

EMPOWERING & ENGAGING TB SURVIVORS AND CHAMPIONS TO RESPOND TO DRUG-RESISTANT TUBERCULOSIS

A Community Engagement Package



RESPECT

Resilient, People-centered, Community-led
Responses to End Drug Resistant Tuberculosis

Stop TB Partnership

hosted by
UNOPS



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PREFACE

Drug-resistant tuberculosis (DR-TB) remains one of the most urgent and complex challenges in the global fight against TB. Despite significant scientific advances and progress towards ending TB, far too many people affected by DR-TB remain undiagnosed and treated—often compounded by stigma, misinformation and lack of information and support. It is clear that ending TB requires not only effective tools, but support from TB survivors, communities and strong civil society leadership.

The Stop TB Partnership, especially through its Challenge Facility for Civil Society, has long supported community-driven responses that place affected people at the center of the TB response. Grounded in our four strategic pillars—strengthening community, rights and gender; catalyzing innovation; driving political will and accountability; and ensuring equitable access to TB services—this initiative reflects our commitment to amplifying the voices and leadership of those most impacted by the disease.

The DR-TB Champions Training and Support Project represents a powerful step forward in this effort. With the generous support of Unitaid through the RESPECT DR-TB project as well as L'Initiative (Expertise France), this project brings together civil society partners to demystify DR-TB, expand community knowledge of new and improved treatment options, and build demand for quality, people-centered care. It aligns closely with both Stop TB and Unitaid's broader efforts to accelerate the uptake of innovative DR-TB tools and ensure that communities are fully informed and engaged in scaling up access and their use.

This project is made possible through the collaboration of five outstanding country partners:

1) Cameroon - DRAF TB. 2) Democratic Republic of Congo - Club des Amis Damien. 3) India - REACH. 4. Moldova - PAS Center. 5) Pakistan - Dopasi Foundation. We are especially grateful to REACH for building on the extensive experience with TB Champions and for coordinating the development of this guide. Their leadership has been instrumental in shaping a practical, adaptable model for community engagement.

This work will extend far beyond these five countries. The tools, approaches, and lessons generated through this initiative will support scale-up across 17-country Challenge Facility for Civil Society network—enabling broader, more inclusive engagement and strengthening the global movement to end TB.

Let's transform the frustration of lack of progress in DR TB globally in ambition and hope and in efforts to to invest in people, communities, and partnerships. By equipping TB Champions with the knowledge, confidence, and tools they need, we must transform the DR-TB response—ensuring it is strong, accessible and equitable.

Together, we can end TB.

Dr. Lucica Ditiu
Executive Director
Stop TB Partnership

FOREWORD

Drug-resistant tuberculosis (DR-TB) remains one of the most urgent and complex challenges of our time. Antimicrobial resistance (AMR) is widely recognised as one of the greatest threats to global health, yet within this growing crisis, DR-TB continues to account for the largest number of deaths linked to AMR.

As a Community Board Member of the Stop TB Partnership, I am pleased to introduce this DR-TB Champions Movement and Capacity Building Module developed under the Challenge Facility for Civil Society, which is the only grant mechanism that is dedicatedly available to empower affected communities to lead the global fight against ending TB.

This initiative reflects the growing recognition that communities – particularly those directly affected by TB – are essential to an effective and strong TB response. Through catalytic investments supported by Unitaid and L'Initiative, the Challenge Facility for Civil Society has consistently strengthened community leadership and accountability, and this tool represents the latest contribution in a long line of efforts designed to empower civil society and affected communities to drive meaningful change.

I extend my sincere appreciation to REACH India and consortium partners from Cameroon, Democratic Republic of the Congo, Moldova, Pakistan as well as the Stop TB Partnership for leading the development of this important resource. Their collaboration demonstrates the power of cross-country learning and solidarity in addressing DR-TB.

To effectively confront drug-resistant TB, we must elevate and equip DR-TB survivors as champions within their communities. These champions play a critical role in raising awareness and providing education, supporting screening and early diagnosis, offering peer support to those undergoing treatment, and conducting community-led monitoring to identify stigma, barriers to care and gaps in the continuous supply of essential services. At the same time, they help build demand for newer and more effective DR-TB tools that can improve outcomes and save lives.

The reality is empowering survivors to lead is not only a strategy for better TB programmes – it is a pathway toward stronger, more resilient health systems and communities. Initiatives like this training module help strengthen community leadership, enhance health security and ensure that the TB response remains grounded in dignity, equity and accountability.

Ultimately, by supporting community champions and civil society leadership, we move closer to a future where no one is left behind, lives are saved and the goal of ending TB finally becomes a reality.

Rhea Lobo

Board Member – Community Delegation, Stop TB Partnership

ACKNOWLEDGMENTS



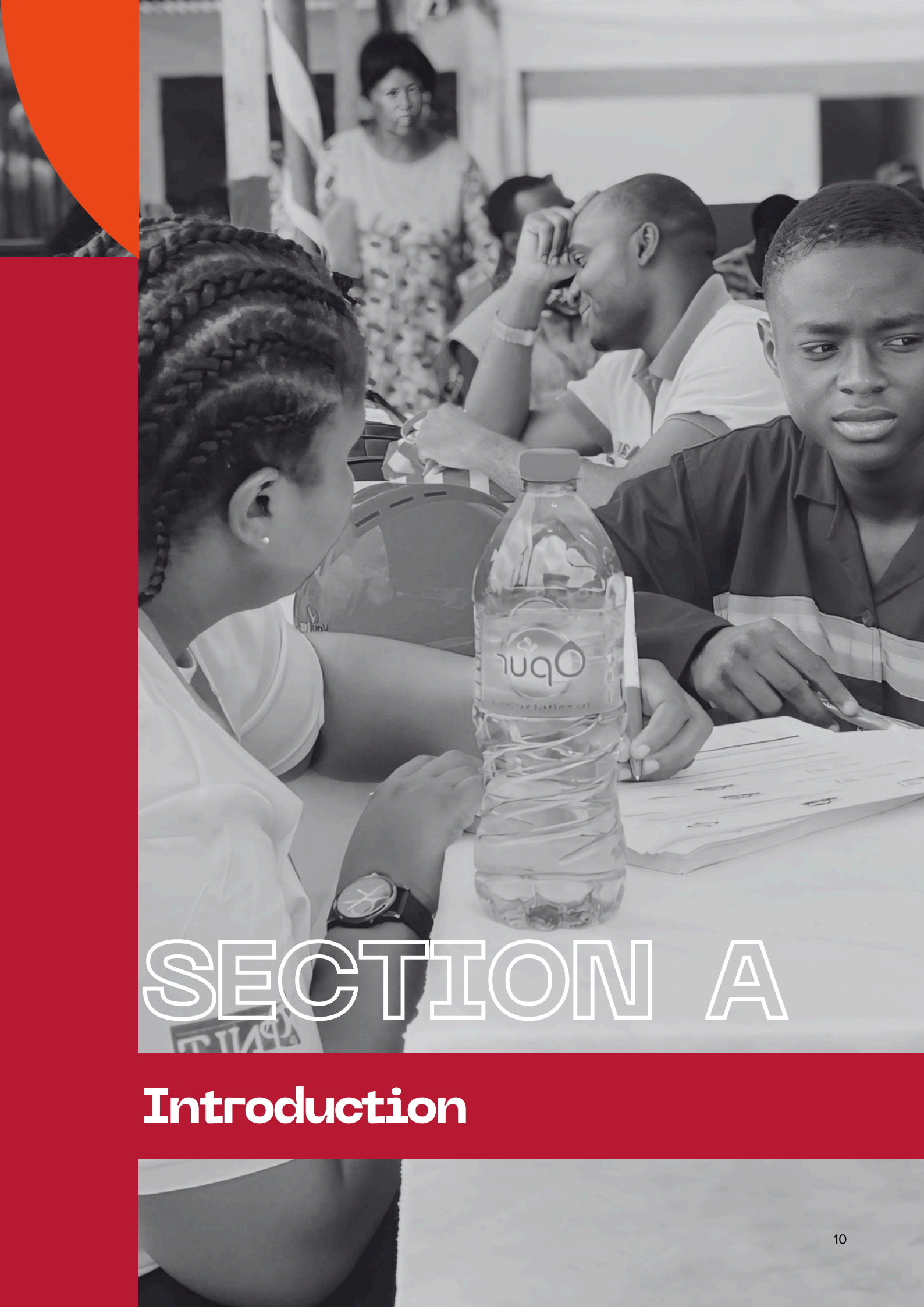
With the generous support of Unitaid and L'Initiative (Expertise France), the development of Empowering and Engaging TB Survivors and Champions to Respond to Drug-resistant Tuberculosis was led by REACH and the Stop TB Partnership as part of the Challenge Facility for Civil Society and the RESPECT DR-TB project.

We gratefully acknowledge the efforts of the REACH team, whose work in India provided the foundation for this tool. Ramya Ananthakrishnan and Anupama Srinivasan developed the structure of the tool and the first draft, with support from Anuradha Panda and Ananya Mahesh. Manjot Kaur reviewed the document and provided substantial inputs to help finalize the tool. Viorel Soltan, Sreenivas Nair, James Malar, and Caoimhe Smyth from the Stop TB Partnership complemented these efforts.

We are grateful for the valuable inputs of the RESPECT consortium partners: the Dopasi Foundation team from Pakistan, led by Kinz ul Eman; the DRAF TB team from Cameroon, led by Bertrand Kampoer; Maxime Lunga and the team from Club des Amis Damien, Democratic Republic of Congo; and the PAS Centre team from Moldova, led by Lilia Jelamschi, for their contributions to the content of the tool and for sharing the photographs used here.

Fellow Challenge Facility for Civil Society partners who were consulted and engaged are also recognised: TBpeople, APCASO, ACT Asia-Pacific, Rekat Peduli Indonesia, KHANA Cambodia, Network of TB Champions Kenya, Survivors Against TB India, TB Alert India, Humana People to People India, TBpeople Cameroon, For Impacts in Social Health, Joint Acting Process for the Success of Sustainable Objectives (JAPSSO), Focus Droits Et Acces, Health for Prisoners, Bridge Consultants Foundation, Active Help Organization, TBpeople Ukraine, ADPP Mozambique, TB Voice Network Ghana, Association of Former Cured Tuberculosis Patients of Benin, AFRIC'MUTUALITE-ONG, Réseau National des ONG et des Associations de Lutte contre la Tuberculose, Alliance Cote d'Ivoire, Collectif des Organisations de Lutte contre la Tuberculose et les Maladies Respiratoire en Côte d'Ivoire, Debriche Health Development Centre, and Center for Supporting Community Development Initiatives.

This tool was designed by Muskan Soni, with inputs from Tanya Timble. The French translation was undertaken by Oneliner.



SECTION A

Introduction

BACKGROUND

The Global Plan to End TB 2023-2030 articulates a shared commitment by governments, researchers, civil society and communities to end tuberculosis (TB) and drug-resistant TB (DR-TB) by 2030. This ambitious plan recognises that achieving TB elimination is not only a biomedical or programmatic challenge, but a social one. Ending TB requires leadership, accountability, and sustained action from (and in support of) the people most affected by the disease. Central to this vision is the meaningful engagement of TB-affected communities, particularly TB survivors, as equal partners in shaping and strengthening national and global TB responses.

A major global mechanism that has helped catalyse the engagement of TB-affected communities is the Stop TB Partnership's Challenge Facility for Civil Society (CFCS), which invests directly in TB-affected communities, TB survivor networks, and civil society organisations. CFCS has helped move community engagement in TB from a peripheral or one-time activity towards a more strategic, sustained and accountable part of the TB response. Importantly, it has supported countries and communities to strengthen four interlinked areas of action: creating demand for better TB and DR-TB services and new tools; addressing stigma and other rights-and gender-related barriers that prevent people from accessing care; advancing community-led monitoring and accountability; and promoting stronger integration of community action within national responses for long-term sustainability. Through this approach, CFCS has contributed to both global momentum and country-level practice, helping demonstrate that TB Champions and survivor-led communities are not an optional add-on to TB programmes, but central actors in building people-centred, rights-based and effective responses to TB and DR-TB.

A recent publication from the Stop TB Partnership – “Operationalizing TB Community Systems Strengthening (TB CSS): A Framework for Action” – has built on existing CSS approaches, making the case that countries need a clearer, TB-specific understanding of what community systems strengthening means in practice. Community engagement in TB is still too often reduced to Community Health Worker-led adherence support and contact tracing, which underestimates the wider roles TB-affected communities can play in shaping policy, reducing stigma, creating demand, strengthening accountability, and improving access for those most at risk.

The framework is organized around six “basic elements”: **(1) Community participation and inclusive governance; (2) Access for all and community-driven innovation; (3) Sustainable financing and capacity development for community-led action; (4) Community-led, people-centred care and support services; (5) Community workforce and organizational strengthening; and (6) Community-led monitoring, accountability, and learning.**

It positions TB survivors, underserved populations, civil society organizations, and regional/global platforms as an increasingly organized TB community system – a system that is already influencing national strategies, running stigma-reduction efforts, expanding peer support, and using community-led monitoring to identify gaps in services. The paper emphasizes that what has been achieved remains fragmented without a shared framework to guide investment standards, coordination, and accountability.

WHAT IS THIS TOOL?

This tool – **“Empowering & Engaging TB Survivors and Champions to respond to Drug-resistant Tuberculosis: A Community Engagement Package”** – builds on the TB-CSS framework. Developed through the Challenge Facility for Civil Society mechanism, this tool is a practical, experience-informed community engagement package developed by the Stop TB Partnership and REACH, in close collaboration with TB Champions, survivor-led networks and civil society organisations across multiple countries. It is a comprehensive resource that outlines various processes in identifying, training and meaningfully engaging TB survivors in a national or local TB response. Drawing on global best practices, it describes in detail the various steps that can be adopted to promote the active involvement of TB Champions in several different roles: as powerful advocates on behalf of TB-affected communities, empathetic peer supporters, persuasive community educators and skilled community monitors. The tool specifically focuses on the role of TB Champions in responding to drug-resistant TB, with an emphasis on the importance of community participation in demystifying DR-TB and improving clinical and social outcomes for people with DR-TB and their families.

The tool draws directly on experiences, insights, and collective wisdom. As such, this is not a technical guideline written about communities; instead, it is a community-authored resource, written with and by people affected by TB. The priorities, and perspectives reflected here are those of TB survivors who have transitioned into TB Champions, and of survivor-led networks that have emerged from lived experience.

Across diverse settings, TB Champions and survivor-led networks have demonstrated that communities are not passive beneficiaries of TB programmes. They are knowledge-holders, peer supporters, advocates, monitors, and change agents. Through this document, TB Champions from many countries come together to share how communities can be engaged in ways that are effective, empowering, and grounded in respect, dignity, and rights. The approaches described here reflect what has worked in practice, what has not, and what needs to change if community engagement is to move beyond tokenism towards genuine partnership and shared ownership.

PURPOSE OF THE TOOL

As highlighted by the TB-CSS framework, there is growing recognition of the importance of engaging TB-affected communities, but translating this commitment into meaningful action remains inadequate. Empowering TB-affected communities requires more than intent; it requires sustained access to the knowledge, skills, and opportunities needed to participate fully in the TB response. This tool outlines a tried-and-tested framework for engaging TB-affected communities through the **'TB survivor to TB Champion'** model, describing ways to identify, train, engage and sustain the genuine involvement of TB survivors. It describes the various processes involved in creating a cadre of TB survivors as Champions and in ensuring that TB-affected communities are meaningfully involved in various aspects of the response to TB.

WHOM IS THE TOOL MEANT FOR?

The TB Champions tool is intended for any national TB programme or a civil society / affected community organisation or TB survivor network that is working to introduce or strengthen mechanisms to involve TB-affected communities, particularly TB survivors, in the country's TB response. It offers a structured (and at the same time, adaptable) framework for identifying, building the capacity of, engaging, empowering, and sustaining TB Champions.

This tool is suitable for use both in countries that do not have such mechanisms in place at all, or in those that have nascent processes in place that they would like to enhance using elements from this tool. The tool can be used by local, regional or national TB programmes (NTPs); similarly, civil society organisations (including TB survivor-led networks) can demonstrate the tool in a restricted geographical area or implement at scale across the region or country. It is also possible that NTPs or implementors may like to use specific sections of the tool – for example, the training curriculum, or the various ways to engage TB Champions, but may not feel that it is feasible to adopt the tool in its entirety.

While all efforts have been made to ensure that the tool is suitable for global use, we do recognise that countries may need to adapt some elements to their specific settings. Additionally, the training curriculum will need to be adapted to focus on the DR-TB context in a specific country; the process of engaging TB Champions, and their roles and responsibilities will need to be tailored to the available resources. Those who are keen to utilise this tool will also need to translate content into various languages, as required.



WHY TB CHAMPIONS ARE AT THE CENTRE OF END TB GOALS

Global efforts to end Tuberculosis (TB) and drug-resistant TB (DR-TB) have been unwavering in the last decade, if somewhat checkered – with several positive developments indicating progress but alongside many emerging challenges that continued to stymie the TB response. On the bright side, we have newer tools to diagnose TB, shorter and safer regimens to treat both TB and DR-TB, greater attention to TB prevention, more sustained multisectoral action on TB and a stronger TB vaccine pipeline. On the other hand, we have also experienced two key setbacks – the COVID-19 pandemic, which significantly derailed efforts to find and treat more people with TB, and the sharp fall in TB funding and investment.

What has significantly changed in the last decade, and undeniably for the better, is the involvement of TB-affected communities, and TB survivors in particular. For too long, the TB response was primarily a biomedical one, driven by the need to manage clinical aspects of the disease, with not enough attention paid to the psychosocial and emotional needs of people with TB. TB responses were designed *for* people affected by TB, but rarely *with* TB survivors or others directly affected. As a result, despite affected communities' deep, unique and first-hand perspective of the impact of TB on people's lives, there was no perceived role for TB survivors, and few mechanisms for their involvement in health systems.

Today however, there is a strong and indisputable acknowledgement of the vital role that TB survivors can and must play in the collective efforts to end TB. Through their lived experiences, they have become advocates, peer supporters, educators, and monitors of health systems. They increase visibility for TB, generate demand for better tools, improve public understanding of the disease, reach and support people on treatment, identify barriers to care, and work actively to challenge stigma and discrimination. Their involvement has shown that survivor leadership improves both experiences of care and treatment outcomes. They have demonstrated that lived experience is not merely anecdotal or secondary knowledge, but a form of expertise that is essential to designing people-centered, effective TB responses.

This shift has been supported by civil society, national programmes, and global partners, including initiatives facilitated by the Stop TB Partnership, which have helped create space for survivor leadership and community-led action. The Stop TB Partnership's Challenge Facility for Civil Society (CFCS) mechanism, supported by L'Initiative, Expertise France and Unitaid has been instrumental in facilitating this shift, both in terms of mindsets and feasibility in many countries. There are more survivor-led networks than ever before (with over 20 country chapters of TBpeople), and their role continues to evolve and expand.

With the support of CFCS, TB survivors have moved from isolated voices to a coordinated, empowered and impactful movement to end TB. TBPeople, for example, is now a global survivor-led movement, with members in all TB high burden countries and **over 30 country chapters.**

TBpeople strives to make national TB responses truly people centered, to ensure all people get access to essential TB services, are treated with dignity, and empowered to contribute to responses that save lives. The involvement of TB survivors can impact the global TB response in several ways. In practice, TB Champions:



Reach people with TB who otherwise would be delayed or would not access health systems.



Engage with policymakers and implementers to ensure justice, rights and dignity for all people with TB and DR-TB.



Generate demand for access and update of new TB and DR-TB drugs, diagnostics and other innovations.



Supplement and complement government initiatives to enforce person-centered laws, policies, and programmes.



Monitor, document and challenge stigma and discrimination towards people affected by TB.



Provide psychosocial support and treatment literacy to people with DR-TB and their families



Advocate for the social security of people with TB and DR-TB as well as their families



Build social acceptance and support for people affected by TB through various mechanisms including social networks (these social networks have effectively broken through the silence around the experiences of affected communities – silence that contributes to stigma)



Bring the perspectives of affected communities front and center to the TB response, at multiple levels to strengthen national TB responses.

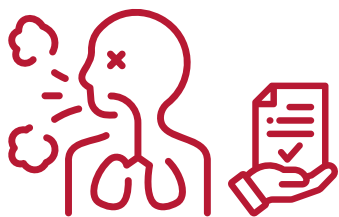


Play a critical role in demystifying DR-TB: challenging fear-based narratives, correcting misinformation, and reinforcing that DR-TB is a medical condition with improving outcomes, not a personal failure.

Perhaps most powerful of all, TB Champions offer tangible hope that a productive and meaningful life – beyond being merely ‘cured’ – after TB and DR-TB is possible.



Specifically in the DR-TB context, the meaningful engagement of survivors is more crucial than ever, not only because of the challenges inherent in this area, but also because of the unprecedented opportunities within reach. Two key factors make survivor leadership especially powerful at this moment:



1

Information about the disease

Although understanding of drug-resistance itself as a concept remains limited within communities, TB survivors are well-placed to lead efforts to demystify the disease. Drawing on lived experience, TB Champions are able to translate complex clinical information into language that people trust and understand. The social and emotional impact on those affected calls for delivery of care that is person-centered; peer support by and from survivors has emerged as a proven, compassionate way to help people navigate treatment with confidence and hope.



2

Access to new tools

In recent years, major advances have transformed what is possible for people with DR-TB. New diagnostic tools, all-oral regimens, and shorter, safer treatment options mean that cure is no longer the exception, but an achievable outcome for many. As survivors, TB Champions have lived through both the older, more punishing forms of treatment and the promise that these newer tools represent. Their role now is to ensure that this promise translates into real access and real outcomes for communities. Drawing on the skills described in this document—peer support, community education, advocacy, and community-led monitoring—they can help increase awareness, demand, and uptake of newer DR-TB tools. They can support people and families to understand treatment options, stay engaged in care, and complete treatment with dignity, this combining better tools with strong, community-led support.

DRUG-RESISTANT TB: A GLOBAL SNAPSHOT

Drug-resistant TB continues to be a major public health threat, with significant levels of resistance to rifampicin, the most effective first-line anti-TB drug. At the same time, recent data point to important gains that create real grounds for optimism. According to the 2025 WHO Global TB Report, an estimated **390,000 people** developed Multi Drug Resistant/Rifampicin Resistant (MDR/RR)-TB in 2024, a decline from 2015 levels. Progress in access to drug susceptibility testing has been especially encouraging. Globally in 2024, 83% of people diagnosed with bacteriologically confirmed TB were tested for rifampicin resistance (**3.7/4.5 million**), up from 79% (**3.4/4.3 million**) in 2023, representing major progress compared with 69% (2.4/3.5 million) in 2021 and 62% (2.2/3.6 million) in the pre-pandemic year of 2019. These gains reflect growing global capacity to detect drug resistance early and accurately which is an essential foundation for effective treatment.

Globally, a total of **164,545 people** were enrolled on rifampicin-resistant TB (RR-TB) treatment in 2024. This was only 42% of the approximately 390,000 people who developed RR-TB in 2024, almost the same as in 2023. Even though this treatment gap remains a concern, treatment success rate has continued to improve, rising to 71% among people with TB who began treatment in 2022, up from 68% for those who started in 2021.

Another significant positive shift is the global expansion of shorter, more tolerable, 6-month and 9-month regimens. In 2024, **34,256 people** with MDR/RR-TB were started on treatment with 6-month regimens, a substantial increase from 5,653 in 2023 and 1,744 in 2022. By the end of 2024, 6-month regimens were being used for treatment of MDR/RR-TB in 97 countries, up from 60 at the end of 2023 and 41 at the end of 2022. Although longer regimens of 18–20 months remain the most widely used (54% of people in 2024), the rapid scale-up of shorter regimens signals a turning point in DR-TB care (the proportion of people on 9-month and 6-month regimens in 2024 was 21% each).

These developments point to a unique opportunity in the global DR-TB response. For the first time, advances in diagnostics, new and repurposed drugs, and shorter, safer regimens make cure a realistic outcome for many more people. Accelerating the uptake of these tools (while strengthening systems to monitor treatment quality, reduce stigma, and address social and structural barriers) can dramatically improve outcomes. Peer support and survivor engagement are central to ensuring that these innovations translate into real access, sustained treatment, and lives saved.

Addressing DR-TB also has implications far beyond TB alone. DR-TB is one of the clearest manifestations of antimicrobial resistance (AMR). Progress in preventing, detecting, and treating DR-TB contributes directly to broader AMR containment efforts.

Similarly, investments in DR-TB diagnostics, surveillance, and community trust strengthen pandemic prevention, preparedness, and response (PPPR), while reinforcing core elements of health security. By acting decisively now – by combining new tools with strong community engagement – we have an opportunity not only to end DR-TB, but to deliver lasting benefits across health systems, protect future generations, and save lives.

Box 1: Drug-resistant TB: A global snapshot

KEY TERMS

Broadly speaking, **community engagement** is defined as the process of working collaboratively with and through communities to address issues affecting their well-being. As people affected by TB, community engagement means being recognized as partners in shaping the responses that influence our lives, rather than as passive recipients of care. The term ‘community’ itself can be interpreted in many ways; in this document, the term 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 someone being treated for TB or their family or someone living with HIV as well as their families. By naming affected communities in this way, we acknowledge both the challenges people face and the collective strength that comes from shared experience. This tool, while recognizing the need for strong and effective community engagement as a whole, specifically focuses on ways to involve TB survivors and the value of lived experience. This is not only personal history that can become a source of connection and power but also expertise that can strengthen TB responses and improve outcomes for others.

Throughout this tool, the term person with TB is used to refer to someone who is on treatment. **Person affected by tuberculosis** is used to refer to any person with TB infection or disease or someone who previously had tuberculosis disease, as well as their caregivers and immediate family members. Using person-first language like ‘people’ rather than ‘case’ or ‘suspect’ is a conscious choice made to reduce stigma and to recognize that TB is not someone’s whole identity. In addition, in the TB context, there are specific **underserved populations** that have inequitable access to TB services and must be prioritized. These can consist of subpopulations that are more prone to TB either due to environmental (overcrowding, poor ventilation), biological (immunologically suppressed, poor nutritional status) or behavioral (directly through airborne transmission or indirectly through behavior that increases the risk of non-TB diseases that suppress immunity) risks or because of legal, human rights, gender or other social barriers in accessing public health services.

Underserved populations need to be defined in country contexts but can include prisoners; people living with HIV; migrants, internally displaced people and refugees; people who use drugs; health-care workers; children; people with diabetes; urban poor and people living in slums; the elderly; miners and people with silicosis; and those who work with or live near animals, amongst others (quoted from 'Words Matter' by the Stop TB Partnership). By acknowledging these populations, we aim to support more inclusive, equitable TB responses that leave no one behind.

TB Champions refers to people who have been affected by TB and who choose to use their lived experience to support others, strengthen TB responses, and advocate for change. For more information on TB Champions, see Box 2 and Box 3.

WHO IS A TB CHAMPION?

In general, a TB survivor who has been trained using the standard curriculum, and is committed to contributing towards TB elimination efforts, is considered as a TB Champion. TB Champions draw on their own journeys through illness and recovery to provide peer support, share trusted information, engage communities, and work with health systems to improve access, quality, and dignity of care. Therefore, lived experience is a key defining feature (and source of power) for a TB Champion. In some cases, the term can be used to define other people in the community – who may not have experienced the disease themselves – but who have demonstrated strong commitment to supporting affected communities and raising their voices as part of the response to TB and DR-TB. This could include a wide range of people – celebrities, ambassadors for TB, community health workers, civil society representatives, political figures, funders and investors etc.

TB Champions work in diverse ways and contexts – either individually or through survivor-led networks. Guided by principles of empathy, solidarity, and accountability to TB-affected communities, they have many roles:

- **At the individual level**, by providing peer support, including treatment literacy, to people with TB and DR-TB and their families, facilitating linkages to care and supporting them to cope with any stigma and discrimination they experience
- **At the community level**, by educating people on TB and DR-TB, thereby helping to improve health-seeking behavior as well as understanding of drug-resistance conceptually; by also engaging various community leaders and influencers and mobilizing community resources for a multisectoral response to TB
- **At the system and policy level**, by providing feedback on the quality of care and services through community monitoring and by speaking on behalf of TB-affected communities as part of national working groups and committees, thereby influencing policymaking.

Box 2: Who is a TB champion?



HISTORY OF THE TB CHAMPION MODEL IN INDIA

In 2016, REACH first introduced the TB survivor-Champion model, through the TB Call to Action project supported by the United States Agency for International Development (USAID). A small cohort of approximately 50 TB survivors from four states were trained and engaged through a systematic process. TB survivors were selected in collaboration with the National TB Elimination Programme (NTEP) and trained through three-day workshops. Following the training, they received the title of “TB Champions” and the encouragement to use the moniker when interacting with communities. They also received additional support through ‘Mentorship Programmes’, developing their own personalized workplans.

