

## Policy Brief

# Meaningful Engagement of Civil Society & TB Affected Communities and the Value of their Role in the TB Response



This policy brief has been prepared to increase meaningful engagement of civil society organizations and TB affected communities in the implementation of Multisectoral Accountability Framework on TB in the time of COVID-19 pandemic in the ECA region

## Executive Summary

Health is central to the sustainable development of every country. A world that is out of balance in matters of health is neither stable nor secure. To achieve this balance in the TB response, the role of civil society and TB affected communities is fundamental.

**The United Nations Sustainable Development Goals (SDGs), the World Health Organization End TB Strategy (the End TB Strategy), the Political declaration of the UN General-Assembly High-Level Meeting on the Fight Against Tuberculosis (the Political Declaration of UN HLM on TB),** and other

strategic documents declared the meaningful and constructive engagement of civil society and TB affected communities in all aspects of the TB prevention and care activities as a priority. The **Political Declaration of UN HLM on TB** articulates the comprehensive role of civil society and TB affected communities in TB response. It also emphasizes the legal, gender, social and economic aspects of the TB response and the role of civil society and TB affected communities in advocacy, monitoring and designing legal, policy, and operational guidance to overcome barriers and facilitate an enabling environment for accessing TB, health and social protection systems, as well as the realization of the right to health for all.

**The Political Declaration of UN HLM on TB** (September 2018) aims to end the epidemic in all countries, and pledges to provide leadership, and to work together to accelerate national and global collective actions, investments and innovations urgently, to fight TB.

**Global TB Report 2020** provides an opportunity to reflect on progress made in the fight against TB and highlight the risks that threaten to erode the gains we have made.

The **Global TB Report 2020** recommends “to contribute to a sharpened focus on the engagement of civil society and TB affected communities in all aspects of the TB response”. The global civil society and TB affected communities reported in 2020 “a deadly divide” between commitments of the Political Declaration of

UN HLM on TB and realities. A **Deadly Divide report**, complements the Global TB Report 2020 by providing a complementary view of the status of the Political Declaration of UN HLM on TB targets and commitments, specifically through the lens of civil society and TB affected communities. Progress towards ending TB will depend on actions across sectors, underscoring the importance of the national adaptation and implementation of WHO’s **multisectoral accountability framework for tuberculosis** (MAF-TB). As part of this adaptation and implementation, and to help operationalize the MAF-TB, it will be important to integrate **6 calls to action** from the Deadly Divide report into the national reports and multisectoral roadmaps considering the baseline assessment using Annex 2 of the MAF-TB Checklist -

**A “Deadly Divide” calls to action** is a strong initiative driven by 150 community and civil society partners from over 60 countries which demand a social justice approach that prioritizes community needs. This report is part of an accountability process.

engagement of civil society and affected communities in the 4 components of multisectoral accountability to End TB at the country level.

The current situation with COVID-19 tangibly demonstrates to the international community, governments, and activists alike, that the fight against infectious diseases knows no borders, and provides a number of lessons on how to respond to such challenges. [Stop TB Partnership Modelling analysis](#) has demonstrated that the TB response has regressed at least 5-8 years as a result of the pandemic, civil society and TB affected communities have documented the increasing barriers and challenges experienced as a result. While COVID-19 has presented serious challenges, as articulated in the Deadly Divide Call to Action 6, we must collectively leverage COVID-19 investments, systems and infrastructure to strengthen national TB responses. One of the lessons learned from the COVID-19 response is that global public health actors are united with a sense of urgency to act and respond. The ambitious goals to achieve national, regional and global commitments to End TB by 2030 cannot be reached without engagement of civil society and TB affected communities.

