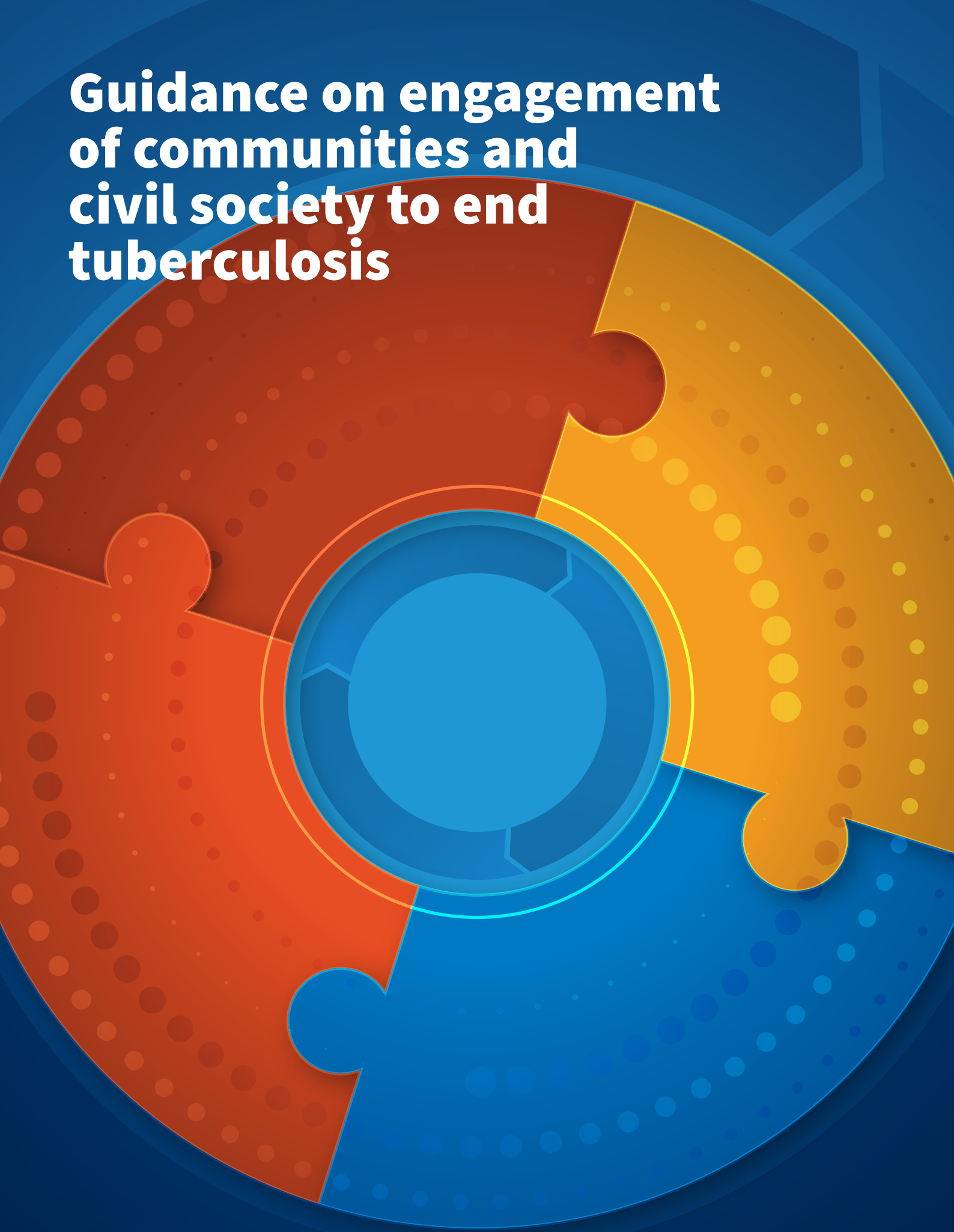
Guidance on engagement of communities and civil society to end tuberculosis



World Health Organization

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Foreword by the WHO Director-General

We are at a critical juncture in the fight to end tuberculosis. Decades of progress have been reversed by the impact of the COVID-19 pandemic, compounded by other major challenges, including chronic underfunding of the global tuberculosis (TB) response and insufficient action on the social determinants of TB. Partnerships are critical in revitalizing efforts to end TB by finding, treating and preventing TB, through action within and beyond the health sector.

This guidance recognizes the special synergy of communities and health systems when they work together in the fight against TB. It describes ways for communities and health systems to partner in the fight to end TB through primary health care as the foundation of universal health coverage. While communities have always been a part of TB service delivery, WHO is committed to placing their lived experience at the centre of the TB response and encouraging health systems to systematically listen to and learn from communities in the response to TB and other health challenges. We will be able to accomplish much more and to reach the end TB targets faster by working hand in hand.

The WHO Civil Society Task Force on TB has been instrumental in bringing this document to fruition, and we encourage community partners, ministries of health, their national TB programmes and other relevant sectors to strengthen their relations in order to identify local problems and innovative solutions to reverse recent trends.

We thank all people who are engaged in the fight to end TB. No one stakeholder can do it alone. This guidance offers concrete pathways for moving forward, together.

Dr Tedros Adhanom Ghebreyesus
Director-General, World Health Organization

Foreword by the Director of the WHO Global Tuberculosis Programme

TB is a global public health threat, with around 10 million people falling ill with the disease and more than 1 million people dying from the disease every year. Around one third of people who develop TB globally are either not reached by TB services or are not reported to the national TB programmes.

The COVID-19 pandemic has reversed years of progress in providing essential TB services and in reducing mortality from TB. Furthermore, the response to COVID-19 demonstrated the important role of communities in any health response. Engagement of communities affected by TB and civil society is critical to improve the reach and sustainability of interventions to address TB and facilitate universal access to timely, people-centred TB services.

The WHO End TB Strategy, aligned with the United Nations Sustainable Development Goals, emphasizes the role of communities and civil society in the global fight to end the TB epidemic by 2030. Furthermore, the political declaration of the 2018 United Nations General Assembly High-level Meeting on TB calls for integrated, people-centred, community-based, gender-responsive health services and strengthening of public health systems, including community care services. The WHO Multisectoral Accountability Framework to accelerate progress to end TB (MAF-TB) promotes engagement of various sectors, including communities.

Despite progress in engaging communities in the TB response, more remains to be done to achieve and sustain meaningful engagement. This guidance promotes engagement of communities in planning, decision-making, promoting sustainable, fair financing, and facilitating the contribution of communities to monitoring and implementing the TB response. It emphasizes the close engagement and involvement of communities affected by TB and civil society to achieve people-centred services for people affected by TB, through close and sustainable partnerships with ministries of health and national TB programmes. This is in line with the global move towards universal health coverage and the vision of resilient health systems with communities as part of the continuum, according to the WHO's Primary Health Care Framework.

I thank all stakeholders, and especially the WHO Civil Society Task Force on TB, for their contributions to the development of this guidance. I look forward to seeing the results of the operationalisation of the principles and approaches included in this guidance, as part of our collective efforts to end TB.

Dr Tereza Kasaeva
Director, WHO Global Tuberculosis Programme

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Acronyms

CLM	community-led monitoring
COVID-19	coronavirus disease 2019
CSO	civil society organization
GTB	WHO Global Tuberculosis Programme
MAF-TB	Multisectoral Accountability Framework for TB
NTP	national tuberculosis programme
PHC	primary health care
TB	tuberculosis

Glossary

Community: Usually defined as a local geographical subset of society; can also be defined by commonalities such as norms religion, shared interests, customs, values and needs of citizens *(1)*.

Community engagement: The process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impacts and outcomes in the community *(2)*.

Community health worker: Usually, people with some formal education who are trained to contribute to community health services, such as TB prevention and patient care. Their profile, roles and responsibilities vary widely among countries. Community volunteers are community members who have been systematically sensitized about selected health topics, either through a short, specific training scheme or through repeated, regular contact with professional health workers *(3, 4)*.

Community-led monitoring (CLM): A form of systematic feedback organized by a community to improve the quality of and access to health-care services in collaboration with health system partners. Contributes to accountability. The process is led and implemented by the community and in consultation with health system partners. CLM provides evidence on what should be improved and provides suggestions to improve outcomes. It focuses on local fact-finding to solve problem and meet the needs of local communities.

Civil society organization (CSO): Non-profit organization that operates independently from the state and from the private for-profit sector. Includes a broad spectrum of entities, such as international, national and local nongovernmental organizations, community-based organizations, faith-based organizations, patient organizations and professional associations. Community-based organizations are non-profit organizations based on volunteer membership, usually self-organized in specific areas (such as a village) to increase solidarity and mutual support to address specific issues. Examples include HIV support groups, women's groups, parent–teacher associations and micro-credit village associations. Usually, all members of a community-based organization are community members; these organizations are therefore considered to most directly represent the community *(3)*.

Health centre committee: A committee (sometimes called a "local health committee") responsible for the governance of a health centre; usually composed of local government counsellers, members of the community served by the health centre and the health centre manager.

Meaningful engagement: Engagement with communities as equal partners, including information about the needs and services related to local issues, to empower them as leaders in identifying problems and co-creating solutions to a specific challenge, such as TB *(5)*.

People-centred: All decisions on planning and services for TB, including development of national strategic plans, involve people affected by TB, to ensure people-friendly, efficient, affordable services.

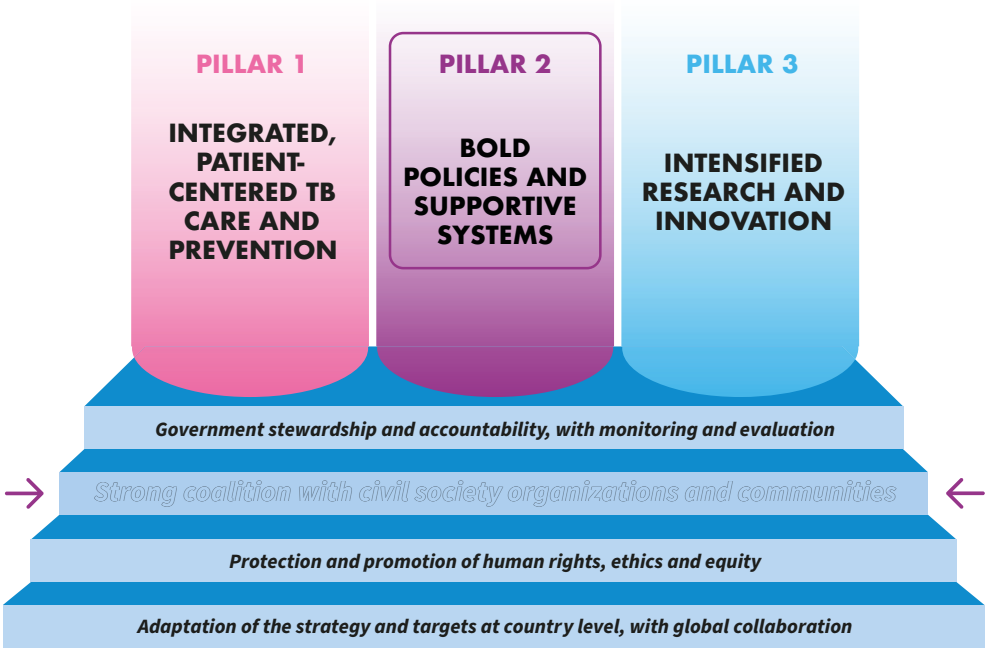
Person affected by TB: Refers to any person with TB disease or who previously had TB disease, as well as their caregivers and immediate family members, and members of key and vulnerable populations, such as children, health-care workers, indigenous people, people living with HIV, people who use drugs, people deprived of their liberty, miners, mobile and migrant populations, women and the urban and rural poor *(6)*.

1 Introduction

TB remains one of the deadliest infectious diseases, with an estimated 1.6 million deaths due to TB in 2021. The 2022 WHO *Global TB Report (7)* noted that the numbers of people with notified TB had fallen in the previous 2 years and the number of deaths had risen for the first time, reversing years of decreases in these numbers between 2005 and 2019, because of COVID-19 *(8).* To address these recent losses in progress, accelerated efforts to reach the goal of ending the TB epidemic by 2030 at global, regional and national levels are necessary, in partnership with civil society and people affected by TB.