An analysis of the experiences and results from the first round of the mentorship programme revealed that the majority of trained TB Champions were especially comfortable in providing psychosocial support and found the experience of advocacy particularly challenging. Based on this feedback, a structured work plan with targets was developed for the second round, in which over 180 TB Champions from over 110 districts of six states were enrolled. Over a six-month period, they touched the lives of over 12,000 people with TB and helped make over 150,000 people aware of TB.

By 2019, the role of TB Champions had organically evolved into **five key areas**:

**To provide emotional support
to people with TB**

**To educate local
communities about TB**

To undertake advocacy

**To address stigma and
discrimination**

**To facilitate feedback from
people with TB/service users
to the programme**

Through their efforts, TB Champions identified people with symptoms of TB and referred them for testing; in many cases, they personally accompanied people with facilities to ensure they were tested promptly. They linked people with TB to available benefits, including India's nutritional cash transfer scheme. They were successful in motivating people with TB who had dropped out of treatment to resume taking their medicines. In many instances, they visited people with TB and their families, often working to dispel misconceptions and emphasizing the importance of family support. TB Champions conducted meetings for community groups and audiences that were previously entirely unaware of TB and used local languages and dialects to convey information on TB. The label 'TB Champion' proved to be an especially significant factor, giving TB survivors a new sense of identity and purpose. Today, TB Champions are increasingly recognized as leaders within their communities and have gradually become the go-to persons for all health issues, extending beyond TB; this was most evident during the COVID-19 pandemic.

The impact of this intervention was also reflected in the updated National Strategic Plan for India that identified communities no longer as passive recipients of care but as active and motivated stakeholders in the nation's response to TB. This was echoed in the 2019 Joint Monitoring Mission, that met with TB Champions for the first time and called for a shift from 'passive community engagement to full community participation and ownership, with reliance on TB Champions and TB survivors working alongside programme staff in advocacy, planning, implementation and monitoring of the local, state and national TB response'. The engagement of TB survivors is now established as a clear priority for the TB programme and integral to its mission to eliminate TB in India.

In collaboration with the NTEP, REACH consolidated the training agenda and materials into the 'TB survivor to TB Champion'_curriculum, which was formally adopted by the Ministry of Health and Family Welfare. The curriculum uses principles of participatory learning and adult pedagogy to build the capacity of TB survivors to become powerful advocates.

The first version of this curriculum, published in 2018, drew on the capacity-building workshops and inputs from a working group established by the NTEP. The second version was developed in 2023-24, based on feedback from lead trainers who had used the curriculum as well as inputs from experienced TB Champions who had evolved from participants to co-trainers.

Box 3: History of the TB Champion model in India



STRUCTURE OF THE TOOL

This document is organized into three main sections, supported by a detailed training curriculum and practical annexures. Together, they are designed to guide readers from the *why* of engaging TB Champions, to the *how* of implementing and sustaining this approach in real-world settings.

Section A sets the foundation for the tool. It introduces the rationale for centering TB Champions within efforts to end TB and DR-TB, clarifies key terms, and explains what this tool is and who it is meant for. This section is intended to create a shared understanding of community-led engagement and to situate the TB Champion model within broader national and global TB goals. It provides a summary of who a TB Champion is or can be. It also identifies some key principles in engaging TB-affected communities and TB survivors in particular.

Section B presents the core of the tool: *From Survivor to Champion*: a three-phase process. This section outlines a practical and adaptable framework for working with TB survivors, structured across three phases:

- **Phase 1: Identify and build capacity**, which focuses on criteria and methods for identifying potential TB Champions, clarifying mutual expectations, and laying the groundwork for meaningful engagement.
- **Phase 2: Engage and empower**, which describes how TB Champions can be supported to take on active roles as peer supporters, community educators, advocates, and contributors to empowerment and leadership processes.
- **Phase 3: Sustain**, which addresses the long-term support, recognition, and systems needed to ensure that TB Champion engagement is ethical, effective, and sustainable over time.

Section C contains the TB survivors to Champions Training Curriculum. This section provides a structured, modular curriculum that can be adapted to different country contexts. The five modules cover DR-TB science and the TB response, the care cascade, the roles and responsibilities of TB Champions, approaches to addressing stigma and discrimination, community-led monitoring, self-care, and the development of TB survivor-led networks. Each module is broken down into sessions with clear learning objectives and content that draw on participatory and adult-learning principles.

While the document is presented in a linear format, it is designed to be modular and flexible. Readers do not need to work through every section sequentially. Instead, they are encouraged to engage with the parts of the tool that are most relevant to their current stage of work and context. For example,

- NTPs and organizations that are new to working with TB survivors may find it useful to begin with Section A and Phase 1 of Section B, which focus on building shared understanding, identifying TB survivors, and clarifying expectations.
- Programmes that have already identified and engaged TB survivors can move directly to Section C, the Training Curriculum, to strengthen capacity and skills.
- More established initiatives may choose to focus on Phase 3: Sustain, which addresses longer-term considerations such as support structures, leadership development, and continuity of engagement.

This flexible approach allows the tool to be adapted to different realities – whether it is being used to design a new TB Champion programme, strengthen an existing one, or reflect on how current practices can be improved. Readers are encouraged to revisit sections over time, as their programmes evolve and as TB Champions themselves shape the direction and priorities of the work.

KEY PRINCIPLES OF WORKING WITH TB CHAMPIONS

- Meaningful and respectful involvement of TB-affected communities in efforts to end TB and DR-TB is essential and fundamental, not desirable or optional.
- Responses to TB and DR-TB that do not engage TB Champions are missing an integral aspect; this will eventually impact the experience and quality of care that a person with TB receives.
- TB Champions do not merely need a seat at the table – they also need to be given the space to speak freely and openly, and to be heard.
- Efforts to engage TB Champions must value their lived experience and expertise and not be merely tokenistic. For example, a TB Champion cannot just be invited to share their personal story of how their lives were impacted by TB, without also being allowed to speak about how programmes can do better.
- TB Champions may be engaged by NTPs or civil society organizations, but this must not create a hierarchical relationship or one of obligation. Respecting their independence is important.
- Sometimes, TB Champions may be critical of NTPs or civil society organizations – this is because their first loyalty is to TB-affected communities, and they speak on their behalf.
- TB Champions are inevitably a diverse, heterogeneous group, and must ideally be representative of underserved populations. Efforts to engage survivors should strive for inclusive representation, including gender diversity and participation from underserved communities.
- One-size-fit-all approaches in working with TB Champions should not be adopted; TB Champions inevitably draw on their personal experiences of TB, and this will significantly inform how they see their roles. Any country that adopts the TB Champion model must recognize that this will evolve based on inputs from their own TB Champions. The process of implementing this model will be a dynamic one, and implementers must be responsive to local needs and feedback.

Box 4: Key principles of working with TB Champions



SECTION B

From Survivor to Champion:
A 3-PHASE PROCESS



What a well-trained, empowered and motivated TB Champion can achieve is limitless. There is significant evidence that survivor-led efforts can catalyze responses to TB and DR-TB to become more person-centered, rights-based and community-led. The process by which TB survivors become impactful Champions is described in this section of the tool.

PHASE I : IDENTIFY & BUILD CAPACITY

1.1

IDENTIFY

This sub-section describes the process of identifying TB/DR-TB survivors, including:



Selection considerations and criteria that can be adapted to local contexts



Different methods of identifying survivors



Initial contact to explain the TB Champion model and clarify expectations



1.1.1 Considerations for selecting TB survivors as potential TB Champions

When identifying potential TB Champions, it is important to recognize that TB survivors are a diverse group, with varying interests, capacities, and circumstances. While many countries have large numbers of TB survivors, not all survivors will wish to take on the role of a TB Champion, and that choice must be respected. The following considerations are intended to guide identification processes in a flexible and context-sensitive manner:

-  **Experience of TB or DR-TB:** Priority may be given to people who have completed treatment for DR-TB, as they are able to reflect on the treatment journey and its outcomes. People who have experienced drug-sensitive TB may also be considered, particularly where their insights are relevant to peer support, community education, or stigma reduction. While direct lived experience of TB remains central to the TB Champion model, individuals who have not personally had TB or DR-TB may still play valuable roles within community-led efforts; for example, as community volunteers, mobilizers, or allies working alongside TB Champions.
-  **Age:** Potential TB champions are adults, 18 years of age or greater (unless the specific objective is to identify and engage pediatric TB Champions, for which processes of informed assent and consent would have to be adopted).
-  **Interest and willingness:** Most importantly, they must be interested in becoming a TB Champion. Motivation and personal readiness are key to sustained and meaningful engagement.
-  **Comfort with disclosure:** They are willing and able to openly acknowledge that they are a TB survivor, i.e. someone who had TB in the past. There have been instances where survivors have been unwilling to speak openly about their history of TB but were keen to work as TB Champions. However, conditional consent is always challenging in an operational context, and it may not be feasible to commit to protecting their privacy. Additionally, their personal TB story is the most powerful tool a TB survivor has, and excluding this from the narrative may be difficult. Implementors should discuss this openly and sensitively during the identification process.
-  **Commitment to advocacy:** They are keen to advocate on behalf of TB-affected communities.
-  **Mobility:** They can travel locally (this is desirable, not essential). Too much emphasis on mobility can deter women or other vulnerable groups from participating and can also exclude those with caregiving responsibilities or mobility constraints.
-  **Participation in training workshops:** They are able to participate in the capacity-building workshop. To ensure that women are also able to participate, workshops should be held, as far as possible, at a 'local' or decentralized level, minimizing the distance and time for travel to the workshop.

Time availability: They can commit a certain amount of time to their efforts as a TB Champion. Again, this depends entirely on the role envisaged for TB Champions, and the level of effort required. TB Champions could be engaged in either a full-time capacity, or for a few hours a week, on an incentive-basis, with specific tasks to perform. This is further discussed in the section titled “Engage and Empower”.

Access to a bank account: They have a bank account in which they can receive any honorarium, reimbursements or incentives (again, this is desirable and not essential. Exceptions can be made and payments directed to bank accounts of family members, if they provide that option). Wherever possible, support can also be provided to create bank accounts for TB survivors.

Education considerations: Specifying any minimum educational qualifications or literacy levels for TB Champions has been a tricky, somewhat controversial criteria. If the TB Champion is expected to submit regular reports on the number of people they have reached, the number of people with TB they have supported etc., then basic reading, writing and numeric skills are essential. However, this could exclude a significant number of survivors, who in many ways could be among the most vulnerable, and best suited to represent their own communities. Not requiring TB Champions to report in English and ensuring reporting takes place in languages they are comfortable with is one potential compromise.

Access to a smartphone: Similarly, while it is helpful if a TB Champion has a smart phone to be able to access applications, it is important to not explicitly make this a criteria. In our experience, even if they do not have a smart phone when they first join the programme, they inevitably go on to purchase one, so as to become a part of peer networks on WhatsApp, and once they have received some financial compensation for their efforts.



1.1.2 Methods of identifying TB survivors

There are multiple ways in which potential TB Champions can be identified from among TB survivors. The choice of method depends on various factors including the resources available, the scale of the implementation, whether this is led by a NTP or a civil society organization etc. Countries can ideally choose one or a combination of methods that best suits their specific contexts. Some potential methods that have worked well include:

1

Through local NTP staff, via official processes. In India, this usually starts at the health facility level, with each local TB supervisor identifying potential TB survivors from among those who have recently completed treatment. It is important to note that this approach could potentially exclude those who have sought care in the private sector and could impact the level of independence with which they work as TB Champions.

2

Through civil society and community organizations working on TB, who would likely have access to TB survivors whom they have previously supported

3

Through TB survivor-led networks. This is likely to be the most effective, but obviously only in countries with existing networks.

4

Through highly engaged private healthcare providers, who can recommend TB survivors (with their consent)

5

Through an open call for applications, publicized widely through news media and social media

6

Through word of mouth within local communities. This is usually effective in a hyperlocal setting.

7

Through specific organized or unorganized networks:

- Networks of people living with HIV, many of whom may also be TB survivors
- Through networks focused on key vulnerable populations, for example, the urban poor, the homeless, miners, migrants, former prisoners, sexual and gender minorities.
- Networks focused on co-morbidities like diabetes and lung health

1.1.3 Initial contact to clarify expectations

This is a critical step to ensure participation in the capacity-building workshop and helps provide the potential TB Champion with more detailed information and an opportunity to ask any questions they may have. This is best done through a phone call from the implementing organization or NTP representative to discuss and clarify the following:





1.2

BUILD CAPACITY

The TB survivor to Champion curriculum has been refined over the last decade based on feedback from TB Champions as well as global TB experts. The curriculum is best delivered through a three-day workshop that is held in-person and ideally as a residential experience, subject to availability of resources. The curriculum is provided in its entirety in Section C and consists of five modules as seen in Figure 1.

1.2.1 Learning Goals

The curriculum is structured with an emphasis on participatory learning and a focus on two key areas:



Knowledge-building

Supporting participants to contextualize their personal experiences of TB and DR-TB in the broader local or country context by providing in-depth information about TB and DR-TB as well as the structure of the NTP, key myths and misconceptions etc.



Skills-building

Helping participants develop advocacy and communication skills, specifically focusing on the ability to tell their stories in an impactful manner and building effective partnerships within their communities to leverage local resources for TB.

By the end of the capacity-building workshop, it is expected that participants would have understood:

- **The basic science** of TB and DR-TB, and the key information they must have, as TB Champions
- **The structure and functioning** of the NTP and the broader public health system
- **The TB and DR-TB care cascade** and potential challenges people with TB and DR-TB may face
- **Their potential role** as TB Champions and how they can lead a community-led response to DR-TB

THE TB SURVIVOR TO CHAMPION CURRICULUM

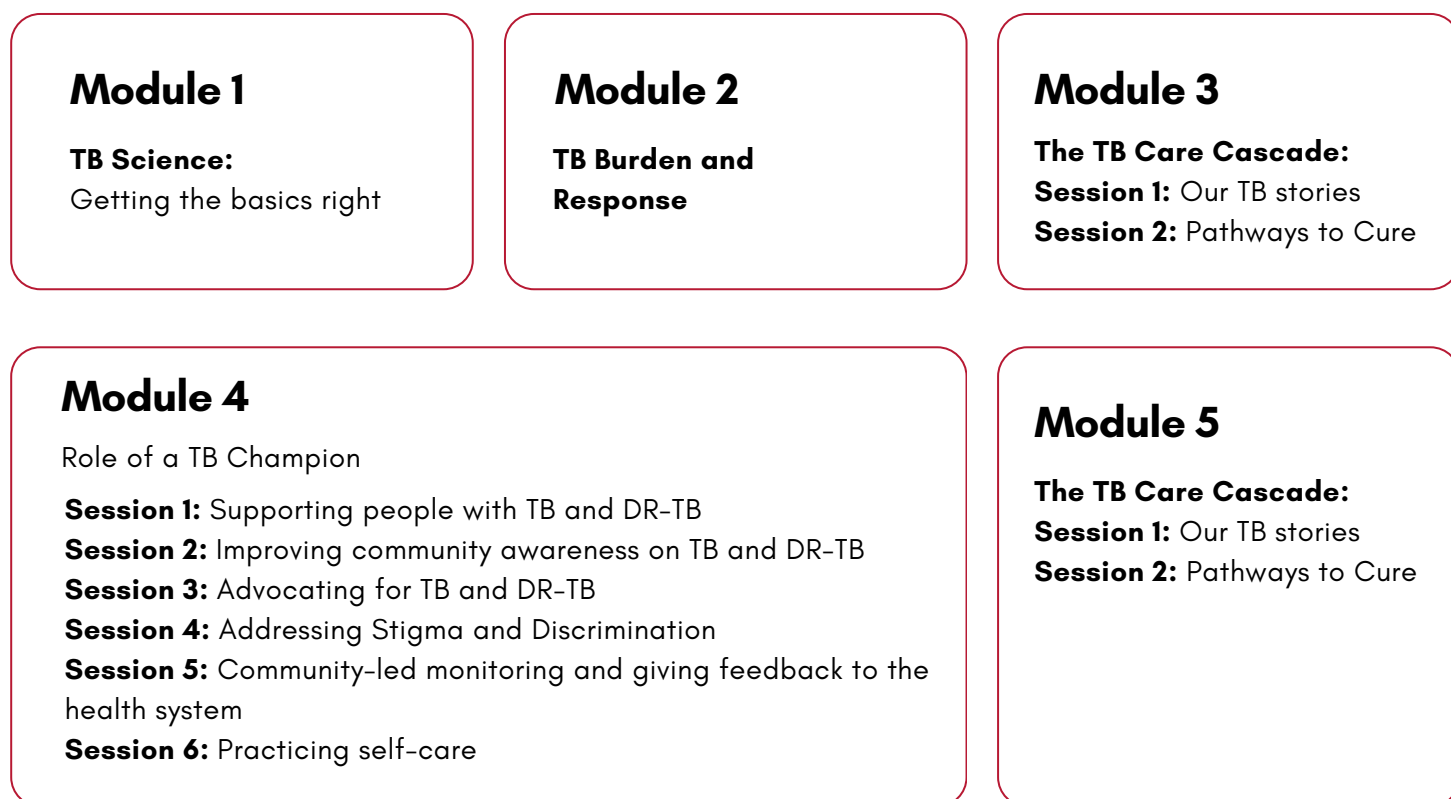


Figure 1: The “TB survivor to Champion curriculum” at a glance

1.2.2 Using and adapting the curriculum:

Some key contextual points to note in implementing the curriculum:

-  The curriculum is divided into five modules, and some modules are further divided into sessions. The total duration of the curriculum is approximately 16–18 hours, although this could potentially be shortened into two full days if resources are limited. A suggested agenda for the workshop is provided in the Annexures.
-  For every module, the objectives of the session and the expected learning outcomes, suggested methods and required materials are outlined. In addition, detailed talking points are provided along with notes for the facilitator. It is expected that the content can be easily adapted to the local context, with relevant data.

PHASE II: ENGAGE AND EMPOWER

2.1

ENGAGE

This sub-section describes what trained TB Champions can do, the different roles and responsibilities they can perform, and what it means to 'engage' a TB Champion. This is the essential next step following the training and capacity-building workshop: capitalizing on the initial enthusiasm and momentum generated from the workshop is important. For practical purposes, the engagement plan can often be introduced at the workshop itself.

WHAT DOES IT MEAN FOR TB CHAMPIONS TO BE 'ENGAGED'?

For the purpose of this tool, the use of the word 'Engage' has two key implications:

1. **Specific role:** TB Champions have a clear sense of specific roles and responsibilities. Ideally, if the engagement is being led by a civil society or community organization for a specific project with a limited duration, it is best to sign a contract or agreement with each TB Champion, clearly outlining the expected work, the financial compensation, and any other terms and conditions. For example, an agreement can state that they are expected to provide peer support 30 people with TB and organize 4 community meetings on DR-TB every month. The agreement should ideally be in their local language. It is good to consult experienced TB Champions in finalizing the role and specific responsibilities. If TB Champions are being engaged by NTPs, an agreement may or may not be feasible. In this case, they should ideally be given all the relevant information during the capacity-building workshop.
2. **Financial Compensation:** Engagement implies that TB Champions are compensated for their time, either through a fixed monthly honorarium or through an activity or results-based incentive model. Information on this is ideally incorporated into contracts that are for a specific time-period.

Box 5: What does it mean to "engage" a TB champion?

TB Champions can be engaged for various purposes and in a variety of activities, depending on the context of a project or the time-bound goals of the contracting organization or the NTP. In general, engagement of TB Champions is geared towards achieving three goals at three levels (Figure 2):

- Providing peer support to affected communities
- Educating communities about TB and DR-TB, and
- Leading advocacy and community-led monitoring (CLM) efforts

IMPACT LEVEL	SPECIFIC ROLE	LINK TO CURRICULUM
 Individual level	Providing Peer Support to people with TB and DR-TB and their families	Module 4, Sessions 1 and 4
 Community level	Educating communities about TB and DR-TB, focusing on KVPs	Module 4, Session 2
 Health system/ policy level	Leading advocacy and community-led monitoring efforts	Module 4, Sessions 3 and 5

Figure 2: Goals for TB champions

Addressing stigma is a cross-cutting aspect of the TB Champion role, and indeed a key aspect of their identity as TB Champions. Stigma mitigation efforts are part of providing peer support, educating communities, and advocacy as well as community-led monitoring.

It is important to note that these three levels are not mutually exclusive, and actions by TB Champions can be at more than one level and have a multifold impact. Ideally, to the extent possible, TB Champions must have the freedom to choose which of these roles most appeals to them. What is common to all roles is the personal experience of TB, the initial identity as a TB survivor, the new identity as a TB Champion and the lived experience that informs all actions. The three goals and levels are described ahead.

2.1.1 Providing Peer Support to people with TB and DR-TB and their families

Broadly, peer support involves the provision of a combination of information and empathy to a person who has been diagnosed with TB. For example, peer support to a person with DR-TB would include:

- | | |
|--|--|
| 1 Demystifying the concept of drug resistance and DR-TB | 5 Supporting any public health actions – completing the diagnostic cascade, particularly LPA testing, contact tracing within families, testing for HIV and diabetes etc. |
| 2 Understanding if they previously had TB, and helping them reflect on what they could possibly have done differently, if at all (important to not cast blame) | 6 Listening to their worries and dispelling their fears (that they may die, that their families will blame them, that they will never work again etc.) |
| 3 Outlining the treatment for DR-TB and what to expect, including potential side effects | 7 Helping to address any stigma within families or at workplaces |
| 4 Explaining all of this to close family members (with the person's consent) and identifying how they can support someone who has DR-TB within the family | 8 Being in constant contact with the person over the treatment duration, until they are cured and can resume 'life after TB'. |

Fundamentally, peer support is also about the social bonds and emotional rapport that a TB Champion is able to establish with a person with TB.

DEFINING PEER SUPPORT DURING ENGAGEMENT

Peer support must be defined in the context of the specific requirements of a programme or project. For example, a TB REACH project supported by the Stop TB Partnership engaged TB Champions to improve pre-treatment loss-to-follow-up among people with DR-TB, specifically focusing on support between diagnosis and treatment initiation. Other projects have engaged TB Champions to improve treatment outcomes among people with DR-TB, which requires constant follow-up over a longer time period. Defining this will provide clarity to the TB Champion and temper any excessive expectations from the health system in terms of the TB Champion's role.

Similarly, again depending on the specific requirement, defining the number of contacts during peer support can be helpful, including from a recording and reporting perspective. This could include a combination of facility-based interactions, home visits (with consent) and telephonic contacts.

Finally, without adopting purely target-driven strategies and risking becoming reductionist, it helps a TB Champion to understand how many people with TB or DR-TB they are expected to support.

Practically, from a project budgeting perspective, this is important to calculate how many TB Champions are required. This can be calculated based on the average caseload in a facility/district; in general, a TB Champion can be expected to support 10-15 new people with TB or DR-TB every month, keeping in mind that the follow-up requirement will increase with every month.



Some useful questions to keep in mind:

- *What are the TB Champion's activities geared towards (define the project outcome)?*
- *Is the TB Champion's role facility-based, or is the primary contact at the home of people with TB? If it is the latter, then mobility is an important criteria in selection of TB Champions?*
- *How many people with TB or DR-TB must the TB Champion support every month?*
- *What are the specific 'services' to be provided? (E.g. treatment literacy, family counselling, contact tracing, support to complete the diagnostic cascade, nutritional counselling etc.)*
- *How does the TB Champion report on their activities (paper-based or digital or a combination)? What is the frequency of reporting?*

Box 6: Defining peer support during engagement

2.1.2 Educating communities about DR-TB

TB Champions can be engaged to improve knowledge and understanding of TB and DR-TB among communities through outreach and sensitisation activities. They can also undertake local community, rights, gender, and stigma (CRGS) assessments, and draw attention to the needs of underserved communities.

One of the biggest advantages that TB Champions have is that they are from the local community themselves. As such, they enjoy greater recognition and have an existing understanding of who the key local community leaders are, how they can be approached and the potential impact their involvement could have for TB-affected communities. Some potential activities TB Champions can undertake at the community-level include:

- Community meetings where they sensitize people about drug-resistant TB, TB symptoms and where to seek care.
- One-to-one outreach to local leaders, including elected representatives, local media, business and industry leaders, health officials, representatives of other departments for multisectoral action etc.
- A local-level CRGS assessment including
 - Mapping of underserved communities in their region, and a needs assessment if required
 - Understanding local gender dynamics and identifying sexual and gender minority groups, if present
 - Assessing the extent of stigma within the community and taking efforts to mitigate any discriminatory practices towards people with TB and their families. This could include organizing anti-stigma campaigns, rallies and other public events specifically focusing on stigma associated with TB

A common thread across all these activities is the TB Champion's consistent use of the most powerful tool at their disposal – their own personal story.



DEFINING COMMUNITY OUTREACH AND EDUCATION

Given the potentially expansive nature of community outreach, clarifying what TB Champions need to achieve within a specific time-period is essential. This could include a combination of one-time activities (e.g. CRGS assessments) and recurring activities (e.g. community meetings). For each of these, quantifying the level of effort is ideal, to the greatest extent possible. For example, they could be asked to ensure they conduct at least one community meeting every week, at different locations. The meetings could prioritize specific communities, based on the CRGS assessments. Similarly, they could line-list key local influencers and prioritize them for action, focusing on one person every month. Developing tangible 'asks' of each person is critical – what does the TB Champion want the local elected leader to do for DR-TB?

While being prescriptive in terms of the quantum of work is desirable, TB Champions must be given the freedom to operationalize the elements themselves – deciding when and where to do meetings, whom to sensitize, whether to adopt formal routes (send a letter) or more informal ones that leverage existing relationships.



Some useful questions to keep in mind:

- *What is the geographical boundary for the TB Champion? Is it a specific kilometer radius around the health facility at which they are based? Or is it based on their place of work or residence?*
- *How many people can the TB Champion potentially sensitize about DR-TB every month, including community meetings and individual outreach activities?*
- *Are there specific vulnerable groups the TB Champion can focus on (if they are a transwoman for example, or someone who works in a particular industry, e.g. mines)?*
- *Will they be paid a monthly honorarium or a fixed amount per activity they conduct?*
- *Are there educational materials on TB and DR-TB that can be given to TB Champions to disseminate during these activities?*
- *From a M&E perspective, how can these activities be verified and validated?*

Box 7: Defining community outreach and education

2.1.3 Leading advocacy and community-led monitoring efforts

TB Champions are uniquely positioned to be powerful advocates on behalf of TB-affected communities, leading advocacy efforts to strengthen the TB response at the community level. This could include advocacy focused on the health system, to improve the quality of TB care and services; media advocacy to increase the frequency of reporting on TB; or advocacy with various key stakeholders, for greater attention to TB or investment in TB. Advocacy can be done by individual TB Champions or as survivor-led networks.

Similarly, TB Champions are best placed to lead community monitoring efforts and gather feedback from service users to inform service providers. They are a powerful bridge between the public health system and TB-affected communities: gathering, collating, analyzing and sharing feedback in constructive, non-confrontation ways. Whenever TB Champions operate through an open, collaborative and problem-solving approach, they contribute to finding and implementing the right solutions for specific challenges.

In general, new TB Champions can be advised to take some time to become comfortable with their role as advocates. Wearing an advocate's hat is something that comes more naturally to experienced TB Champions. Initially, TB Champions tend to be most comfortable with peer support, and sometimes with community outreach. It is therefore important to be realistic about expectations from newly trained TB Champions – they need time to grow in confidence. **Some potential elements of advocacy could include identifying specific needs of the local community** (e.g. social protection schemes are there but being poorly implemented), **developing advocacy strategies and action plans**, and implementing them over a period of time.

Community-led monitoring (CLM) or feedback is also best done by experienced TB Champions, who can use simple tools to measure the quality of care and services being provided at specific health facilities

This feedback can be collected through the ONEIMPACT platform or other locally available alternatives and shared with the health system for action. This requires the use of considerable tact and diplomacy, and TB Champions must be adequately trained to carefully navigate this process, positioning themselves as partners rather than adversaries to the health system (the extent to which partnership can be embodied depends on the specific local context).

DEFINING ADVOCACY AND COMMUNITY-LED MONITORING

In many ways, advocacy is relatively intangible, as well as time-consuming, with potential outcomes that are hard to predict. As such, it is considerably harder to define clear actions for advocacy. However, TB Champions can define their own advocacy goals, and develop an action plan with timelines, to work towards these goals. Quantifying advocacy actions may not be possible.

Community-led monitoring depends on the CLM model that is being adopted in the local setting. TB Champions can be involved to help achieve specific targets; for example, the number of people they encourage to download or use a specific application; or the number of people with DR-TB or DR-TB survivors from whom they gather feedback. The role of TB Champions must extend beyond data collection; they must always be acknowledged as an integral part of solution-finding efforts.

Sometimes, TB Champions, particularly those directly engaged by NTPs, and those who receive financial compensation from NTPs, may be reluctant to be critical of them; creating an enabling environment that empowers TB Champions to speak freely without fear of reprisal is an important aspect.