## What is Meaningful Engagement of civil society and TB affected communities?

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***“Ending TB is not just a job for governments. Everyone has a role to play, from those in the corridors of power to those in the villages and streets where people live and die with TB”***

*[Dr Tedros Adhanom Ghebreyesus](#)*

*Director-General World Health Organization*

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The central role of civil society and affected communities in the response to TB has long been recognized by the global community and policymakers as an ethical and pragmatic imperative for the successful implementation of National TB Programmes (NTPs). In many countries, especially where TB is fuelled by HIV, government health-care providers have been stripped of their ability to cope with the levels of service delivery needed to meet targets. Engagement of civil society and TB affected communities in the TB response at all levels, especially during the COVID-19 pandemic should become not only an additional supportive factor for NTPs, but an integral part of an effective strategy to achieve the goal of Ending TB. There is a strong body of evidence that the engagement of civil society and TB affected communities is vital to improving strategies for health, as the communities can speak for themselves about their priorities and the strategies needed to overcome the social, political, cultural, legal and economic barriers to accessing TB services, care and support from the TB survivor’s perspective.

**Civil society and TB affected communities need to be given an important role not only in direct services provision but also in the process of governance, coordination, and communication.**

They can respond to specific issues and needs, including the provision of direct services: case-finding, social, psychological, and other services during diagnosis, treatment, and rehabilitation, through the TB care cascade.

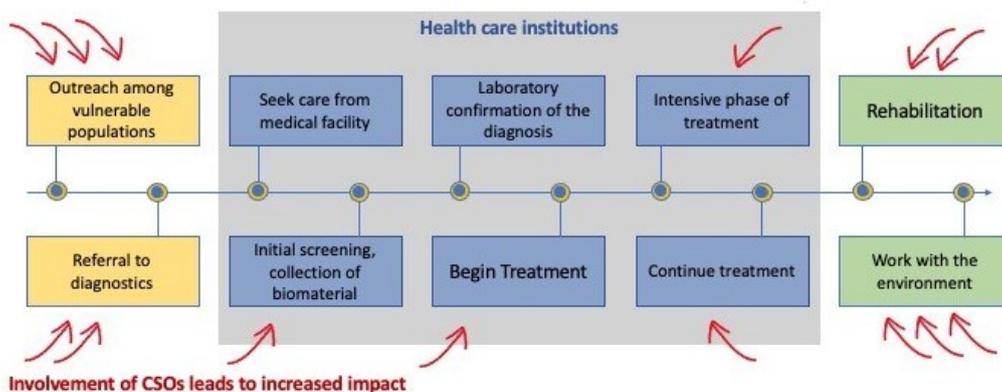


Fig.1 Provision of services to the general public through CSOs at the stages of the TB care cascade (1) developed by Mikhail Volyk

Figure 1 shows the care cascade for people with TB, which usually starts from outreach (active case missed by the healthcare system) among vulnerable populations and ends with rehabilitation. The common target is to act according to the “no one left behind” principle which means that every person affected by TB should be reached and no one should be left without TB care services.

This care cascade shows that most activities are traditionally concentrated in medical institutions (highlighted in gray), but it is not limited to this. The yellow boxes represent outreach aspects of the cascade, as well as the referral of people at risk of getting TB or who have symptoms of TB. The role of civil society and TB affected communities is becoming more critical in terms of establishing, consolidating and scaling up key community linkages with essential services, especially in the underserved, difficult-to-reach areas and with marginalized population groups. This is the field where the medical system has limited, or in most cases, no access to such groups, authority, or enough resources for service provision.

TB care should not end even after effective treatment (green boxes), since there is still a need for rehabilitation and/or resocialization.

Red arrows in Figure 1 shows where participation of civil society and TB affected communities has already proven its effectiveness. The higher the role of civil society and TB affected communities; the more arrows are indicated at the stage of service provision.

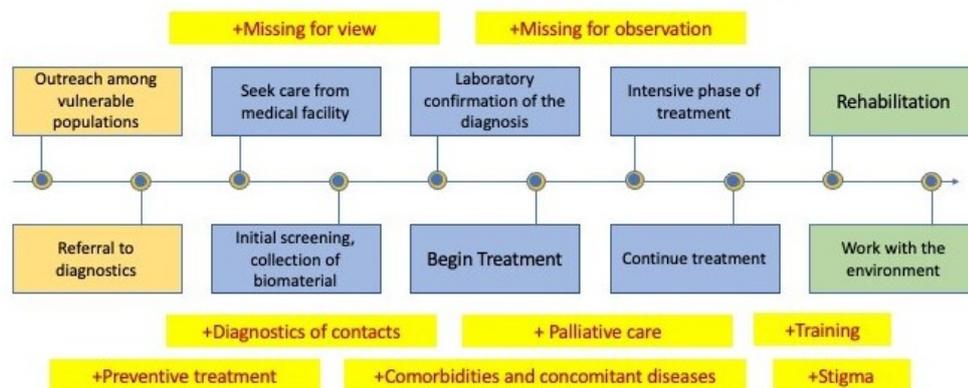


Fig. 2. Provision of services to the general public through CSOs at the stages of the TB care cascade (2) developed by Mikhail Volyk