Launched in 2014, the End TB Strategy envisions a world free of TB, with zero deaths, disease and suffering due to TB. It consists of three pillars, with four underpinning principles. Its three key targets are an 80% decrease in the number of new cases, a 90% decrease in the number of people dying of TB by 2030 as compared with 2015, and elimination of catastrophic costs for families affected by TB *(9).* "Building a strong coalition with civil society and community" is one of the principles of the End TB Strategy and a major component of pillar 2 (Fig. 1).

Fig. 1. **The End TB Strategy**



Source: WHO (9)

The political declaration of the United Nations General Assembly High-level Meeting on TB in 2018 *(10)* includes commitments by Member States for:

- ensuring strong and meaningful engagement of civil society and communities affected by TB in the planning, implementation, monitoring and evaluation of the tuberculosis response, within and beyond the health sector.

This requires the engagement of people affected by TB as equal partners with the health system and facilitating their empowerment to contribute to the response as experts on local needs and priorities.

Community engagement, defined by WHO as "a process for developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes", is central to achieving health for all *(2)*. Community engagement is also central to achieving Sustainable Development Goal 3, towards good health and well-being, which includes a target for ending TB by 2030 *(11).*

1.1 Rationale for updating the guidance

Communities and their representatives are valued partners in many national TB programmes (NTPs) *(8)*. Despite progress made in engaging communities as valued partners and geographical extension of community-based TB activities within and between countries affected by TB, much remains to be done to achieve meaningful engagement of communities in efforts to end TB. The 2012 WHO ENGAGE-TB approach *(3)* provides a framework for NTPs to engage with nongovernmental organizations and communities. The importance of community and civil society engagement to end TB has been highlighted in various strategies and global commitments. The WHO End TB Strategy, aligned with the United Nations Sustainable Development Goals, emphasizes the role of communities and civil society in ending the TB epidemic by 2030. Furthermore, the political declaration of the 2018 United Nations High-level Meeting on TB highlights the need to develop integrated, people-centred, community-based, gender-responsive health services.

The process for developing this guidance included an evaluation of community engagement in countries, a rapid review of evidence on global health agendas and advances to support the End TB Strategy and open consultation with a wide variety of stakeholders. The evaluation included a desk review of data on communities and TB provided annually by Member States, an in-depth desk review of information on six high-burden countries, and interviews with stakeholders. The rapid evidence review comprised a literature scan and a review of advances in global health related to community engagement to end TB. The review indicated that many communities have been engaged in service delivery, with weak involvement in national platforms for governance and joint planning, decision-making and monitoring. Both the evaluation and the desk review recommended alignment with global health priorities for universal health coverage and development of new indicators to better measure community engagement.

The table below summarises key observations from the evaluation:

Key findings:

- commendable progress in community engagement, as evidenced by the number of countries reporting community contributions to TB notification, successful treatment of people who received community support for adherence to treatment, and the number of health centres that engaged communities in referring people with TB symptoms

Challenges:

- lack of a sustainable, systemic approach to community engagement;
- insufficient investment in community system development;
- major focus on service delivery;
- weak institutional and managerial capacity of community networks and community organizations; and
- insufficient indicators to track community engagement beyond service delivery and insufficient use of community-related data for programme planning.

Way forward:

- sustainable system approach to community engagement aligned with global health priorities based on the PHC framework for universal health coverage;
- an enabling environment, including sustainable financing for community engagement;
- definition of meaningful engagement with the full spectrum of community engagement;
- capacity-building in communities and civil society for meaningful engagement to end TB; and
- indicators to track meaningful engagement of civil society and communities beyond service delivery.

The *WHO guidance on engagement of community and civil society to end TB* was developed in collaboration with civil society and other partners, in order to further strengthen engagement and leverage capacities of communities and civil society in line with the End TB Strategy. The guidance emphasizes the complementarity of health systems and community systems; the key roles that people affected by TB should play in planning, decision-making, implementation and monitoring; and the role of ministries of health and their NTPs. It underlines the importance of fair, sustainable financing and of a policy environment for community and civil society engagement.

1.2 Intended readership

The purpose of this publication is to provide guidance for communities and for all stakeholders in the health system on working together to end TB and to strengthen people-centred care. Stakeholders in national responses to TB vary in different countries, but usually include ministries of health, other government ministries, the private sector, civil society and communities affected by TB, academic and research institutions, and technical and funding partners. The terminology and language used in this guidance is intended to be easily understandable by wider groups of readers, such as community groups, CSOs and nongovernmental organizations working in various developmental sectors.

1.3 Use of the guidance

Community and civil society engagement is significantly influenced by the local context. Activities to address TB are implemented mainly at the lowest health facilities and at community level. The diverse conditions in most countries (e.g. heterogeneous populations, geography, culture, social norms and TB disease burden and determinants) must be considered in the approach to engagement of communities and civil society. Engagement should be context driven and community-led, and a top–down or standardized approach is unlikely to result in meaningful engagement. Innovations in engagement should be encouraged, and this guidance proposes key principles and provides some practical examples, which can be adapted to the local context and adopted.

1.4 Key principles

Meaningful community and civil society engagement to end TB requires that people affected by TB are equal partners in the TB response, with ministries of health and their NTPs. As equal partners, community members are empowered as experts on local needs and priorities. The following key principles were developed by representatives of communities, ministries of health and their NTPs and stakeholders in the fight to end TB.

- **Health and community systems must be considered complementary, within one system.** Health systems and community systems represent a continuum of roles and actions. In the notion of "one system", this guidance provides a framework for communities and civil society to engage in the TB response at the nearest level of health services, as experts on community needs and solutions, with an emphasis on the primary health care (PHC) concept, with community empowerment, integrated care and multisectoral action.

- **Shift towards meaningful community engagement.** Meaningful engagement is a dynamic process that keeps people at the centre of the response to TB and ensures their empowerment. It empowers community members to be leaders in identifying problems and co-creating solutions with ministries of health and their NTPs to specific challenges. The community is considered a partner in the entire process, starting from planning, not only as an additional work force for service delivery. Health systems should work with community leaders and representatives to define stakeholders who can meaningfully engage in the TB response, with their strengths, capacities and specific roles. When necessary, civil society can bridge gaps between health systems and people affected by TB.

- **The full spectrum of community engagement should be considered to end TB.** Community engagement for the TB response includes engagement in governance, policy development, decision-making, implementation, monitoring and evaluation at various levels, from local health facility to national level. Examples include development of strategic plans for TB, programme reviews, technical working groups, resource mobilization, advocacy, demand creation, monitoring and evaluation, community-led monitoring, research and provision of TB services.

- **An enabling environment is a prerequisite for meaningful engagement,** to achieve the desired results. The implementation approach described in this guidance includes sustainable financing, legal and policy frameworks and a coordination platform to discuss with ministries of health and their NTPs as enabling factors. These are facilitated by use of continuous learning that builds on existing WHO recommendations, including WHO's multisectoral accountability framework (MAF-TB) *(12)*, to empower communities as equal partners in planning, deciding, implementing and evaluating national plans to end TB.

- **Meaningful engagement must be measured to track progress.** A comprehensive set of indicators is necessary to track the extent of meaningful engagement with communities and civil society to end TB in countries. This guidance includes indicators for global reporting and a checklist of questions that can help partners to identify quantitative and qualitative information on the level of community engagement at all levels of the TB response (Annex 1).

> To end TB, meaningful community engagement is necessary to acknowledge the strengths and aspirations of affected communities, such as people with TB and TB survivors. Harnessing the experiences, skills and insights of affected communities allows better tailoring of programmes and interventions, making them more community-centred and context-specific.
>
> **WHO Civil Society Task Force on TB**

2 Who are the community and civil society partners?

In this guidance, United Nations definitions for CSOs and community groups are used. A CSO is any non-profit, voluntary citizens' group organized at a local, national or international level *(13)*. In the context of this guidance, "community engagement to end TB" refers to communities and CSOs within and beyond the health system, individuals, groups and informal networks that "interact, coordinate, and deliver responses to the challenges and needs affecting their communities" *(14)*. These include people with TB and their families, those who have recovered from TB, people at risk of TB, advocates, religious and opinion leaders, local individuals, families and communities, community advisory boards for TB/HIV, and CSOs (Fig. 2). Formal community systems include registered CSOs, while informal systems can include unregistered but important networks of care providers, opinion leaders and other stakeholders. Both informal and formal community systems are important partners for health systems.

Fig. 2. **Partners in the "one system" to end TB**

2.1 Communities and civil society as equal partners

Equal partnership requires all stakeholders in the TB response to recognize each other's roles, responsibilities and comparative advantages, including people with TB as experts of the lived experience. Often, representatives of community and civil society voice their experiences and needs through engagement with individuals in the community, families, opinion and religious leaders, groups or networks or CSOs. Different partners are often involved in efforts to end TB, depending on the country and context.

2.2 Communities complement health systems

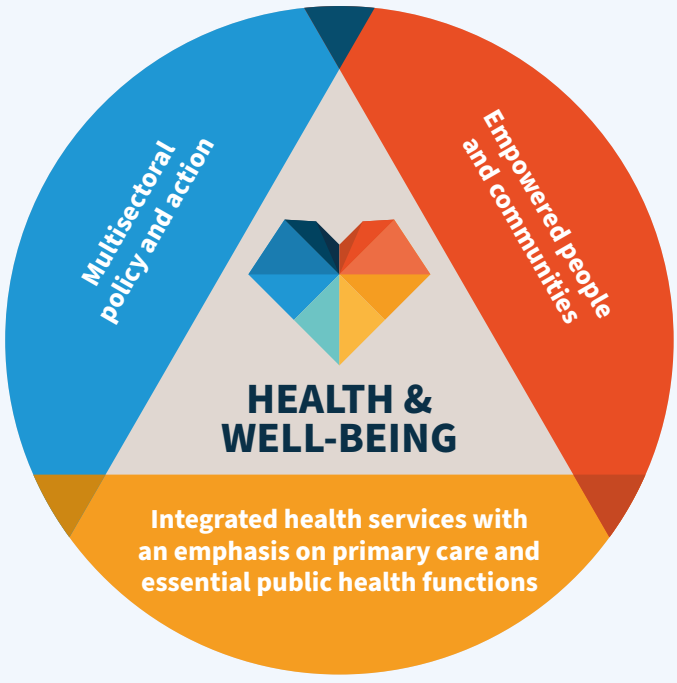
Communities have always played a role in the provision of TB treatment and care, as formally stated in the DOTS *(15)* and Stop TB *(16)* strategies, and are included more recently as foundational to WHO's End TB Strategy *(11)*. Consideration of communities and health systems as part of the same system strengthens the complementary partnership. This guidance acknowledges that the partnership is at various stages of maturity in different countries and promotes establishment and progressive strengthening of such partnerships as part of one system. Health professionals and community representatives share responsibility for deliberate engagement to end TB at local and national levels. While health-care providers provide health services, including diagnosis and treatment of TB, communities can complement them by providing vital information on the needs and priorities of people affected by TB. Furthermore, community representatives are well placed to mobilize their constituents to seek care, as they are aware of the context-specific challenges and solutions. Envisioning communities and health systems as complementary to each other helps to foster meaningful engagement with communities and civil society, towards a people-centred, holistic approach to health. The provision of people-centred services requires consideration of the experiences of people affected by TB in decision-making at all levels.

The political declaration of the United Nations General Assembly High-level Meeting on universal health coverage in 2019 includes commitments to build "people-centred, resilient and sustainable health systems that uphold the human right to health, promote social justice, empower individuals and communities and address the determinants of health" *(10)*. Primary health care is considered the most inclusive, equitable, cost-effective way to achieve universal health coverage. The complementarity between health systems and communities as part of the same system is a critical component of PHC, and the potential strategic advantages of the partners can advance achievement of this goal.

2.3 Community engagement in the context of PHC

The WHO concept of PHC comprises three interrelated, synergistic components: integrated health services with an emphasis on primary care and essential public health functions as central pieces; multisectoral policies and actions to address the upstream and wider determinants of health; and engaging and empowering individuals, families and communities for increased social participation and enhanced self-care and self-reliance in health. The PHC framework provides an opportunity for communities to increase awareness of TB and provide services for TB prevention, diagnosis and treatment in a human rights-based approach and to bring services closer to individuals and families (Fig. 3). Hence, the PHC framework provides a basis for the one system approach described below.