Some useful questions to keep in mind:

- *What is the specific challenge or gap in an area that requires advocacy?*
- *Are advocacy efforts to be focused towards the public health system, or the private sector, or local leaders?*
- *Is advocacy required at the national or local level, or both (if there are drug stockouts, for example)?*
- *Is advocacy to mitigate stigma required?*
- *How can TB Champions be compensated for advocacy efforts, which are inevitably very laborious and time-intensive?*
- *What is the specific CLM model in place, what is the frequency of feedback required, whom must this feedback be shared with? What is the role of TB Champions in this model?*

Box 8: Defining advocacy and community-led monitoring

In practice, an engagement plan for TB Champions may include elements at all three levels – some peer support and some community education and outreach, as well as advocacy and community monitoring. All TB Champions must be given a workplan that clearly explains what is expected of them. This must ideally be developed with their inputs and in a consultative manner, keeping in mind the requirements of the NTP or a specific project. The workplan must be aligned with reporting formats and payment approvals.



2.2

EMPOWER

The importance of applying an empowerment lens throughout the training and engagement of TB Champions cannot be overstated. Empowerment is central to the very principles of engaging communities, particularly TB survivors, and can significantly influence confidence, independent functioning and evolution into long-term advocates.

In many ways, the goal of engaging TB-affected communities is to have an empowered cadre of powerful advocates who are independent thinkers and can speak on behalf of those most impacted or vulnerable. Empowered TB Champions are better peer supporters, more effective community educators and stronger advocates, and better equipped to contribute towards collective efforts to end TB and DR-TB.

2.2.1 The Empowerment Process

An empowerment-first approach must be at the heart of all actions to identify, train and engage TB Champions. This requires the teams responsible for training TB Champions and subsequently mentoring them, whether from the NTP or a civil society or community organization, to adopt a certain unique mindset that is different from how they would approach programmes or projects normally. An NTP that is keen to have an empowered community as part of the TB response, and a project team that is working towards creating an empowered cadre of community advocates, must be deeply cognizant of the key tenets of empowerment. This includes but is not limited to the following:



Establishing and fostering the unique identity that TB Champions have



Creating the public narrative of who TB Champions are and how they can contribute to the TB response



Encouraging them to speak freely from the first point of contact, and during the first capacity-building workshop



Creating a non-judgmental platform through the capacity-building workshop where they can respectfully agree to disagree with each other or with the facilitators



Being respectful in all communication, written and verbal; and building the capacity of the team to adopt similar behaviors



Making TB Champions feel special and good about themselves by praising them at public forums, and acknowledging their efforts to support their communities



Recording and disseminating the efforts of TB Champions through various multimedia formats



Promoting TB Champions by featuring them in photo essays, short films, podcasts, through the media, on social media platforms etc.



Developing publications focused on TB Champions, their personal narratives and their 'change' stories



Inculcating a sense of freedom and independence among TB Champions by constantly reminding them that their first loyalty must always be with affected communities



Creating and fostering peer networks for a strong sense of community and mutual interdependence

THE 'TB CHAMPION' IDENTITY

Establishing the TB Champion identity is an important step, particularly in countries where this model is being introduced for the first time. The objective of this is to ensure that all key stakeholders – policymakers and bureaucrats, health officials at national, regional and local levels, health care providers and workers, elected representatives and various others – understand who a TB Champion is, that they are TB survivors who are committed to contributing to efforts to end TB. As a result, TB Champions inevitably grow to be proud of their identities, often transitioning from their own feelings of shame and fear as people who had TB to openly sharing their TB experiences. This not only cements their identities within their communities but also helps build relationships of trust.



Some strategies that can be applied to establish this identity include:

- *Developing and consistently using a TB Champion logo and branding across all collaterals*
- *Giving each TB Champion a badge and encouraging them to wear these everyday as part of their work*
- *Creating posters featuring individual TB Champions, their name and contact details (if they are comfortable sharing this information), and getting these displayed at various health facilities*
- *Helping TB Champions create accounts on social media platforms and providing training to help them create content that reinforces their identity*
- *Producing short films as well as publications that feature individual and collective stories of TB Champions*

Box 9: The 'TB Champion' identity



2.2.2 The TB Champion Empowerment Index

What is the TB Champion Empowerment Index?

In the context of empowerment, a relevant tool is the TB Champion Empowerment Index tool which was developed by the Stop TB Partnership and REACH as part of Round 10 of the Challenge Facility for Civil Society. The tool was developed as a response to insights that emerged over the evolution of the TB Champion model in India. By then, it was evident that the engagement of TB Champions has had a two-fold impact on India's TB care landscape:

- The first observed impact was on the TB response, including directly on people with TB (improving their experience and thereby adherence and outcomes and reducing stigma, for example) and on the overall TB programme (improving TB awareness and thereby case finding, for example). This impact is usually clearly measured through projects and at the NTP level.
- In addition, impact was seen on the TB Champions and community itself, in terms of their own personal empowerment. Anecdotally, the impact of the capacity-building efforts and the engagement experiences were visible, and TB Champions spoke frequently of feeling more confident and articulate, not just in the work as TB Champions but personally in all dimensions of their lives. However, there were no standard indicators to measure and track this in a quantitative manner, and this formed the basis for the development of the Empowerment Index.

The Empowerment Index was developed in 2020-21 through an informed and systematic process, which included secondary research, one-to-one interviews and group discussions with TB Champions and stakeholders, development of a data collection tool, piloting of the tool, analysis of responses received and finally, construction of the Index.

How does it work?

The TB Champion Empowerment Index (TBCEI) provides users with a unique opportunity to quantify and measure what has so far been believed to be abstract experiences of individual and shared power. It defines empowerment as an interplay of three interconnected elements: Individual, Social and Systemic. Individual is the self; Social is being part of a family and community; and Systemic is being part of the TB care system.

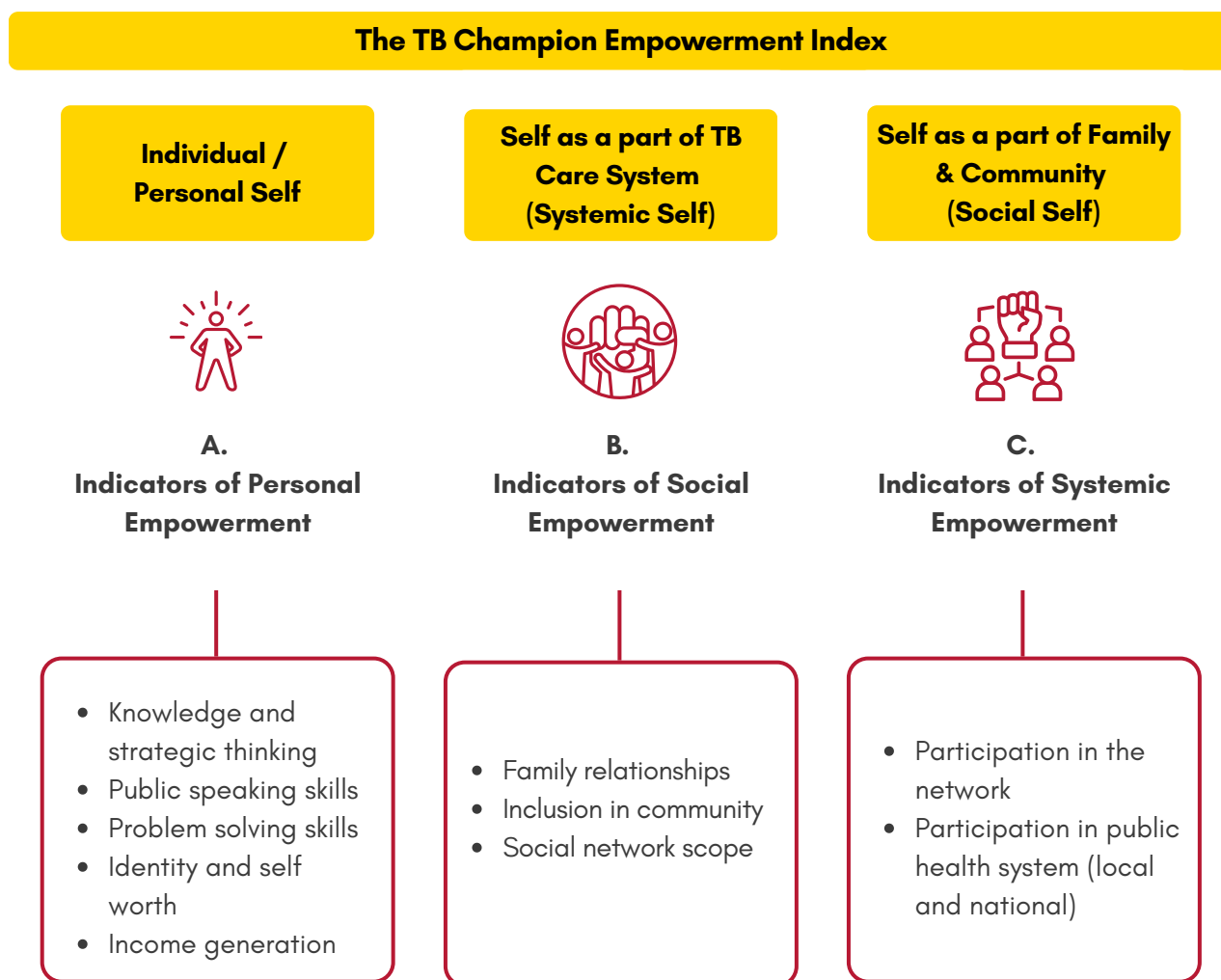


Figure 3: TB Champion empowerment index

Figure 3 above shows the representation of the three interconnected elements – individual, social, and systemic – that sum up the TB Champions’ experience. The TB Champions who participated in the initial discussions perceive themselves as being made of these three interconnected elements and shared anecdotes that pointed to an increased experience of power across all the elements.

The degree of empowerment resulting from their participation in capacity-building and from their work as TB Champions can vary across the three elements. For example, some Champions reported significant increases in their authority as individuals or as members of their community and smaller increases in their power to engage with the system. The TBCEI, therefore, measures empowerment with a set of indicators under three themes:



Theme 1: Personal Empowerment

There are five indicators related to *Personal Empowerment*:

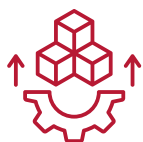
- 1 Knowledge and strategic thinking skills
- 2 Public speaking skills
- 3 Problem solving skills
- 4 Identity and self-worth
- 5 Income generation



Theme 2: Social Empowerment

There are three indicators related to *Social Empowerment*:

- 6 Family relationships
- 7 Inclusion in community
- 8 Social network



Theme 3: Systemic Empowerment

There are two indicators under *Systemic Empowerment*:

- 9 Participation in the survivor-led network
- 10 Participation in public health system

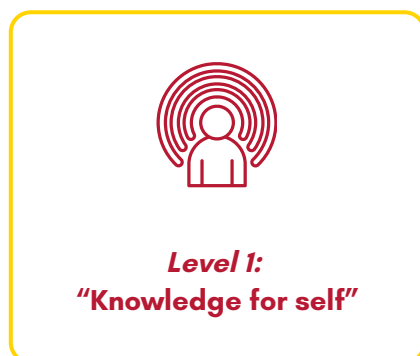


No.	Indicator	Level 1	Level 2	Level 3
THEME 1: PERSONAL EMPOWERMENT				
1	Knowledge and strategic thinking	Understands the science around TB – the disease, diagnosis, and treatment; also understands the structure of the TB programme	Understands what needs to be done when the needs of a person with TB are not being fulfilled; can engage with the public health system	Understands the need to be patient and persistent in engaging with the public health system
2	Public speaking skills	Speaks effectively in network events and with small groups of people with TB and overall community, with some help from other network members	Frequently organises and addresses large community events	Communicates effectively with leaders in the community and the public health system
3	Problem-solving skills	Can respond to most questions from people with TB, sometimes needs help from senior network members	Responds to issues raised by people with TB with minimal help from other TB Champions; escalates via effective channels	Advises and supports other, newer TB Champions in solving their problems
4	Identity and self-worth	Has been able to regain the dignity that was lost when faced with the stigma of having had TB; can now talk about their TB journey without shame	Able to speak about personal TB experiences to increasingly larger groups with confidence; aware that their work is helping people with TB	Experiences a sense of identity and pride in themselves and their work; aware that they are playing an important role in their communities
5	Income generation	Has been able to increase their income to a small extent, which has brought some level of economic independence	Have become eligible for new employment opportunities or increased their income-generation capacity	Their work in TB has resulted in a full-time career that allows them to support their families
Theme 2: SOCIAL EMPOWERMENT				
6	Family relationships	No longer experiencing stigma from family (or reduced stigma)	Family members are accepting of their work as a TB Champion	Family members are supportive of and proud of them and their work as a TB Champion
7	Inclusion in community	No longer experiencing stigma from community (or reduced stigma)	Their community respects them for their work	Their social power has positively impacted their families' standing in the community
8	Social network scope	No longer experiencing isolation because of the connection with other TB survivors	Their network of connections in their community has expanded significantly	Feel confident being part of and supported by a wide social network; think of the network as family
THEME 3: SYSTEMIC EMPOWERMENT				
9	Participation in network activities	Carries out one or more of the following activities – provide peer support and person centred care and/or organise local community awareness generation meetings	Represents networks at meetings with government bodies; takes initiative to add more TB survivors into the network	Actively reaches out to, supports and mentors fellow TB Champions in their work; participates in problem solving for the network; takes initiative for network-related activities
10	Participation in public health system	Can communicate with local public health stakeholders	Recognized and accepted by local public health actors	Seen as a partner by public health partners; invited to key meetings and forums and given opportunities to speak

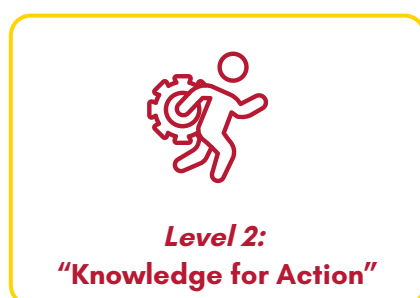
Figure 4: Levels of progress in the TB Champions empowerment index

Levels of Progress

Three ascending levels of progress are defined for each of the ten indicators (Figure 4):



At this level, there is a new but rapidly expanding understanding of the TB Champion's own ability to first, take charge of their own lives (each of them having had experienced varying degrees of loss of control over their lives as a result of having had TB); second, to help other people in the community; and third, to impact the public health system in small but definite ways. Most TB Champions appear to arrive at this awareness of their internal source strength within a few months of beginning the TB Champion role and joining survivor-led networks.



At this level, usually arrived at after a TB Champion has been working for some period of time (can vary from a few months to 2-3 years), there is a high degree of self-confidence in terms of their position in society and their capabilities in each of the three selves (personal, social and systemic); this self-confidence is demonstrated through acts of courage and persistence.



At this level, the key features are independent thinking and awareness of responsibility towards TB-affected communities and others in the network. This responsibility is demonstrated by taking initiative and expressing interest in making the network self-sustaining.

When TB Champions arrive at this level for any indicator, it becomes fairly evident that there is a degree of being self-driven and a clear demonstration of leadership qualities whenever necessary.

Figure 4: Levels of progress in the TB Champions empowerment index

The TB Champion Empowerment Index can be administered at different time points during a programme or project, with the same or different cohorts. The Index can be used by survivor-led networks at multiple time-points and intervals, to discern the needs of members and identify strategies for engagement. Finally, the use of the TB Champion Empowerment Index can generate evidence that could help strengthen the case for enhanced and more strategic investment in TB-affected communities.

For the full tool, please refer to <https://slink.com/EmplIndex>

PHASE III: SUSTAIN

Creating a movement of TB Champions is merely the first step. How is the work sustained for the long term? How does the cadre of advocates continue to grow and evolve? Sustaining this movement over time requires deliberate investment, ongoing adaptation, and a shift from short-term project thinking to long-term ecosystem building. TB Champions are not a static cadre; they evolve, take on new roles, experience periods of fatigue, and may transition in and out of active engagement as their personal and professional lives change. A sustainable approach must therefore be flexible, layered, and responsive to these realities.

This third phase of the process focuses on how countries, programmes, and community organizations can move from *engaging* TB Champions to *retaining, renewing, and institutionalizing* survivor leadership. It is important to recognize that there is no single ‘blueprint for sustainability’; different countries must experiment with various strategies, test a combination of approaches to identify what works best in the medium to long-term, and remain open to course correction over time.

Sustainability is challenging for communities, particularly at a time when funding for global health has been severely compromised and investment in communities continues to dwindle. As the roles and responsibilities of TB Champions continue to evolve and expand, it is imperative that there be continued investment in communities. The investment should not just focus on and stop at capacity-building but should also prioritize lives and careers in the long-term. TB Champions must be compensated fairly for their time and efforts.

3.1 Core Principles for Sustainability

Before outlining specific strategies, a few overarching principles are worth emphasizing:

- **Sustainability is relational, not only financial.** While funding is essential, long-term engagement also depends on trust, respect, recognition, and meaningful roles.
- **Not all TB Champions will remain active forever (and that is both expected and acceptable).** A healthy survivor-led movement allows for entry, exit, rest, and re-engagement without stigma.
- **Leadership must be distributed.** Concentrating responsibility in a small number of highly visible TB Champions increases burnout and fragility.
- **Institutionalization should not dilute independence.** Integration into national systems must preserve the ability of TB Champions to speak critically and represent affected communities

3.2 Strategies for Sustainability

The following strategies have emerged as particularly important for sustaining TB Champion movements:

I. Building master trainers from among TB Champions:

As TB Champion initiatives scale, reliance on a small group of external facilitators or civil society staff can become both costly and limiting. Identifying and nurturing master trainers from within the TB Champion community is therefore a critical sustainability strategy. Some of these trainers might come from civil society or community organizations, or existing survivor-led networks while others may come from the NTP. Potential master trainers are typically TB Champions who:

- Have several years of engagement experience
- Are confident communicators and facilitators
- Are respected within peer networks
- Demonstrate a strong understanding of both technical content and community dynamics

An important additional step after identifying potential trainers from among TB Champions is to build their capacity as master trainers through Training-of-Trainer workshops. This can be done using the existing curriculum and adding elements of a TOT, including practical hands-on sessions where participants get to demonstrate how they would deliver specific sessions. Key elements that were useful inclusions into the master training curriculum are:

- Adaptive leadership and facilitation skills
- Management of group dynamics
- Data analysis and storytelling skills

A roster of available master trainers, shared with the NTP, can help decentralize training, reduce costs, and reinforce survivor leadership as a core feature of the programme.

II. Offering advanced training to further strengthen capacities:

Sustained and reliable capacity cannot be built through a one-off workshop but needs continued learning pathways that allow TB Champions to deepen, diversify and practice skills. The first three-day workshop must be followed by refresher training at regular (every 6–12 month) intervals, to reinforce technical knowledge and share new developments in TB (a new diagnostic tool or regimen, a new policy that has been adopted etc.). In addition, there are several potential areas of advanced training for committed TB Champions:

- Training to enhance advocacy skills
- Communications skilling to strengthen their overall communication skills, thereby helping them become better advocates
- Rights-based training, to equip them with knowledge of legal barriers and provisions
- Data for Action training, to support TB Champions to better understand and use data effectively for advocacy
- Leadership training for network members and leaders
- Training on Communities and underserved populations, Rights, Gender and Stigma
- Training on TB and Disability

Advanced trainings allow experienced Champions to take on more complex roles. As advanced trainings are designed and rolled out, it is also important to recognize that not all of them need or want the same skills – some TB Champions may specialize in peer support, others in advocacy, training, or network leadership. Sustainability improves when TB Champions are supported to grow in directions aligned with their interests and strengths.

III. Creating and sustaining survivor-led networks:

Survivor-led networks are one of the most powerful mechanisms for long-term sustainability. They provide TB Champions with collective identity, mutual support, and a platform for action that extends beyond individual projects. Global experiences have shown that effectiveness as TB champions, as well as safety, confidence, and longevity at least partly depend on being embedded within survivor-led networks. Survivor-led networks are not merely collectives of TB Champions. They are social, political, and organizational structures that allow survivors to move from individual action to collective power. Networks provide:

- A safe space to share experiences of stigma, discrimination, and system failures
- A protective buffer that allows survivors to raise difficult issues without fear of retaliation
- A shared identity that gives legitimacy when engaging with government and other power holders
- A platform for coordination, learning, and scale

These insights, critical for the sustainability of TB Champions' work, emerged from REACH's 2023 deep-dive of the existing survivor-led networks India and are summarized in a document called the "Roadmap for Survivor-led networks". The roadmap distills the purpose of survivor-led networks into two core, interlinked roles:

- **The TB watchdog role:** advocacy for ethical, rights-based, people-centered and gender-responsive care, surfacing system failures (stockouts, diagnostic gaps, delays, disrespectful care), and representing the lived realities of people with TB in decision-making spaces.
- **The peer support and community outreach role:** psychosocial support and counselling, stigma reduction and community awareness and linkages to diagnostics, treatment, nutrition and social protection.

Sustainability depends on protecting both roles. NTPs and other implementing partners can ensure long term survival for survivor-led networks typically via a few "enablers":

- **Building organizational capacity:** Strengthening skills related to planning, financial management, fundraising, and accountability; helping networks establish transparent structures, leadership roles, and decision-making processes.
- **Facilitating connection:** Creating spaces (both in-person and virtual) for TB Champions to come together regularly. Predictable resources for seemingly modest needs (travel costs, meeting logistics, office space) have an outsized impact on sustainability. When these are absent, governing bodies meet less frequently, local chapters weaken and peer learning stalls.

- **Livelihood pathways for members:** For many survivors, continued engagement is inseparable from economic security. Networks sustain participation by linking members to paid public health roles, facilitating livelihood training, and acting as a bridge to longer-term employment.

An important lesson from global experience is that sustainability requires more than one-off training or short-term engagement of TB Champions. It requires investment in community systems, leadership, and accountability over time. The Stop TB Partnership's Challenge Facility for Civil Society offers an important example of this approach.

Across countries, CFCS has supported community and survivor-led action through four pillars:

- Demand creation for TB and DR-TB services and innovations;
- Reduction of stigma and other barriers that limit access to care;
- Community-led monitoring and accountability to improve the quality and responsiveness of services; and
- Integration of community action into broader national and local TB responses for sustainability.

These pillars offer a useful framework for countries seeking to sustain TB Champion efforts beyond individual projects. In practical terms, this means not only continuing to train and engage TB Champions, but also investing in survivor-led networks, enabling regular feedback to health systems, creating platforms for advocacy, and embedding community-led approaches within NTP planning. Investments like CFCS build a foundation on top of which sustainability can be built using NTP-led social contracting, financing and review mechanisms.

Box 10 provides a snapshot into existing survivor led networks which continue to demonstrate that keeping these principles at the core is both essential and feasible.

SURVIVOR-LED NETWORKS

This box briefly describes some examples of country-level survivor-led networks:

1. TBPeople Ukraine

TBPeopleUkraine is a community-led charitable organization working to combat TB and support people affected by the TB in Ukraine. Established in 2018 by a small group of advocates united by the goal of overcoming TB, the organization has grown into a large, impactful community focused on addressing TB in the country. It brought people affected by TB, civil society members, healthcare professionals, and partners together to advocate for TB policies and improved TB services at both national and international levels. The organization works to strengthen the capacity of TB-affected communities, promote innovative and people-entered approaches to TB care, and ensure that the voices of people affected by TB are reflected in health policies and programs..

Through partnerships with government institutions, healthcare providers, and international organizations, TBPeopleUkraine also supports TB awareness programs, access to treatment, and social support services for people undergoing TB treatment. TBPeopleUkraine's mission is to overcome TB and create conditions for effective prevention programs, while working toward the long-term vision of a world free from TB. The organization also prioritizes eliminating stigma and discrimination and strengthening community leadership in the fight against TB.

2. Rekat Indonesia

Rekat Peduli Indonesia is a survivor-led organization dedicated to supporting TB and MDR- TB affected communities across Indonesia. The initiative began in 2010 as an informal forum where people with TB and MDR-TB could share experiences and discuss the side effects of TB treatment. The forum gradually evolved into a structured organization. In 2015 it was formally registered through a decree from the Ministry of Law and Human Rights as the Surabaya Rekat Association, and in 2020 it was renamed as the Rekat Peduli Indonesia Foundation.

Driven largely by survivors, the organization provides peer support to people undergoing TB treatment, helping them understand the therapy process and remain committed until completion. Rekat Peduli Indonesia also raises awareness through community outreach, social media engagement, and initiatives led by local volunteers known as "TB rangers." The foundation's mission is to help reduce the rate of DR-TB in Indonesia and eliminate stigma and discrimination against TB and DR-TB. It also empowers affected individuals through skills training and community education, strengthening both livelihoods and resilience among TB-affected communities.

3. CAD in the DRC

The Club des Amis Damien (CAD) is a TB survivor led network established in 1999 in the Democratic Republic of Congo (DRC). It emerged after the closure of a TB healthcare centre in Kinshasa, when a nurse working with TB patients mobilized survivors and affected individuals to continue supporting patients and strengthen TB care services. CAD was built on the principle that people affected by TB can play a critical role in raising awareness, supporting treatment adherence, and reducing stigma in their communities.

Over time, CAD has expanded its reach from Kinshasa to 13 provinces across the country, mobilizing TB survivors and community members to actively participate in the national TB response. The network focuses on empowering communities, strengthening engagement of people with TB, and promotes collaborations with civil society, healthcare providers, and government stakeholders. Through initiatives such as community consultations, resource mapping, and advocacy platforms, CAD works to address stigma, improve communication among stakeholders, and ensure that the perspectives of TB-affected communities inform policies and programs aimed at ending TB in the DRC.

4. The Network of TB Champions, Kenya

Network of TB Champions Kenya is a community-led movement that unites people affected by tuberculosis (TB) across all 47 counties of Kenya. The network brings together more than 800 members, primarily TB survivors and caregivers, who use their lived experiences to advocate for improved TB services, raise community awareness, and strengthen demand for screening and treatment. Through grassroots engagement, the network works to identify people with TB who might otherwise be missed, promote treatment adherence, and improve treatment outcomes. The organization plays an active role in shaping the national TB response and is recognized by Kenya's National TB Program as the umbrella network representing TB-affected communities.

TB Champions contribute to the development of policies and guidelines, while also strengthening national level engagement through local chapters and leadership structures. The network has achieved significant advocacy milestones, including influencing resource allocation for TB in Meru County and advocating for improved people-centric TB services in Taita Taveta County. In 2020, the network received the prestigious KOCHON Award for its leadership and coordination in global TB advocacy. Supported by the Stop TB Partnership's Challenge Facility for Civil Society, the Network of TB Champions Kenya continues to empower communities, reduce stigma, and ensure that the voices of TB survivors remain central to efforts to end TB in Kenya.

5. Survivors Against TB, India

Survivors Against TB (SATB) is one of India's first national survivor-led networks that has been a consistent and credible voice for people affected by TB. Founded and driven by TB survivors themselves, SATB played a pivotal role in bringing survivor lived experiences to India's TB response, challenging stigma, shaping policy, programs and public narratives through sustained media engagement reaching millions.

Their advocacy with policymakers has brought policy change in access to new diagnostics and drugs, food support, stigma reduction and bringing person-centered gender responsive care and social protection for TB affected people. Most recently, SATB's work has included reports such as "My Care, My Metrics" and "TB and Mental Health: Addressing the Twin Epidemics," frameworks that define quality TB care from the perspective of people affected by TB.

Investments such as the Challenge Facility for Civil Society (CFCS) have helped bolster survivor-led advocacy and the mobilization of TB champions, stigma reduction, demand for new TB and DR-TB tools, and help find missing people with TB, seeking accountability across the TB response. This work reflects SATB's core belief: TB survivors are leaders, advocates, and essential partners in ending TB.

Box 10: Survivor led networks

IV. Investment by NTPs in engaging TB Champions:

In some countries, NTPs may be willing to directly invest in training and engaging TB Champions, through domestic sources. This could take the form of incentive-based models, where TB Champions receive a fixed amount per community meeting they organize, for each person with TB they support etc. Ensuring that payments are made regularly and on time is critical.

Domestic investment by National TB Programmes is a key marker of sustainability. Where feasible, NTPs can integrate TB Champions into routine programme activities through:

- Budget lines for incentives, honoraria, or activity-based payments
- Formal recognition of TB Champions' roles at facility or district levels
- Inclusion of TB Champions in planning, review, and monitoring forums

Payment mechanisms must be predictable, timely, and transparent. Delays or inconsistencies can quickly erode trust and motivation. While incentive models vary by context, fairness and clarity are essential.

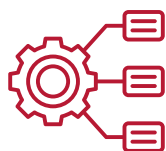
At the same time, it is important that institutional engagement does not compromise independence. Clear role definitions and safeguards help ensure TB Champions can continue to represent community perspectives honestly—even when these are critical of programme performance.

V. Measuring success and demonstrating value:

Sustainability is reinforced when the contribution of TB Champions is visible and valued. Supporting NTPs and partners to track engagement through a defined set of meaningful indicators (Box 11) can help anchor survivor leadership within broader TB strategies. When NTPs include a TB-Champion related indicators in their annual targets or National Strategic Plans, it strengthens the efforts to make the survivor-led movements thrive. Developing a robust M&E framework is an essential element of this process. Some potential metrics are listed below.



