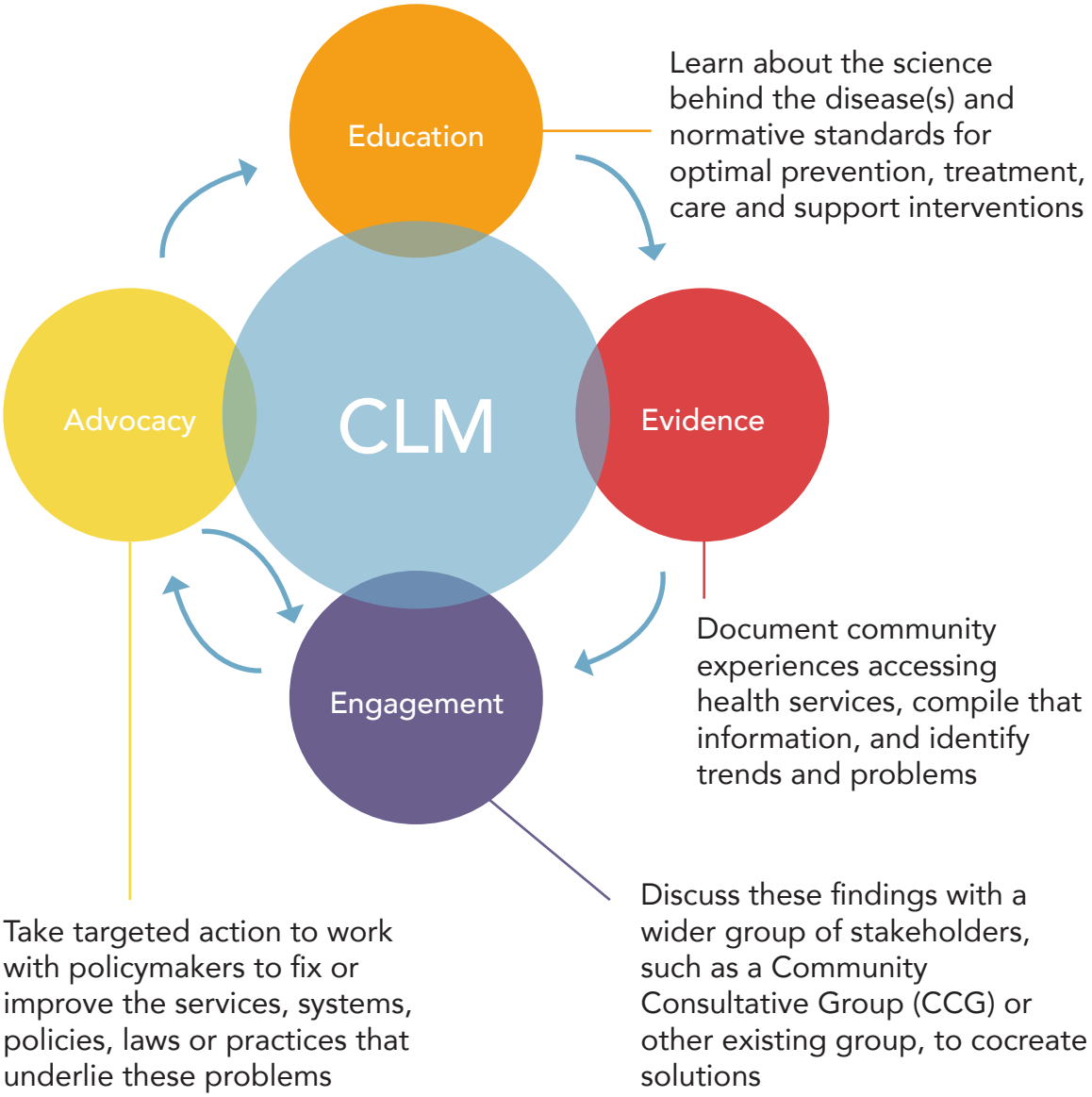
d. Why both qualitative & quantitative data in CLM
    - Qualitative data provide a detailed understanding of a problem while quantitative data provide a more general understanding. Facilitates the identification of relevant stakeholders
    - Qualitative understanding arising out of studying a few individuals and exploring their perspectives in great depth whereas quantitative arises from examining many people
    - Both provide different perspectives, and each has its limitations
    - A combination of both data provides a more complete understanding of the issue than either approach by itself
    - Strong evidence for a conclusion
    - Words and narratives will add more meaning to numbers
e. What to consider before planning for mixed method
    - Is there sufficient time to collect and analyze two different types of data?
    - Are there sufficient resources to collect and analyze both data?
    - Skills to collect both the data
    - Mixed method design involves collecting more types of data and analyzing and interpreting more data