Fig. 3. **Primary health care components**



Source: WHO (17)

2.3.1 Empowered people and communities

Activities that are led by communities and respond to the needs of people affected by TB are often provided in small, informal structures based on the shared interests of local communities for social interaction. When communities are empowered and funded, they can be leaders in health solutions for social determinants of TB, such as nutrition support or health education and promotion *(18, 19)*. Political and financial support from the government and other partners are essential to strengthen community leadership and contribute to an enabling environment for meaningful community engagement.

In the context of the PHC framework, community engagement provides a means to make communities an integral part of collective action to end TB, with their active participation in planning, decision-making, implementing and evaluating *(20)* national and local responses to TB. This can be institutionalized by participation of communities on health centre governance. People affected by TB may also provide complementary services for people with TB at health facilities. Their work should be remunerated in accordance with local employment rules and regulations *(21)*. At national level, representatives of communities and civil society should be involved in planning and making decisions. They should include individuals from different groups working on TB in various contexts. NTPs can work with communities to create platforms and mechanisms for collective planning, implementing and evaluating the national response to TB (see section 5.5).

2.3.2 Integrated people-centred health services

Integrated people-centred health services constitute one of the major components of the PHC framework *(22)*. This component is consistent with one of the three central pillars of WHO's End TB Strategy *(9)* and can facilitate timely, high-quality care for people with TB, including for related comorbidities and determinants. WHO defines person-centred as "empowering people to take charge of their own health, rather than being passive recipients of services" *(23)* To promote empowerment through health services, integrated care in health centres should include community-led interventions to link people to services or support.

2.3.4 Multisectoral policy and action

As TB is driven by social and economic determinants, multisectoral action is necessary to address them and the impact of TB through national and local interventions. In 2019, WHO developed the Multisectoral Accountability Framework for TB (MAF-TB) to accelerate progress to ending TB by 2030 *(12)*. This framework has four components for strengthening accountability for the TB response nationally and globally, namely, commitments, actions, monitoring and reporting, and review. Civil society and communities have key roles to play in each of these components. (See Annex 2 of the MAF-TB *(24)* for more details.)

CSOs have successfully partnered with NTPs, with support from WHO, in conducting baseline MAF-TB assessments, including assessment of the engagement of civil society and communities in the national TB response *(25)*. Multisectoral policy and action require government commitment to promote human rights and dignity, special attention to vulnerable populations, and active involvement of civil society and people affected by TB in national strategic planning. Such policies also facilitate engagement of the broader community and civil society, such as those involved in other health programmes (e.g. HIV, maternal and child health, mental health) and those beyond the health sector (e.g. poverty reduction, education, environment) to address local drivers of the TB epidemic. This leads to synergy between community groups working in TB and those working in other areas.

SECTION 2.
TAKE-HOME MESSAGES

Health system considerations:

Review key principles (people-centeredness, “one system”, enabling environment) at national and subnational levels to initiate or strengthen interactions with communities affected by TB and CSOs.

Communities and CSO considerations:

Advocate for a strong TB response in line with the key principles (people-centeredness, “one system”, enabling environment) in order to build a common understanding with the TB programme at all levels, local government and related stakeholders, by reviewing their status, identifying challenges and finding possible solutions.

“

The most crucial step in an effective TB response is identifying who your community is, as both a target and a key. They are a ‘target’ because they have the highest risk and are most vulnerable to TB, and they are ‘key’ because their voices and contributions, once they are enabled, can curb the TB pandemic.

WHO Civil Society Task Force on TB

3 What does meaningful engagement look like?

3.1 Levels of community engagement

Meaningful engagement keeps people at the centre of the TB response. *Community engagement: a health promotion guide for universal health coverage in the hands of the people (26)* lists five levels of community engagement, developed from the spectrum of public engagement framework, and adapted for this guidance. The levels are: inform, consult, involve, collaborate and empower. A move towards these levels of engagement will increase meaningful engagement to empower the community. All the levels require regular communication and involvement to nurture meaningful engagement.

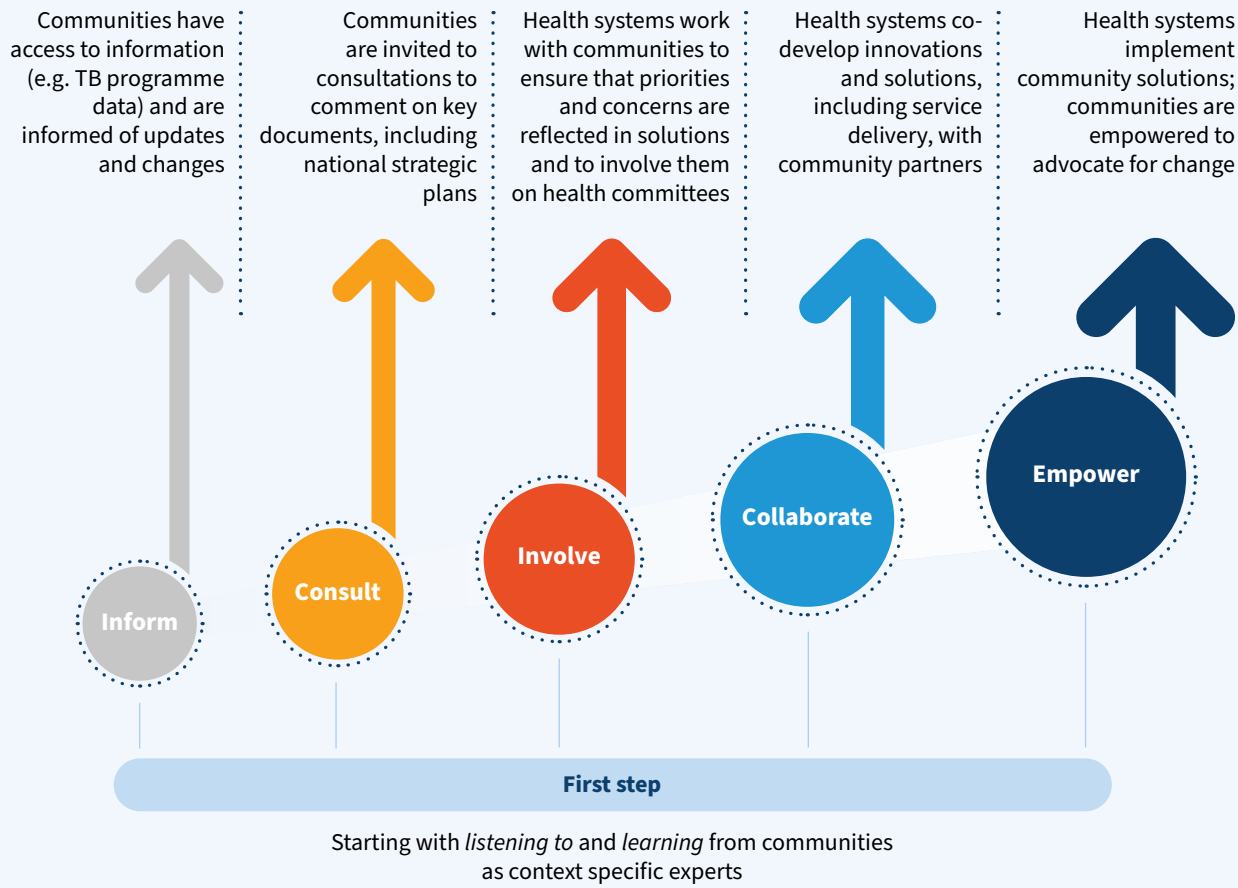
- "Inform" refers to dissemination of objective information to communities about a problem (e.g. a profile of the TB situation in the country or locality). This can also include opportunities for the communities to provide feedback.
- "Consult" refers to the level at which the community has opportunities to provide feedback, such as at meetings to develop a national strategic plan.
- "Involve" refers to the level at which the community is involved to ensure that their concerns and proposed solutions are considered.
- "Collaborate" refers to the level at which the community is part of the solution as an equal partner and which may implement projects and programmes.
- "Empower" refers to the level at which communities are involved in decision-making and have organizational capacity to advocate for changes in policy, for example.

As described in *Community engagement: a health promotion guide for universal health coverage in the hands of the people (26)*, levels of community engagement are useful for understanding the power dynamics and relations of communities in their interaction with the health system, and for using published information on tactics and practices to assist communities in further defining their engagement. Health systems should ensure that communities are encouraged to engage and to transition from informing and consulting community members to involving, collaborating with, and empowering them, as both a process and a goal.

3.2 Community engagement starts with listening

Listening to communities affected by TB and civil society can provide valuable insights into their health concerns and needs, which can inform effective TB response strategies. By listening to and engaging with communities, ministries of health and their NTPs (and health-care providers) can gain a deeper understanding of their needs and perspectives and tailor their strategies and efforts accordingly. Meaningful engagement begins with listening to community members and representatives and people who have had or have TB to understand their lived experience. Fig. 4 illustrates how the spectrum of public participation *(4)* can be adapted to start listening *(27, 28)*.

Fig. 4. **Levels of community engagement**



Source: Adapted from WHO (2)

In addition to their lived experience, communities understand the local context. Ministries of health and their NTPs, local government and health staff and providers may have to build their capacity for them to be able to effectively listen to the community. Meaningful engagement involves ongoing dialogue with the community, with deliberate effort to reach out to those least powerful in the process, community-based participatory research and community participation for decision making *(29)*. Learning from and listening to communities are important to capture the local knowledge and power at the start of the engagement spectrum (Fig. 4).

3.3 Lessons from the COVID-19 pandemic and response

COVID-19 has demonstrated the importance and feasibility of communities and civil society playing critical roles in effective responses *(30, 31)*. Community engagement has been key to maintaining access to essential health care during lockdowns. As highlighted in *Progress towards the achievement of global tuberculosis targets and implementation of the political declaration of the high-level meeting of the General Assembly on the fight against tuberculosis (32)*, recovery from COVID-19 will require engagement with communities and CSOs to rebound from the huge number of "missing" people with TB due to the disruptions. In 2020, just over half of all the estimated number of people who fell ill with TB were newly diagnosed, with a slight increase in 2021 *(33)*. As part of efforts to provide health services during the pandemic, development and use of digital technologies accelerated globally, including digital technologies to support psychosocial well-being, patient rights, and adherence to TB treatment *(34)*. This has resulted in extended use of digital technologies by communities and a growing body of evidence on the importance of these technologies in securing favourable TB outcomes and better performance of NTPs *(35, 36)*.

3.4 Mapping stakeholders for community engagement to end TB

Stakeholder mapping is a continuous process that should be based on findings at every stage of planning *(37)*. Mapping of community and civil society stakeholders and their focus areas, competence and concerns at central or national, subnational and peripheral levels will help TB programmes to plan strong engagement in national and subnational responses to TB. National and local partner coordination platforms and similar fora can be used for sharing information and joint planning with civil society and people affected by TB. To support mapping exercise, Annex 2 lists the possible roles of different stakeholders, with examples of their comparative advantages and strengths and their potential capacity and roles in a national response to TB.

3.5 Civil society as a bridge between community, ministries of health and their NTPs

Civil society can play an important role in bridging the gap between the health system and people affected by TB. CSOs, which are registered organizations, can help communities to organize themselves and represent specific constituencies, monitor government policies and actions and hold the government accountable, while respecting their own roles, responsibilities and commitments *(38)*. At global level, CSOs can advocate for decision-makers to commit to meaningful engagement.

3.6 Reaching key and vulnerable populations

TB is closely linked to poverty and particularly impacts individuals and groups that face barriers to accessing services *(39, 40)*. In general, everyone who is exposed to someone with infectious TB can get infected. Some populations are however particularly vulnerable to TB. For purposes of this guidance, vulnerable populations are operationally defined as people at higher risk of exposure to TB or developing TB once exposed because of biological, structural or socioeconomic factors. Furthermore, the access of these populations to health services and the success of treatment may be less optimal than for other populations. Partnerships between health systems and communities are critical in identification of context-specific vulnerable populations who require additional attention in the TB response. Ministries of health and their NTPs, in collaboration with communities and civil society, should identify groups who require more support and may not be reached by health services due to their disadvantaged socioeconomic position or other reasons, including biological or geographical factors. As vulnerable populations may lack access to health services provided within the formal health system, community systems can play a vital role in identifying the most vulnerable and the barriers they face in accessing care.