KEY INDICATORS



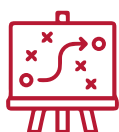
Process Indicators

- Number of TB survivors trained as TB Champions (disaggregated by gender, DS/DR-TB status, age, geography, and key/vulnerable populations)
- Number of TB survivors formally engaged as TB Champions (through written agreements or defined roles)
- Number of capacity-building workshops conducted for TB Champions



Output Indicators

- Number of TB Champions providing peer support
- Number of people with TB receiving peer support (disaggregated by DS/DR-TB status, gender, and age)
- Number of community meetings organized by TB Champions
- Number of people sensitized on TB and DR-TB through community activities
- Number of advocacy actions undertaken by TB Champions and/or survivor-led networks
- Number of survivor-led networks formed or strengthened
- Number of TB survivors enrolled in survivor-led networks
- Number of anti-stigma campaigns conducted
- Number of community-led monitoring activities conducted (including use of tools such as ONEIMPACT)



Outcome Indicators

- Treatment outcomes of people with TB receiving peer support (including DR-TB, where feasible)
- Number of survivor-led networks that are formally registered or legally established
- Changes in community knowledge and attitudes related to TB and DR-TB (e.g., through KAP surveys)
- Changes in levels of stigma and discrimination experienced by people with TB across settings (people diagnosed with TB and DR-TB, families, communities, health facilities) through stigma assessments

Box 11: Indicators to measure success and demonstrate value

VI. Caring for the carers: preventing burnout and attrition

Sustaining TB Champions requires explicit attention to wellbeing. Many TB Champions are repeatedly exposed to stories of illness, loss, and injustice often while navigating our own post-TB realities. Sustainability strategies should therefore include:

- Normalizing pauses and transitions
- Promoting peer support and mentorship
- Embedding self-care practices into trainings and meetings
- Recognizing contributions publicly and privately
- Creating pathways for TB Champions to transition into new roles (trainers, advisors, advocates) when direct community work becomes too demanding

Finally, it's also essential to ensure that TB Champions are recognized members of both community-led platforms and NTP-driven forums (working groups, programme reviews etc.) and have opportunities to share their views.





SECTION C

TB Champions TRAINING CURRICULUM

MODULE 1:

THE **SCIENCE** OF TB AND DR-TB

GETTING THE BASICS RIGHT

OPENING GUIDANCE FOR FACILITATORS



TIME REQUIRED

90 minutes



NUMBER OF SESSIONS

One

Session structure



- Module 1 forms the basis of the training and should be done over **one session**
- The module includes a total of seven sub-sections:
 - ***What is TB?***
 - ***Screening and diagnosing TB and DR-TB***
 - ***Treating TB***
 - ***Drug-resistant TB***
 - ***Who is especially vulnerable to TB?***
 - ***TB prevention***
 - ***Supporting the person with TB, family and community***
- Given that the major focus of this training is drug-resistant TB, the facilitator should spend the largest amount of time on sub-section 4, but sub-sections 1-3 should not be skipped because building an understanding of DR-TB can only be built on top of an understanding of drug-sensitive TB, its diagnosis and treatment.

Objectives of the Session



To explain the science of TB, DR-TB and TB infection to participants



To describe the diagnosis and treatment of TB and DR-TB, and prevention of TB



To emphasise the social and economic dimensions of TB and DR-TB

Expected Learning Outcomes

- Participants have understood **the basics of the science of TB and DR-TB**, including disease spread, its diagnosis, treatment, prevention, social determinants and risk factors.
- Participants have understood **drug-resistance**, how it develops and how it can be diagnosed, treated and prevented.
- Participants have learned to **identify various myths and misconceptions** on TB and DR-TB, as well as the correct facts for each.
- Participants have learned all **the essential information about TB and DR-TB** to share with their communities.

Setting the Context

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

Why should participants learn the basics of TB and DR-TB

- Fundamental to understanding the subsequent sessions and the curriculum as a whole
- Forms the basis for providing treatment literacy and psychosocial support to people with TB and DR-TB
- Forms the basis of undertaking advocacy and providing feedback to the programme

OTHER IMPORTANT PRE-TRAINING GUIDANCE

- The facilitator begins the session by giving a short overview of the topics and the different modalities of the sessions.
- The facilitator should aim to keep a tone of optimism and positivity; TB and DR-TB are preventable, treatable and curable conditions in the present time and it is important that the new cohort of TB Champions begin their journeys with this understanding in mind.
- They divide the participants into small groups and lead them through a short quiz. This will help the facilitator gauge the level of knowledge about TB and pitch subsequent sessions accordingly.
- Each sub-section will have a PowerPoint but will be interspersed with “knowledge questions”. This is important to keep the participants engaged.
- The facilitator must remember that as people who have had TB and/or DR-TB, participants may be familiar with some of the information but not all of it.
- The sub-section on supporting the person with TB/family, in particular, must be crowd-sourced and not merely didactic, given that participants are likely to have experienced several of the social and economic consequences of TB themselves.
- The facilitator can lead participants through a brief exercise in pairs, asking participants to list the support they received/would have liked to receive during their treatment.
- The facilitator can also initiate a small group exercise on role play for contact screening.
- Short films can be shown wherever relevant and possible.

Suggested Methods

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



Materials Required



Presentation with
projection facilities



White board/flip charts
with markers



Small gifts for
quizzes



A4 paper

Session Content



Sub-section 1: What is TB?

- TB is an infectious disease caused by a germ called 'Mycobacterium Tuberculosis'.
- TB mostly affects the lungs (causing pulmonary TB) but can also affect other organs, including bones and joints, kidneys, brain, genitals, urinary tract, spine, lymphatic system, intestines, etc. In other words, it could affect all organs except hair and nails.
- When TB affects any organ other than the lungs, it is called extra-pulmonary TB.
- TB spreads through air. When someone with pulmonary TB coughs, spits or sneezes, droplets of mucous carrying TB germs may be expelled into the air. Anyone who inhales these droplets could get infected with TB .
- When someone inhales the TB bacteria and develops TB infection, the person can be said to have TB Infection (TBI) or be infected with TB.
- TBI is where the person is infected but with no symptoms, the germ only produces an immune reaction and doesn't spread the infection, while active TB Disease is when the germ multiplies in the body, affect body organs like lungs, where a person starts having certain signs like that in Chest X-ray and symptoms like cough/fever, becoming potentially able to spread infection.
- However Active TB can occur without any symptoms. This type of TB is called asymptomatic TB. Asymptomatic TB is usually detected with Chest X-ray followed by rapid molecular test.
- Factors like malnutrition, smoking, lack of ventilation, diabetes, HIV, pregnancy, or any other condition that lower body's immunity can lead to activation of the disease and development of signs and symptoms.
- A person with TB infection can develop TB disease when their immunity is lowered. Approximately 5-10% of those infected with the TB bacteria will develop active TB disease at some point in their lives.
- Smoking is a risk factor as it damages the lungs and also reduces immunity.
- Alcohol use can predispose someone to TB and adversely impact treatment outcomes.
- Anyone who is in close contact with someone who has pulmonary TB is at a greater risk of developing TB infection. Those who have TB infection has the risk of developing TB Disease.
- Children can also get TB. TB in children represents about 10% of the total TB cases (adapt for context).
- TB can affect anyone; however, it disproportionately impacts the poor and is often a vicious cycle, with poverty creating conditions that make people vulnerable to TB, and TB diseases driving families into poverty.
- TB is preventable and curable.



Sub-section 2: Screening and Diagnosing TB

The symptoms of pulmonary or lung TB are:

- Persistent cough for over two weeks
 - Fever
 - Loss of weight
 - Night Sweats
 - Loss of appetite
 - Chest pain
 - Blood in sputum
-
- Some of these symptoms are common to pulmonary and extrapulmonary TB – fever, night sweats, loss of weight and loss of appetite.
 - If someone has had a persistent cough for over two weeks, it is important to consult a doctor and get tested for TB.
 - However pulmonary TB without any symptoms may also occur, now referred to as asymptomatic or subclinical TB. Recent reviews indicate that 30% to 50% of people with active TB could be asymptomatic at the time of detection. This could be even higher in some settings. People with asymptomatic TB do not report typical symptoms like cough, fever, or weight loss, and may or may not progress to symptomatic disease. They may contribute to disease transmission, although the extent of this remains unclear as yet. Countries are revising diagnostic algorithms to include screening for asymptomatic TB.
 - Pulmonary TB is diagnosed through a NAAT/Rapid Molecular Test, or by sputum culture. Chest X-ray is a very sensitive screening test, but not a confirmatory test. Rapid Molecular Tests are the ideal, recommended tests for TB diagnosis. Sputum microscopy is still used in many countries but is not recommended for as a test for TB diagnosis.
 - In the case of extra-pulmonary TB, the person will develop symptoms that are specific to the affected area. For example, in the case of intestinal TB, the person may experience diarrhoea or in the case of TB of a particular joint, the person may experience pain and swelling in that area. Besides this, fever in the evenings, night sweats, loss of appetite and weight loss are also possible.
 - Extra-pulmonary TB is ideally diagnosed by examining the affected organ or site, e.g., lymph node or fluid around the lungs. This is done by means of a biopsy or Fine Needle Aspiration Cytology (FNAC) from the affected site and testing the sample in the laboratory including by NAAT. The specimen must also be sent for mycobacterial culture and drug sensitivity testing whenever possible. When a biopsy is not feasible, e.g. in the case of the spine, the diagnosis is made with a combination of X-rays, CT or MRI scans and clinical examination.
 - TB infection is asymptomatic and is diagnosed by various tests including the Interferon Gamma Release Assays (IGRA), the Mantoux test which is a Tuberculin Skin Test (TST) and the Cy-TB test, to identify individuals with TB infection in their bodies. This is done among high-risk populations including asymptomatic contacts of a person diagnosed with TB. These tests should not be used for diagnosis of TB disease.

- Screening is sometimes done prior to referring an individual for diagnosis. Screening means assessing whether someone is vulnerable to the disease or has TB symptoms and needs to be referred for diagnosis. Chest X-rays are used to screen for pulmonary TB, in addition to verbal screening or asking a person a few questions to see if they have any symptoms.
- In recent years, artificial intelligence (AI)-based chest X-ray screening has been introduced in several countries to improve TB case detection and potentially help identify TB even in people without symptoms, thereby reducing delays in diagnosis.



Sub-section 3: Treating TB

- The average course of treatment for drug-sensitive TB is six months, although shorter regimens are in the pipeline.
- Drug-sensitive TB is treated with a combination of 4 drugs, (Isoniazid, Rifampicin, Ethambutol and Pyrazinamide) with the dosage based on the weight of the person with TB
- 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 TB does not recur and that the bacteria does not become resistant to the anti-TB drugs (and cause a more serious complication, i.e., drug-resistant TB).
- TB can easily be treated on an outpatient basis. Only those with severe or complicated TB or other co-morbidities may require hospitalization for treatment.
- TB treatment is available free of cost at all public health facilities (adapt to context).
- All those with TB should be counselled about the possibility of common side effects or adverse drug reactions. The adverse effects could be minor, requiring reassurance and counselling, or major, requiring a change of drugs and could affect the person with TB for a short period or the entire duration of treatment.
- The adverse effects could include abdominal discomfort, red/orange urine, nausea, vomiting, jaundice, itching, numbness in limbs, joint pain, impaired vision, ringing in ears, dizziness etc.
- A person with TB should seek help from a doctor/care provider if they experience adverse drug reactions and should not take the decision to stop or change the drugs on their own.
- A pregnant woman diagnosed with drug-sensitive TB can start on treatment during pregnancy. If she has been diagnosed with TB shortly before delivery, then the child should also be investigated for TB.

<https://www.who.int/teams/global-programme-on-tuberculosis-and-lung-health/tb-reports/global-tuberculosis-report-2024/featured-topics/asymptomatic-tb>



Sub-section 4: Drug-resistant TB

- Drug-resistant TB (DR-TB) happens when TB bacteria stop responding to key medicines.
- When someone with TB shows resistance to one of the most effective drugs like Isoniazid, the person is said to have Isoniazid-resistant TB.
- When someone with TB develops resistance to two of the most effective drugs used in the treatment (Isoniazid and Rifampicin), with/without resistance to other drugs, the person is said to have multi-drug resistance TB (MDR-TB).
- There are two ways through which people can get DR-TB. One is through the direct transmission of drug-resistant TB from a person with DR-TB to another person. This is called 'primary drug-resistant TB. Another common way that people get DR-TB is when they are on treatment for DS-TB and the treatment is unsuccessful due to various reasons. This is called "acquired or secondary drug-resistant TB"
- Globally, it is estimated that about 70% of the DR-TB cases are primary DR-TB; in other words, less than one-third of the cases are acquired or secondary DR-TB. This means a large majority of people are infected directly with a drug-resistant strain, rather than developing resistance during treatment. This is important to understand to counteract the idea that DR-TB is caused by 'poor treatment adherence' which contributes to blaming affected communities and increases stigma.
- However, this may vary across countries, based on the overall TB epidemiology. This includes understanding the proportion of people with DR-TB who are diagnosed with TB for the first time vis-à-vis those who are considered as 'retreatment', and drug-resistance among these two groups.
- DR-TB spreads like normal TB – by breathing in germs from someone with infectious TB of the lungs. It does not spread through touch, sharing food, or clothes.
- The symptoms of DR-TB are the same as DS-TB but often more severe – a persistent cough, chest pain, fever, loss of appetite and weight.
- Modern molecular tests can quickly show if the TB is resistant to key medicines. Additional lab tests can help decide which drugs will work best for the type of TB a person has.
- DR-TB is diagnosed by testing the sputum samples through Line probe Assay (LPA) or culture and drug sensitivity. LPA is less time consuming (2-3 days) and widely used as compared to culture which takes anywhere from three to six weeks to get results (this involves growing the TB bacteria from the sputum in a laboratory and testing the bacteria's resistance to anti-TB drugs).
- NAAT is now widely used to diagnose TB and DR-TB. NAAT is more sensitive than AFB in diagnosing TB, which means that sometimes people with TB do not test positive on smear microscopy but can be diagnosed via NAAT.
- NAAT also tells us if rifampicin would be effective in a person with TB – i.e. it gives us the rifampicin sensitivity status. This means that those with TB who are resistant to rifampicin are identified at the beginning itself and given the appropriate course of treatment if they have MDR-TB.
- XDR-TB is an advanced stage of MDR-TB in which the bacteria, in addition to being resistant to isoniazid and rifampicin, is also resistant to fluoroquinolones and or Bedaquiline/Linezolid which are crucial drugs for the treatment of MDR-TB. As a result, treatment options for XDR-TB are limited, highly expensive, and have many severe ADRs.

- Once drug resistance is confirmed, the treating doctors choose the safest, most effective all-oral regimen. Starting quickly improves the chances of full recovery from DR-TB.
- Recently, the DR-TB treatment has been simplified to all oral drugs; injections, which were very painful for those on treatment, have been removed from the regimen. This has increased acceptance from people with DR-TB and improved the treatment completion rate. As countries transition completely to all oral regimens, this is expected to further improve.
- The DR-TB regimens currently available are H mono/poly DR-TB regimen (6-9 months), BPaLM regimen (6-9months), Shorter oral MDR/RRTB regimen (9-11 months) and longer oral MDR/RRTB regimen (18-20 months). Most countries are looking to phase out the longer regimens as soon as possible.
- New six-month all-oral regimens using medicines like bedaquiline, pretomanid, linezolid, and moxifloxacin (BPaLM) are now the most preferred ones. They cure faster and are easier to complete.
- Not everyone can take the same regimen. Eligibility depends on test results, age, pregnancy, and other health conditions. Treating doctors are trained to choose the right treatment plan for each person with TB.
- If the new all-oral regimen is not suitable for someone, alternative shorter regimens using other effective medicines are available. These still aim for a similar cure rate.
- Children can also develop DR-TB and are mostly treated with all-oral regimens suited to their weight and age. With proper care, most children recover fully and live healthy lives. We urgently need more research to develop more child-friendly DR-TB formulations.
- Pregnant women can be safely treated for DR-TB with carefully chosen medicines. However, some countries advice medical termination of pregnancy if feasible (adapt for local setting).



Sub-section 5: Who is especially vulnerable to TB and DR-TB?

- TB and DR-TB are opportunistic infections – this means that someone with a weakened immune system is more likely to develop TB and DR-TB than someone with a healthy immune system.
- TB is the most common opportunistic infection in people living with HIV. This means that those with HIV are at ten times increased risk of TB and considered vulnerable to TB on account of their lowered immunity.
- This co-infection also contributes to the increased mortality, with almost a quarter of deaths among people living with HIV due to TB.
- Most National TB Programmes mandate that people with HIV should be regularly screened for TB and those with TB and presumptive TB should be tested for HIV.
- Similarly, the links between TB and diabetes are also strong. People with diabetes have an increased risk of active TB or TB disease (3-4 times higher than people without diabetes).
- There is evidence to show that diabetes worsens TB treatment outcomes, leading to more deaths and poor completion rates.
- For these reasons, it is essential that anyone diagnosed with TB is tested for diabetes regularly and vice-versa.

- For the person affected, managing two co-morbid conditions can be difficult, and support from families and communities is essential.
- Undernutrition and TB are also closely linked. Undernutrition affects a person's immune system and makes them more vulnerable to TB. When undernourished, the body's ability to control the TB infection diminishes, leading to the activation of TB and an increased risk of developing active TB disease.
- Undernutrition worsens the prognosis of TB and DR-TB, as the weakened immune response hampers the ability to fight the active infection effectively.
- Additionally, undernutrition increases the likelihood of TB relapse, posing challenges to successful long-term treatment outcomes.



Sub-section 6: TB Prevention

- A person is said to have TB infection (previously called "latent TB") if they are infected with the TB bacteria but do not have signs of active TB disease and do not feel ill. However, they could possibly develop TB disease at some point in the future. Approximately x% of the population (adapt for context) is estimated to have the TB bacteria, but not everyone falls ill and develops the symptoms or TB disease.
- The risk of developing TB is higher among household contacts of people with TB, PLHIV, those who have diabetes, who are malnourished, and other people with immunocompromised conditions.
- In many countries, TB preventive treatment has been expanded to household contacts of people with pulmonary TB and immunocompromised persons. However, ruling out TB disease is mandatory for all groups before providing TPT.
- For the expanded group, countries may follow either 'treat all' or 'test and treat' models. Testing for TB infection using IGRA/TST and mandatory TPT for those who test positive is recommended. However, TPT should not be deferred in the absence of access to or availability of TBI tests, for household contacts in particular.
- People who are over 5 years of age who are household contacts of people affected by pulmonary TB will be provided TPT after screening for TB infection using Mantoux or IGRA. TPT must not be withheld in the absence of access to testing for TB infection.
- WHO has recommended various regimens for TPT, including 1HP, 3HP, 3HR, 4R, 6H or 9H. These are now available in countries to varying degrees. This is an evolving area and WHO continues to review the emerging evidence.
- For household contacts of people with DR-TB, a 6-month daily levofloxacin (6Lfx) regimen can be used. Alternatively, for contacts of people with DR-TB who are isoniazid-resistant, the 4R regimen can be used.
- In general, TPT is less toxic than Anti TB Treatment (ATT), has fewer ADRs and prevents a person from developing painful symptoms.
- The best way to prevent or reduce TB transmission is through increased awareness of symptoms, early diagnosis and treatment, treatment adherence and cough etiquette.

I. Prevention in Hospital/facility settings:

- In general, health facility premises should have adequate information displayed on infection control measures such as cough etiquette, disposal of sputum and biomedical waste management.
- People with symptoms such as runny nose, cough should be encouraged to use masks in the hospital settings whether or not they are diagnosed with TB. The COVID-19 pandemic has normalized the use of masks in case of respiratory symptoms. Continuation of this practice in the post-pandemic period will greatly reduce the spread of all respiratory illnesses including TB.
- Those with respiratory symptoms must be assisted to meet the care provider in an expedited fashion – this will reduce exposure among other attendees at the health facility.
- The wards or waiting areas should have adequate ventilation.
- DR-TB wards should have certain specifications in order to minimize the spread of DR-TB – for example, the spacing between beds should be at least six feet.

II. Prevention in the community:

- People with lung TB or any respiratory infection should practice respiratory hygiene and cough etiquette.
- There should be no indiscriminate spitting.
- People with TB, especially in the first few weeks after diagnosis, should be encouraged to wear a mask.
- Those with TB should live or work in rooms which are well-ventilated. If ventilation is limited and the family of the person with TB lives in the same room, all of them can be encouraged to wear masks indoors.

III. Contact tracing or investigation:

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

IV. TB Vaccine:

- The BCG (Bacille Calmette Guerin) vaccine: BCG is currently the only vaccine available for TB. This is a weakened strain of TB that causes the body to build immunity against TB. BCG protects young children from severe forms of TB such as meningitis and disseminated TB.
- It does not prevent the development of pulmonary TB in children or in adults. BCG also provides a moderate protective effect against leprosy. 2021 marked a hundred years since the discovery of BCG.
- The TB vaccine pipeline is now showing genuine promise. At present there are multiple newer vaccines at various stages of development and testing, and there are indications that a new vaccine will be available in the next couple of years. Several late-stage candidates – for example, the M72/AS01E, MTBVAC, and mRNA-based platforms – are progressing through

Phase 2 and Phase 3 trials, with early results demonstrating meaningful efficacy in adolescents and adults.

- The 2023 UN High-Level Meeting on TB set an ambitious target for at least one new TB vaccine to be available by 2027, reflecting growing political and scientific momentum. If this milestone is achieved, it would represent a transformative shift in global TB control strategy particularly for high-burden countries where transmission remains difficult to interrupt through treatment alone.



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

- TB affects an individual in multiple ways. The psychosocial and economic impact of DR-TB is even more severe than drug-sensitive TB.
- Apart from the physical symptoms, TB also has an effect on the earning capacity of an individual and people with TB are often unable to work or support their families.
- Those living in poverty are at a greater risk, on account of overcrowded homes, poorly ventilated surroundings or low immunity caused by malnutrition.
- People with TB face considerable stigma from their families, providers and communities and can be isolated or ostracized. TB can destroy relationships and impact livelihoods.
- TB continues to be associated with various age-old myths and misconceptions that worsen the stigma. For instance, many people believe that TB is hereditary – it is not. Some people stand the risk of losing their jobs, their homes and incomes because of stigma.
- TB is a gendered disease and affects men, women and sexual and gender minority (SGM) persons in different ways (see Box 12).
- Those from sexual and gender minority groups experience considerable stigma and discrimination, including among health care providers, inhibiting them from seeking care. There is inadequate information on TB among SGM persons, particularly when excluding the TB-HIV coinfection context.
- People with TB are vulnerable to depression and suicide ideation and require counseling and social support.
- Family and friends also play an important role in this. The treatment for TB generally lasts for 6 months or more. During this period, a person with TB needs the support of family, friends, well-wishers and community members.
- A good support system can help prevent a person from spiraling into depression and giving up the treatment.
- Access to good nutritious food is important during TB treatment and is being provided in many countries through social protection schemes.

GENDER AND TB

Gender shapes who gets TB, how quickly people are diagnosed, the quality of care they receive, and whether they are able to complete treatment. While men globally bear a higher reported burden of TB, women, girls, and gender-diverse people often face distinct and compounding barriers to diagnosis and care – driven by stigma, limited decision-making power, financial dependence, and health systems that do not recognize or respond to their needs. These barriers can result in delayed diagnosis, under-detection (particularly of extrapulmonary TB), and poorer treatment experiences. Gender norms also influence health-seeking behaviors, with men more likely to delay care or disengage due to work, migration, or substance use, contributing to ongoing transmission and preventable morbidity.

These gendered barriers are especially acute in the context of drug-resistant TB (DR-TB), where long, toxic regimens place extraordinary social, economic, and psychological demands on people affected. Evidence shows that loss to follow-up in DR-TB treatment is often higher among men due to migration and employment pressures, while women face heightened risks of stigma, abandonment, and loss of social security when diagnosed. Gender-responsive TB responses – grounded in survivor leadership – are therefore essential to DR-TB control. Engaging TB Champions and survivor-led networks helps surface hidden barriers, support treatment adherence, challenge harmful norms, and ensure that DR-TB services are designed around the lived realities of those most affected.

Source: Stop TB Partnership 2021 Paper: “Gender and TB”

Box 12: Gender and TB

FACILITATOR NOTES FOR WRAPPING UP THE SESSION

I. Summarizing the session

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

II. Connecting the dots

- Connect the basics of TB and DR-TB to some aspects of the NTP structure – where are labs, how are results recorded and communicated, what is the diagnostic algorithm etc.
- Emphasize the TB Champion's role in improving treatment literacy and how a lot of this information would need to be conveyed to people with TB at various points in time.



MODULE 2:

THE TB BURDEN AND THE RESPONSE



TIME REQUIRED

90 minutes



NUMBER OF SESSIONS

Two (approximately 45 minutes each)

Session 1: Understanding the TB burden

Session 2: Understanding the NTP and the role of the private sector

OPENING GUIDANCE FOR FACILITATORS

About this module



- This module is intended to help participants understand the burden of TB and DR-TB in their respective country as well as the current TB response. Through the sessions in this module, participants will:
- Learn about the TB and DR-TB burden in their country and in their region, if relevant
- Understand the basic epidemiological profile of TB and its relevance to their role as TB Champions
- Understand the structure and functioning of the NTP at various levels
- Learn about the role and relevance of other key actors in the TB response, including the private healthcare sector.

SESSION 1:

UNDERSTANDING THE BURDEN OF TB AND DR-TB

Session structure



The first session of module 2 includes 4 sub-sections:

- TB and DR-TB burden
- Treatment outcomes
- Disease trends
- Challenges

The facilitator is advised to spend the majority of the time on the DR-TB burden; the burden of disease for DS-TB can briefly mentioned and used as a reference and comparison point.

Objectives of the Session



To provide basic information about the TB burden, its distribution, mortality and morbidity, outcomes, and trends over the years.



To help participants understand the challenges their country faces in responding to TB.

Expected Learning Outcomes

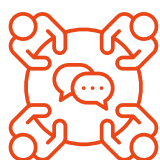
- Participants have understood the extent and magnitude of the TB burden and its epidemiology
- Participants have begun to understand some of the many challenges their country faces in eliminating TB

Suggested methods

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



Materials Required



Presentation and discussion



Use of infographics, graphs, charts, diagrams etc. in slides



Crowd-sourcing responses wherever possible to ensure an interactive session



Adequate time for questions & clarifications

Why learn about the burden of TB?

- To understand how many people are being affected every year and the number of deaths due to TB
- To understand the regional burden specific to a state or district

Session Content

(Note: content is not provided for this module, as it would be specific to each country setting. Instead, guidance is provided on the content that should ideally be covered in this module. Partners may also refer to any landscape analysis they have done of TB/DR-TB for their respective countries.)

Setting the context

- This session has a lot of technical information and technical jargon. The facilitator must simplify and explain all terms, as many times as required, and must try not to overwhelm the participants with complicated terminology.
- This session may bring up some grim data on morbidity and mortality related to TB and DR-TB. As mentioned previously, it is important to stress that there have been recent developments (better diagnostics and better treatment regimens) which give us reasons to be hopeful). The new cohorts of TB champions can play a role in changing the shape of TB and DR-TB burden in their countries.

OTHER PRE-TRAINING NOTES FOR FACILITATOR

- The facilitator begins the session by explaining terms such as burden, incidence, mortality etc., as simply as possible.
- The facilitator then moves on to explain the TB burden and DR-TB in the country. The main objective here is to convey the scale and magnitude of the problem without creating a sense of alarm and defeat.
- In the second sub-section, the facilitator explains the meaning of treatment outcomes, and why this matters.
- In the third sub-section, the facilitator introduces the participants to trends and explains why tracking trends in diseases is important. The facilitator also explains some key concepts like notification, if relevant in their context.
- In the final sub-section, the facilitator asks the participants to name some challenges the country could be facing. This part of the session must be crowd-sourced so as to be more interactive.
- The facilitator can agree, disagree, clarify and explain the challenges as and when they are named.
- At the end of each sub-section, the facilitator must share state or region specific data and information, based on the training setting.



Sub-section 1: TB and DR-TB burden

- *Explain who can be affected by TB and DR-TB, i.e. anyone*
- *How many people are diagnosed with TB every year, globally?*
- *How many of these people are in your country? What is the % of burden? Does your country have a high burden of TB?*
- *What is the global burden of DR-TB, and what is the burden in your country?*
- *What is the global TB mortality rate, and what is it in your country? How many people die every day of TB?*
- *What is the global DR-TB mortality rate, and what is it in your country? How many people die every day of DR-TB?*
- *Subnational or local regions with high TB incidence, if required or relevant?*



Sub-section 2: Treatment outcomes

- TB is a fully curable disease, if diagnosed and treated properly. Treatment outcomes for DR-TB were suboptimal in the past but with the rollout of new regimens, outcomes are much better
- *What are treatment success rates among people with TB?*

- What are treatment outcomes for people with DR-TB on various regimens?
- Subnational or local regions with poor outcomes, if required or relevant



Sub-section 3: Disease trends over the years

- Why are trends important? They help us understand if our efforts are improving the TB and DR-TB situation in the country.
- What do trends reveal about your country?
- What is notification? This means the number of TB cases reported to the public health system.
- What is TB and DR-TB mortality in your country? How has it been changing over the past 5 years?
- Compare notification with prevalence and explain the concept of missing people.