- Time and resources are important issues to consider

Facilitator's Note

After the data collection tools have been developed, the next phase is data collection. Depending on the program's priorities and focus, this can involve any combination of surveys, individual interviews, and focus groups, collected in clinics, the surrounding communities, and/or in respondents' homes. These data are then analyzed by the implementation team. Finally, meetings with both the CLM implementer, civil society organizations, and the broader community are held to analyze the information and translate data into actionable insights and advocacy priorities.

3. ITPC Conceptual model of CLM



4. Donor Landscape
   a. Greater recognition by the donors of the CLM
   b. CLM is now a funded priority
   c. The Global Fund - supporting effective implementation of CLM in HIV, TB, malaria, RSSH and C19RM grants

d. The PEPFAR COP Guidance recognizes the importance of engaging with communities in the development and implementation of HIV programming. Operating Units (OUs) are required to fund the development and implementation of community-led monitoring activities

e. Stop TB Partnership – CFCS Grant

Facilitator's Note

In February 2020, the Global Fund held a global meeting in Geneva, entitled "Towards a Common Understanding of Community-based Monitoring and Advocacy"[6]. This meeting brought together implementers, donors, and other stakeholders to review the current understanding of CLM. Several key findings from this convening were summarized in a white paper that created a first definition of the CLM model[7].Two years since this convening, CLM implementation has expanded dramatically. COP20, PEPFAR has required all programs to develop and support a CLM program and the Global Fund Strategy has signaled a strong commitment to "putting the community at the center," in part through scaling up investments in CLM[8].

In August 2022, a second global convening on CLM was held by Global Fund in Bangkok, with the aim of working "Towards a Global Agenda for Community-Led Monitoring". During this meeting, 66 CLM implementers and 7 technical assistance providers were invited to a three-day meeting to review the findings, experiences, and lessons learned from CLM implementation. This report presents a global consensus that emerged from the meeting, including the fundamental stages of the CLM cycle, the core principles of CLM, and recommendations for strengthening CLM[9].

5. End the session with any questions, comments or deliberation (10 mins)

[6] The Global Fund. Towards a Common Understanding of Community-based Monitoring and Advocacy. February 2020. Geneva Switzerland.

[7] Health GAP, HEPS-Uganda (the Coalition for Health Promotion and Social Development), ICWEA(The International Community of Women Living with HIV Eastern Africa), ITCP (International Treatment Preparedness Coalition), O'Neill Institute for National and Global Health Law, SMUG (Sexual Minorities Uganda), TAC (Treatment Action Campaign). Community-Led Monitoring of Health Services: Building Accountability for HIV Service Quality (White Paper).

[8] The Global Fund. Fighting Pandemics and Building a Healthier and More Equitable World. Global Fund Strategy (2023-2028).

[9] The Global Fund. Towards a Global Agenda for Community-Led Monitoring. Meeting Report. 29 August - 1 September 2022. Bangkok, Thailand

Annexure 1
Pre & Post Training Self-Assessment

1. TB affects only the lungs.
   Yes No

2. TB is the most common opportunistic infection for people living with HIV.
   Yes No

3. What is the full form of BPaL and BPaLM?

4. WHO latest guidelines for MDR/RR-TB treatment is

5. Can BPaL/BPaLM be used for pregnant and breastfeeding women?
   Yes No

6. Is BPaL presently being implemented in India?
   Yes No

7. Can BPaL/BPaLM PLHIV coinfected with MDR-TB?
   Yes No

8. Where was the NIX-TB study conducted?

9. Can bedaquiline be used among pregnant women?
   Yes No

10. The estimated number of people with MDR/RR-TB in the world is

11. The following are the avenues to engage with audiences who can impact decisions for change:

12. Reactive advocacy is the only kind of advocacy that works.

13. CLM is Service Providers carrying out monitoring projects with the support of recipients of care.
    Yes No

Annexure 2

HANDOUT A: ALL ABOUT DRUG-RESISTANT TUBERCULOSIS

Drug-resistance

- Drug resistance means that the TB medicines are not able to kill the bacteria causing TB in a person. The bacteria have become resistant to some 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), with/without resistance to other drugs, the person is said to have multi-drug resistant (MDR) TB
- Drug-resistant forms of TB spread through the air just like other forms of TB
- In some cases, people directly get MDR-TB by inhaling MDR-TB infected droplets
- The symptoms of MDR-TB are the same as 'ordinary' TB – a persistent cough, chest pain, fever, loss of appetite and weight
- Those who come into frequent contact with someone who already has MDR- TB or a TB patient 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 approved for treating MDR-TB and WHO has issued guidelines for their usage.
- 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)