SECTION 3. TAKE-HOME MESSAGES

Health system considerations:

Map stakeholders relevant for the national TB response, in partnership with CSOs and people affected by TB, using the guidance provided in Annex 1. When partnership with communities is not yet well established, they may begin by learning from resources and a forum for dialogue with people affected by TB.

Communities and CSO considerations:

Map stakeholders in partnership with the ministry of health and their NTPs to use community expertise and understanding of local settings and the lived experience of TB (see Annex 1). This will help to define vulnerable populations and the barriers they face in accessing TB care, as well as possible solutions.

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Meaningful engagement is based on understanding that communities are not just mere recipients of care but are valuable partners in the TB response. All decision-making mechanisms must include an informed member of the community to bring lived experience and ground realities to the table.

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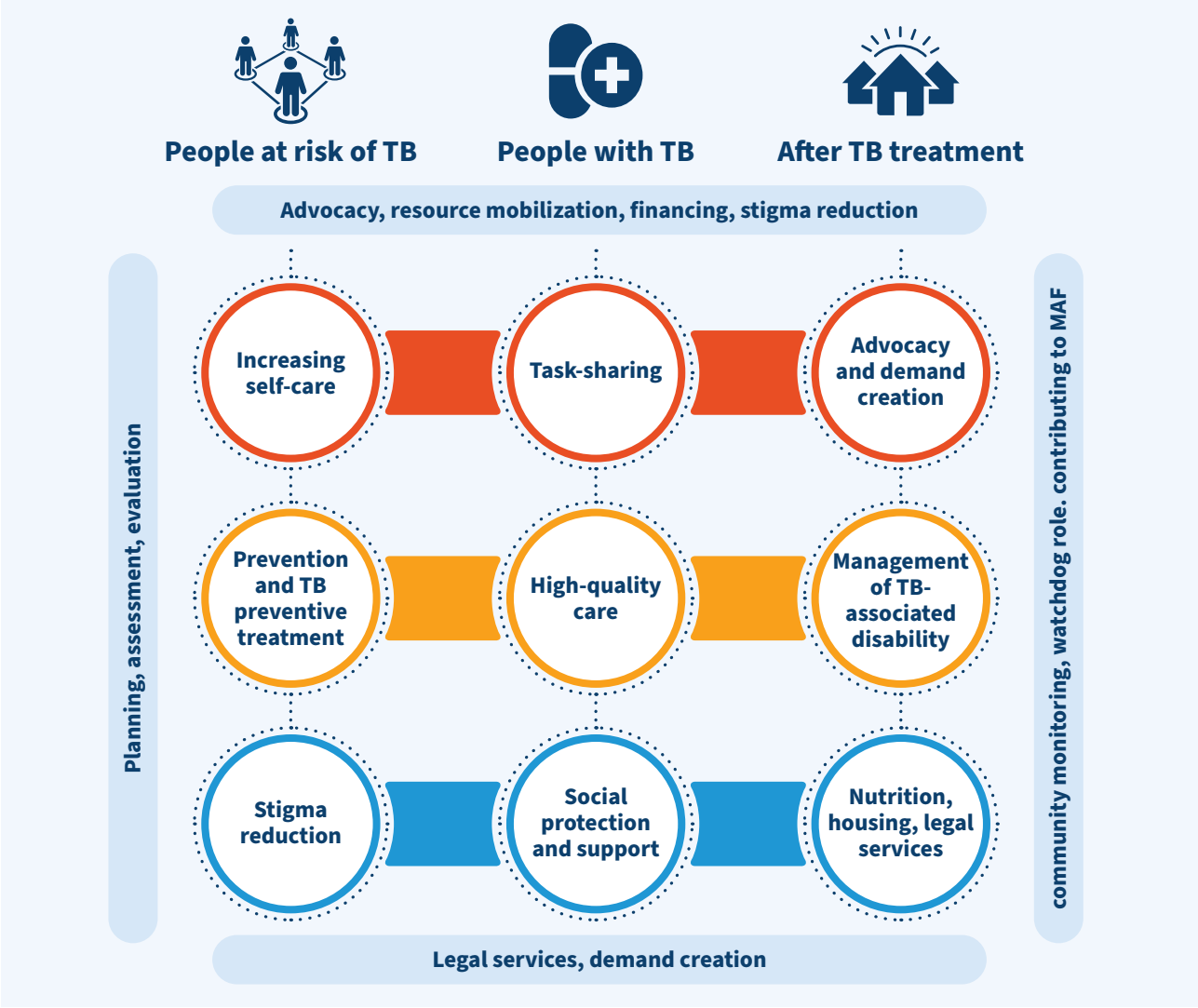
4 What can be done to facilitate meaningful engagement?

The number of countries that report to WHO on the contribution of communities to TB outcomes has been increasing, from 13 countries that reported relevant data in 2013 when the data were first collected, to 62 countries in 2020 when comparable data was most recently collected *(40)*. Routine collaboration between WHO and NTPs, however, indicates that only a handful of countries engage with communities for decision-making and monitoring of progress to end TB. Much more remains to be done to achieve meaningful engagement of people affected by TB and TB-vulnerable population in national responses.

The full potential of community engagement in the TB response has not yet been realized in most countries. Their potential contributions in service delivery include activities before and after TB diagnosis and treatment, such as promotive, preventive, curative and rehabilitative services and palliative care. Beyond service delivery, communities should contribute to planning, assessment, research, monitoring, and evaluation. Communities play a major role in demand creation, advocacy and resource mobilization, and in the multisectoral response to TB and the associated accountability framework. Fig. 5 illustrates the different actions communities can contribute to, from the needs of individuals and communities affected by TB through all stages of their TB journey. Communities contribute from the perspective of people and keep people at the centre of the TB response, contributing to all three pillars of the End TB Strategy.

Fig. 5. **Thematic areas for community action along the TB pathway**



The suggested actions and approaches can be performed at global, national, and local levels (with appropriate variations specific to each level). Engagement at local level helps to ensure that the needs of local communities are identified and effective solutions identified through collaborative problem-solving. Local TB programmes can ensure community engagement by facilitating coordination and/or ensuring a platform for local engagement.

For engagement to be successful, it should start at the local community and at the lowest level of the health system. The community perspective can be expressed through participation in the heath committees of the primary care centres. Using the PHC framework as the foundation for meaningful engagement, the following sections give examples of activities that may contribute to the respective PHC components at the different stages of the TB journey.

4.1 What can be done to ensure meaningful engagement to minimize risk of TB?

The End TB Strategy emphasises the importance of reaching people before they contract TB, with preventive measures such as infection control, and after TB infection but before development of TB disease, with TB preventive treatment. Health promotion in local communities should increase their self-reliance and self-care, including for those with TB disease. Examples of joint actions by communities, CSOs and national and local TB programmes are described below, organized by the three components of PHC: empowered people, integrated health services and multisectoral action.

Examples of actions that contribute to *Empowered people and communities*

- **Health literacy and promotion** to help communities understand the risk factors for TB, the options for prevention options and when to access care
- **Awareness-raising** to ensure that communities affected by TB are aware of means for prevention, screening, diagnosis and early treatment
- **Building the capacity of health systems and community systems and networks** to measure progress in accessing TB preventive treatment by eligible patients and other relevant indicators
- **Reducing stigma** in important community fora, such as schools, religious institutions, workplaces, markets and sports halls; measurement of stigma
- **Safeguarding health as a human right, by facilitating access to legal aid** and respect for commitments to universal health coverage and the primary care concept for government advocacy
- **Planning for prevention,** in partnership with ministries of health and their NTPs, especially vaccine preparedness and TB preventive treatment; providing support for preventive treatment
- **Supporting** research on implementation of TB strategies, community priorities and keeping communities involved
- **Community-led monitoring** for evidence-based advocacy, action and advances towards programmatic goals.

Examples of actions that contribute to *Integrated health services*

- **Screening for TB with respect for autonomy and privacy,** especially for stigmatized communities
- **Providing TB preventive treatment** for all people who are eligible and who agree to the treatment, with support to complete a full course of treatment
- **Providing access to diagnostic tools and protocols to link people to care,** with no economic consequences for affected people and their families
- **Assessing and evaluating ways** for sensitizing populations and preparing them to enter care, including engaging communities in monitoring and evaluation and improving the quality of care
- **Implementing infection control at health centres and in the community,** including promoting ventilation, cough hygiene and other lessons learnt from COVID-19
- **Building capacity and training for peer groups, champions and advocates to reduce stigmatization and discrimination;** use of the TB stigma index *(41)*
- **Using digital technologies,** e.g. to share information, mobilize communities, diagnosis, reminders, test results
- **Preparing for vaccination,** using lessons from COVID-19 in preparing messages and systems for vaccine deployment.

Examples of actions that contribute to *Multisectoral policy and action*

- **Interventions to address social determinants of TB,** including gender, nutrition support, housing, education and poverty reduction
- **Resource mobilization** and advocacy for fair financing for community and civil society engagement to end TB
- **Policies to decentralize services and ensure diagnostic capability closer to the first entry point into the health system**
- **Infection prevention,** including regularly updating guidance documents, supporting workplace infection control measures and providing resources in various settings
- **Strengthen community literacy and capacity on human rights in the TB response.**

4.2 What can be done to ensure meaningful engagement for communities in TB care and treatment?

Community engagement to facilitate access to early diagnosis for people with TB symptoms and to ensure adherence to treatment have been functions of NTPs for decades. Below, examples are given of joint action by ministries of health, their NTPs and communities to facilitate meaningful engagement of communities in TB care and treatment.

Examples of actions that contribute to *Empowered people and communities*

- **Promoting a human-rights-based approach** by use and understanding of the Declaration of the Rights of People Affected by TB *(6)*
- **Finding people with TB by providing accessible care pathways,** especially for vulnerable populations and families of people with TB. Examples include community referral of people with TB symptoms, transport of sputum samples or support to access diagnostic services
- **Providing home-based care,** including increasing TB and health literacy, access to diagnosis, referrals for household contacts of persons undergoing TB treatment, support for treatment adherence, psychosocial counselling, and interventions to reduce stigma
- **Advocacy for access to medicines** and high-quality care to ensure successful treatment of TB
- **Advocacy for shorter treatment or TB preventive treatment** and promotion of uptake of these treatments once they are available
- **Community-led monitoring of service needs and deficits** identified by community members to create demand for high-quality care and ensure continuous access.

Examples of actions that contribute to *Integrated health services*

- **Engagement of communities** in referral of people with symptoms, sputum transport and collection, and engagement with local opinion and religious leaders, traditional healers and private providers
- **Integrated screening and care for co-morbid conditions,** including HIV, diabetes and COVID-19, and risk factors such as smoking and alcohol use disorder
- **Using digital technology** to ensure adherence to treatment, referral pathways for receiving integrated care and providing feedback on service to improve the quality of care
- **Evaluating household contacts and linking them to TB preventive treatment,** including referral for testing for TB disease for household members with TB symptoms
- **Facilitating access to and/or delivering care for TB-associated disability.**

Examples of actions that contribute to *Multisectoral policy and action*

- **Social protection and support from a holistic health service** that considers employment status, housing, nutrition support, transport to health facilities (if necessary), prevention for families affected by TB
- **Ministry of health and NTP engagement of communities in multisectoral collaboration and action, including in implementation of MAF-TB,** baseline and annual assessments, with attention to Annex 2 of MAF TB on meaningful engagement
- **Legal services** for people affected by TB who require support in accessing treatment (such as undocumented or irregular migrants or transgender people) or for example in protection of their employment or housing.

4.3 What can be done to ensure meaningful engagement of communities in full recovery from TB?

Vulnerable populations should be supported to access any assistance they require due to loss of income and excessive expenditure during treatment (e.g. transport cost for follow-up visits to health services during treatment or inability to engage in income-generating activities) and full re-integration into society by collaborating with social support systems. For example, a person with TB might require vocational training or help in re-engaging in income- generating activities and paid work.

Below are examples of joint actions by ministries of health, their NTPs and communities that can facilitate meaningful community engagement for full recovery from TB.

Examples of actions that contribute to *Empowered people and communities*

- **Awareness-raising by TB survivors as experts**
- **Community-led monitoring** to collect and analyse data and disseminate information on gaps and challenges in TB services
- **Empowering people through focus group such as TB clubs,** family and community sensitization and awareness-raising for those who faced stigmatization or ostracization due to TB.