Sub-section 4: Challenges

- Identify the top five challenges related to TB and DR-TB response in your country (can also be crowd-sourced).

FACILITATOR NOTES FOR WRAPPING UP THE SESSION

I. Summarizing the session

- The facilitator ends the session by asking the group if they have understood the concepts introduced in the session.
- The facilitator must emphasize that newer drugs and shorter, all-oral regimens have transformed treatment experiences for many people, reducing duration, side effects, and disruption to daily life.
- The facilitator asks participants to name the top two takeaway messages from the session. Here it may be valuable to encourage participants to voice a sense of anticipation around the new diagnostics and new treatment regimens. For example, the facilitator may ask – “what makes you feel hopeful about the future of TB and DR-TB response in your area?”
- The facilitator urges the participants to focus on understanding their local context – i.e. the burden and profile of TB in their respective areas where they plan to work.

II. Connecting the dots

- The burden of the disease is closely linked to the nature of the disease – airborne transmission, long incubation period, absence of an effective vaccine etc.
- The large burden necessitates the involvement of community and TB Champions to support the programme in eliminating the disease.

SESSION 2:

UNDERSTANDING THE NTP

Note: This session is best led and delivered by a NTP representative, with inputs from a trained TB Champion/master trainer.

OPENING GUIDANCE FOR FACILITATORS

Session structure



This second session of module 2 includes five sub-sections:

- The National Strategic Plan
- The country's healthcare structure
- NTP structure
- Social protection and linkages
- People seeking care in the private sector

As before, the facilitator is advised to continue the focus on DR-TB and highlight the relevant sections of the NSP and healthcare structure where DR-TB is a recognized priority.

Objectives of the Session



To introduce the participants to the fundamental tenets of the country's National Strategic Plan (NSP).



To familiarize the participants with the basic structure of NTP from national level to sub-district level.



To familiarize the participants with the basic structure of the public health system as a whole



To introduce the participants to the need for social support schemes for TB and DR-TB



To provide participants with an overview of the role of the private health care sector and private providers in the TB and DR-TB response

Expected Learning Outcomes

Participants are familiar with the commitments and strategy of their country's NTP.

Participants have understood the hierarchical structure and functioning of the NTP and the health systems at various levels.

Participants are aware of the appropriate NTP facilities and officials that they will have to engage with, while doing their advocacy work or providing support to those affected by TB and DR-TB.

Participants have understood the need for links to social schemes for people with TB and DR-TB and are equipped to identify schemes relevant to their locations.

Participants recognize that irrespective of where someone seeks diagnosis or treatment for TB or DR-TB (i.e. public or private sector), they are entitled to the highest quality care possible.

Participants are equipped to provide any necessary guidance to people with TB and DR-TB who are accessing services from the private sector.

Suggested methods

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

Materials Required



Presentation with projection facilities



White board/flip charts with markers

Why understand about the NTP

- To understand who are usually involved in providing services to people with TB and DR-TB at the health facility level
- To understand whom TB Champions are likely to interact with, during their work
- To guide people with TB and DR-TB to approach the right cadre of health staff and access the required services at the appropriate facility

Setting the context

- The facilitator begins the session by reminding participants that they were introduced to the extent of the TB and DR-TB burden in the previous session.
- The facilitator reminds the participants that their country provides access to free diagnosis and treatment for TB and DR-TB through a vast public health system. Understanding the healthcare system as it relates to the management of TB and DR-TB is very important for the TB Champions.
- The facilitator asks participants to name the different cadres of healthcare workers and providers they are aware of and have interacted with during the course of their illness. This can be converted into a visual activity, where participants can fill in names of different providers to construct a tree or a similar visual representation.
- The facilitator asks the participants to share, briefly, any experiences they may have had with the private sector.
- The facilitator explains that every individual has the right to seek the provider of their choice, in either the public or private sector. However, irrespective of where they go, they should have access to the highest quality of diagnosis and treatment for TB and DR-TB.

Conveying the key information/messages

- The facilitator briefly explains the basic tenets of the NSP to participants and gives examples of how policies affect them at the district or sub-district level.
- The facilitator moves on to explaining the structure of the NTP at various levels, ensuring that they crowd-source what the participants already know at different points through the session.
- The facilitator can use a white board or flip charts to draw the structure, as they explain it, in addition to the diagram on the PPT.
- Once the facilitator is confident that participants have understood the structure, they can move on to explaining the need for social protection schemes for those affected by TB.
- The facilitator reminds participants that it is assumed that a majority of those not yet diagnosed are seeking care in the private sector or remain undiagnosed in the community.
- The facilitator explains that, at the core of private sector engagement is ensuring that those seeking care in the private sector have access to all or as many of the benefits in the public sector as possible, including diagnostics, treatment, and other services.

Session Content



Sub-section 1: National Strategic Plan

- Describe the key points of your country's NSP, goals and targets



Sub-section 2: Country's healthcare structure

- Explain the health care system of your country briefly.
- Clarify if the NTP is a vertical or horizontal programme and how it works with the broader public health system.



Sub-section 3: NTP structure

- Describe the structure of the NTP
- How is policy made?
- Where are diagnostic and treatment services available?
- Who are the key actors at each level?
- In this section, the facilitator may introduce the Global Drug Facility. The Global Drug Facility (GDF), managed by the Stop TB Partnership, serves as a critical procurement mechanism for ensuring access to quality-assured tuberculosis (TB) and drug-resistant TB (DR-TB) diagnostic and treatment tools. By consolidating global demand and negotiating with pre-qualified manufacturers, GDF enables countries (particularly those in low and middle-income settings) to procure DS-TB and DR-TB medicines (including the new DR-TB regimens), rapid molecular diagnostics at significantly reduced costs. Its stringent quality assurance standards ensure that the medicines and diagnostics reaching patients meet international safety and efficacy benchmarks. For national TB programmes and implementing partners, GDF offers not just procurement support but also technical assistance, supply planning, and forecasting guidance making it an indispensable partner in closing gaps in TB commodity access.
- The facilitator may consider providing a [*GDF catalogue link*](#) to the participants if they are likely to work closely with NTP procurement teams.



Sub-section 4: Social protection and linkages

- Although TB services are free of cost in most countries, there are often some indirect costs that the person has to incur – payments for ancillary drugs, additional diagnostic tests as well as considerable non-medical costs such as expenditure for transport and accommodation.
- This is compounded by reduced incomes due to lower productivity or loss of wages. People with DR-TB need additional social protection due to the greater severity of their symptoms which may contribute to larger income losses.
- There will also be intangible costs due to stigma associated with the disease.
- For those seeking services in government health facilities, diagnostic tests are available free of cost. For those seeking treatment from the private sector, reimbursements to private labs or providers can be made (adapt for context).
- Treatment for TB and DR-TB is often free under the public sector, and many countries have provisions to provide free drugs to all those seeking care in the private sector through pharmacists or private providers. In order to increase treatment adherence and eliminate catastrophic expenditures for people with TB and DR-TB, there are government social schemes available.
- Explain the various schemes that are available in your country



Sub-section 5: People seeking care in the private sector (if relevant)

- About x% of the population seek care in private hospitals and clinics (adapt for context).
- Describe the private sector in your country
- Explain that people seeking care in the private sector incur significant out-of-pocket expenditure, and that quality of care varies.
- Diagnosis and treatment in the private sector can tend to be expensive, and this is especially true for diagnosis and treatment for DR-TB.
- Explain the role of pharmacies, laboratories and other key private sector stakeholders.

FACILITATOR NOTES FOR WRAPPING UP THE SESSION

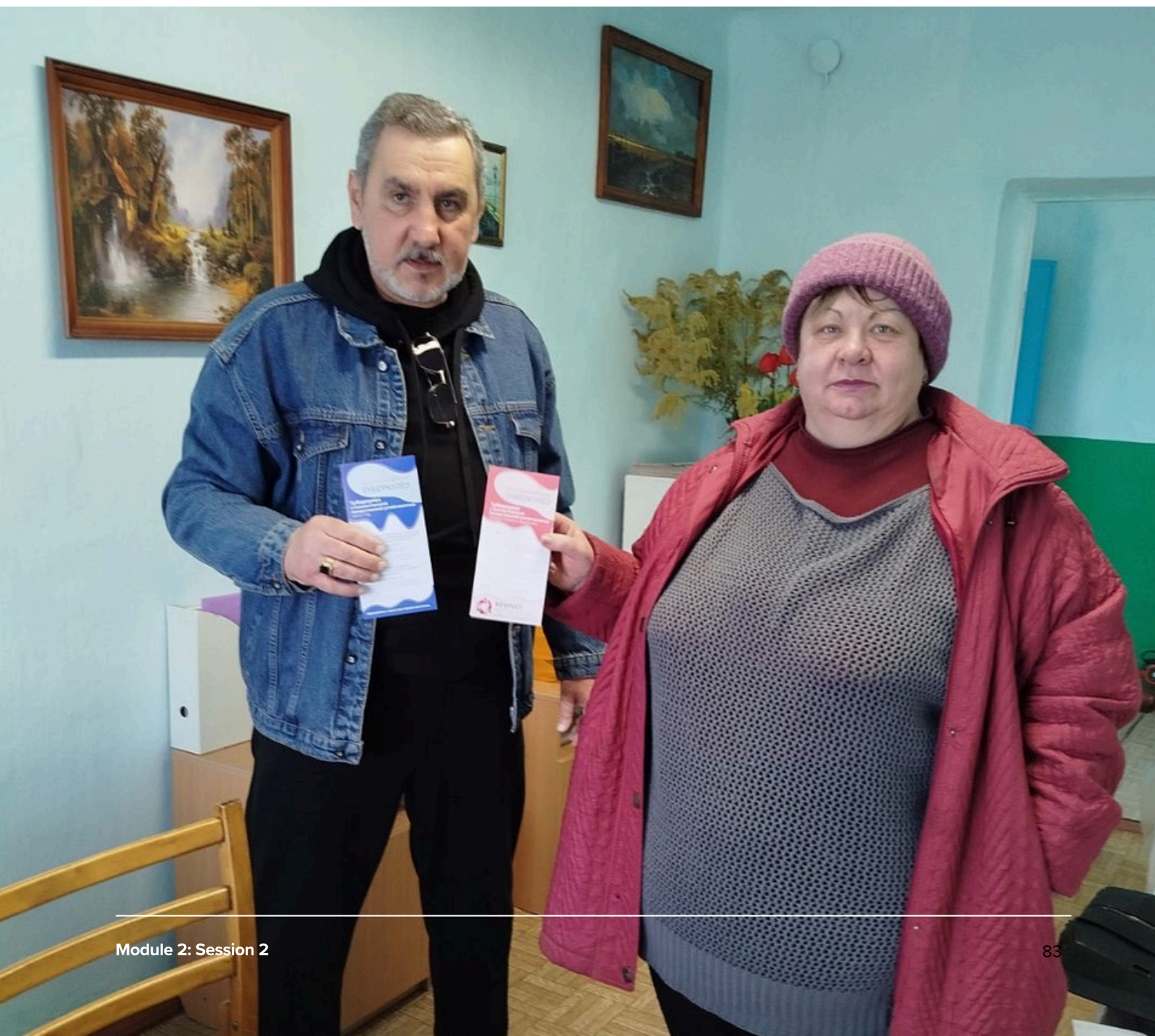
1. Summarizing the session

- The facilitator asks participants to take a sheet of paper and draw the NTP structure of the city/town/district/region where they live, along with names of the key NTP cadres they will find at the facilities.

- The facilitator reminds participants of the need to introduce themselves to key NTP staff, and to work closely with them in their capacity as TB Champions.
- The facilitator tells participants that this relationship is key to achieving their goals as TB Champions.
- The facilitator urges participants to find out more about the schemes relevant to their country or region. Based on this, they could advocate for new schemes and simultaneously work to ensure that those affected by TB and DR-TB are aware of the existing schemes and how best to access them.
- The facilitator ends the session by asking participants to name the top two takeaway messages from the session.
- The facilitator ends the session by asking participants to identify some key private providers that they may be interested in engaging with, in their respective areas.

Connecting the dots

- The facilitator must emphasize that understanding the structure and different personnel in NTP is critical to understanding the role of a TB Champion.



MODULE 3:

THE TB CARE CASCADE



TIME REQUIRED

3 hours



NUMBER OF SESSIONS

Two

- **Session 1: Our TB Stories (90 minutes)**
- **Session 2: Pathways to Cure (90 minutes)**

About this module



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

- Share their personal experiences of TB and DR-TB and its impact on their lives
- Work together to understand and identify potential barriers along the care cascade for those affected by TB and DR-TB
- Begin translating these barriers into opportunities for advocacy, community sensitisation or peer support

The sessions in this module are ideally facilitated by experienced TB Champions themselves and preferably DR-TB survivors.

I.

SESSION 1: *OUR TB STORIES*

OPENING GUIDANCE FOR FACILITATORS

Session structure



- The first session of module 3 consists of one section, to be facilitated over 90 minutes.
- If possible, the facilitator is advised to bring in a significant number of participants who are DR-TB survivors and encourage them to share their stories.

Objectives of the Session



To encourage participants to share their TB stories by creating a safe, conducive environment.



To build solidarity among participants based on their common identity as TB survivors.



To help participants understand the power and potential impact of their stories.

Expected Learning Outcomes

Participants have begun to share their personal stories with each other.

Participants have had an opportunity to hear how TB and DR-TB has affected the lives of others.

Participants have understood the many dimensions of how TB and DR-TB impacts people.

Why share stories?



- The very process of articulating their TB stories aloud is a new and empowering experience – most participants have rarely shared stories with friends or families.
- Listening to each other's stories builds a collective understanding of the challenges faced by people with TB and DR-TB.

Materials Required



Drinking Water



A calm environment with as little disturbance as possible – phones on silent



Seating arrangement in a circle. It could be on the floor, on chairs etc. This seating is important to create the right setting for this activity

Suggested methods



The participants sit in a circle, either in chairs or on the floor on mats.

Participants take it in turns to share personal stories of how TB and DR-TB impacted their lives.

Some participants may also share how they, and their families, responded to TB.

Setting the context

- The facilitator introduces the session and its objectives and invites participants to join in.
- This session is ideally facilitated by a TB Champion, who begins the session by sharing their story.
- The facilitator may consider opening with a brief “grounding exercise” which helps participants arrive fully in the space before sharing difficult stories of navigating their TB and DR-TB experiences. The exercise can establish psychological safety by reminding participants that they have choice and control over how much they share. Beginning this way reduces anxiety, lowers emotional intensity, and creates a respectful listening environment. The exercise is described in detail in Annexure 2.
- It is recommended to keep adequate time – once the participants start sharing it is not recommended to interrupt or stop them midway. The assumption for 90 minutes is that approximately 20 participants will share their stories and speak for 3–4 minutes each.
- The facilitator ensures that there is no disturbance and only the participants and facilitator/s are present for the session. The facilitator makes it very clear that this is a voluntary exercise and not everyone needs to share their stories. There should be no pressure on the participants to share. A non-judgmental environment is created, and participants must be assured of confidentiality.

OTHER PRE-TRAINING NOTES FOR THE FACILITATOR

- The facilitator introduces the session and its objectives and invites participants to join in.
- This session is likely to be an emotional experience and requires the facilitator to be extremely sensitive and gently guide the flow.
- Participants can also be given some time to write down their thoughts on a piece of paper. This may be particularly helpful for those who are nervous about public speaking.
- Stories are powerful and used in the right manner can become excellent advocacy tools.
- Where appropriate, invite TB Champions to share positive lived experiences of recovery, improved care, or changes they have witnessed (while remaining honest and respectful of ongoing challenges).

Session Content

- There is no specific prescribed content for this session.
- This is a session that gives space to people who survived TB or DR-TB to share their stories freely without instruction or coaching. In the context of these conditions, where the human side of the disease is often unknown, this space provides a unique opportunity for people to talk openly and without restriction about their very personal experiences.
- An affirmative and positive outcome of this session should be the sense of empathy, solidarity, cohesion, and unity among the group, which could bring about many positive outcomes.
- Usually for many in the group, it ends up being the first time they can openly share their experiences and to hear how TB and DR-TB has affected the lives of others.

FACILITATOR NOTES FOR WRAPPING UP THE SESSION

I. Summarizing the session

- The facilitator closes the session at the appropriate moment, thanking the participants for their sharing.
- To close the session appropriately, the facilitator can use the exercise described in Annexure 3. This exercise helps participants emotionally “contain” what was shared, rather than leaving the session feeling raw or overwhelmed. It gently brings attention back to the present moment and supports nervous system regulation after storytelling. Ending with intentional closure helps participants transition back to daily life feeling steadier and respected. Strong emotions are not a failure of the session. But leaving people emotionally “open” without closure can be harmful. Always allow time to close the space, even if it means shortening time for discussion.

II. Connecting the dots

- This session transitions to the next session where participants will identify challenges at different stages along the TB and DR-TB care cascade.
- Note down challenges related to diagnosis, stigma, treatment adherence etc. as experienced by the TB Champions and recall them at different points throughout the rest of the training to help participants connect better with the concepts that are introduced.
- Observe how participants are connecting/interacting with each other and build on this connection while introducing them to the concept of networks.



SESSION 2:

PATHWAYS TO CURE

OPENING GUIDANCE FOR FACILITATORS

Session structure



- The second session of module 3 consists of one section, to be done over 90 minutes. The 90 minutes can be distributed as follows:
- 15 minutes: Introduction (including dividing into groups and explaining stages)
- 45 minutes: Group work
- 30 minutes: Reporting back, sharing and discussion
- The facilitator is advised to continue to focus on DR-TB and highlight the ways in which the care cascade differs (and is more challenging) in DR-TB as compared to DS-TB.

Objectives of the Session



To strengthen participants' understanding of the TB and DR-TB care cascade.



To support participants to draw on their personal experiences of TB and DR-TB to identify potential challenges through the care cascade.



To work as a group to understand that these are challenges faced by many people with TB, men, women and gender and sexual minorities.

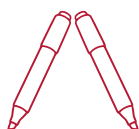
Expected Learning Outcomes

- Participants have understood the TB Care Cascade and its stages.
- Participants have identified the barriers they personally experienced at every stage.
- Participants have learnt about the barriers that others experienced at different stages and have understood that some barriers are specific to different genders.
- Participants have begun to understand the commonalities and differences in their TB experiences.

Materials Required



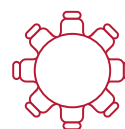
Chart papers, minimum 10, colorful ones are preferred



Markers/
sketch pens



Post it
notes



Tables for
group work

Why look at challenges along the care cascade

- The care cascade exercise helps participants look at all possible challenges that may arise along the pathway in a structured manner.
- Anticipating the challenges that a person with TB and DR-TB may face is a critical aspect of providing peer support.
- Understanding gendered barriers will help TB Champions to provide gender-responsive support to people with TB.

Setting the context

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

OTHER PRE-TRAINING NOTES FOR THE FACILITATOR

- The facilitator can give examples but preferably does not guide the participants.
 - For example, participants could have questions about when one stage ends and another begins.
 - Or participants could ask which stage to include stigma at, considering it's a cross-cutting barrier.
 - The facilitator should ask participants to reflect on how people with DR-TB will experience the case cascade differently, and if any steps are expected to be particularly challenging
- The facilitator should encourage groups to select a leader at the beginning, who will be responsible for reporting back.
- The facilitator should keep a close watch on any particularly silent groups and provide them with any additional guidance if necessary.
- The facilitator should encourage the groups to think of any gender-specific barriers along the care cascade by highlighting a few examples.
- The facilitator should remind participants to ask themselves a simple question, drawing on their own personal experiences with the health system – ‘at every stage, what change would you like to see?’

Suggested methods



This session is intended to facilitate group work. **Participants can be divided into four groups of ideally 5-7 each.** Each group is assigned a stage and given a chart paper with the name of the stage written on it. Working together, and with inputs from the facilitators, each group identifies barriers and challenges for the stage they have been assigned.

Participants are encouraged to think about how society has different expectations from people of varying genders and how they think this will influence the barriers along the care cascade. For example, a male person with TB may find it difficult to get a diagnosis because he prioritizes work and earning and does not find an opportunity to get himself tested. A woman with TB may be sent to her mother's place when she is diagnosed with TB. Each group reports back to the larger group. Participants are free to give inputs to the other stages as well.

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

Session Content

"Pathways to Cure" is a group exercise that enables participants to identify the challenges and barriers in health and community settings that impacted their own pathway to cure. Encouraged to draw on their personal stories (from the previous session), participants are stimulated to think about their TB and DR-TB experience in a more structured way, using the framework of the TB care cascade to identify problems that impacted or could have more seriously impacted their lives. The barriers or challenges can be identified in **four stages** which may be defined on colourful chart papers that are displayed along a long wall or on tables. The table below is an example of some barriers participants could identify, from the individual or community perspective as well as the health system perspective. **The four stages are:**



Developing symptoms

- Poor understanding of TB and lack of information
- Lack of support from family
- Superstitious or religious beliefs around TB
- Self-medication
- Poor health seeking – health not a priority
- Fear of stigma
- Financial restrictions in seeking care



Getting a diagnosis

- Tendency to seek care in private facility
- Inability to bring out sputum
- Having to return to the facility more than once for diagnosis
- Restrictions at work for availing leave repeatedly / losing wages
- Financial restrictions
- Inadequate trust in government facilities
- Need for multiple visits to the health facility
- Need to be accompanied to health facilities for diagnosis in case of women and the elderly



Initiation and completion of treatment

- Lack of counselling
- Fear of adverse effects
- Poor care and support in case of adverse effects
- Difficulty in swallowing pills
- Poor nutritional status and inability to afford nutritious food
- Difficulty in managing comorbidities – such as Diabetes / HIV / Other chronic illnesses / smoking / alcohol problem
- Loss of employment
- Migration during treatment
- Discontinuation of treatment once symptoms disappear
- Stigma especially against young girls and women

Figure 5: Pathways to care



Getting cured and getting back on track

- Residual symptoms even after treatment due to lung damage
- Disability – in the case of brain / spinal TB
- Inability to maintain optimal nutritional status thereby incurring risk of recurrence
- Poverty due to out-of-pocket expenditure
- Lack of support groups
- Continued unemployment
- Poor guidance / adherence to follow-up tests

Together, the participants can analyze and group the challenges faced in both health and community settings. Too often, discussions on TB focus on the individual and system-related challenges in isolation and in doing so, ignores the whole experience and overall needs of people with TB.

By examining each stage of the TB care pathway in a structured way, participants are able not only to identify where people encounter difficulties, but also to surface practical opportunities for intervention, support, and change. This holistic analysis should reframe TB (and DR-TB in particular) not as an inevitable or overwhelming condition, but as one that can be addressed through timely diagnosis, people-centered care, community support, and responsive health systems. In doing so, the exercise reinforces a central message of this curriculum: that with the right tools, partnerships, and survivor leadership, the challenges of DR-TB can be mitigated, and cure, dignity, and life beyond TB are achievable.

FACILITATOR NOTES FOR WRAPPING UP THE SESSION

I. Summarizing the session

- Once the participants have completed their discussions, the facilitator should invite them to share with the larger group. The facilitator should encourage discussion of gender-specific barriers during the presentation by groups.
- Alternatively, the full group could walk around the room, examining and discussing the different chart papers.
- While discussing pathways to care, intentionally balance challenges with progress. Acknowledge real barriers but avoid leaving participants with a sense of inevitability or despair.
- Remind participants that DR-TB is increasingly treatable, and outcomes today are significantly better than even a decade ago.
- The facilitator ends the session by thanking the participants for introspecting on their TB experiences and suggests that each of these barriers could be potential opportunities for intervention. This will be discussed in subsequent sessions.

II. Connecting the dots

- The facilitator could hint at the role of a TB Champion by noting that addressing these barriers is essential along with the provision of diagnostic and treatment services. And in addressing these barriers lies the major role of TB Champions.
- The facilitator can talk about how some barriers like stigma that are crosscutting cannot always be addressed by individual TB Champions and how a group of TB Champions (i.e. networks) may have a greater impact.



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MODULE 4:

ROLE OF A TB CHAMPION



TIME REQUIRED

7 hours



NUMBER OF SESSIONS

Six

- **Session 1: Supporting people with TB and DR-TB (120 mins)**
- **Session 2: Improving community awareness on TB and DR-TB (60 mins)**
- **Session 3: Advocating for TB (120 mins)**
- **Session 4: Addressing Stigma and Discrimination (30 mins)**
- **Session 5: Community-led monitoring and giving feedback to the health system (60 mins)**
- **Session 6: Practicing self-care (30 mins)**

About this module



TB survivors and Champions are an integral component of the TB response and can play a critical role in several key areas. This module introduces participants to the specific role that TB Champions can play and begins to build their understanding and skills in these areas. By the end of the module, participants will have a clear understanding of their roles and responsibilities and will have begun to understand how they can begin/continue their work as TB Champions.

I.

SESSION 1:

SUPPORTING PEOPLE WITH TB AND DR-TB

Total Time required: 120 mins

OPENING GUIDANCE FOR FACILITATORS

Session structure



- The first session of module 4 consists of five sub-sections which should be completed over 2 hours. The five sessions are as follows:
 - Why psycho-social support matters
 - What TB Champions can do?
 - Key aspects of person-centered peer support
 - Skills TB Champions need
 - Interpersonal communication
- As before, the facilitator is advised to continue the focus on DR-TB and highlight the different (and greater) support requirements of people with DR-TB. Facilitators should also emphasize that recovery from DR-TB is possible, and that many TB Champions present in the room are living examples of resilience, strength and hope.

Objectives of the Session



To help participants understand how peer support can be effective in helping people with TB and DR-TB



To empower participants to use best practices when providing support to people with TB and DR-TB while reinforcing messages of recovery, dignity, and possibility



To ensure participants know when to refer people with TB and DR-TB to doctors or other providers for further assistance

Expected Learning Outcomes

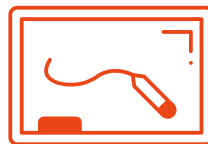
- Participants would be able to articulate the major psychological and social issues faced by people affected by TB and DR-TB, their family, and friends.
- Participants would have understood active listening and the usage of simple interpersonal communication skills to address psychosocial issues. They will have learned how to imbibe a sense of hope grounded in knowledge and understanding. Participants will clearly understand their role and limitations in providing this support to people with TB and DR-TB.

Suggested methods



- Presentation
- Discussion
- Role Play

Materials Required



- Presentation + projection
- White board/flipcharts

Why learn about supporting people with TB

- Most TB Champions feel that supporting people with TB is a very gratifying experience and is often what comes most naturally to them. “No one else should suffer like I did” – is what a majority of TB Champions articulate as their motivation for doing the work they do. This motivation is often even stronger among DR-TB survivors, who have experienced longer, more difficult treatment journeys.
- For people on DR-TB treatment, hearing from someone who has completed treatment can be a powerful source of reassurance and motivation.
- The knowledge to be shared with people with TB should be structured and scientific, and not ad hoc. Clear, accurate information is especially important in DR-TB, where misinformation can increase fear and treatment discontinuation.

Setting the context

- The facilitator will begin the session by reminding participants that supporting people with TB is at the core of a TB Champion’s role. They should explicitly acknowledge that this support may need to be sustained over many months in the case of DR-TB.
- The facilitator will define some key terms such as “psychosocial health” and “peer support”.
- The facilitator will ask the participants to give responses to this question: “*Why is a TB Champion best placed to provide psychosocial support?*”. All the responses should be written on a board or flip charts.

OTHER PRE-TRAINING NOTES FOR FACILITATOR

- The facilitator leads the participants through a discussion on how a TB Champion can provide support to people with TB, DR-TB and their families.
- The facilitator will also clarify what the TB Champion cannot and should not do. For example, the TB Champion is not a substitute for a doctor or a trained counsellor to treat depression or other mental health issues.
- The facilitator can include many small activities in this session, including:
 - Write all the points in the table above (what TB Champions can/cannot do) and have the participants place them under the correct heads.
 - Call out judgement-loaded statements and ask participants to restate them to be neutral questions. For e.g.: 'you should not have gone from one doctor to another, wasting your time and delaying your diagnosis'. This is an example of a judgement-loaded statement.
- The facilitator introduces the participants to the importance of good interpersonal communication as part of peer support.
- The facilitator then conducts the activity described above and ensures that all participants have time to do this role-play exercise.
- The facilitator should ideally refer to the barriers or challenges identified during the 'Your Story' and 'Cough to Cure' sessions.