The traditional health care system is not able to reach and cover all people with TB, such cases are called *lost to follow-up*; someone may not be reached at all and be completely lost for review, we should also remember about terminal and incurable conditions (palliative care), because TB is still a fatal disease (Figure 2).

A huge range of services is also necessary for concomitant diseases, because according to the people-centred approach, we do not treat a disease, but we focus on meeting all health needs of the person with TB. A people-centered continuum of care should take into consideration an individual's psychological and sociological context. Affected people face multiple challenges, which may increase in intensity and change over time, so any psychosocial support should be designed in a way that engages a wide range of stakeholders – including health professionals, social workers, affected people, communities and civil society/public organizations – transforming everyone into an active player.

**Psychosocial support is of high importance in addressing the many inextricably linked complexities of the TB. Such support will ultimately contribute to improving TB treatment outcomes, as it helps to keep the patient on adequate treatment through improved adherence.**

**What is “meaningful engagement”? How to understand that the engagement of civil society and TB affected communities is really meaningful?**

The Article 21 from the [Declaration of the Rights of People Affected by Tuberculosis](#), prepared by a network of TB survivors and affected communities, TB People, with the support of leading human rights lawyers and the Stop TB Partnership clarifies what the right for participation is and what is meant by the right to **meaningful participation**.



**The right to participate meaningfully in all processes and mechanisms for the development, implementation, monitoring and evaluation of laws, policies, regulations, guidelines, budgets, and programs related to tuberculosis, health care for tuberculosis, and medical research for tuberculosis at all levels of governance, with support from and, when necessary, reasonable accommodation provided by the State, international organizations.**

This definition is fully consistent with suggestion by [WHO's Multisectoral Accountability Framework to Accelerate Progress to End TB by 2030](#) (MAF-TB) and [Annex 2](#) of the [MAF-TB Checklists for the baseline assessment](#), based on participatory approaches and meaningful engagement of civil society and TB affected communities at all stages of the TB response will foster accountability on the achieved progress.

## Meaningful Engagement of civil society and TB affected communities in the Multisectoral Accountability Framework implementation

**MAF-TB was agreed by all nations at the United Nations High Level Meeting on TB in September 2018.** It is an approach that fosters collaboration and mutual accountability to end TB within and beyond the health sector. It aims to ensure that the political commitments made by the Member States to end TB are implemented into practice through **specific actions, which are monitored, reported on and reviewed.**

### The MAF-TB development and implementation

The driving force to come up with the development of MAF-TB was the sense of urgency, which was fuelled by the recognition of the fact that investments and actions were falling short of thresholds needed to reach the targets and milestones of the WHO's End TB Strategy. This strategy was adopted to guide accelerated action in the TB response from 2016 and it has been aligned with the SDGs target 3.3 of ending the TB epidemic by 2030. Additionally, Stop TB Partnership subsequently developed the Global Plan to End TB, as a road map for achieving the End TB Strategy. Understanding that the End TB Strategy and the Global Plan are linked with broader Member States commitments to advance the SDG agenda, provides additional leverage for civil society and TB affected communities to advocate both for putting TB high on the political agenda and advancing a multisectoral response in the fight to end TB. SDGs are built upon the idea that **no single sector has the resources and expertise to**

**MAF-TB can be a steering wheel mobilizing political commitment to keep the fight to end TB on track and to ensure continuous progress. Finding ways to support sustainability in the TB response in times of health emergencies, such as COVID-19 will be critical.**

achieve the SDGs alone. The confluence of social and health inequities, demands multisectoral action.