Examples of actions that contribute to *Integrated health services*

- **Management of TB-associated disability,** including persistent pulmonary dysfunction, which can occur even after successful completion of TB treatment
- **High quality follow-up** for early detection of relapse and reinfection.

Examples of actions that contribute to *Multisectoral policy and action*

- **Income generation and vocational training** for recovery from catastrophic expenditure.

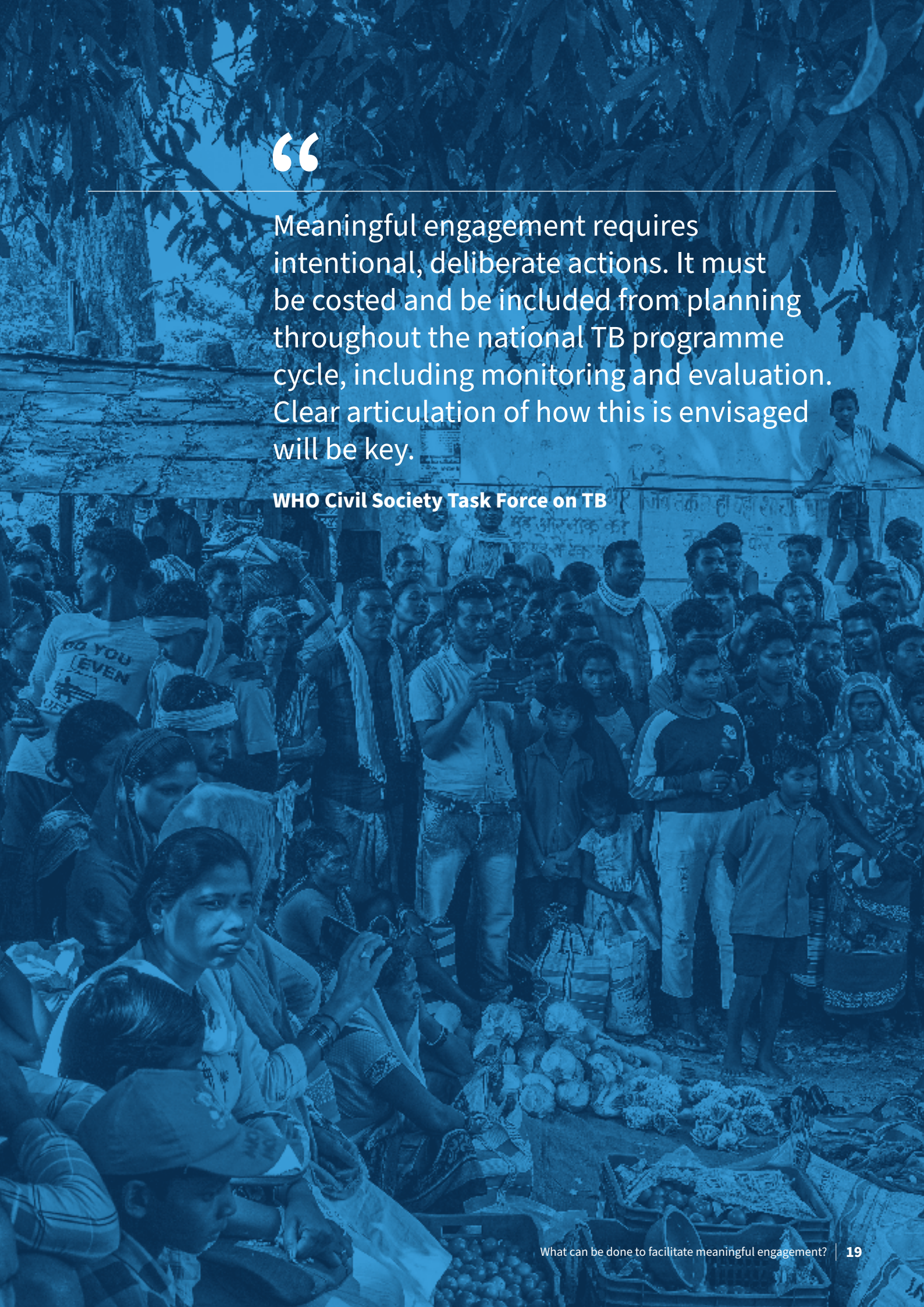
SECTION 4.
TAKE-HOME MESSAGES

Health system considerations:

Review the spectrum of community engagement to understand and benefit from the full potential of communities in the TB response. The review should include identification of actions before and after TB diagnosis and during treatment that have not yet been part of the TB response, and work with communities to develop local solutions.

Communities and CSO considerations:

Identify gaps in the joint actions suggested above, in partnership with health system staff and community health workers, and adapt them as necessary according to the available local expertise.



> Meaningful engagement requires intentional, deliberate actions. It must be costed and be included from planning throughout the national TB programme cycle, including monitoring and evaluation. Clear articulation of how this is envisaged will be key.
>
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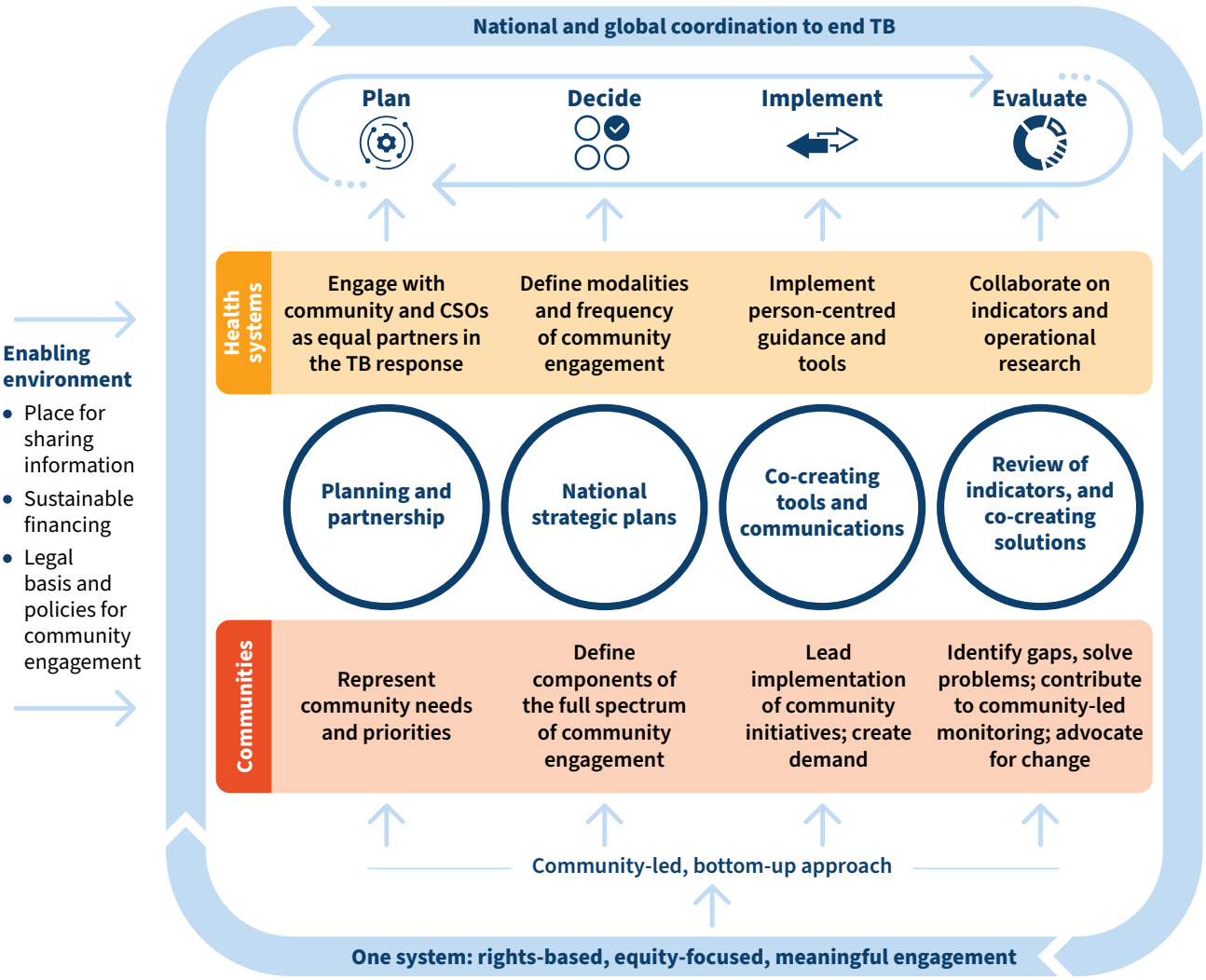
5 How can meaningful engagement be ensured?

"The modalities of community engagement depend on the context and country, which are widely diverse. Even within a country, there may be different norms and cultural and social behaviours. In community engagement, the community should be considered an equal partner with the ministry of health and the NTP, and engagement should be led by the local community. A standardized approach may not be appropriate to ensure meaningful engagement everywhere. Local innovation should be encouraged, as should local community engagement in responding to local specificities and needs. The proposed implementation approach described below should be contextualized, adapted and adopted locally.

5.1 Community engagement

The proposed implementation approach (Fig. 6) for community engagement to end TB includes community-led planning, decisions, implementing and evaluation of components of the TB response. The approach should help ministries of health, through their NTPs and other health system programmes and partners, to engage meaningfully with communities in the response to TB. The approach is applicable to countries at various stages of meaningful engagement of communities in the TB response. Through this approach, policy-makers and health programme leaders partner with communities to develop innovative solutions for bottlenecks and challenges in TB programmes that complement and expand on the examples described above.

Fig. 6. **Model for implementing community engagement to end TB**



The requirements for meaningful partnership are listed on the left, under Enabling environment. As mentioned above, ministries of health and their NTPs should determine the elements necessary to become "one system, with support from community partners, even if the enabling environment is not yet established. Once the enabling environment is in place, the four processes for partnership follow, with continuous learning for engaging communities and civil society in implementing the TB response. At any time, a "cross-sectional snapshot" can be taken of where community and health partners are in the learning loop (plan, decide, implement and evaluate) and the actions they can take. Locally led action should be encouraged in efforts to end TB, which should be coordinated nationally and globally, in accordance with the concepts described in section 3, for a human-rights-based approach with empowered people and communities as partners in integrated health systems.

5.2 An enabling environment

An enabling environment is the foundation for community engagement. Within the PHC framework, this consists of a conducive environment where partnerships can grow. Meaningful engagement requires financing for sustainable engagement, a coordination platform or network and legal and policy frameworks to support civil society and people affected by TB in the health system response to TB.

5.2.1 Ensuring sustainable financing

To realize community engagement and civil society engagement to end TB, funding must be secured for key activities. In many countries, community engagement has been largely funded by donors; however, for sustainable funding, donor funding should progressively be replaced by domestic funding.

Donor funds have been essential for initiating community engagement activities and providing support for capacity-strengthening and community-led solutions. The Global Fund to Fight AIDS, Tuberculosis and Malaria in particular has provided many countries with opportunities to develop community engagement activities for TB. To sustain these initiatives, countries must increasingly transition to domestic funding for core activities for meeting community engagement goals and commitments.

Compensation or remuneration for communities involved in health care delivery remains an issue, as highlighted in recent unpublished reports of the Global Fund's Technical Review Panel. In many cases, community contributions remain voluntary or are linked to performance-based incentives. Community health workers should not be regarded as a way to save costs or as substitutes for health care professionals, but as an element of integrated PHC teams. WHO recommends remunerating practicing community health workers for their work with a financial package commensurate with the job demands, complexity, number of hours, training and roles that they undertake. WHO also underlines the importance of not paying community health workers exclusively or predominantly according to performance-based incentives *(4)*. Effective payment schemes may be secured through social contracting, through which CSOs receive funding to deliver prevention, treatment, care, and support services *(42)*.

5.2.2 Coordination platform or network

A coordination platform or network of community and civil society stakeholders enables community engagement at national and subnational levels. It facilitates discussions with ministries of health and their NTPs by providing a unified voice from the community. Coordination platforms and similar fora can be used to share information and for joint planning with civil society and people affected by TB. The platform can be facilitated by ministries of health and their NTPs, or a CSO could coordinate it.