Session Content



Sub-section 1: Why psycho-social support matters for people with TB

- TB is a disease that affects both the physical and emotional health of an individual. A person may be on treatment for TB but not necessarily receive emotional or psycho-social support. TB Champions can fill this important gap. This gap is often wider for people with DR-TB, who may experience prolonged isolation, side effects, and uncertainty about recovery.
- *Psycho-social health* is the mental, emotional, social, and spiritual dimensions of what it means to be healthy. Psychosocial health is the result of complex interaction between a person's own psychology and how they perceive and interact with others.²
- If a person is psychosocially healthy, they are better equipped to deal with the problems associated with TB, more likely to successfully complete treatment, and more likely to have better health outcomes. This is particularly critical in DR-TB.
- TB Champions, in their capacity as survivors, are peers and can provide valuable support to those with TB and their families. Peer support is the process of giving and receiving encouragement and assistance to achieve long-term recovery. Peers offer emotional support, share knowledge, teach skills, provide practical assistance, and connect people with resources, opportunities, communities of support, and other people.³

² Donatelle, R. J., & Davis, L. G. (2011). *Health: the basics*. Benjamin Cummings.

³ Mead, S. *Defining Peer Support*. (2003). Retrieved from <http://www.mentalhealthpeers.com/pdfs/DefiningPeerSupport.pdf>

- A TB Champion can use their lived experience of recovery from TB (and DR-TB), as well as skills learned in formal training, to provide support to promote adherence, mind-body recovery, and resilience to deal with the disease.
- By sharing lived experience and accurate information, TB Champions help in demystifying DR-TB, replacing fear and blame with clarity, reassurance, and realistic hope.



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

- They can provide compassionate listening, and a positive vision of the future. Additionally, they can work with individuals in problem solving and developing achievable action plans. For people with DR-TB, this includes acknowledging hardship while reinforcing that recovery is possible, and treatment outcomes are now far better than they were in the past.
-
- Peer support can take many forms: one-on-one in person, in a group, over the phone, via WhatsApp or online.
- The relationship between a TB Champion and a person with TB is usually built on trust – the latter seeks to learn from and emulate the former’s successful recovery from TB. This modelling of recovery is especially powerful when the TB Champion is someone who has completed DR-TB treatment.
- They can play an important role in supporting people to self-manage their illness and working towards whole health goals. TB Champions are uniquely qualified to assist others in connecting with their communities, strengthening supportive relationships, accessing formal and informal resources, and working with cultural humility to support people across a wide range of people.
- A TB Champion’s interactions with people with TB are rarely one-off and usually⁴ last for several months, with multiple interactions. When the person with TB is feeling better, and is nearing the end of the treatment, the TB Champion can encourage them to also become a TB Champion themselves and join the survivor-led network.



⁴ Hendry, P., Hill, T., Rosenthal, H. *Peer Services Toolkit: A Guide to Advancing and Implementing Peer-run Behavioral Health Services*. ACMHA: The College for Behavioral Health Leadership and Optum, 2014.

What a TB Champion Is/Does	Is Not/Does Not
A person who has been treated for TB/DR-TB or was affected by TB/DR-TB (for example, a close family member of someone who was affected by TB or died due to TB)	A medical professional (with the exception of situations where the TB survivor may themselves be a medical professional or healthcare worker)
Shares lived experience	Gives professional advice
A role model	An authority figure
Sees the person as a whole in the context of the individual's roles, family, community	Sees the person as a case or diagnosis
Motivates through hope and inspiration	Motivates through fear of negative consequences
Teaches how to acquire needed resources	Gives resources and money to the person
Uses language based on common experiences	Uses clinical language
Helps the person find professional services from doctors, psychologists, lawyers	Provides professional services
Helps to set personal goals	Mandates tasks and behavior



Sub-section 3: Key aspects of person-centered peer support

TB Champions can provide peer support to people with TB that addresses their emotional needs and provides them with the critical information they need to complete treatment successfully. Some aspects are listed below. However, it is essential that the TB Champion customizes the peer support based on the individual's needs. It is also important to note that peer support is not counseling (particularly for those people with TB who may require professional mental health support), and TB Champions are not necessarily trained counsellors.

Some key aspects of peer support that the TB Champion can provide include:

- Treatment literacy or providing information on what to expect during treatment – the pill burden and medications, the duration of treatment, how and when medicines should be taken and the follow up tests and visits required. For DR-TB, this should include preparing people for longer durations and possible changes in regimens.

- Vulnerability assessment or understanding the risk of not completing treatment owing to various challenges. Once identified, these challenges (clinical or social) can proactively be addressed.
- Providing gender-responsive psychosocial support to ensure adherence to treatment (i.e. support that takes into account any gender-specific needs the person with TB may have).
- Explaining the disease to families, and speaking to family members on how best to support a person on treatment.
- Educating the family, including the person with TB, on contact screening and TB preventive treatment for all household contacts.
- Offering information about potential side effects or adverse drug reactions and encouraging people to seek medical care if required while reassuring them that side effects can often be managed with timely support.
- Giving information on the importance of nutrition and any modifications to diet and lifestyle that may help during treatment.
- Ensuring families are screened for TB and offered TB preventive therapy as required.
- Screening for mental health illnesses (depression, anxiety) and linkages to mental health services.
- Facilitating linkages to appropriate medical services for comorbidities such as diabetes or HIV and follow-up.
- Assisting in linkages to appropriate services if required (smoking cessation, deaddiction programmes etc.)
- Providing support and follow-up in case of discontinuation of treatment with a non-judgmental approach that focuses on re-engagement rather than blame.
- Giving information on cough etiquette and safe disposal of sputum.
- Providing information on any existing social protection schemes.

Note on gender-sensitive support and family support:

All of us have experienced gender disparities in various settings. As discussed in the 'pathways to cure' exercise, there are some gender-specific barriers to cure at every stage along the care cascade. These barriers should be borne in mind while providing support to people with TB. For example, men may migrate more frequently in search of work. Women may have inequitable access to nutrition. Transwomen may experience stigma or not have any support from families. TB Champions can try to identify any gender-specific needs people with TB may have and try to address them.



Sub-section 4: Skills TB Champions need to provide peer support

- **Being judgement-free:** The most important attribute of a good peer supporter is not questioning or criticizing someone who is facing the significant challenges posed by a TB diagnosis, whether for themselves or a loved one. Everyone's problems and processing of an illness is different. It is important to avoid judgmental statements, as well as judgmental questions and tones.

- **Active listening** builds trust and rapport. An active listener will use open-ended questions, reflect feelings, and provide affirmations while avoiding communication roadblocks.
 - The facilitator can give closed or judgement-loaded questions and participants will need to restate them to be active listening questions.
- **Positivity:** It is important to provide empathy but never criticize someone or their family or friends. TB Champions can use questions and their own stories to help guide them to positive solutions. Positivity does not mean minimizing difficulty; it means holding space for struggle while keeping sight of recovery.
- **Storytelling:** Through stories, peer supporters can reveal their vulnerabilities and strengths and reinforce their peer identity. In the process of sharing their lived experiences, peer supporters can model positive behaviors without being proscriptive, which can stimulate problem-solving and motivate peers in their own self-care. The only caveat is to balance storytelling against oversharing; that is, watching for peer supporters with strong personalities that may dominate conversations with their own stories.⁵
 - A peer supporter should ideally have the following qualities and be:
 - Non-judgmental
 - Calm and friendly
 - An effective communicator and active listener
 - Able to document their work well
 - Adapt to different situations
 - Accountable
 - Willing to share their TB experience to help others
 - Willing to contribute to society at large

DO

- Share your TB experience
- Provide the right messages on TB
- Support the public health care system in providing TB care services.
- Refer people with TB to the doctor in case they have technical queries
- Engage with people with TB and help them feel motivated
- Support people with TB to make the right choices
- Communicate TB messages after assessing the level of understanding of each person with TB
- Maintain a professional relationship

DONT

- Share too much personal information about yourself if you are not comfortable doing so
- Give incorrect TB messages
- Make people with TB feel stigmatized
- Speak negatively of the health staff from the public system
- Impose your decision or feel bad that they do not follow your advice
- Make TB information complicated by using jargon
- Take any money from people with TB for services
- Engage with people with TB for any business ventures

⁵

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



Sub-section 5: Interpersonal communication for effective peer support

- Understanding how to communicate during interpersonal interactions is central to providing effective peer support to people with TB.
- Interpersonal communication is the direct exchange of information, views or experiences between two people or in a small group.
- Listening is a vital part of interpersonal communication (Figure 6). Equally important is ensuring that the other person is aware that they are being heard and therefore encouraged to share more information.
- Recall the qualities of a good peer supporter, many of which are aspects of interpersonal communication:
 - Respecting people's time
 - Accepting people as they are without identifying flaws
 - Remaining patient and respectful during conversations
 - Giving correct information always.
 - Motivating people to speak freely and ask questions

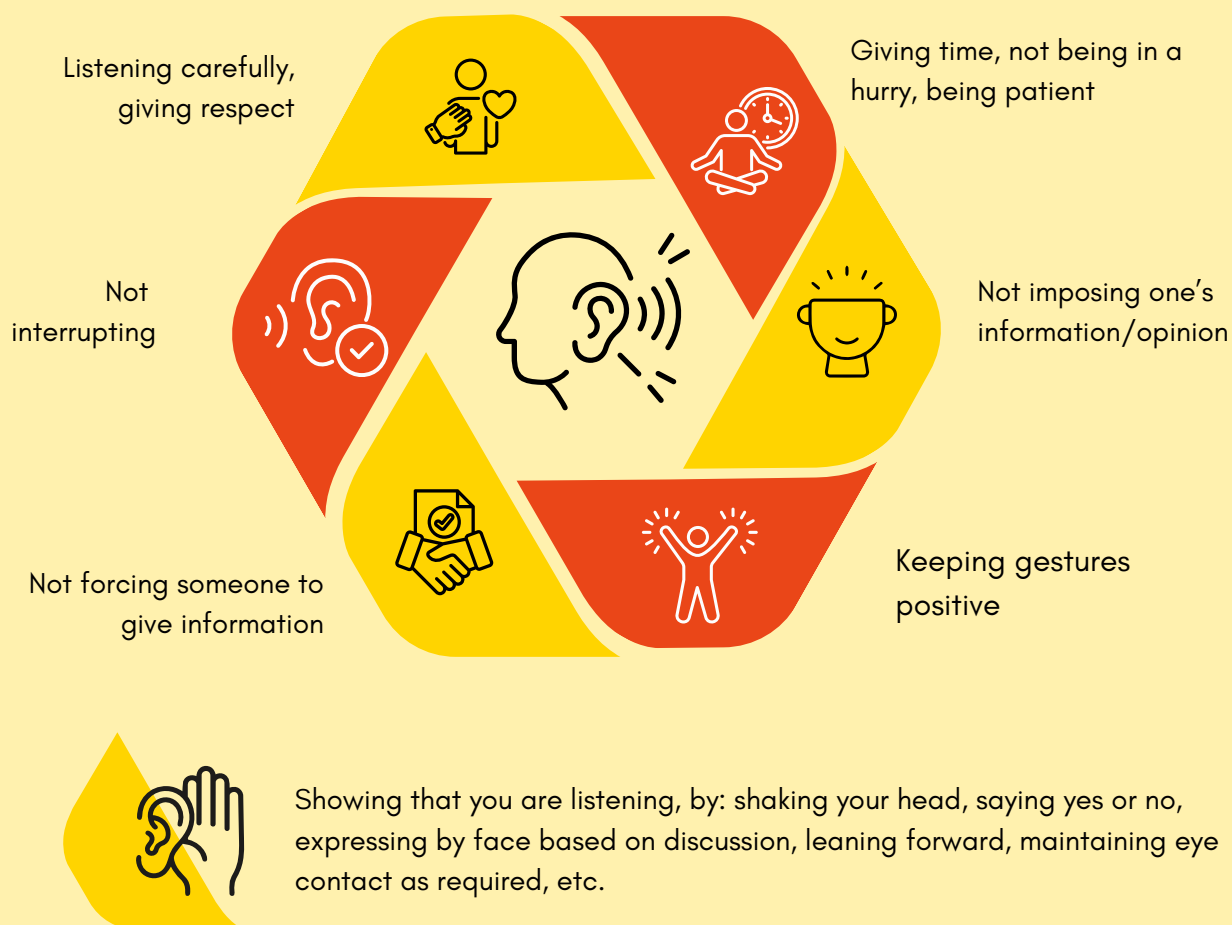


Figure 6: How to listen well

GROUP ACTIVITY

- The facilitator will call on two volunteers who will role-play a first interaction between a TB Champion and a person on treatment (3–5 minutes). This can be acted out over the phone or in face to face. Encourage each participant to identify two or three things they found challenging and use those for discussion.
- After the roleplay, the facilitator will lead a brief discussion on the conversation and what they did well and could improve upon. Although some criticism can be levied, try to keep the feedback mostly positive.
- Have all participants pair off and act out a first interaction, with each person adopting the role of a person with TB and a TB Champion once.
- After the paired exercise, ask the group what they found challenging and what they thought a good peer supporter would require. Have the group brainstorm solutions to difficult situations that were shared.

FACILITATOR NOTES FOR WRAPPING UP THE SESSION

I. Summarizing the session

- The facilitator leads participants through a joint analysis of the role play, what they found challenging and what worked for them.
- The facilitator concludes the module with a review of the key terminology and asks participants to name their top two takeaways from the session.
- The facilitator encourages participants to practice the skills needed to be effective peer supporters.
- They remind participants that even small acts of consistent support and frequent reminders of positive treatment outcomes can make a significant difference in DR-TB treatment journeys.

II. Connecting the dots

- Supporting people with TB requires that the TB Champions have the right knowledge on TB.
- Encourage participants to have a second look at the 'Pathways to cure' charts to see they can identify any other ways to support people with TB.
- While providing support to people with TB, participants should be encouraged to note the issues or concerns that could be addressed with the support of the NTP, local leaders or networks. This information forms the basis of feedback and advocacy.

II.

SESSION 2:

IMPROVING COMMUNITY AWARENESS ON TB AND DR-TB

Total Time required: 60 mins

OPENING GUIDANCE FOR FACILITATORS

Session structure



- The second session of module 4 consists of three sub-sections which should be completed over one hour (so each sub-section can take 20 min each). The three sub-sections are as follows:
 - Why improve community awareness?
 - Organizing community awareness meetings
 - Public speaking
- As before, the facilitator is advised to continue the focus on DR-TB through the discussions.

Objectives of the Session



To help participants understand the need to improve awareness of TB and DR-TB among their communities



To ensure participants understand the key messages they need to convey while sensitizing their communities about TB and DR-TB



To help participants identify potential avenues for sensitizing local communities



To empower TB Champions to share messages that reduce fear and build confidence in the TB care system while emphasizing that DR-TB treatment, though longer, can lead to recovery

Expected Learning Outcomes

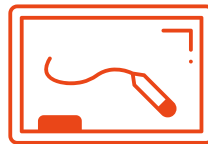
- Participants have understood the importance of and the need to sensitize their communities.
- Participants have understood the key messages they must convey to improve awareness on TB: basic information about the disease and where to seek care.
- Participants have understood that the involvement of communities can reduce stigma and discrimination and end the silence around TB.

Suggested methods



- Presentation
- Discussion
- Role Play

Materials Required



- Presentation + projection
- White board/flipcharts

Why learn about improving community awareness

- Community awareness leads to better health-seeking and early diagnosis and could help bring down the transmission of TB.
- In general, there may be limited understanding of what drug-resistance is among communities. It is important to strengthen this knowledge.
- Sustaining the attention of a group needs a structured flow of information. This session will help in understanding this structure.
- Most of us are not used to public speaking. This session will help discuss challenges in public speaking and how they can be overcome.

Setting the context

- The facilitator begins the session by asking the group if anyone can explain the meaning of community awareness. Depending on the responses, the facilitator builds the meaning using flip charts.
- The facilitator then shares best practices across public health issues on how community mobilization has brought about a sea change in health seeking behavior.
- The facilitator explains how community awareness is crucial for a holistic public health response. The facilitator could ask the participants why knowledge on TB and DR-TB needs to be shared with communities and note down the responses.

- The facilitator goes on to explain how community structures can be identified and specific aspects of TB that can be discussed in different settings. For e.g., in a school setting, symptoms of TB will be more appropriate rather than stigma and TB.
- The facilitator then outlines the various steps in doing community awareness. This could be a crowd-sourced activity.
 - Where and when will the TB Champion organize a community meeting?
 - Who are the expected participants? Is it the general population or a specific group?
 - How will the TB Champion inform them about the meeting?
 - Can any local leaders attend the meeting?
 - What will the TB Champion say at the meeting?
 - Will any others be invited to speak?
 - Will the TB Champion take questions from the participants?
 - Will any TB programme representatives be present at the meeting?
 - Are follow-up meetings required?

OTHER PRE-TRAINING SUGGESTIONS FOR FACILITATORS

- The facilitator introduces the participants to the importance of public speaking and encourages them to practice and build their confidence.
- The facilitator emphasizes that this is not a one-size-fits-all solution. Awareness raising efforts must be tailored to the needs of specific communities including factors such as the time of the meeting.
- Facilitators should explicitly address common fears and misconceptions about DR-TB early in the session, while reinforcing that DR-TB is treatable and that early diagnosis and adherence save lives.
- The tone of the session should balance realism with reassurance, avoiding fear-based messaging. The facilitator can use prompts such as: “How can we talk about DR-TB honestly without frightening people?”; “What messages helped you continue treatment when it felt long or difficult?” “How can sharing recovery stories change how communities see DR-TB?”
- If discussion becomes fear-heavy, gently redirect by asking participants to share examples of recovery, resilience, or community support they have witnessed.

Session Content



Sub-section 1: Why improve community awareness on TB and DR-TB?

- Despite the scale of TB globally, public understanding remains poor and there are several misconceptions associated with TB and DR-TB.
- Improving awareness on TB and DR-TB is critical to reducing fear among communities and thereby improving health seeking behavior.
- Improving awareness can also help address stigma and discrimination associated with TB.
- Communities that are aware and knowledgeable of TB can support others to seek diagnosis early, thus reducing delays and thereby transmission within the community.
- As TB survivors, TB Champions are best placed to help improve community awareness on TB.

- They can draw on their own personal experiences to demand public attention to TB.
- They can help communities become more aware of their rights, and how best they can access the TB services that are available to them.
- Communities need the right information in order to participate in the TB response. Empowering communities and making them aware of TB can help in demand generation and help improve the quality of services in the public and private sector.
- A key role of TB Champions is demystifying DR-TB at the community level by explaining how and why drug resistance occurs, how it is treated today, and how present outcomes are far better than in the past, and why early diagnosis and adherence matter.



Sub-section 2: Organizing community awareness meetings

- TB Champions can organize community meetings at multiple locations, and for different groups of people. A few are listed below but must be customized to the specific local setting.
- For organizing a community meeting with certain groups, it may be necessary to approach the concerned manager or leader to seek permission. TB Champions would need to explain the need for the meeting and how the participants would benefit from the meeting to this manager or leader.
- At every community meeting, TB Champions must ensure they provide the basic information on TB and DR-TB and dispel any myths or misconceptions people may have. Some key aspects are listed below.
- Whenever possible, local leaders and influential persons can be invited to the community meeting and encouraged to speak about TB.
- When projector/screens are available, videos featuring TB Champions can be screened.



POTENTIAL TOPICS

- Why speak about TB – why should communities be interested in TB
- Drug-resistant TB
- Social impact of DR-TB
- How TB and DR-TB spread
- Types of TB
- Symptoms of TB and the importance of early diagnosis
- Myths and misconceptions about TB and DR-TB
- What TB tests are available, and where
- Treatment available free of cost
- Importance of nutrition
- Stigma and the need to support people with TB
- Emphasize symptoms of TB, need to get tested and need for joint action to eliminate TB.
- Call to action – how the community can support people with TB, people with symptoms of TB and survivor-led networks



POTENTIAL LOCATIONS/GROUPS

- Local governance meetings
- Health camps
- Religious gatherings
- Self Help or women's groups
- Youth clubs
- Fan clubs
- Workers unions
- Occupational groups - factory workers/miners
- TB Survivors
- People with TB at health facilities
- Community service providers and health workers
- School students
- College students
- Teachers/Lecturers



Sub-section 3: Public speaking

- TB Champions will often have to address large gatherings and speak in public about TB.
- Some early challenges may include a lack of confidence, uncertainty on what to say, inability to connect with the group etc. All of these can be addressed and overcome with practice.
- TB Champions must pre-plan the TB messages they will share and tailor these messages to their audience.
- A speech can broadly be divided into four parts:
 - Address, where the speaker welcomes the audience
 - Introduction, where the speaker introduces themselves and the purpose of their talk, as well as some background information. Here, the TB Champion's personal story is especially important.
 - Key messages or the central part of the story, where the speaker uses simple language to deliver the most information. For example, the symptoms of TB, when to seek care, where to go for a diagnosis etc.
 - Closing session, where the speaker states the expectations and the call to action from the audience.
- Some simple tips:
 - Keep the local language and environment in mind.
 - Address everyone at the start of the session.
 - Use simple, easy and familiar words.
 - Discuss the topic or issue with confidence and clarity.
 - Maintain eye contact with the audience.
 - Use humor, whenever possible or appropriate to the topic.
 - Give relevant examples.
 - Ask simple questions to keep the meeting interactive and encourage questions from the audience.

FACILITATOR NOTES FOR WRAPPING UP THE SESSION

I. Summarizing the session

- The facilitator ends the session by asking a couple of participants to suggest how they would begin the process of improving awareness of TB among their own communities.
- If time permits, the facilitator can invite TB Champions to conduct mock meetings and practice what they would say.
- Remind participants that every accurate, hopeful conversation about DR-TB helps prevent stigma and saves lives.

II. Connecting the dots

- While supporting people with TB is important to ensure a successful treatment outcome, addressing communities is important to mitigate stigma and to ensure early diagnosis; both interventions go hand in hand.
- Community meetings, similar to provision of support to people with TB, can also be an opportunity to understand the concerns of the community in accessing health services and this feedback could be conveyed to the NTP and the health system.





SESSION 3:

ADVOCACY FOR DR-TB

Total Time required: 2 hours

OPENING GUIDANCE FOR FACILITATORS

Session structure



- This third session of module 4 consists of four sub-sections which should be completed over two hours (so each sub-section can take about 30 min each). The sub-sections are as follows:
- What is advocacy? How does it enhance other TB responses?
- Identifying and utilizing advocacy opportunities
- Types of advocacy
- Using personal stories
- As before, the facilitator is advised to continue the focus on DR-TB. Facilitators should emphasize that advocacy is one of the most powerful ways DR-TB survivors can transform difficult personal experiences into improvements in care for others.

Objectives of the Session



To enable participants to understand the importance of advocacy in the TB response particularly in addressing persistent gaps in DR-TB care



To help participants understand how advocacy can be an effective tool in bringing about a positive change



To build the capacity of TB Champions to use simple advocacy strategies grounded in lived experience of TB and DR-TB



To enable participants to identify the key stakeholders they can advocate to, especially for DR-TB-specific issues such as treatment regimens, side effects, and social protection



To help participants understand that different advocacy strategies and tools are required for different stakeholders



To describe the importance of communication and storytelling for effective advocacy



To provide participants with the knowledge and skills required to tell their personal stories effectively for different audiences

Expected Learning Outcomes

- Participants are able to explain the meaning of advocacy and its basic principles with examples from TB and DR-TB.
- Participants have understood why advocacy is necessary for TB and DR-TB and learn some advocacy tools they can use.
- Participants are able to identify challenges and convert them into advocacy priorities.
- Participants will be able to name the key stakeholders for effective advocacy and the different kinds of advocacy.
- Participants will be able to identify some key advocacy strategies and tools.
- Participants have a clear understanding of the basics of effective storytelling that balances honesty with hope.
- Participants have learnt how to use their own personal story of the TB journey (especially DR-TB treatment, recovery, or resilience) as an advocacy tool.
- Participants have understood the elements of a good story.
- Participants will have had an opportunity to practice some of these tools.

Suggested methods



- Presentation
- Open discussion
- Roleplay and Group work
- Practice sessions in small groups for peer feedback, time permitting

Materials Required



Presentation
with slides



Flipcharts



Any props
required for
roleplay



A4 size
individual
sheets



Pens



Short videos
of personal
stories by TB
Champions

Why learn about advocacy

- The community, leaders, and media often focus on newer illnesses that are prevalent at that point of time. To achieve the goal of TB elimination, the focus of all stakeholders towards this common goal is essential. Advocacy helps bring the focus back to TB and its consequences. This is particularly important for DR-TB, which can be invisible in public discourse despite its high burden on individuals and families.
- Advocacy is integral to every aspect of a TB Champion's role including providing peer support and addressing stigma. For DR-TB survivors, advocacy can be a way to reclaim voice, dignity, and agency after prolonged treatment journeys. TB Champions can go on to become powerful advocates and community leaders, with the voice and means to convey the concerns of people with TB to the programme and other leaders, elected representatives etc.

Setting the context

- The facilitator begins the session by asking the group if anyone can explain the meaning of advocacy. Depending on the responses, the facilitator builds the meaning using flip charts and slides. Follow-up prompt: **"Can you think of one example where advocacy has already improved TB or DR-TB care in your area or country?"**

- The facilitator then shares their own advocacy experience. They go on to explain that this will be a session with a formal presentation. Participants will have an opportunity to ask questions at the end/at any point during the session.
- The facilitator then explains how advocacy fits into and complements a holistic public health response, in other words, the need for advocacy. The facilitator could ask the participants why TB needs advocacy and note down the responses. Suggested prompt participants to reflect on: “Why does DR-TB, in particular, require strong survivor voices?”
- The facilitator goes on to explain how advocacy opportunities can be identified.
- The facilitator then outlines the various steps in doing advocacy. This could be a crowd-sourced activity.
- The facilitator identifies the qualities of a good advocate. Again, this could be crowd-sourced so as to make it more interactive.
- The facilitator recalls the community engagement activities to be carried out by TB Champions. The linkage between all sessions should be highlighted with examples – A community awareness meeting in a school can be conducted only after outreach to the school headmaster or headmistress. At the community meeting, if the TB Champion identifies a family member of a student who is on treatment, they can provide peer support to that person.
- At the beginning of sub-section 4, the facilitator asks the group why personal stories are important for advocacy. The facilitator crowdsources the elements of a good story and then shares the relevant slides
- The facilitator makes the case for effective storytelling and its potential impact on listeners, conveying that there is no substitute for honest, emotional storytelling.
- The facilitator shows 2-3 short videos featuring TB Champions as examples of good storytelling.

Other pre-session notes for facilitators

- The tone of the session should balance urgency with optimism, highlighting that sustained advocacy has already led to important improvements in DR-TB diagnosis, treatment regimens, and patient support.
- The facilitator can explain the concept of the story spine with an example (not necessarily related to TB).
- The facilitator then leads a discussion on the ground rules for effective storytelling, preferably with examples for each rule. The facilitator will explain that these are not meant to be prescriptive as much as suggestive and that individual personalities must shine through personal stories.
- The facilitator reminds participants that body language and expressions are as important as what they are saying.
- After the discussion, the facilitator asks each participant to take ten minutes to write their individual stories on paper.
- The facilitator encourages participants to work in the language they are comfortable in. Depending on the group’s literacy levels, this can be converted into an exercise in pairs.
- As a final exercise, the facilitator divides the participants into groups of 4-5. In these groups, each participant can share their story at least once and get feedback from their peers.
- The facilitator invites 2-3 volunteers to come share their stories before the larger group and get feedback. Alternatively, the facilitator can call on a participant they know is likely to be eager/confident to share and will be a good example for the others to emulate.

Session Content



Sub-section 1: What is advocacy? How does it complement and advance other TB response actions?

- 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. Many improvements in DR-TB treatment – such as shorter regimens and reduced use of injectables – were achieved through years of advocacy by survivors and civil society.
- Advocacy combines various complementary initiatives in order to achieve an objective. Advocacy influences policymakers, funders and decision-makers; a variety of channels. It seeks to ensure that governments are committed to implementing TB care and prevention, and working towards TB elimination.
- Advocacy can take many forms. In relation to TB, it could for example be:
 - a coalition of civil society organizations (CSOs) holding a press conference or jointly signing an open letter.
 - a meeting with a country's President.
 - a play about rights performed for key decision-makers by actors living with TB.
 - advocacy by DR-TB survivors sharing their treatment experiences has influenced changes in national and global guidelines.
 - advocacy from DR-TB survivors has also led to treatment regimens becoming more affordable. In 2023, after sustained survivor-led campaigning, Johnson & Johnson announced it would not enforce key secondary patents, opening the door for affordable generic production of Bedaquiline.
- Advocacy can be written, spoken, sung or acted. It can also vary in the time it takes – from a few minutes to several years, but the change that takes place due to the advocacy inevitably takes longer. We can do advocacy on our own or with others. It is possible to advocate for other people or for ourselves.
- Advocacy is only one approach to influencing TB prevention, care, impact and policy work. Other approaches include community mobilization, education, public health measures, good medical services and community support.
- By gaining the support of people in power and changing the social environment in which this work takes place, advocacy can enhance these other approaches, making them more effective.
- Almost all non-government organizations (NGOs) have experience of doing advocacy – even if they do not realise it, or do not use the word 'advocacy'.