Summary of WHO Guidelines for DR-TB treatment

Regimen for rifampicin-susceptible, isoniazid-resistant tuberculosis

- In patients with confirmed rifampicin-susceptible, isoniazid-resistant tuberculosis (Hr-TB), treatment with rifampicin, ethambutol, pyrazinamide and levofloxacin is recommended for a duration of 6 months.
- In patients with confirmed rifampicin-susceptible, isoniazid-resistant tuberculosis, it is not recommended to add streptomycin or other injectable agents to the treatment regimen.

Shorter all-oral bedaquiline-containing regimen for multidrug- or rifampicin-resistant tuberculosis

- A shorter all-oral bedaquiline-containing regimen of 9–12 months duration is recommended in eligible patients with confirmed multidrug- or rifampicin-resistant tuberculosis (MDR/RR-TB) who have not been exposed to treatment with second- line TB medicines used in this regimen for more than 1 month, and in whom resistance to fluoroquinolones has been excluded.

Longer regimens for multidrug- or rifampicin-resistant tuberculosis

- In multidrug- or rifampicin-resistant tuberculosis (MDR/RR-TB) patients on longer regimens, all three Group A agents and at least one Group B agent should be included to ensure that treatment starts with at least four TB agents likely to be effective, and that at least three agents are included for the rest of treatment if bedaquiline is stopped. If only one or two Group A agents are used, both Group B agents are to be included. If the regimen cannot be composed with agents from Groups A and B alone, Group C agents are added to complete it.

The bedaquiline, pretomanid and linezolid (BPaL) regimen for multidrug-resistant tuberculosis with additional fluoroquinolone resistance

- A treatment regimen lasting 6–9 months, composed of bedaquiline, pretomanid and linezolid (BPaL), may be used under operational research conditions in multidrug-resistant tuberculosis (MDR-TB) patients with TB that is resistant to fluoroquinolones, who have either had no previous exposure to bedaquiline and linezolid or have been exposed for no more than 2 weeks.

Monitoring patient response to MDR-TB treatment using culture

- In multidrug- or rifampicin-resistant tuberculosis (MDR/RR-TB) patients on longer regimens, the performance of sputum culture in addition to sputum smear microscopy is recommended to monitor treatment response. It is desirable for sputum culture to be repeated at monthly intervals.

Starting antiretroviral therapy in patients on second-line antituberculosis regimens

- Antiretroviral therapy is recommended for all patients with HIV and drug-resistant tuberculosis requiring second-line antituberculosis drugs, irrespective of CD4 cell count, as early as possible (within the first 8 weeks) following initiation of antituberculosis treatment.

Surgery for patients on multidrug-resistant TB treatment

- In patients with rifampicin-resistant tuberculosis (RR-TB) or multidrug-resistant TB (MDR-TB), elective partial lung resection (lobectomy or wedge resection) may be used alongside a recommended MDR-TB regimen.

Care and support for patients with multidrug- or rifampicin- resistant tuberculosis

- Health education and counselling on the disease and treatment adherence should be provided to patients on tuberculosis (TB) treatment.
- A package of treatment adherence interventions may be offered to patients on TB treatment in conjunction with the selection of a suitable treatment administration option.
- One or more of the following treatment adherence interventions (complementary and not mutually exclusive) may be offered to patients on TB treatment or to health care providers:
    - » Tracers and/or digital medication
    - » Material support to the patient
    - » Psychological support to the patient
    - » Staff education

The following treatment administration options may be offered to patients on TB treatment:

- Community- or home-based directly observed treatment (DOT) is recommended over health facility-based DOT or unsupervised treatment.
- DOT administered by trained lay providers or health care workers is recommended over DOT administered by family members or unsupervised treatment.
- Video-observed treatment (VOT) may replace DOT when the video communication technology is available, and it can be appropriately organized and operated by health care providers and patients.

Patients with multidrug-resistant TB (MDR-TB) should be treated using mainly ambulatory care rather than models of care based principally on hospitalization.

A decentralized model of care is recommended over a centralized model for patients on MDR-TB treatment.