5.2.3 Legal and policy environment for community engagement

A supportive legal and policy environment for community and civil society engagement can help to establish true partnerships. This guidance proposes actions to facilitate an enabling legal and policy environment for meaningful engagement of communities in the response to TB.

Examples of actions stakeholders can take to facilitate an enabling environment for meaningful community engagement	
Communities (locally)	Advocacy for adequate, sustained local funding, and programme-hosted opportunities to share information and expertise Formation of a coordination platform or community network.
Communities (nationally)	Advocacy for adequate, sustained national funding and routine monitoring by the NTP (e.g. review meetings), technical working groups and similar fora for sharing community expertise Advocacy for policy and legal frameworks that recognize community expertise and value Formation of a national coordination platform or community network.
Health systems	A legal and policy framework for communities as partners in national strategies Advocacy for and allocation of funding for community engagement.

5.3 Community engagement in planning

Community and civil society have a major role in planning. The engagement should start at the very beginning of the process, by creating room and opportunities for communities to identify gaps and contribute to recommendations.

Planning starts with listening to communities in order to understand their needs and their perspectives on possible solutions to address challenges and bottlenecks. Health system partners, including NTPs, and communities should plan TB services together. NTPs can engage in discussions with communities and align their plans with community processes and expertise. Communities can define stakeholders and their strengths, capacity and roles in national and subnational planning. Community partners should also define any resource needs and service deficits and propose how those could best be delivered. The NTP might work with communities to determine where their expertise is necessary. For example, the NTP may suggest service delivery characteristics that require local adaptation, and community members could then define service delivery modalities, for example for key and vulnerable populations.

The MAF-TB assessment and review of Annex 2 of the MAF-TB should be included in this step, and communities can review and assess national commitments that have been made or are pending. They can also collaborate with the NTP on the actions to be implemented by civil society and communities as part of MAF-TB.

Examples of actions to facilitate planning, by stakeholder	
Communities (locally)	Review strategies, and plan local implementation in partnership with the NTP Share community expectations in discussions with health facility managers.
Communities (nationally)	Map national stakeholders and their strengths, capacity and roles Participate in planning Identify resource needs and funding sources.
Health systems and NTPs	Facilitate discussions with communities and align ministry of health and NTP plans in accordance with community engagement, available expertise and needs Initiate MAF-TB baseline assessments or engage the community in ongoing actions as part of the MAF-TB.

5.4 Community engagement in decision-making

Communities should be part of joint decision-making in development of national strategic plans and subnational implementation plans. NTPs and local implementing partners should transition the mechanisms of community engagement from "inform" and "consult" to "involvement" of communities and civil society in making decisions on national strategic plans, "collaboration" and finally, "empowerment" to lead components of the plan. This will facilitate community-defined and community-led service delivery for relevant services.

Examples of actions to facilitate decision-making, by stakeholder	
Communities (locally)	Map local stakeholders, their strengths, capacity and roles; identify any local resource needs and deficits.
Communities (nationally)	Define full spectrum of community engagement in national strategic plans according to the available resources and capacity Involve representatives of people affected by TB in each step in decision-making.
Health systems and NTPs	Change community engagement from "inform" to "empower" for identifying deficits in national TB responses and co-developing solutions.

5.5 Community engagement in implementation

NTPs are responsible for developing effective approaches, guidance, and tools for community engagement in collaboration with community and civil society representatives. Communities and civil society should be encouraged by the local TB programme to lead the identification of locally suitable solutions for communities affected by TB and implementation of initiatives that are in their scope of their activities. Communities must therefore be capacitated and empowered to assume leadership of these initiatives.

Examples of actions to facilitate implementation, by stakeholder	
Communities (locally)	Adapt and facilitate decisions with local tools and activities in partnership with the local programme or office Identify vulnerable populations that might require additional support Lead the design, implementation and monitoring (in collaboration with the local TB programme) of appropriate initiatives.
Communities (nationally)	Adapt and facilitate decisions with national tools and communication in partnership with the NTP Identify vulnerable populations that might require additional support Lead initiatives within the national or regional scope of influence.
Health systems and NTPs	Fund and co-develop tools and communications to end TB in partnership with communities and civil society.

5.6 Community-led monitoring

Community-led monitoring (CLM) is a form of systematic feedback organized by the community to improve the quality of access to services, in collaboration with the health system. It contributes to the accountability mechanism. In CLM, communities, particularly people who use health services or local CSOs, identify issues that "matter to them" *(43)*, define indicators, collect both quantitative and qualitative data systematically and routinely, and monitor them. The process is led and implemented by the community in consultation with health system partners.

CLM provides evidence on what should be improved and provides suggestions to improve outcomes. Issues and challenges identified through CLM should be addressed jointly with the ministry of health and the NTP. Communities can conduct evidence-based advocacy and campaigns until corrective actions are identified and implemented. CLM can also document innovations and effective practices in the TB response, to inform further planning and scaling-up. In this way, CLM helps in holding decision-makers accountable and provides an opportunity for communities to act as "watchdogs". Partnerships with facility managers, health service providers, government authorities at various levels, donor and development partners, and technical support agencies will ensure that CLM brings about change to improve programme *(43)*.

CLM is not a substitute for routine TB programme monitoring and evaluation (described below). It complements routine monitoring and evaluation and provides insights to improve services from the community perspective. It captures the experience of populations affected by TB and uses local fact-finding to solve problems in order to meet the needs of local communities. The priorities for CLM should be decided in community consultations, free from the influence from external entities and agendas *(43)*. The findings of CLM may inform both local and national systems.

It is important to build the capacity of communities and CSOs to conduct CLM and empower them to find indicators to track their issues and priorities, collect and share data, and communicate their findings to other stakeholders. The tools and methods of data collection should be appropriate for local capacity and context. An example of CLM is described in Box 1.

Box 1. **Example of CLM**

The issue:
Community consultation identified people in a certain area who were not accessing health services for TB-related issues. The community decided to implement CLM.

Modality:
Monthly collection of data on attendance at the health centre, interviews with the population.

Implementer:
A local community organization with expertise in data collection, interviewing and report-writing.

Outcome:
Data on monthly attendance at the health centre showed that very few people from the area accessed health services; interviews showed that people in that area speak a local language and do not understand instructions from health workers.

Proposed solution:
A health worker from the area who speaks the same language should be present in the reception area of the health centre.

Consultation with health facility manager:
The community provided evidence, shared outcomes and proposed a solution.

Outcome:
The facility appointed a health-care worker who speaks the language spoken in the disadvantaged area.

Follow-up:
Monthly data on health centre attendance showed improvement in attendance from the area.

5.7 Community engagement in monitoring and evaluation

Continuous monitoring, evaluation and review of programme is used for quality improvement and accountability. Several indicators for measuring meaningful engagement of communities in the TB response are included in section 5.

NTPs should collaborate with communities and civil society in deciding on the indicators to be used in the national surveillance system, and communities should play an active role in order to identify gaps, solve problems and advocate for change and improvement. Advocacy may be in the form of political advocacy for policy change and/or implementation of policy and community advocacy to address service deficits and needs as part of CLM.

Communities and civil society should consider a mechanism for accountability for use by the people they represent to ensure that their partnership with the NTP reflects the priorities, cares and concerns of people affected by TB.

Examples of actions to facilitate monitoring and evaluation, by stakeholder

Communities (locally)	Community-led monitoring Creation of demand for capacity-building in monitoring and evaluation Identification of solutions for the identified challenges and deficits Monitoring and review of accountability by constituencies according to an agreed mechanism.
Communities (nationally)	Participation in MAF-TB processes and review Community-led monitoring Creation of demand and advocacy for solutions based on the findings of monitoring Monitoring and review of accountability by constituencies according to an agreed mechanism.
Health systems and NTPs	MAF-TB review in partnership with communities Collaborate in developing and tracking indicators of and operational research on community engagement.

SECTION 5. TAKE-HOME MESSAGES

Health system considerations:

- Ensure that implementation is based on an enabling environment, starting with listening to and learning from communities.
- Domestic funding is essential to ensure the sustainability of community engagement.
- Use of the continuous learning model can help in assessing the necessary actions, which can be increased in partnership with people affected by TB.

Communities and CSO considerations:

- Identify actions in implementation that are lacking, and develop and implement solutions in partnership with health systems.
- Advocate for funding, especially sustainable domestic funding, to sustain community engagement.
- Use community-led monitoring to identify additional needs and to develop solutions.

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Community engagement is essential in TB care and prevention. Community members at the grassroots level, including TB survivors, can assist in finding people with TB and can support them in adhering to their treatment. With their local knowledge, communities are also reliable advocates, who can mobilize mass support in the fight against TB. To strengthen meaningful engagement of communities, they must be supported by the other stakeholders, including government to establish an enabling environment and the private sector to mobilize resources and advance innovations.

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6 How can meaningful engagement be measured?

To assist stakeholders in assessing the value and impact of community engagement, key indicators should be measured and reported routinely. This should be part of national strategic planning, and should be streamlined into the monitoring and evaluation system for the national strategic plan.

6.1 Indicators of meaningful community engagement

Indicators for measuring community engagement at national level are listed below. The first two indicators measure the outcomes of community-based activities and should be part of the routine monitoring and evaluation system. The third indicator measures community participation in planning, while the fourth measures achievement of an enabling environment.

Indicator 1	**Referrals and new notifications *(3)***
Definition	Number of new diagnosed and notified cases of TB (all forms) who were referred by community health workers and community volunteers, expressed as a percentage of all new cases notified in the basic management unit during a specified period.
Numerator	Number of new cases of TB (all forms) referred by community health workers or community volunteers to a health facility for diagnosis and notified to the basic management unit(s) in a specified period.
Denominator	Number of new cases of TB (all forms) notified to the basic management unit(s) in the same period.

Indicator 2	**Treatment success**
Definition	New cases of TB (all forms) successfully treated (cured plus completed treatment) who received support for treatment adherence from community health workers or community volunteers among all new cases of TB (all forms) given support for treatment adherence by community health workers or community volunteers (number and percentage).
Numerator	Number of new cases of TB (all forms) successfully treated and given support for treatment adherence by community health workers or community volunteers in the basic management unit(s) in a specified period.
Denominator	Total number of new cases of TB (all forms) given support for treatment adherence by community health workers or community volunteers in the same period.

Indicator 3	Community representation in national decision making
Definition	Representatives of communities affected by TB or civil society had a formal role in key NTP processes and activities during the year.
Description	Representatives of communities affected by TB or civil society had a formal role in the past year in (tick yes/no/not applicable): ● development of the national strategic plan ● preparation and conduct of the TB programme review ● development of the national annual TB report ● development or update of national TB guidelines or manuals This yes/no response will be supplemented by a qualitative description of the degree of involvement as a case study.
Qualitative measures	Description of document development, level of involvement and specific inputs to the NTP review.
Purpose	To define the extent to which communities affected by TB and civil society are engaged in decision-making for national TB responses. This can provide insight into the qualitative aspects of national TB responses and the extent to which community priorities and needs are reflected in national processes and documents.
Method	NTP representative to share information on the formal role of communities affected by TB and civil society in national processes and documents, from reports, acknowledgements in the national strategic plan and documents on the national TB response.
Periodicity	Annual
Strengths and limitations	Strength: Confirms that communities affected by TB and civil society are (or are not) part of the national processes and activities (to be supplemented by a case study and qualitative explanation). Limitation: The level of engagement cannot be specified from a simple yes/no response.
Responsibility	NTP
Measurement tools	Meeting reports and acknowledgement sections.

Indicator 4	Level of committed funding for community engagement in the TB response at national level
Definition	Percentage of overall funding, expressed in US$, available for community engagement activities nationally.
Numerator	Amount of confirmed funds in the national strategic plan for community engagement, in addition to service delivery (defined as funding specifically for "advocacy and communications" and "community engagement"), expressed in US$.
Denominator	Total amount of confirmed national strategic plan funds, expressed in US$.
Purpose and rationale	To assess the commitment of the government to sustainable community engagement in the TB response. Fair financing (i.e. fair sharing of resources between the health and community systems) is the basis of meaningful engagement with community and civil society to end TB, aligned with the primary health care framework. The aim is to assess whether funding has been committed for core components of national efforts to engage communities and civil society in the TB response.
Method	National ministry of health (NTP or other relevant ministry of health department) to share the relevant confirmed funding.
Periodicity	Annual
Strengths and limitations	Strength: Strong indicator of overall funds committed for community and civil society engagement in health and TB. Limitation: Funding levels might be difficult to calculate, depending on how budgets are structured at the ministry of health and/or NTP level.
Responsibility	Ministry of health (NTP or other relevant ministry of health department)
Measurement tools	Confirmed funding for the annual national strategic plan, including breakdown of spending on "advocacy and communication" and "community engagement" in budget line 4.7; ministry of health budget and expenditure on community health worker programme (or similar), where relevant. Percentage of overall national funding spent on community engagement activities.