Sub-section 2: Identifying and operationalizing advocacy opportunities

- To effectively identify opportunities for influencing funding and the programme and policy process, advocates need first to understand the usual rules and procedures a country uses to make funding, programme and policy decisions.
- These may be at the national level, where discussions are focused on broad policy issues and official national policies, or at the operational level, where specific resource allocation and service delivery guidelines are formulated.
- They can be 'reactive', which requires moving fast when a local, national or international event provides an opportunity for TB advocacy.
- Or they may be 'proactive', which requires a strategy and planning for the future in order to have maximum impact in what you are saying and on the people you are trying to influence.
- Identify issues or challenges in the TB response (like in the Pathways exercise, for example)
- Select an issue or problem you wish to address. Consider DR-TB-related challenges such as long treatment duration, side effects, loss of income, stigma, and access to mental health support.
- What DR-TB issue in your community feels most urgent? And what realistic change could advocacy achieve in the next one year?
- Analyze the problem using any creative method – e.g. the problem tree approach – and potential solutions.
- Develop specific objectives for your advocacy work. This must be distinct from a programmatic objective. For example, an advocacy objective could be to demand that the NTP switch to shorter treatment regimens for DR-TB and avoid using the longer regimens with injectables. Another objective could be to advocate for all people with TB to be given nutritional support, or for integration of mental health care within TB services, or for travel support for all people with TB to travel to the health facilities. Another advocacy objective could be to ensure that frequent stock outs of drugs do not occur.
- Identify your targets (whom do you need to influence to achieve this objective?).
- Identify your resources (what funds will you need? What other resources do you have?).
- Identify your allies (who will you work with?).
- Create an advocacy plan with specific goals, outcomes, dates and responsibilities.
- Implement, monitor, document and evaluate your work (ongoing and amend it as you go along).



Sub-section 3: Types of advocacy

Advocacy by TB Champions can take multiple forms and each form contributes towards demystifying TB and DR-TB and towards building people centered TB responses. Globally, community and civil society advocacy in TB and DR-TB has increasingly been shaped around four interconnected areas, reflected in the work of the Stop TB Partnership's Challenge Facility for Civil Society (CFCS).

- *Demand creation:* This includes raising awareness about TB and DR-TB, encouraging early care-seeking, promoting uptake of diagnostic and treatment services, and building community demand for newer, better and people-centered tools and services. TB Champions can help communities understand that quality TB care is available and worth seeking, while also motivating people to complete treatment and access support.
- *Advocacy to overcome stigma and other barriers to access:* TB Champions also advocate by addressing the barriers that prevent people from accessing care. These may include stigma, discrimination, fear, misinformation, gender-related barriers, mobility constraints, financial hardship, and other social or structural obstacles. In this type of advocacy, Champions help create safer, more supportive environments for people affected by TB and DR-TB to seek diagnosis, start treatment, and stay in care.
- *Community-led monitoring and accountability:* Advocacy also includes documenting and elevating the lived experiences of people affected by TB. TB Champions and community networks can identify gaps in services, collect feedback from patients and families, and bring community perspectives into dialogue with health providers and programme managers. This helps strengthen accountability and improve the quality, responsiveness and equity of TB services.
- *Integration for sustainability:* A further type of advocacy focuses on ensuring that community voices and TB Champion initiatives are not treated as temporary or standalone efforts. This includes advocating for the integration of TB Champions, survivor-led groups and community-based responses into routine TB planning, implementation and review processes. Such integration is essential for long-term sustainability and for building a stronger, more people-centered TB response.

Taken together, these four areas show that **advocacy by TB Champions is broad, practical, systems oriented and plays a role in demystifying TB at every level of the system.** It includes not only speaking publicly or sharing personal stories, but also creating demand, reducing barriers, improving accountability and helping embed community leadership within the TB response over time.

- Below are a few additional terms that are useful to understand:
 - Policy advocacy: Informs politicians, elected representatives, etc. how an issue will affect the country; requests specific actions to improve laws and policies.
 - Programme advocacy: Targets programme implementors at various levels to take action.
 - Media advocacy: Validates the relevance of a subject; puts issues on the public agenda, prompts the media to cover TB-related topics. Positive stories of DR-TB recovery shared through media can counter fear and stigma while still highlighting system gaps.
 - The facilitator can also introduce other terms such as budget and financial advocacy, which can be addressed in advanced training.

Some advocacy tools and techniques

- | | |
|-------------------------|----------------------------|
| • Parliamentary debates | • Letter writing campaigns |
| • Political events | • Using social media |
| • Community meetings | • Personal stories |
| • Petitions | • Working with the media |



Key messages

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

Group discussion



- The facilitator begins the group discussion by saying that participants will now have an opportunity to practice what they learnt in the previous session.
- As a first step, each participant will be asked to map the key stakeholders (this could be for a geographical area or a specific thematic aspect of TB-related advocacy).
- The facilitator will then lead an open discussion of the different kinds of stakeholders TB Champions can and should work with.
- For the second exercise, the facilitator divides participants into groups of no more than 7-8 at the maximum.
- Each group is asked to identify a specific advocacy objective. The facilitator asks the participants to first identify the issue(s) they wanted to advocate on/for, based on the pathways exercise.
- Each group then works on developing their campaign objectives and a preliminary outline of how this could be achieved. For example, one group could prepare and present a pitch to an elected representative in their area over an ongoing stockout of drugs. Another group could present a mock press conference on a DR-TB issue in their community. A third group could draft a letter to the programme with information from the field and a request to take action.
- The facilitator wanders around the room, providing inputs where required and encouraging the participants to be as innovative and creative as possible.
- The three groups present and get feedback from their peers.
- The facilitator asks the groups to identify what they enjoyed about the process and what they found challenging.
- The facilitator ends the group activity by reminding participants that advocacy often begins with small wins that build momentum over time.



Sub-section 4: Using Personal Stories for Advocacy

- **Why is personal storytelling important for advocacy? Why should TB survivors share their stories?**
 - Way to share knowledge or information, simply and easily
 - Can convey a wealth of information and high level of detail
 - Provides context, yet is personal
 - Helps listener connect and identify with an issue/situation
 - Listener learns
 - So does the storyteller
- Good stories can trigger behavior change (image to be added)
- **What are the elements of a good story?**
 - About something that really happened to you
 - *“When I was ...”*
 - *“My colleague or friend told me about when they ...”*
 - *Told from your perspective*
 - Describes something at a specific time and location
 - *“Last year when I was working on / helping someone ...”*
 - *Good stories have a ‘story spine’. It builds tension for the reader and takes her/him to a logical outcome/conclusion (story spine image to be added)*
- **What are some ground rules for effective storytelling?**
 - Keeping it simple and personal
 - The focus should be on the TB Champion’s story, not the burden of TB or what happened to other people.
 - Knowing your audience and being able to tell the same story in different ways for different people
 - For example, a TB Champion who meets an elected leader must highlight policy-level issues.
 - A TB Champion who meets a programme manager must identify ground-level issues that need to be resolved.
 - A TB Champion who speaks to other survivors must inspire and motivate them.
 - All of these can be based on the same personal story, just drawing on different elements.
 - Knowing which details to include and which ones are not relevant and keeping it short
 - The TB Champion must identify the important message they want to convey – is it diagnostic delays, inaccessibility of services, adverse effects, stigma, loss of wages, expenditure, etc.
 - Every detail of a personal story is vital for the storyteller, but not necessarily the audience.
 - The diagnostic pathway the TB Champion experienced may, for example, be relevant for a certain audience but not all.

- Understanding that a powerful story need not be a sad story and that your aim is not to make listeners cry. Stories of coping, adaptation, and recovery during DR-TB treatment can be as powerful as stories of suffering.
- Personal stories should not evoke pity in the listener but instead galvanize them to action. The goal is to show what needs to change – and that change is possible
- Accepting that some details may be too personal to share. But be honest about it and acknowledge that it is too painful to share some information related to how TB impacted the Champion's life.

GROUP ACTIVITY

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

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

Time permitting, they will then divide into small groups of 4-5 and practice telling each other the stories. Ideally, each person should get at least one opportunity to share their story, based on what they've written. 2-3 volunteers can be invited to share their stories to the group and receive feedback from their peers.

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

FACILITATOR NOTES FOR WRAPPING UP THE SESSION

I. Summarizing the session

- The facilitator ends the session by giving some examples, preferably from the local context, of what effective advocacy has achieved. Include at least one example related to DR-TB improvements (treatment regimens, diagnostics, support for affected communities).
- The facilitator can clarify that broadly speaking, there are two reasons for advocacy: to draw attention to TB and to ensure the smooth functioning of the programme and delivery of services

- The facilitator summarizes the importance of storytelling and encourages all TB Champions to share their stories boldly and openly, without fear of judgment or stigma.
- Reinforce that their voices have already shaped TB and DR-TB policy and will continue to do so.

II. Connecting the dots

- There are sometimes issues that cannot be addressed at the individual level. Advocacy is a tool to bring about systemic change that will benefit a large number of people.
- Storytelling is a powerful tool for advocacy and can help identify gaps in the TB response.
- For DR-TB, sustained survivor-led advocacy is essential to ensure that care continues to improve, becomes more humane, and remains people-centered.



IV.

SESSION 4:

ADDRESSING STIGMA AND DISCRIMINATION IN TB AND DR-TB CARE

Total Time required: 30 mins

OPENING GUIDANCE FOR FACILITATORS



TIME REQUIRED

7 hours

Session structure



This fourth session of module 4 consists of five sub-sections which should be completed over 30 minutes (so each sub-section can take about 5 min each). The sub-sections are as follows:

- What is stigma?
- Impact and types of stigma
- What is discrimination?
- Stigma and discrimination
- What can TB Champions do?

As before, the facilitator is advised to continue the focus on DR-TB. They should highlight how many people continue to operate from a place of blaming affected communities, believing that DR-TB is caused primarily due to non-compliance with TB treatment even though in reality, primary DR-TB is more common.

Objectives of the Session



To help participants understand stigma and discrimination conceptually, and in the TB/DR-TB context



To help participants identify how they can address stigma



To help participants see that for people with DR-TB, stigma may persist for much longer due to repeated contact with health systems.



To help participants understand how stigma, in association with other factors such as gender, can deter people with TB and DR-TB from accessing services or completing treatment

Expected Learning Outcomes

- Participants are able to explain the meaning of stigma at various levels.
- Participants are able to differentiate between stigma and discrimination.
- Participants are able to make their plans to address stigma as part of all their activities.

Suggested methods

- Presentation and Discussion

Materials required

- Presentation with slides
- Flipcharts
- Videos of TB Champions speaking on stigma



Why learn about stigma

- Stigma affects people with TB at different stages; care-seeking, getting a diagnosis and completing treatment. Addressing stigma can eliminate barriers across the care cascade.
- Addressing stigma may prevent people with TB from interrupting or discontinuing treatment.
- Addressing stigma in communities can improve health-seeking behavior and promote early diagnosis thus reducing transmission in the community.
- As TB survivors, participants are best placed to understand and talk about stigma with others affected by TB.

Reducing stigma is especially important for DR-TB, where treatment fatigue and social isolation are common.

Setting the context

- The facilitator begins the session by reminding participants that this is a core support that they can provide to those affected by TB.
- They should acknowledge that stigma may look different (and can often be more intense) for people with DR-TB.
- The facilitator defines some key terms such as lack of access to TB care, poor health seeking behavior, social impact of a disease etc.
- The facilitator will ask the participants to give responses to this question: “Why is a TB Champion best placed to work on stigma reduction?” Prompt participants to reflect on how lived experience of TB or DR-TB builds credibility and trust when challenging stigma. All the responses should be written on a board or flip charts.

OTHER PRE-TRAINING SUGGESTIONS FOR FACILITATORS

- The facilitator states that two of the major issues that affect someone with TB are stigma and discrimination. The facilitator will then define stigma and discrimination.
- The facilitator can then develop two lists or discuss the ways in which People with TB are stigmatized and discriminated against.
- The facilitator then conducts the activity described above and ensures that all participants have time to do this role-play exercise.
- Facilitators should explicitly emphasize that DR-TB is a medical condition (and not a sign of failure) and that stigma rooted in blame is both inaccurate and harmful.
- The tone of the session should acknowledge harm while reinforcing that stigma can be challenged and reduced through informed, compassionate action.

Session Content



Sub-section 1: What is stigma?

- Stigma, literally, means a mark of shame or discredit, or a stain.
- Stigma is a social determinant of health linked to economic and social conditions. Stigma is shaped by community norms, personal attitudes, institutional rules that portray a trait, or behavior of an individual or a group as undesirable and devalued.
- Those who are stigmatized often have a low opinion of themselves, have shame, guilt, and disgust, and withdraw from society.
- Stigma has an adverse impact on health and health-seeking behavior of people with TB and DR-TB.
- Stigma can be more devastating than the disease itself.
- The potential impact of stigma of TB prevents people from accessing healthcare in a timely manner. The impact can be more severe for people diagnosed with DR-TB.
- Stigma cuts across class, caste and economic background, and is gendered in nature.



Sub-section 2: Impact and types of stigma

Medical impact of stigma

- Is a barrier to access
- Delays diagnosis and deters health-seeking
- Impedes access to care
- Affects treatment adherence and outcomes; this risk is higher in DR-TB due to longer treatment duration, side effects, and repeated interactions with health facilities.

Social impact of stigma

- Disproportionate impact on women
- Loneliness, isolation, depression
- Dismantling of relationships
- Loss of work, access to school, and descent into poverty

Sites of Stigma

- Self-stigma
- Stigma by family members
- Stigma by communities/neighbors
- Stigma at the workplace or schools/colleges
- Stigma by healthcare providers. People with DR-TB may experience additional stigma in health settings due to preconceived ideas about “non-compliance” contributing to drug resistance.



Sub-section 3: What is discrimination?

- Discrimination is when stigma is enacted. Discrimination excludes and leads to inequality and injustice.
- While stigma is a social, community and individual perception, discrimination is a violation of rights. Discrimination is unfair and unjust.
- People with TB often face discrimination at their workplace, in healthcare, in education, within families, etc. For people with DR-TB, discrimination may include greater degrees of denial of employment, housing, or respectful care due to fear or misinformation.



Sub-section 3: Stigma and Discrimination

- Stigma is a negative judgement or label people place on a person or a group of people because of a characteristic, like TB diagnosis.
 - What are other things people are stigmatized for (crowdsource as much as possible)
 - Answers could include caste, race, religion, age, socioeconomic status, gender identity, sexual orientation, gender expression, sex characteristic, education, disease (HIV, for example), place of origin or citizenship
- Discrimination is when a person is treated less favorably as a result of their condition or characteristic.
- What are some of the stigmatizing thoughts people have in general about someone with TB (crowdsource as much as possible)
 - Answers could include Poor, dirty, alcoholic, unemployed, hereditary, bad family, cursed
- What are some ways in which people with TB are discriminated against (crowdsource as much as possible)
 - Answers could include lose or cannot get job, shunned by family and friends, can't get married, receives poor medical treatment
- What additional assumptions are made when someone is known to have DR-TB?
- People who face unaddressed stigma and discrimination have poorer psychosocial health and are less likely to recover from TB.
- Addressing stigma can therefore directly improve treatment completion and recovery, including in DR-TB.

⁶ Baral, S. C., Karki, D. K., & Newell, J. N. (2007). Causes of stigma and discrimination associated with tuberculosis in Nepal: a qualitative study. *BMC Public Health*, 7(1), 211.

⁷ Baral et al, (2007).



Sub-section 5: What can TB Champions do?

- Counsel people with TB on self-stigma and support them to come to terms with their TB diagnosis. Emphasize that being diagnosed with TB is nothing to be ashamed of. For people with DR-TB, emphasize that drug-resistance is not their fault and does not diminish their worth or dignity.
- Counsel family members on stigma and the importance of family support.
- Undertake community awareness on stigma and TB. Include messages that normalize DR-TB as a treatable medical condition and highlight stories of recovery and resilience.
- Advocate for ending stigma or discrimination at health facilities/ workplaces etc. with concerned stakeholders.
- TB Champions can talk to families which stigmatize or discriminate against people with TB and explain that those on treatment usually become non-infectious after a few weeks. TB Champions can speak to families, reassure them and convince them to support people with TB.

OVERVIEW OF GLOBAL TRENDS ON TB STIGMA

- Across countries, community (25%) and self-stigma (23%) were the most frequently reported settings where people with TB (PwTB) experienced stigma that hindered access to services, followed by health facilities (18%), home or family (18%), and workplaces (16%).
- The most common attitudes driving stigma included self-isolation among PwTB, families hiding members with TB, community avoidance (such as reluctance to share food or drink), and healthcare workers' endorsement of forced isolation for treatment.
- Notably, 30% of healthcare workers also reported experiencing stigma, primarily from colleagues. Stigma most often occurred before individuals presented at health facilities – particularly during symptom recognition and treatment adherence – and disproportionately affected women and underserved populations.
- While most countries reported having protective laws and policies (often non-TB-specific and embedded in general health or constitutional provisions), enforcement and media coverage were frequently inadequate, especially regarding workplace safety, privacy, discrimination, and protection against involuntary isolation). **These findings underscore that stigma remains a leading barrier to TB care and that there is a need to strengthen TB stigma reduction programmes by:**
 - targeting specific settings and stages of TB journey,
 - tailoring awareness activities to address prevalent stigmatizing attitudes,
 - improving enforcement and media coverage of existing legal protections,
 - prioritizing interventions for disproportionately affected sub-populations,
 - enhancing cocreation with and implementation by people affected by TB.

Source: <https://tbstigma.org/>

Box 13: Global trends on TB stigma

FACILITATOR NOTES FOR WRAPPING UP THE SESSION

I. Summarizing the session

- The facilitator reminds participants that people with TB and DR-TB can experience stigma at any point in time but may be hesitant to share this with anyone else. It is up to the TB Champion to use active listening skills and create a support environment that will encourage people with TB to speak freely.
- The facilitator also reminds participants that although healthcare workers might stigmatize or discriminate against people with TB, they may experience stigma themselves.
- The facilitator ends the session by summarizing the key points and asking the TB Champions to refer to the NTP's Strategy to End Stigma and Discrimination (if available).
- If emotions run high, gently redirect toward actions TB Champions can take to challenge stigma and support dignity. Emphasize that stigma is learned - and therefore can be unlearned - through consistent, compassionate engagement.

II. Connecting the dots

- The roles of a TB Champion are intertwined - supporting people with TB helps in identification of stigma, identifying stigma would lead to addressing it through family counseling, advocacy and community meetings
- Stigma in health care settings is not uncommon. Any such instances should be conveyed to the NTP and the health system.
- While TB Champions can address stigma in the family and the community, the networks have the potential to call broader attention to stigma.



SESSION 5:***COMMUNITY-LED MONITORING AND GIVING FEEDBACK
TO THE HEALTH SYSTEM*****OPENING GUIDANCE FOR FACILITATORS****TIME REQUIRED****60 minutes****Session Structure**

This fifth session of module 4 consists of two sub-sections which should be completed over one hour (so each sub-section can take 30 min each). The two sub-sections are as follows:

- Community accountability and feedback to NTPs
- Community-led feedback mechanisms

As before, the facilitator is advised to continue the focus on DR-TB. Facilitators should emphasize that community-led monitoring (CLM) has already contributed to measurable improvements in TB and DR-TB services in many countries, including availability of medicines, responsiveness of services, and patient experience.

Objectives of the Session



To demonstrate and help participants understand CLM for people-centered care and health system improvements including and especially for DR-TB services



To orient participants on the available CLM tools being used in TB (with particular emphasis on ONEIMPACT as the most widely adopted CLM platform)



To orient participants on best practices for initiating, scaling up, and institutionalizing CLM within national TB responses

Expected Learning Outcomes

- Participants have information and tools to advocate for CLM for health system improvements that focus on people-centered TB and DR-TB care.
- Participants are familiar with available CLM tools being used in TB, particularly ONEIMPACT (Box 15).
- Participants are clear about their role in this process and how they can get involved and how community insights can lead to concrete programme action and better outcomes.

Suggested methods

- Brainstorming
- Presentation
- Group Discussion



Materials required

- Presentation + projection
- White board/flipcharts



Learning how community feedback and CLM can improve health systems

- TB Champions provide insight into patient experiences.** TB Champions have deep, personal knowledge of how people experience TB services. By sharing these experiences, they can help improve quality of care. This is especially important for DR-TB, where treatment pathways are more complex and can make system gaps more visible.

- **TB Champions connect communities and health services.** TB Champions are in a unique position to act as a conduit of feedback between people with TB and the NTPs. When this feedback is collected, organized and shared through CLM, this feedback has greater legitimacy, reach, and impact.

Setting context

- The facilitator begins the session by crowd-sourcing the meaning of community-led monitoring and feedback
- They then ask participants why community feedback is necessary, and what the role of TB Champions is in this process.
- The facilitator shares that the aim of community-led monitoring is to provide a joint platform of engagement between affected communities, health services and NTPs to reach all people affected by TB and improve the quality of TB care. Emphasize that CLM focuses on finding solutions and strengthening the health system, through a process of community empowerment, mobilization and engagement. Recognizing and celebrating health system improvements as they occur is an important part of CLM.

OTHER PRE-TRAINING NOTES FOR FACILITATORS

- Frame CLM as a practical process for change – not only for identifying gaps, but for accelerating improvements that are already underway.
- The facilitator gives examples of different community-led feedback mechanisms to participants.
- Explicitly mention ONEIMPACT and the experience of Stop TB Partnership / CFCS countries where CLM has been scaled successfully.

WHAT IS ONEIMPACT?

ONEIMPACT is a comprehensive digital platform that integrates individual and family support, community systems strengthening, and health system strengthening to close persistent gaps in TB prevention, screening, diagnosis, treatment, and care. ONEIMPACT functions as a multi-directional support and data platform that connects people, communities, and health systems in real time. It provides trusted information, enables service navigation and peer support, and translates community-reported barriers into actionable health system responses. Through this integrated approach, ONEIMPACT provides a joint platform for engagement and directly addresses one of the main challenges of TB programmes: to consistently reach, engage, retain, and support people, in particular the underserved populations across the full TB care cascade, resulting in large numbers of people being missed, diagnosed late, or lost from care.

ONEIMPACT's Contribution Across Three Interconnected Levels:

I. Individual and Family Support

ONEIMPACT functions as a digital platform of support and empowerment for people affected by TB and their families.

It provides trusted information, service navigation, peer connection, and simple mechanisms to report barriers to care. By strengthening health literacy, reducing stigma, and improving access to services, ONEIMPACT promotes earlier care-seeking, reduces diagnostic and treatment delays, improves treatment adherence and completion, and lowers loss to follow-up, directly improving patient experience and outcomes while reducing the number of people missed along the TB care cascade.

II. Community Systems Strengthening

ONEIMPACT strengthens community systems and civil society capacity by transforming lived experience into structured, real-time evidence. It enables communities to document barriers, identify service gaps, and engage constructively with health authorities. By converting community voice into actionable data, ONEIMPACT strengthens community-led monitoring and advocacy, enables rapid identification of inequities and bottlenecks, and supports targeted community action and referral, creating a functional bridge between communities and health systems and ensuring services are more responsive, inclusive, and people-centered.

III. Health System Strengthening

ONEIMPACT serves as a real-time data and accountability platform for facilities, districts, and national TB programs. By aggregating community-reported data into actionable dashboards, it enables health systems to detect service failures and access barriers early, improve service quality and responsiveness, target supervision and resource allocation, and strengthen accountability and performance management. This drives faster corrective action, improved programme effectiveness, and accelerated progress toward screening, testing, and treatment targets.

Source: <https://stoptbpartnershiponeimpact.org>

Box 14: What is ONEIMPACT?

Session Content



Sub-section 1: Community accountability and feedback to the programme

- Community accountability is an integral part of a community-led response to TB. It is central to people-centered care, enhanced accountability, and continuous improvement of TB and DR-TB services.
- Communities provide valuable, real-time, from-the-field information that may otherwise not be available. For DR-TB, this includes treatment side-effects, delays, stigma, and continuity of care issues that may not appear in routine data.

- Community feedback connects service users directly with service providers in structured ways, allowing challenges to be identified and addressed promptly rather than waiting for formal reporting cycles.
- Community accountability seeks to constantly ask – how can we further improve and ensure that all TB-affected communities, in particular those who are missed by the system (underserved populations for example) can access the highest quality of services possible? This approach has contributed to improved DR-TB regimens, better support for affected communities, and more responsive services in multiple settings.
- An effective and robust CLM system enables timely problem solving. It ensures the direct flow of information while creating an environment conducive to real-time problem solving.
- Real time feedback from communities can bring to the attention of the officials the deficiencies or lack of manpower / logistics such as reagents/drugs or other qualitative aspects of services.
- Community accountability is not fault-finding. It also highlights successes and improvements, fostering trust, reinforcing good practices and creating a feedback culture that supports continuous learning and stronger health systems
- Facilitator prompt: “Can you think of examples where community feedback led to improvements in TB or DR-TB services?”



Sub-section 2: Community-led feedback mechanisms

- Describe any existing CLM mechanisms in your country, if any. If there are no such mechanisms, are you aware of any that were implemented or tested in project mode? In this context, it is important to distinguish between mechanisms that are community-led, i.e. are truly independent from the health system, as opposed to mechanisms built into the health system to occasionally collect feedback (such as review missions, for example).
- Describe ONEIMPACT if it is currently operational in your country, or if there are plans to introduce it. ONEIMPACT should be presented as a flagship CLM tool in TB, widely used across RESPECT and CFCS countries, enabling information sharing, community building, joint engagement of communities and programmes in the TB response.
- TB Champions, those on treatment and survivor-led networks can directly provide feedback on TB services to the relevant officials. Relaying feedback as a network may be more effective in certain situations.
- Relaying feedback through networks and CLM platforms like ONEIMPACT increases credibility, visibility, and follow-up—particularly for systemic DR-TB issues.
- Work-planning for CLM: Facilitators should briefly guide participants to reflect on whether CLM in their country is at the stage of initiation, scale-up, or institutionalization, and what role TB Champions and networks can play at each stage.

FACILITATOR NOTES FOR WRAPPING UP THE SESSION

I. Summarizing the session

- Ensure a shared understanding of CLM as a process that combines community mobilization, empowerment, and accountability to improve people-centered care.
- The facilitator ends the session by asking participants if they can think of any other ways to provide feedback, and to name their main takeaway from the session.
- Reinforce that CLM has already helped improve TB and DR-TB services in many settings – and that stronger, more systematic community feedback can further accelerate progress. Emphasize that CLM turns lived experience into evidence, and evidence into action.

II. Connecting the dots

- Communicating actionable feedback to the NTP is one way of advocating for people with TB. For DR-TB, this is critical to improving treatment experience, retention, and outcomes.
- Feedback can be communicated to the NTP at the health facility level, the district or the state level.
- Networks and forums are important structures which can convey feedback about issues/ concerns that are common to a large number of people with TB or issues which span bigger geographies. Institutionalized CLM mechanisms such as ONEIMPACT help ensure this feedback leads to sustained system change rather than one-off responses.

ONEIMPACT CASE STUDY: MOZAMBIQUE – FINDING MISSING CHILDREN WITH TB

In Zambezia Province, Mozambique, childhood TB prevention and detection have historically lagged behind national targets due to stigma, limited access to services, geographical barriers, and lack of systematic contact screening.

To address these gaps, community partners – supported by the Stop TB Partnership’s Challenge Facility for Civil Society (CFCS) and Dure Technologies – adapted and deployed ONEIMPACT’s community-led monitoring approach in two districts.

Through a community-wide poll administered via ONEIMPACT to nearly 2,500 people affected by TB, the CLM team identified that 88% of respondents reported that children in their households under age 15 had not been screened for TB, revealing a critical service gap.