The MAF-TB should help to develop a transparent and effective system to monitor progress, to flag issues, delays, underperformance or failings in the same way as to create enabling environment for sharing lessons, finding joint solutions, and nurturing resilience through enhanced multisectoral accountability and collaboration. Civil society and TB affected communities’ voices, community-led monitoring is an important part of informing this process – bringing in different perspectives and roles should be vital and active in the MAF-TB.

National measures to ensure the meaningful engagement of civil society and TB affected communities in the TB response in the EECA region are often limited to the process of participation rather than on the extent of civil society and TB affected communities’ power to engage in decision-making process.

It is important to build an understanding of bottom-up approaches and the extent, power, and outcome of civil society and TB affected communities’ engagement in the TB response. The Annex 2 of the MAF-TB Baseline Assessment Checklist suggests wide list of areas for civil society and TB affected communities’ engagement within four elements of the MAF-TB (Figure 3).

<p><b>COMMITMENTS</b></p>	<p><b>Annex 2</b> stems from the overarching principle in the End TB Strategy of a “strong coalition with civil society organizations and communities’, <b>commitments</b> of the Political declaration of the UN HLM on TB and how those have been implemented in practice.</p>
<p><b>ACTIONS</b></p>	<p><b>Set of actions</b> suggested for measuring engagement of civil society and affected communities in the End TB response include, but is not limited to: establishment of a TB civil society forum or equivalent, participation in the national strategic or operational planning and budgeting; participation in TB service delivery; participation in national research agenda-setting, including clinical and operational research; collaboration with civil society for addressing other health priorities and sectors. Besides, two important markers, which are mediators of the meaningful engagement of civil society are suggested. Those markers include availability of the yearly operational budget to support civil society work and a dedicated focal point in the National TB Programme to support civil society.</p>

<p><b>MONITORING &amp; REPORTING</b></p>	<p><b>Monitoring and Reporting</b> elements related to civil society include involvement in regular monitoring meeting of the National TB Programme; being consulted in design of major TB-related surveys; being involved in the design and conduct of gender, stigma and legal environment assessments, as well as civil society audits for service review and access. Actions of civil society and affected communities within the suggested monitoring and reporting are closely linked to the Stop TB Partnership compendium of the Communities, Human Rights and Gender tools, which are responsive to the needs of key and vulnerable populations.</p>
<p><b>REVIEW</b></p>	<p><b>Review part</b> of the assessment at the Annex 2 suggests measuring if representatives of civil society are part of any high-level review mechanism on TB, as well as if they are part of the full process of joint monitoring/review missions for National TB Programme.</p>

Fig. 3. Unpacking multisectoral collaboration & accountability in the end TB response: Reference guide for civil society and TB affected communities on background, essentials and key actions, TBEC (2020)

**Engagement of civil society and TB affected communities in MAF-TB baseline assessments** will help to make sure that **elements, which need to be adopted or strengthened** for the equitable, people-centred, gender-sensitive, and rights-based TB response to address the needs of key and vulnerable people and communities **are identified and taken care of.**

## How civil society and TB affected communities can advance the MAF-TB agenda in line with Advocacy, communication and social mobilisation

### 1. Social mobilisation

Find supporters among civil society, communities, and technical partners.

Define your goal, objectives and multisectoral indicators of success around the issues identified.

Seek support from the National TB Programme and WHO country office

Seek technical cooperation from the WHO Regional Office for Europe.

### 2. Communication

Map what decision-makers and decision-making platforms aim to reach collectively.

Outline priorities by agreeing on key issues.

Reach out to decision-makers through letters, press briefings, opinion editorials and events.

### 3. Advocacy

Identify windows of opportunity and agree on stages of the MAF-TB implementation, including MAF-TB baseline assessments.

Advocate for the costs of MAF-TB and inclusion of the MAF-TB approach in national strategic priorities.

Make sure you are part of the discussion and planning process for the MAF-TB from the earliest stage.

Actively participate in filling the MAF-TB assessment Checklist Annex 2.

Ensure transparency of the MAF-TB assessment findings.

Advocate for formalisation of the country MAF-TB mechanisms.