6.2 Checklist for measuring meaningful engagement

In addition to the indicators described above, NTPs and communities can review additional measures that reflect community engagement. The checklists below can be adapted to national planning and evaluation systems; they should also be used to track meaningful subnational engagement. The data are used to monitor the quality and scope of community engagement and their contribution to the TB response. They may be quantitative, from which overall numbers and proportions can be objectively measured, or qualitative, which can provide rich contextual information and are subjective, especially with respect to the quality of care. Review and analysis of the information should contribute to continuous learning and improvement of the TB response through community engagement.

Measurement of meaningful engagement requires both quantitative and qualitative national, subnational and local information. The table below provides key indicators of community and civil society engagement in the national and subnational TB response.

Indicators of community and civil society engagement in the national and subnational TB response	Quantitative	Qualitative
Planning:		
Has a situation assessment on community and civil society engagement in the TB response been conducted?	Yes/No	Stigma, community knowledge, attitude, practice
Decision-making:		
Are communities and CSOs involved in national strategic planning and in local planning and decision-making?	Yes/No How many representatives? How frequently?	Who? How are they involved? Who is the focal point for their engagement?
Are communities and CSOs involved in advocacy, demand creation and a multi-sectoral accountability framework?	Yes/No	Is there a clear mechanism for follow up?
Do communities and CSOs co-develop strategic communication and tools on TB?	Yes/No	What plans and tools?
Have service and/or capacity needs and deficits identified by communities been discussed with the NTP during the past year?	Yes/No	What needs and deficits? How were they incorporated?
Are capacity-building activities conducted for communities and CSOs?	Yes/No	What activities?
Monitoring and evaluation:		
Are communities and CSOs involved in TB programme review and monitoring?	Yes/No	Who? How are they involved? Any examples of community led monitoring?
Enabling environment:		
Is funding for community related activities on TB available?	Yes/No	What types of activities are covered?
Does a coordination platform/network for communities and CSOs exist?	Yes/No	What types of platform/ network?
Is policy for legal support for community involvement available?	Yes/No	Which level? What policy?

Routine collection and analysis of qualitative and quantitative data will facilitate identification of challenges to implementation and areas that require attention. Local research is critical to identifying solutions to local problems and to ensuring access to technology. Many national strategic plans and national TB road maps include operational research and capacity-strengthening as priorities for investment. More locally led solutions are necessary in these areas to "optimize implementation and impact, and promote innovations", as highlighted in the WHO's End TB Strategy *(44)*.

According to the *WHO global strategy for tuberculosis research and innovation (45)*, civil society, indigenous peoples and affected communities can support governments by contributing to social innovations, improving patient and community engagement in research, supporting resource mobilization, improving public acceptance of innovation, and supporting innovative approaches to scientific research on eliminating the stigmatization and discrimination associated with TB. Operational, implementation, health system and social science research are necessary to facilitate the introduction of all new tools. Community involvement will contribute to high-quality TB research and innovation, as well as acceptance and uptake of innovations.

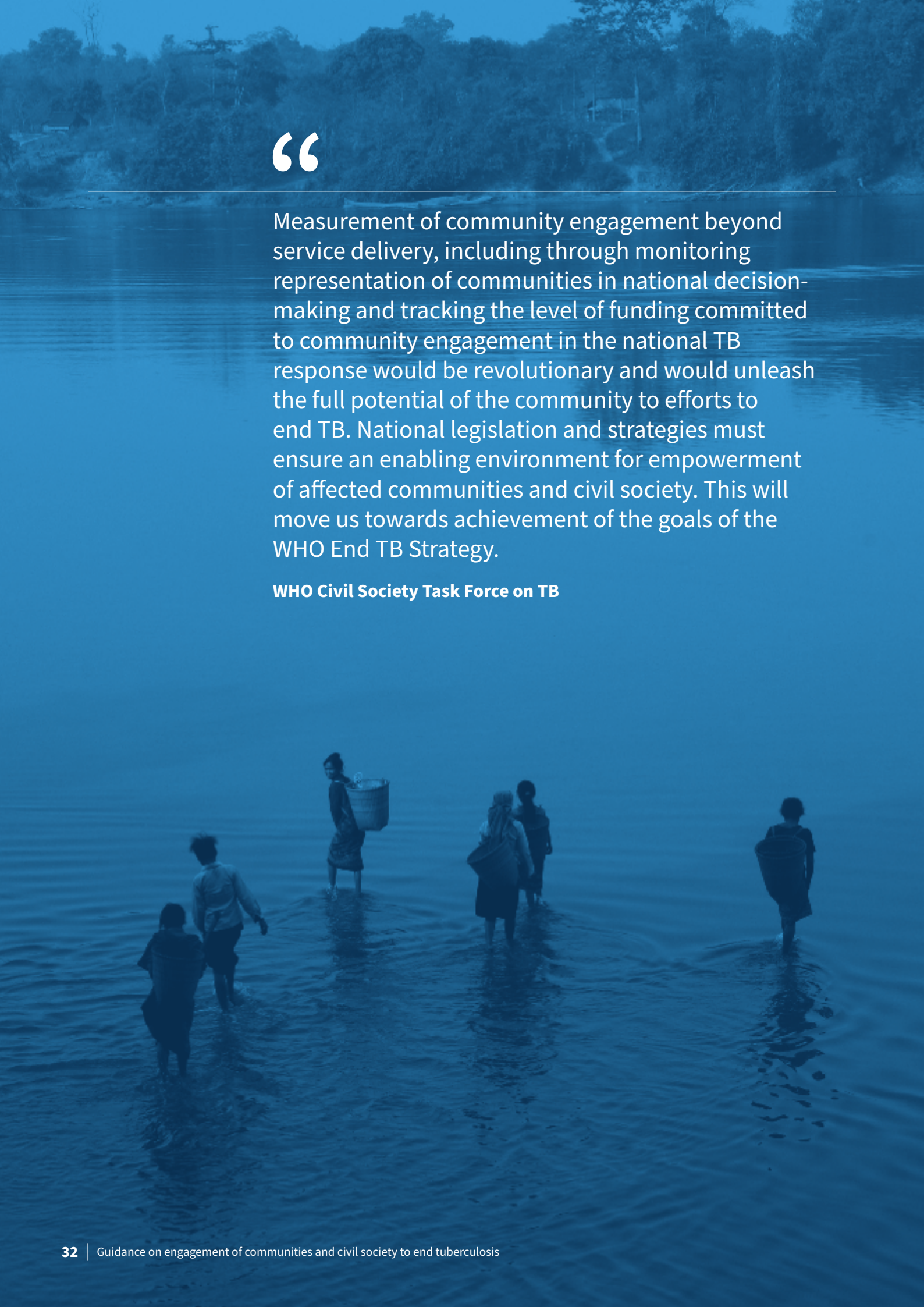
SECTION 6.
TAKE-HOME MESSAGES

Health system considerations:

- Determine how to collect new indicators of an enabling environment to end TB. Review the checklist for meaningful engagement with community partners.

Communities and CSO considerations:

- Advocate for transparent data collection on indicators of community engagement in the national TB response.
- Track the level of participation by people affected by TB in decision-making bodies, and partner with health systems to review the checklist for meaningful engagement.
- Advocate for identification and implementation of solutions to address gaps as part of development and review of the national strategic plan.



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Measurement of community engagement beyond service delivery, including through monitoring representation of communities in national decision-making and tracking the level of funding committed to community engagement in the national TB response would be revolutionary and would unleash the full potential of the community to efforts to end TB. National legislation and strategies must ensure an enabling environment for empowerment of affected communities and civil society. This will move us towards achievement of the goals of the WHO End TB Strategy.

WHO Civil Society Task Force on TB

References

1. United Nations community engagement guidelines on peacebuilding and sustaining peace. New York: United Nations; 2020 (https://www.un.org/peacebuilding/content/un-community-engagement-guidelines-peacebuilding-and-sustaining-peace-0, accessed 25 May 2022).
2. Community engagement: a health promotion guide for universal health coverage. Geneva: World Health Organization; 2020 (https://www.who.int/publications/i/item/9789240010529, accessed 29 June 2023).
3. ENGAGE-TB approach: operational guidance. Geneva: World Health Organization; 2012 (https://www.who.int/publications/i/item/9789241504508, accessed 29 June 2023).
4. WHO guideline on health policy and system support to optimize community health worker programmes. Geneva: World Health Organization; 2018 (https://www.who.int/publications/i/item/9789241550369, accessed 29 June 2023).
5. The Ottawa Charter for Health Promotion. First international conference on health promotion, Ottawa, 21 November 1986. Geneva: World Health Organization. https://www.who.int/teams/health-promotion/enhanced-wellbeing/first-global-conference, accessed 13 June 2022).
6. Declaration of the Rights of People Affected by Tuberculosis. Geneva: StopTB Partnership; 2019 (https://stoptb.org/assets/documents/communities/FINAL%20Declaration%20on%20the%20Right%20of%20People%20Affected%20by%20TB%2013.05.2019.pdf, accessed 29 June 2023).
7. Global tuberculosis report 2022. Geneva: World Health Organization; 2022 (https://www.who.int/teams/global-tuberculosis-programme/tb-reports/global-tuberculosis-report-2022, accessed 29 June 2023).
8. Multisectoral accountability framework to accelerate progress to end tuberculosis by 2030. Geneva: World Health Organization; 2019 (https://apps.who.int/iris/handle/10665/331934. Accessed 29 June 2023).
9. Goal 3: Ensure healthy lives and promote well-being for all at all ages. New York: United Nations; 2023 (https://www.un.org/sustainabledevelopment/health/, accessed 29 June 2023).
10. Tuberculosis. Geneva: World Health Organization; 2023 (https://www.who.int/health-topics/tuberculosis#tab=tab_1, accessed 31 May 2022).
11. The end TB strategy. Geneva: World Health Organization; 2015 (https://www.who.int/publications/i/item/WHO-HTM-TB-2015.19, accessed 31 May 2022).
12. Political declaration of the UN General-Assembly High-Level Meeting on the Fight Against Tuberculosis. Geneva: World Health Organization; 2019 (https://www.who.int/publications/m/item/political-declaration-of-the-un-general-assembly-high-level-meeting-on-the-fight-against-tuberculosishttps://www.un.org/en/ga/73/resolutions.shtml, accessed 29 June 2023).
13. The UN and civil society. New York: United Nations; 2023 (https://www.un.org/en/get-involved/un-and-civil-society#:~:text=Association%20with%20the%20UN%20Department%20of%20Global%20Communications&text=A%20civil%20society%20organization%20(CSO,local%2C%20national%20or%20international%20level, accessed 25 May 2022).
14. Community Systems Strengthening Framework. Geneva: The Global Fund; 2014 (https://www.theglobalfund.org/media/6428/core_css_framework_en.pdf, accessed 29 June 2022).
15. What is DOTS? A guide to understanding the WHO-recommended TB control strategy known as DOTS. Geneva: World Health Organization; 1999 (https://apps.who.int/iris/handle/10665/65979, accessed 29 June 2023).
16. The stop TB strategy. Building on and enhancing DOTS to meet the TB-related Millennium Development Goals. Geneva: World Health Organization; 2008 (https://apps.who.int/iris/handle/10665/69241, accessed 29 June 2023).
17. Primary health care: health systems, communities and the planet. Geneva: World Health Organization; 2022 (https://www.who.int/news-room/feature-stories/detail/primary-health-care-health-systems-communities-and-the-planet, accessed 24 June 2022).
18. Dongre AR, Deshmukh PR, Garg BS. Community-led initiative for control of anemia among children 6 to 35 months of age and unmarried adolescent girls in rural Wardha, India. Food Nutr Bull. 2011;32(4):315–23. doi:10.1177/156482651103200402.
19. SEARCH Collaboration. Evaluating the feasibility and uptake of a community-led HIV testing and multi-disease health campaign in rural Uganda. J Int AIDS Soc. 2017;20(1):21514. doi:10.7448/IAS.20.1.21514.
20. Sacks E, Schleiff M, Were M, Chowdhury AM, Perry HB. Communities, universal health coverage and primary health care. Bull World Health Organ. 2020;98:773–80. doi: 10.2471/BLT.20.252445.
21. WHO guideline on health policy and system support to optimize community health worker programmes. Geneva: World Health Organization; 2018 (https://www.who.int/publications/i/item/9789241550369, accessed 29 June 2023).
22. Primary health care. Geneva: World Health Organization; 2023 https://www.who.int/health-topics/primary-health-care#tab=tab_1, accessed 18 August 2022).