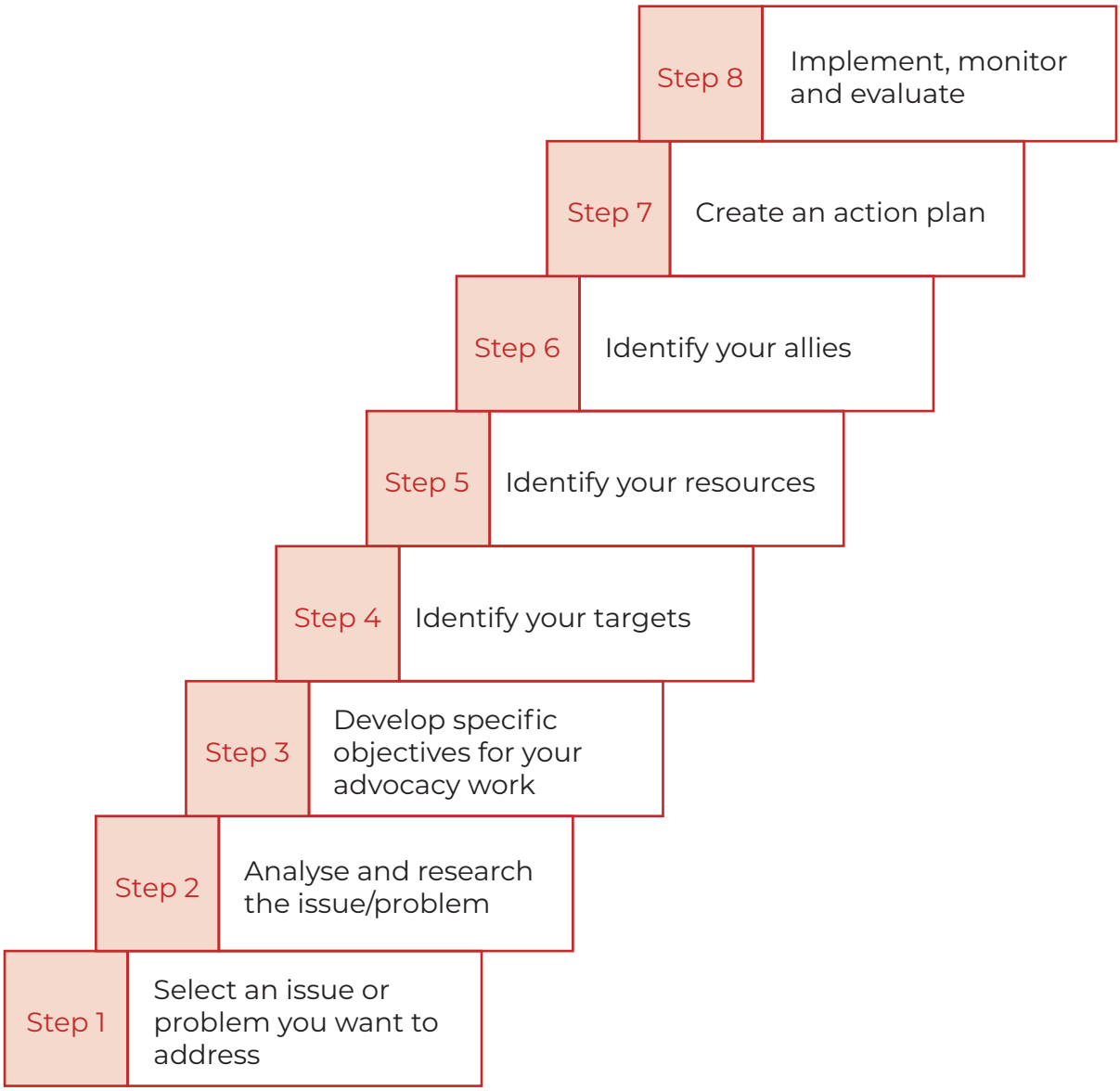
Annexure 3
HANDOUT B: REGIMEN OPTIONS

Regimen	MDR/RR-TB fluoroquinolone susceptible	Pre-XDR TB	XDR TB	Extensive pulmonary TB	Extrapulmonary TB	Age <14 years
6-month BPaL/BPaLM	Yes (BPaLM)	Yes (BPaL)	No	Yes	Yes- except TB involving CNS, miliary TB or osteoarticular TB	No
9-month all-oral	Yes	No	No	No	Yes, except TB meningitis, miliary TB, osteoarticular TB and pericardial TB	Yes
Longer individualized 18-month	Yes*/No	Yes*/No	Yes	Yes	Yes	Yes
Additional factors to be considered if several regimens are possible	Drug intolerance or adverse events Treatment history, previous exposure to regimen component drugs or likelihood of drug effectiveness Patient or family preference Access to cost of regimen component drugs					