Ensure civil society and TB affected communities are adequately represented in the MAF-TB coordination and High-level Review mechanisms.

Advocate for inclusion of the section on civil society and TB affected communities' inputs in the TB response to the annual National TB report.

## Contributions from the WHO, Stop TB Partnership for civil society and TB affected communities' meaningful engagement in TB response

**"We are all accountable for delivering on the commitments we have made. But none of us can meet those commitments alone. We can only do it together. We need all hands-on-deck"**

*[Dr Tedros Adhanom Ghebreyesus](#)*

*Director-General World Health Organization*

WHO has been increasingly aware of the important role that civil society and TB affected communities play in the global health. It established the [WHO Civil Society Task Force on TB](#) and published a report on [Engagement with Civil Society as the Driver for Change](#), highlighting the importance of civil society, and recent projects to build collaboration between the WHO and TB civil society. The WHO also developed the MAF-TB in response to Member States' and civil society requests.

The [Regional Collaborating Committee on Accelerated Response to Tuberculosis, HIV and Viral Hepatitis](#) (RCC-THV), initiated by the WHO Regional Office for Europe in 2012, is also a key platform that aims to build a united and intersectoral response to these diseases. The RCC-THV provides an opportunity to share good practices and lessons learnt on the latest developments in TB, HIV and viral hepatitis.

Critical to the MAF-TB implementation is [Community, Rights and Gender](#). Advocacy for the adaptation and implementation of MAF-TB and the promotion of CRG tools and approaches to the

TB response is a strategic entry point to advance meaningful participatory engagement of civil society and TB affected communities in the TB response through the participatory approach, as seen through the CRG Assessments conducted, TB CRG Action Plans developed and led by community and civil society organizations in collaboration with National TB Programs in [Ukraine](#), [Kazakhstan](#), [Kyrgyzstan](#), [Georgia](#) and [Tajikistan](#).

Stop TB Partnership has developed a series of **tools to assist countries in transforming the TB response** to be equitable, rights-based, gender-transformative and people-centred.

Stop TB Partnership, through the Global Plan to End TB, reaffirmed that community engagement and systems strengthening (C), the promotion and protection of human rights (R), and gender equality (G) are key (CRG) components required to End TB. To support the operationalization of these commitments to CRG, Stop TB Partnership, and civil society and TB affected communities' partners developed a global CRG strategy, as well as CRG briefs and assessments, while also augmenting [the Challenge Facility for Civil Society](#) (hereinafter – CFCS). CFCS is the Stop TB Partnership grant mechanism to enhance CRG in TB Responses. In 2021, 7.5 million USD is being made available to civil society and TB affected communities' engagement in the TB response. It is through this funding source that civil society and TB affected communities have been empowered and supported to complete CRG Assessments, community-led monitoring of human rights barriers, and human rights capacity building, sensitisation as well as law and policy reform.

It is through this Challenge Facility mechanism, that Stop TB Partnership has supported the formation and/or strengthening of civil society and TB affected communities networks at global (including TBpeople, TB Women), regional (including TB Europe Coalition) and national level (including TBpeopleUkraine and Stop TB Partnership Tajikistan), many of which have moved from informal collectives of advocates and peer supporters, to coordinated and strategic organisations, who are recipients of grants from organisations like the Global Fund, USAID and the Stop TB Partnership. Stop TB has also now formalized civil society and TB affected communities in global TB governance. TB affected communities and civil society have seats on the Board of Stop TB Partnership, and are supported by formalized and funded [Delegations](#). The professionalisation of civil society and TB affected communities is further demonstrated through the [Deadly Divide: TB Commitments vs TB Realities](#) report, an initiative of the three Stop TB civil society delegations, and the [Impact of COVID-19 on the Tuberculosis Responses](#), where those same Delegations, joined other community partners to co-author this influential report – the recommendations of which feature in the recent Global Fund Information Note on [COVID-19 Catch Up Plans for Tuberculosis](#). It has been critical for the Stop TB Partnership to lead by example in terms of prioritising and formalising meaningful civil society and TB affected communities' engagement, participation and governance for accountability.