23. World Health Assembly adopts Framework on Integrated People-Centred Health Services. Geneva: World Health Organization; 2016 (https://www.who.int/news/item/28-05-2016-world-health-assembly-adopts-framework-on-integrated-people-centred-health-services, accessed 25 July 2022).

24. WHO Multisectoral Accountability Framework for TB (MAF-TB) Baseline assessment checklist for country use in pursuing a national MAF-TB. Geneva: World Health Organization; 2020 (https://www.who.int/publications/m/item/who-multisectoral-accountability-framework-for-tb-(maf-tb)-baseline-assessment-checklist-for-country-use-in-pursuing-a-national-maf-tb, accessed 29 June 2023).

25. The WHO multisectoral accountability framework for TB (MAF-TB): Progress in adaptation and implementation. In: Global tuberculosis report 2021. Geneva: World Health Organization; 2021 (https://www.who.int/publications/digital/global-tuberculosis-report-2021/featured-topics/maf-tb, accessed 29 June 2023).

26. Community engagement: a health promotion guide for universal health coverage in the hands of the people. Geneva: World Health Organization; 2020 (https://www.who.int/publications/i/item/9789240010529, accessed 29 June 2023).

27. Dodor EA, Kelly S, Neal K. Health professionals as stigmatisers of tuberculosis: insights from community members and patients with TB in an urban district in Ghana. Psychol Health Med. 2009;14(3):301–10. doi:10.1080/13548500902730127.

28. Biermann O, Atkins S, Lönnroth K, Caws M, Viney K. "Power plays plus push": experts' insights into the development and implementation of active tuberculosis case-finding policies globally, a qualitative study. BMJ Open. 2020;10(6):e036285. doi:10.1136/bmjopen-2019-036285.

29. Roundtable on Population Health Improvement. The role and potential of communities in population health improvement: workshop summary. Washington DC: National Academies Press; 2015 (https://www.ncbi.nlm.nih.gov/books/NBK284644/, accessed 29 June 2023).

30. Gilmore B, Ndejjo R, Tchetchia A, de Claro V, Mago E, Diallo AA et al. Community engagement for COVID-19 prevention and control: a rapid evidence synthesis. BMJ Glob Health. 2020;5:e003188. doi:10.1136/bmjgh-2020-003188.

31. Pai M, Kasaeva T, Swaminathan S. Covid-19's devastating effect on tuberculosis care – a path to recovery. New Engl J Med. 2022;386(16):1490–3. doi:10.1056/NEJMp2118145.

32. Progress towards the achievement of global tuberculosis targets and implementation of the Political Declaration of the High-Level meeting of the General Assembly on the Fight Against Tuberculosis; report of the Secretary-General. New York: United Nations; 2020 (https://digitallibrary.un.org/record/3887628?ln=en, accessed 29 June 2023).

33. 1. COVID-19 and TB. In Global Tuberculosis Report 2022. Geneva: World Health Organization; 2022 https://www.who.int/teams/global-tuberculosis-programme/tb-reports/global-tuberculosis-report-2022/covid-19-and-tb, accessed 18 November 2022).

34. COVID-19 response mechanism. Information note. Geneva: The Global Fund; 2021 (https://www.theglobalfund.org/media/10749/covid19_c19rm-technical_informationnote_en.pdf, accessed 11 June 2022).

35. Stevenson LJ, Jager LB, Graham MA, Swanepoel DW. Community-based ototoxicity monitoring for drug-resistant tuberculosis in South Africa: an evaluation study. Int J Environ Res Public Health. 2021;18:11342. doi:10.3390/ijerph182111342.

36. Vo LNQ, Vu TN, Nguyen HT, Truong TT, Khuu CM, Pham PQ et al. Optimizing community screening for tuberculosis: Spatial analysis of localized case finding from door-to-door screening for TB in an urban district of Ho Chi Minh City, Viet Nam. PLoS One. 2018;13:e0209290. doi:10.1371/journal.pone.0209290.

37. Guidance for national strategic planning for tuberculosis. Geneva: World Health Organization; 2022 (https://www.who.int/publications/i/item/9789240052055, accessed 29 June 2023).

38. Ingram G. Commentary. Civil society. An essential ingredient of development. Washington DC: Brookings Institution; 2020 (https://www.brookings.edu/blog/up-front/2020/04/06/civil-society-an-essential-ingredient-of-development/, accessed 29 June 2023).

39. Gianella C, Pesantes MA, Ugarte-Gil C, Moore DAJ, Lema C. Vulnerable populations and the right to health: lessons from the Peruvian Amazon around tuberculosis control. Int J Equity Health. 2019;18(1):28. doi:10.1186/s12939-019-0928-z.

40. Global tuberculosis report 2020. Geneva: World Health Organization; 2020 (https://www.who.int/publications/i/item/9789240013131, accessed 29 June 2023).

41. Assessing TB stigma. Investment package. Community, rights & gender. Geneva: Stop TB Partnership; 2020 (https://www.stoptb.org/file/9323/download, accessed 27 February 2023).

42. Social contracting. New York: United Nations Development Programme; 2023 (https://www.undp-capacitydevelopment-health.org/en/transition/social-contracting, accessed 29 June 2023).

43. Establishing community-led monitoring of HIV services. Principles and process. Geneva: UNAIDS; 2021 (https://www.unaids.org/sites/default/files/media_asset/establishing-community-led-monitoring-hiv-services_en.pdf, accessed 7 June 2022).

44. Implementing the end TB strategy: the essentials, 2022 update. Geneva: World Health Organization; 2022 (https://www.who.int/publications/i/item/9789240065093).

45. A global strategy for tuberculosis research and Innovation. Geneva: World Health Organization; 2020 (https://www.who.int/publications/i/item/9789240010017, accessed 29 June 2023).

Annex 1.

Checklist for implementation of this guidance by health systems and communities

This guidance is for all stakeholders in TB programmes, including ministries of health, communities and civil society, programmes for community health and private care practitioners. It recognizes the strengths of all partners and their shared responsibility in the TB response. This checklist of action items for partners in health systems and communities can be used for implementation of this guidance.

Health systems

- [ ] **Plan:** to initiate or strengthen interactions with communities and CSOs, the ministry of health and the NTPs to review considerations of people-centeredness, the one system approach, and creating an enabling environment with staff and resources to build the TB response and interactions with people affected by TB.
- [ ] Map stakeholders in the TB response (Annex 1), in partnership with CSOs and people affected by TB. If a partnership with communities is still being established, collective learning can be encouraged by providing resources and a forum for dialogue with people affected by TB.
- [ ] **Decide:** Review community engagement to understand the full experience of communities in the TB response. Identify the actions to be implemented before and after TB diagnosis and treatment that are not yet part of the TB response, and develop local solutions with communities.
- [ ] **Implement:** Ensure meaningful community engagement by providing an enabling environment according to the needs and preferences expressed by communities. Funding is essential for ensuring the sustainability of community engagement. Continuous learning is a useful approach for assessing the required actions, in partnership with people affected by TB.
- [ ] **Evaluate:** Identify how to collect the indicators of an enabling environment for meaningful engagement to end TB. Review the checklist for meaningful engagement with community partners and stakeholders.

Communities and CSOs

- [ ] **Plan:** To build common understanding, communities and CSOs can advocate for TB responses to incorporate and reflect the considerations of people-centeredness, work towards a one system approach and develop an enabling environment.
- [ ] **Decide:** Bring in expertise and local knowledge by stakeholder mapping (Annex 1), and define key and vulnerable populations and the barriers they face to accessing all levels of TB care.
- [ ] **Implement:** Partner with health system officials and community health workers to identify current gaps in the best practices described in section 4, and adapt them as necessary according to expertise in the local context.
- [ ] Identify actions in the implementation approach (section 5) that are currently lacking, and partner with health systems to find solutions. Advocate for funding to sustain community engagement, especially domestic funding. Use community-led monitoring for identifying additional needs and solutions.
- [ ] **Evaluate:** Advocate for transparent national data collection on indicators of community engagement in the end TB response. Monitor the level of participation by people affected by TB in decision-making bodies, and collaborate with health systems to review the checklist for meaningful engagement. Advocate for gaps to be addressed in the development and review of a national strategic plan.

Annex 2.

Potential roles of various stakeholders

Stakeholders	Strengths	Quantitative	Qualitative
General population	Lived experience of being at risk for TB	Dependent on education and resources; social determinants	Local knowledge of prevention, social determinants, health literacy and promotion, awareness raising, stigma reduction
People affected by TB (those with TB, and those who have recovered)	Lived experience	Leadership development, identifying and developing strategies and interventions to address barriers to services, including stigma reduction, community legal empowerment	Advocacy, community strengthening, legal empowerment, service delivery, design of programs and interventions
Key and vulnerable populations	Lived experience	Leadership development, identifying and developing strategy to address barriers to care, including stigma reduction, legal empowerment	Demand creation, community-led monitoring, documenting, and addressing barriers
Community networks and groups	Link community services with the health system; education; support for adherence; and home care	Leadership development; Community education and stigma reduction; improving health systems linkage; community-led monitoring (CLM)	Service delivery, CLM, Health and human rights literacy and promotion, stigma reduction
CSOs	Organized, registered stakeholder groups	Leadership development; Community education and stigma reduction; improving health systems linkage; CLM; organized advocacy	Advocacy, service delivery, CLM, Health and human rights literacy and promotion, stigma reduction
National, regional, and global coalitions of people affected by TB (including community care workers)	Networks and local, regional, and global links; knowledge hub for community needs and activities	Leadership development; Community education and stigma reduction; improving health systems linkage; CLM; organized advocacy	Advocacy, service delivery, TB preventive therapy, CLM, Health and human rights literacy and promotion, stigma reduction
Community health workers	Often, first point of contact for people with TB and their families; front line of prevention and treatment	Service delivery, leadership development, stigma reduction, CLM	Community case management, service delivery, prevention, TB preventive therapy, vaccination, CLM
Private health care sector	Access point for people with TB; may be front line for case detection	Linkages to national systems, service delivery, stigma reduction	Service delivery, linkages to care

Stakeholders	Strengths	Quantitative	Qualitative
NTPs	Service delivery, policies and reporting	Policies, guidelines, funding, and training; community health worker linkages	Working closely with communities, to move from inform to empower, describing level of community funding and engagement
Ministry of health (NTP funders) and local governments	Provide funding and support for policies and staffing	Policies, guidelines, funding, and training; community health worker linkages	Setting national and local policy for community involvement in End TB strategies; health commodity distribution
WHO country offices	Provide support to NTPs	Support for implementation of WHO policies	Provide technical support and catalyse relations among local CSOs, community and NTP
Regional WHO offices	Regional action plans that include, for example, collection of feedback on MAF-TB implementation	Support for implementation of WHO policies	Provide technical support and catalyse relations among local CSOs, community and NTP
WHO/GTB	Global guidelines and guidance; WHO Civil Society Task Force on TB	Mainstreaming community engagement into reporting requirements; leadership development; technical assistance	Policy-setting, providing guidance, guidelines and technical support; platform for dialogue and exchange with civil society and TB survivors (WHO Civil Society Task Force on TB)
Financial partners	Current funding for many community engagement activities	Mainstreaming community engagement, strengthening efforts to create an enabling environment for grant requirements; leadership development; technical assistance	Sustainability plans: requirements for NTPs to fund community engagement; support to community systems; strengthening responses; and programmes to address barriers to human rights-related barriers
Technical partners and experts	Working within high-burden countries to provide resources and tools	Mainstreaming community engagement into End TB strategies; leadership development; technical assistance	Sustainability plans; capacity development for health systems and community groups

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