BPaL: bedaquilie, pretomanid and linezolid | BPaLM: bedaquilie, pretomanid, linezolid and moxifloxacin | CNS: Central Nervous System | MDR/RR-TB: multidrug- or rifampicin-resistant TB | TB: tuberculosis | XDR-TB: extensively drug resistant TB

* When 6-month BPaL\BPaLM and 9-month regimens could not be used.

Annexure 4
HANDOUT C: ADVOCACY FRAMEWORK



Reference: Adapted from an advocacy framework developed by the International HIV/AIDS Alliance

Annexure 5

HANDOUT D: COMMUNICATIONS AND DEVELOPING SKILLS FOR SOCIAL MEDIA

1. Being able to communicate effectively is the most important of all life skills.
2. Communication is simply the act of transferring information from one place to another, whether this be:
    a. Vocally/verbally (using voice)
    b. Written (using printed or digital media such as books, magazines, websites or emails)
    c. Visually (using logos, maps, charts or graphs)
    d. Non-verbally (using body language, gestures and the tone and pitch of voice)
3. How well this information can be transmitted and received is a measure of how good our communication skills are.
    a. Communication is the process of imparting or interchanging of thoughts, opinions, or information by speech, writing, or signs.
    b. Principals 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
4. How to get maximum hits on Facebook
    a. Post regularly
    b. Use images, gifs, memes or videos
    c. Keep it short
    d. Add a link to all of your emails
    e. Invite members and stakeholders to write on your wall
    f. Use contests
    g. Tell don't sell. Use the 80/20 Rule
    h. Make it personal, show your human side
5. How to get maximum traction on Twitter
    a. Post regularly
    b. Use images/gifs/memes/videos
    c. Re-use your top posts
    d. Use hashtags strategically
    e. Reply to mentions
    f. Make it personal, show your human side
    g. Build an in-house army of micro-influencers

Annexure 6

HANDOUT E: SOCIAL MEDIA ADVOCACY AND ESSENTIAL SKILLS FOR SUCCESS

1. Promote awareness
   Education and advocacy are one of the first steps to affecting change. Share your message on social media. Communicate your mission to new followers and spread the word about new initiatives, campaigns, and issues within your community. And connect with the people who need support.

2. Build communities
   Grow your base and recruit potential volunteers, speakers, advocates, and mentors. Social media can be a powerful community building tool. Create channels and groups where people can engage, share resources, and stay informed about issues that matter to them.

3. Inspire action
   Rally people behind your cause with concrete actions they can take to support your cause. Promote marches, protests, marathons, and other events. Encourage followers to call politicians, pressure or boycott bad actors, or simply adopt more mindful behaviour.

4. Share your impact
   Show people what you can accomplish. Build momentum by celebrating victories, big and small. Let your contributors know you value their contributions and see how their help has made a difference. Share achievements, gratitude, and positivity, and you'll attract more support down the line.

5. Technical details to keep in mind for different platforms

   a. Twitter: With 280 characters, Twitter is a great platform to say what you need to say in a short and concise manner. It might feel restricting, but it is a great platform to reach Government Media and other stakeholders. Tag the relevant people and use the appropriate hashtag in all your posts and see the magic happen!

   b. YouTube: YouTube is all about videos. When you make videos of more than 60 secs, it is best to upload on YouTube and share the link within your network and on other platforms to increase views. Although it might seem difficult, it is very simple to upload a video on YouTube and have the world see it.

   c. Instagram & Facebook: Instagram and Facebook are favorable amongst youth. It is a creative space where you can share long form posts, Stories, you can go LIVE, do live interviews with others, you can share 60-sec or longer videos, and multiple pictures!

   d. Get your creative hats on and use stickers, filters, gifs, and share informative and positive content on Instagram. Again, use hashtags and tag people to reach maximum audience.

   e. WhatsApp: WhatsApp is a great way to stay connected to your immediate peer group and your community. you can form groups, share informative and motivational content with a large group of people who are on the platform. You can also use this platform to talk to people at length. Leverage this to bust myths that might be circulated here.

Supported by TB Alliance