TB Europe Coalition (TBEC) under the CFCS grant is focusing on Eastern Europe and Central Asia to enhance civil society and TB affected communities' coordination and capacity to strategically contribute to national and regional efforts and achieving the targets of Political Declaration of UN HLM on TB. The project addresses the regional and national operational dimensions of the meaningful engagement of civil society and TB affected communities in TB response and ensure the learning channel between neighbouring countries to share evidence on effective approaches of community advocacy for sustainable TB finance and rights-based, gender-equitable and people-centred TB services.

**TBEC is a regional partner of the WHO/Europe Regional Office in baseline assessment implementation using Annex 2 on MAF-TB in countries of the EECA region, and would welcome the opportunity to technically support civil society and TB affected communities' representatives who would take the initiative and want to initiate the implementation of MAF-TB in their country.**

## Conclusion

TB advocates can make a real difference in ensuring that progress towards political commitments is made. TB advocates should remember that sustainability in TB issues mainly depends on political commitment. If we do not progress year by year, then TB will progress day by day. We should have an ongoing sustained engagement on issues that impact the lives of people living with TB. Lofty promises and goals for ending TB in some distant future will not mean anything unless concrete steps are taken now to "get the job done". There are less than two years left to fulfil targets set, and take action on the commitments made at the United Nations High-Level Meeting on TB in 2018 so, **The Clock Is Ticking**.

There is a "deadly divide" between agreed goals of the Political Declaration of UN HLM on TB and SDG by 2030 and the realities experienced on the ground. This will continue as long as those most in need are deprived from access to quality and affordable TB prevention, diagnosis, treatment, care and support. On this World TB Day, TBEC calls for increased global health solidarity to address health issues within global security agenda. Universal health coverage can only be achieved with the removal of human rights barriers, the elimination of catastrophic costs in TB financial burden on families and individuals caused by out-of-pocket expenditures and loss of income.

Countries have committed to protect and promote human rights, universal access to quality, affordable treatment and to End TB by 2030, but this needs to be backed up by concrete action in the short term, rather than only in the long term. Strong political will, which can only be achieved through civil society advocacy, will help overcome each of these barriers.

Civil society and TB community must come together to catalyze and sustain the political will to deliver on the Political Declaration of UN HLM on TB, pushing governments to prioritize the role of civil society and TB affected communities to End TB. A critical step for governments is the revision of national TB policies backed up by necessary legal provisions in accordance with the new Monitoring framework of the WHO European Region TB action plan 2021-2030 (Figure 4) and to mobilize every available resource necessary to support meaningful engagement of civil society and TB affected communities in TB response.

Country **adopted standards and operational procedures** for civil society organizations in the provision of psycho-social support services to ensure treatment adherence for people with TB

Country **adopted procedures of subcontracting mechanisms** under the state funds or other relevant funding mechanisms for CSOs in the provision of psycho-social support and active case-finding services for people with TB

Proportion of people with TB found through **active case-finding** activities implemented through CSOs

Proportion of people with TB who started TB treatment and who received any form of **treatment adherence support** from CSO (including psycho-social support)

Fig.4. Four community systems and civil society engagement indicators, Monitoring framework of the WHO European Region TB action plan 2021-2030

Suggested four indicators are highlighted as the “minimum package” for multisectoral response and to ensure sustainable participation of civil society and TB affected communities in the response to TB.

Civil society and TB affected communities have a fundamental role to play in all components of multisectoral collaboration and accountability related to TB, as acknowledged in the Sustainable Development Goals, the End TB Strategy, the Moscow Declaration and the political declaration of the General Assembly high-level meeting on tuberculosis in 2018. Civil society and TB affected communities should mobilize collective action and sensitize government stakeholders for the importance of the multisectoral collaboration, with the broader engagement of civil society and TB affected communities, including the launch of MAF-TB baseline assessments in coordination with NTP. 2023 timeframe for Heads of States to report at the UN High-Level meeting on the progress achieved in TB, following the commitments of the Political Declaration of UN HLM on TB contributes towards the creation of the enabling environment for accelerating MAF-TB processes.

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***This window of opportunity should be used now, The Clock Is Ticking!***

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