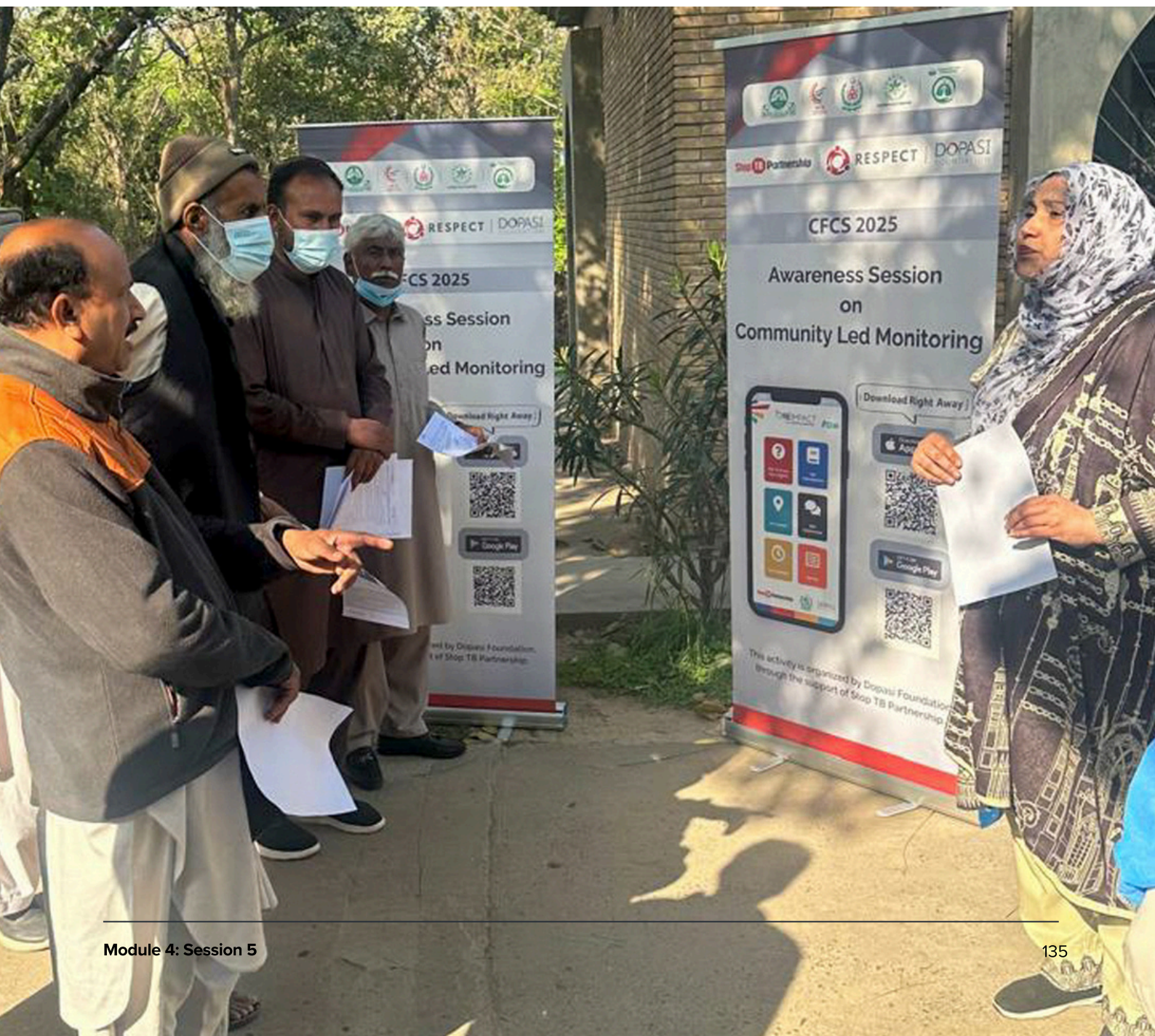
Acting on this insight, community actors and health facilities collaborated to screen and link 397 children to appropriate TB services, demonstrating how ONEIMPACT data can trigger rapid, real-world action to improve service delivery.

Beyond this immediate impact, the initiative engaged nearly 10,000 people, documented over 2,100 community-reported challenges, and resolved a high proportion of those issues, illustrating the platform’s ability to bridge community insights with health-system responsiveness.

The success of the Mozambique experience has informed CLM practice elsewhere and supported the scale-up of ONEIMPACT to more facilities and districts, embedding community voice in ongoing efforts to improve TB care – including for DR-TB and other vulnerable populations.

Source: <https://stoptbpartnershiponeimpact.org/>

Box 15: ONEIMPACT Case Study: Mozambique – Finding Missing Children with TB



VI.

SESSION 6: *SELF-CARE FOR TB CHAMPIONS*

OPENING GUIDANCE FOR FACILITATORS



TIME REQUIRED

30 minutes

Session Structure



This sixth and final session of module 4 consists of three sub-sections which should be completed over half an hour (so each sub-section can take 10 min each). The three sub-sections are as follows:

1. Protecting oneself from TB
2. Balancing life as a TB Champion with other responsibilities
3. Dealing with the loss of a person with TB

As before, the facilitator is advised to continue the focus on DR-TB. Facilitators should emphasize that self-care is not a sign of weakness but a core competency for TB Champions, especially when supporting people with long and complex DR-TB treatment journeys.



Objectives of the Session



To support participants to understand how to balance their role as a TB Champion with other responsibilities.



To reinforce that looking after oneself enables Champions to continue this work over time without harm to their health or wellbeing.



To help participants understand what infection control practices they need to adopt to protect themselves from TB and other infectious diseases.



To equip participants with the knowledge required to cope with the loss of a person with TB

Expected Learning Outcomes

- Participants are able to use the knowledge about TB transmission to protect themselves.
- Participants have understood the level of effort required to work as a TB Champion.
- Participants have understood that they may feel overwhelmed at times and must prioritize their own emotional and mental health.

Suggested methods

- Presentation
- Group Discussion



Materials required

- Presentation with slides
- Flipcharts



Why self-care?

- TB Champions interact with people with TB and DR-TB on a regular basis. It is important for them to understand how they can protect themselves and ensure they do not get TB once again.
- Supporting people with TB and advocating for people with TB is a long process. Although there will be progress, it is easy to lose sight of oneself at some point and feel exhausted, disillusioned or burnt out.

- The mortality among people with TB is an estimated 10–15% and can be higher in some countries. Even though there are many reasons to look at the future with optimism, not all outcomes will be positive, and it is important to be prepared. In the course of their work, TB Champions will inevitably see people dying, including those they are directly supporting. It is easy to start blaming oneself for someone's death. A basic understanding of when to seek help can help TB Champions cope with losses.

Setting context

- Begin the session by noting that any health-care worker can efficiently support other people only if they are well-taken care of, physically and emotionally.
- The facilitator could ask the TB Champions what difficult situations they anticipate while working as a TB Champion. Prompt reflection on long-term DR-TB support, repeated follow-ups, and emotional fatigue.

The facilitator could paraphrase the responses and build on some of the responses from the TB Champions which are relevant to self-care.

Session Content



Sub-section 1: Protecting oneself from TB

- All TB Champions who have completed treatment recently should ensure that they undergo clinical examination, X-ray screening and sputum examination once in six months for two years after completion of treatment, or as specified by the NTP guidelines. This is especially important for DR-TB survivors, whose post-treatment monitoring may need closer attention.
- TB Champions, particularly those living with HIV, must also ensure they have completed their TB Preventive Therapy regimen.
- It is also important to consume a diet rich in vegetables, fruits and proteins to ensure that nutritional status is optimal. Maintaining an ideal BMI is an indicator of desirable nutritional status.
- Physical activity not only keeps non-communicable diseases like diabetes and hypertension at bay, it also contributes to overall immunity as a whole. Moderate to severe physical activity, three times a week for thirty minutes is the bare minimum everyone must aspire to.
- Wearing a mask and ensuring that people with TB also wear a mask during all interactions will minimize the chances of reinfection with TB. COVID-19 has normalized the usage of masks. Normalizing mask use helps protect both TB Champions and people with DR-TB and reduces fear during prolonged interactions. TB Champions can address and alleviate perceived stigma, if any, associated with wearing a mask. Reframe masks as a sign of care, professionalism, and self-respect rather than fear.
- A distance of at least two meters must be maintained while interacting with people with TB or those with symptoms. TB Champions must speak with their masks on and encourage the same of those they interact with.

- While interacting with people with TB, TB Champions must convey to them that they should wear a mask as well. During visits to the home of a person with TB, TB Champions can continue to wear a mask and try to have interactions outdoors if possible.



Sub-section 2: Balancing being a TB Champion with other responsibilities

Some guidelines for TB Champions:

- Draw boundaries between the work you do for people with TB and your other work and family time. This is especially important when supporting people with DR-TB, where contact may be of a longer duration.
- Do inform people you care for as to what time you would prefer to be contacted. They can contact you outside those hours in case of an emergency.
- There are some practices you can adopt to define boundaries between your work as a TB Champion and your other responsibilities.
- For ex: You can leave the bag containing all documents related to TB in a cupboard / drawer or a bag in the living room. Once you have put the bag / documents in its place, pick it up only when you are stepping out to carry out TB Champion activities.
- You can use the badge similarly, pinning it to your clothes when you undertake TB Champion activities. Remove it and keep it safe when you are spending time with family and taking care of other responsibilities.
- There may be times when you feel burnt out and tired from supporting people with TB. Even doctors, nurses and other healthcare professionals feel this fatigue once in a while. When this happens, do not feel bad – take a day or two off from the role of a TB Champion. Understand that burnout does not mean failure; it is a sign that your body and mind are asking for rest. Stepping back temporarily helps ensure you can continue contributing in the long run.
- Talk to other TB Champions who have been assisting people with TB. Learn from them what you could do differently to prevent a burn-out or how to deal with a burn-out. Peer support within survivor-led networks is one of the strongest protections against burnout.



Sub-section 3: Dealing with the loss of a person with TB

- An estimated 10-15% of people with TB lose their lives annually. Loss may be more visible among people with DR-TB (even though treatment outcomes are far better in present in comparison to in the past).
- While providing psychosocial support to people with TB, it is important to remember that any adverse effects or deterioration in health should be brought to the notice of medical officers immediately.

Some guidelines for TB Champions:

- In case a person whom you have been taking care of passes away, it is natural to feel sad, it is normal to grieve. Feeling grief does not mean you did something wrong.
- Make sure you are eating well, sleeping well and exercising every day.
- Spend time with the family of the person with TB. They will appreciate your being with them. Your presence can be meaningful even when words feel inadequate.
- Take time to reflect and think about your feelings. Some of us process our feelings quickly and return to our normal lives, some of us take a little longer. There's nothing wrong with having some 'down time'. At the same time, if a person's loss is affecting you for longer than you would have expected it to, reach out to other TB Champions or to the survivor-led network.
- If a TB Champion you know is grieving/ feeling low and is not getting better, try and arrange for counselling.

FACILITATOR NOTES FOR WRAPPING UP THE SESSION

I. Summarizing the session

- The facilitator must remind all TB survivors on the importance of testing for TB every six months, for up to two years after recovery (or as per the respective country's post-treatment guidelines).
- The facilitator can emphasize the use of masks by TB Champions and people with TB.
- The facilitator must stress on drawing boundaries and preventing burnout.
- The facilitator can remind participants that outcomes for people with DR-TB are improving – newer treatment regimens are shorter, more effective, and less toxic than in the past, and treatment success rates are steadily increasing.

II. Connecting the dots

- Recall the mode of transmission of TB from the basics of TB session, that it is airborne. TB, like COVID-19, spreads through the air and hence masking is important to protect TB Champions from either of these illnesses.
- Link this session to the emotional needs of people with TB. TB Champions should seek mental health support for themselves and the person with TB if the emotions they are dealing with are affecting their daily activities and relationship with families.
- Connect this session with the structure of the NTP and how it links to mental health services provided by the Ministry of Health or any private entities.

MODULE 5:

TB SURVIVOR-LED NETWORKS

OPENING GUIDANCE FOR FACILITATORS



TIME REQUIRED

60 minutes



NUMBER OF SESSIONS

One

Session Structure



- Module 5, the final module is done over one single hour-long session. This session is ideally led or facilitated by a founding member of an existing network. If possible, this should include someone with experience of DR-TB advocacy or network-led change.
- The module includes a total of three sub-sections, each of which can be covered over 20 min each:
 - What are networks and what can they do?
 - How are networks formed?
 - Role of network in TB care and prevention
- Facilitators should emphasize that survivor-led networks have played a critical role in improving TB and DR-TB care globally and nationally.
- This module should be framed as a hopeful, forward-looking session that shows how collective survivor action has already led to better treatments, policies, and support systems—especially for DR-TB.

Objectives of the Session



To understand the significance and potential of networks as a means of advocacy and community strengthening including for relatively complex challenges such as DR-TB.



To describe the processes that can be adopted for effective network-building that includes DR-TB survivors and caregivers.



To describe the scope and responsibilities of survivor-led networks in improving TB and DR-TB outcomes.

Expected Learning Outcomes

- Participants have clearly understood the power of networks, and their role in building them. They recognize that collective survivor action has already improved DR-TB response.
- Participants are equipped with the preliminary knowledge and skills required to build a strong network.
- Participants have understood the role and scope of networks in assisting the programme across various areas of TB care and prevention.

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

Suggested methods

- Presentation
- Open discussion
- Small Group activity



Materials required

- PPT
- Chart Papers
- Markers
- Double sided tape



Why learn about or form TB survivor networks

- Collective action can sometimes have a far-reaching and greater impact than individual efforts. This has been especially true for DR-TB, where survivor-led advocacy has contributed to shorter, safer, and more effective treatment options.
- Survivor-led networks that have been established physically and virtually for several diseases have been a source of support, guidance and inspiration to people who are newly diagnosed with an illness. For people starting DR-TB treatment, networks can be a vital source of hope and practical guidance.
- A network is a critical structure that can communicate with the programme in ways the individual TB champions may not be able to.

Setting the context

- The facilitator begins the session by asking the group to provide the first word that comes to their mind when they think of networks. These responses would be listed on a flip chart.
- The facilitator crowdsources the reasons for forming a network and then shares the relevant slides.
- The facilitator can show short videos of the work of networks to provide an idea of the kind of thematic areas that the network can work in.
- The facilitator leads the participants through the short group exercise described in this section.

OTHER PRE-TRAINING NOTES FOR FACILITATORS

- The facilitator must also emphasize the importance to build partnerships with others working on TB, to leverage and share resources whenever possible.
- Networks are an important tool for advocacy. The facilitator must amplify this in the presentation and provide examples of existing networks.
- Facilitators should highlight concrete examples where survivor networks have influenced DR-TB policies, access to medicines, or patient support.
- If time permits, the facilitator can also introduce other team-building exercises.



Sub-section 1: What are networks and what can they do

- Networks are a closely connected group of people who work towards a common goal. Networks of People living with HIV have demonstrated how successful a network can be in supporting people with HIV and improving the quality of services for HIV. Similarly, TB survivor-led networks—including those led by DR-TB survivors—have shown that collective voices can influence programmes, reduce stigma, and improve quality of care.

- Similarly, TB survivor-led networks have the potential to work alongside NTPs to ensure that the concerns of people with TB are conveyed to the programme and to ensure communities are aware of the scope of services and benefits available to them. This partnership has already contributed to better DR-TB treatment approaches and more people-centered services.



Sub-section 2: How networks are formed

- The first step is a recognition by the group or potential members of the need for a network.
- Once this decision has been taken, members should discuss and agree on the objective of a network, and what they hope to achieve. For example, objectives may explicitly include improving DR-TB care, support, and treatment outcomes.
- They can identify the geographies they plan to work in as well as how the network will expand and more members can be identified.
- The criteria for membership should be discussed (e.g.: only survivors, those currently on treatment, family members, TB-affected communities, etc.). Including people currently or previously on DR-TB treatment can strengthen the network's relevance and credibility.
- The networks can also discuss reaching out to and bringing into the group people who are affected by TB, how this outreach can be done, what materials would be needed to sensitize potential network members and how they will be enrolled in the network.
- Networks can define the establishment of district chapters, the role of district chapters and the mechanism of coordination with the district chapters. This is a future priority and not necessary during this workshop.
- At the next stage and once formed, networks should develop a road map and workplan and also put in place governance mechanisms.
- Network members should take a decision on registration of networks and their legal status.
- Do the members want legal registration?
- A network should identify its key functionaries such as the president, secretary, treasurer who will be engaged in taking the necessary steps regarding registration and network activities.
- A network should ensure that there is good representation from different genders and from underserved populations. This is especially important for DR-TB, where vulnerability and stigma may be compounded.



Sub-section 3: Role of networks in DR-TB care and prevention

- Networks can provide real-time feedback to the NTP regarding availability of care, support and services in different health facilities and the community.

- Networks can effectively advocate for interventions / services that benefit people with TB. These services could include medications, diagnostic tests or services such as counselling for both people with DS and DR-TB. While individual advocacy at different levels is important, networks are likely to be more effective in calling attention to critical gaps or issues related to TB. Survivor-led networks have been instrumental in advocating for improved DR-TB regimens, diagnostics, and psychosocial support.
- Networks can mobilize resources from multiple stakeholders to support people with TB who are in need of financial support to meet their medical / hospitalization expenses, to ensure that malnourished people with TB receive adequate nutritional support or to make arrangements to assist with rehabilitation of someone who has completed DR-TB treatment.
- Networks can act as a source of knowledge for its members and people with TB – networks can update themselves on the availability of different tests or schemes and pass on this information to the members.
- Networks can also organize events alone or in coordination with other civil society organizations in order to increase awareness about TB, to mitigate stigma against TB and to address misconceptions prevailing in the community.
- Networks can provide psychosocial support to its members who have recovered from TB and continue to live in challenging situations. The strong bond that develops between the members of a network forms an effective social net which the members can seek support from.

GROUP ACTIVITY

Following the discussions, participants are divided into **four small groups**. Each group gets a thematic area to discuss (Advocacy and provision of feedback to NTP, community awareness, supporting People with TB and enrolling/building capacity of new members).

Facilitators should encourage groups to include at least one example related to DR-TB to illustrate the added value of collective action.

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

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

FACILITATOR NOTES FOR WRAPPING UP THE SESSION

I. Summarizing the session

- The session concludes with a quick summary of the importance of important points of the session.
- The facilitator should also emphasize that many improvements in TB and DR-TB care today exist because survivors organized, spoke up, and worked collectively. Reinforce that while challenges remain, DR-TB outcomes are improving, and survivor-led networks are a key reason why. Networks remain essential to sustaining and advancing these gains.
- The facilitator, after the session, asks the participants if they want to form a network in their country (if the network is not already formed). If the network is already in existence, the facilitator informs participants about the network and its work.

II. Connecting the dots

- The collective knowledge of networks on TB can help in building capacity of new members and to ensure newer services are available to people with TB. This includes passing on up-to-date information on improved DR-TB diagnostics, regimens, and support systems.
- There is some overlap between the roles of the TB Champions and the roles of networks but the scale at which these roles are carried out is larger in case of networks.



CLOSING SESSION:

MIND MAP ACTIVITY

Time required: 30 minutes

Objectives

- To consolidate the knowledge gained by participants over the three days
- To encourage TB Champions to identify specific areas where they can begin work
- To help participants recognize how far TB and DR-TB responses have come, and where survivor action can accelerate further progress

Expected learning outcomes

- Participants are able to create a map containing several interventions discussed throughout the training.
- Participants are able to identify which areas/ interventions need strengthening.
- Participants are able to identify areas where TB and DR-TB services have improved, and where continued advocacy and engagement are known to make a difference.

Suggested methods



Group
work

Materials Required



Charts
and markers

Why a mind-map

- A mind map is a visual representation of the combined knowledge of all participants that will help individual participants and the potential network to plan activities.
- It helps make visible the progress already achieved, especially in DR-TB diagnostics, treatment, and support.
- The mind map will act as a foundation of knowledge on which newer ideas and developments can be built upon. This includes knowledge of newer, more effective approaches to DR-TB care that did not exist a decade ago.

Setting context

- Reiterate that there are several elements to a comprehensive TB response and that community engagement is one of them.
- Emphasize that improvements in DR-TB outcomes are the result of multiple elements working together—including survivor leadership.
- Having this rough mind map as a starting point, TB Champions and networks can advocate for strengthening of certain interventions or introduction of those that are absent.
- Encourage participants to see themselves as contributors to the next phase of improvement, not just observers of the system.

Session Content

- Divide the TB Champions into two to three groups and ask them to create a mind map of several interventions required to achieve the goal of TB elimination. Ask groups to explicitly include DR-TB-specific interventions and supports in their maps.
- The facilitators could show the sample of a mind map as a demonstration.
- The facilitators could help group several intervention pieces under broad heads, as outlined in the Pathways exercise. For example, Detect/Search, Treat, Prevent are all broad categories. Facilitators may prompt: “Where have we already seen progress? Where are outcomes better than before?”
- The groups can be allowed to present their mind maps for a few minutes each and the facilitator can summarize the presentation and add to the interventions the TB Champions have identified.

FACILIATOR NOTES FOR WRAPPING UP THE SESSION

I. Summarizing the session

- TB Champions can play an important role in the evolution of the programme and services provided. The mind map they just constructed is the big picture that all stakeholders can use as a starting point.
- The facilitator should summarize the session asking the participants to take photos of the mind map on their phones and save this for future reference.

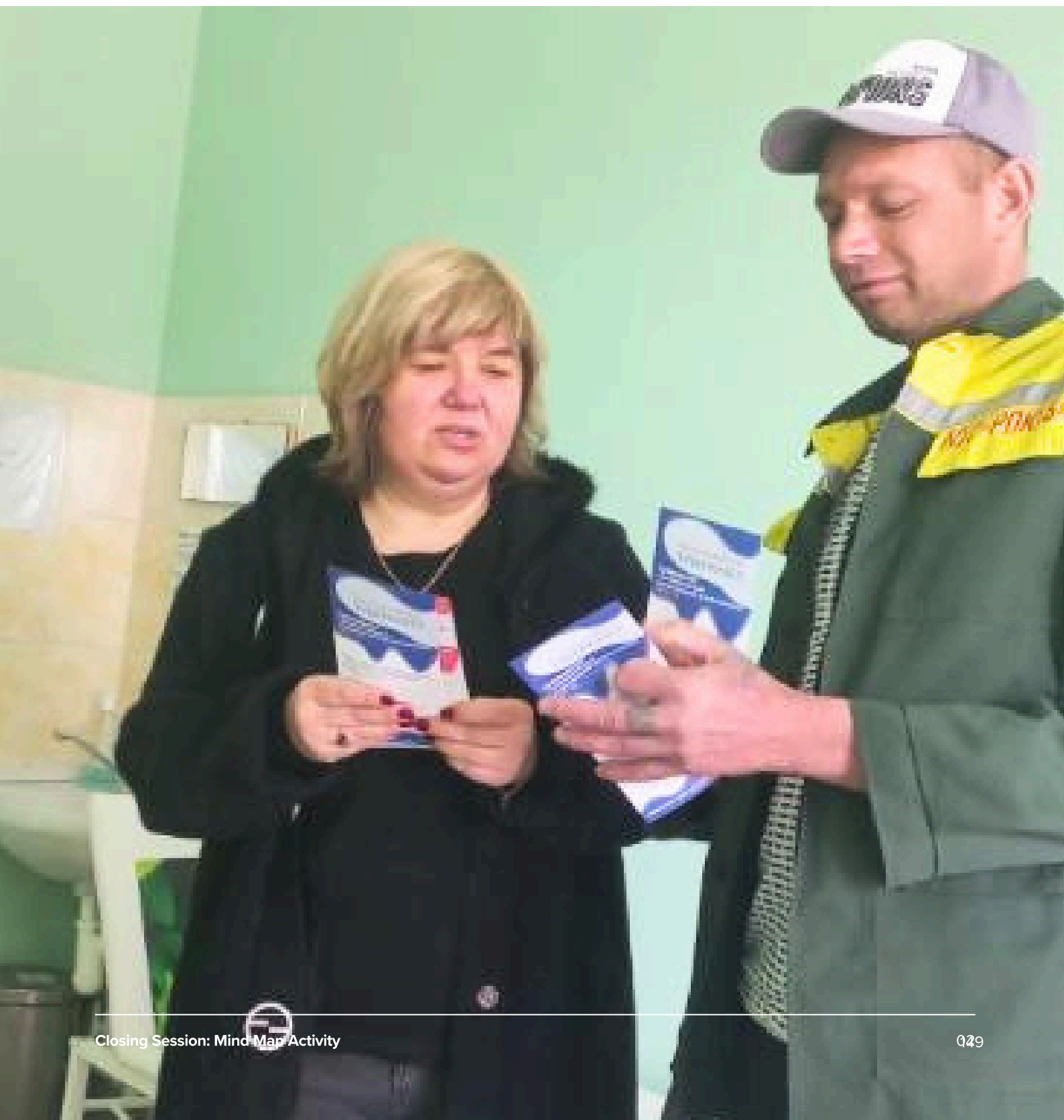
II. Connecting the dots

- The mind map developed as a part of this exercise is a reference image stored in the minds of participants from which they can draw information while advocating to different stakeholders.
- The mind map can also be used to provide context for feedback that is provided on TB forums or other platforms.

The workshop can end with a brief valedictory session, chaired by a TB Champion, an elected representative, a senior health official or a key influencer.

The workshop should close on a note of recognition and hope.

The chairperson may be requested to acknowledge the commitment of TB Champions and affirming that collective survivor action has already changed TB and DR-TB care for the better. Participants must be given certificates and their active engagement over three days appreciated. Participants must also be made aware of potential engagement plans and ways in which they can actively work as TB Champions.



ANNEXURE 1

AGENDA FOR THE CAPACITY-BUILDING WORKSHOP

Note: this agenda is for reference only. Partners may adapt from this as relevant to their specific settings and based on the resources available for training.

DAY 1

9am – 9:30am	Registration and Pre-test
9:30am – 10:15am	Opening Session (Introductions, workshop expectations, objectives)
10:15am – 11:45am (tea during the session)	Module 1: TB Science – getting the basics right
11:45am – 1:15pm	Module 2: The TB burden and the response
1:15pm – 2:15pm	Lunch
2:15pm – 3:45pm	Module 3, session 1: Our TB Stories
3:45pm – 5:15pm	Module 3, session 2: Pathways to Cure
5:15pm – 5:30pm	Closing reflections
9am – 9:30am	Registration and Pre-test
9:30am – 10:15am	Opening Session (Introductions, workshop expectations, objectives)

DAY 2

9am – 9:30am	Recap and opening reflections on Day 1
9:30am – 10am	Module 4: Role of a TB Champion (introduce the role, show some short films etc.)
10am – 12 noon (tea during the session)	Module 4, session 1: Supporting people with TB and DR-TB
12 noon – 1pm	Module 4, session 2: Improving community awareness on TB and DR-TB
1pm – 2pm	Lunch
2pm – 4pm	Module 4, session.3: Advocating for TB and DR-TB
4pm – 4:15pm	Tea
4:15pm – 4:45pm	Module 4.4: Addressing Stigma and Discrimination
4:45pm – 5:30pm	Module 4.5: Community-led monitoring and giving feedback to the health system

DAY 3

9am – 9:30am	Recap and opening reflections on Day 2
9:30am – 10:30am	Summarize role of a TB Champion Module 4.6 Practicing Self-care
10:30am – 12:30pm	Module 5: Survivor-led networks
12:30pm – 1:30pm	Lunch
1:30pm – 2:30pm	Mind map exercise
2:30pm – 4pm	Engagement modalities if relevant (explain how TB Champions will be engaged, what is expected of them, reporting requirements, financial compensation etc.). Confirm consent to participate in the project.
4pm – 5pm	Valedictory session Feedback from participants Post-test form

ANNEXURE 2

OPENING GROUNDING EXERCISE

Time required: (5–7 minutes)

When to use this: At the beginning of Module 3, Session 1: Our TB stories

Purpose: Arrive, feel safe, and choose how much to share

Exercise: “Arriving in the room”

Facilitator script (adapt language as needed):

“Before we begin sharing our TB stories, let’s take a few minutes to arrive—physically and emotionally. This is not a test, and there is no right or wrong way to feel here. You are always in control of what you share.”

1. Gentle settling (2 minutes)

- Ask participants to sit comfortably, feet on the ground.
- Invite them to notice:
 - One thing they can feel (feet on the floor, chair under them)
 - One thing they can hear
 - One thing they can see in the room
- No need to close eyes; eyes can remain open.

1. Choice-based check-in (3–4 minutes)

- Ask participants to reflect silently on this prompt: “As we begin this session, notice where you are today—emotionally and physically.”
- Then offer one of two ways to respond (choice is key): Share one word that describes how you are arriving today. Or simply say ‘I’m here’
- Go around the circle once. The facilitator only listens; does not comment or respond.

This exercise grounds people in the present, not in the trauma. It also signals choice and control from the very start, lowers pressure to “perform” a story and creates emotional safety without forcing vulnerability.

ANNEXURE 3

CLOSING GROUNDING EXERCISE

When to use this: At the beginning of Module 3, Session 1: Our TB stories

Time required: 6–8 minutes

Purpose: Contain emotions, restore regulation, and transition out safely

Exercise: “Placing the story down”

Facilitator framing (important):

“When we share our stories, we open something meaningful—and sometimes heavy. Before we leave today, we’re going to take a moment to gently close this space, so no one carries more than they need to.”

1. **Guided reflection** (2–3 minutes): Invite participants to sit comfortably again.
2. **Slowly read:** “Take a moment to notice what you’re carrying right now—emotionally or in your body. Now, imagine that everything you shared, heard, or felt today can be placed somewhere safe—for example, in a box, on a shelf, or wrapped carefully in cloth. You are not throwing it away. You are simply choosing not to carry it all with you right now.”
3. **Pause for silence.**
4. **Anchoring back to the present** (2 minutes): Ask participants to:
 - Take one slow breath in, and one slow breath out (twice)
 - Press their feet gently into the ground
 - Notice the room again
5. **Closing round:** future-oriented and light (2–3 minutes): Invite each participant to complete one of the following sentences (their choice):
 - “One thing I’m taking with me from today is...”
 - “One thing I will do to take care of myself after this session is...”

Emphasize: short responses only. No explanations needed.

Why this works:

- It contains emotion rather than amplifying it
- It avoids abrupt endings after vulnerability
- It brings attention back to the body and present moment
- It supports participants who may be returning to work, travel, or family immediately after

NOTES

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