TB REP

TB REP 2.0: Advancing People-Centered Quality TB Care - From the New Model of Care Towards Improving DR-TB Early Detection and Treatment Outcomes

TB EUROPE COALITION

TRANSITION TO PEOPLE-CENTRED MODEL OF TB CARE: ROLE OF CIVIL SOCIETY AND AFFECTED COMMUNITIES

EECA Regional Policy Document

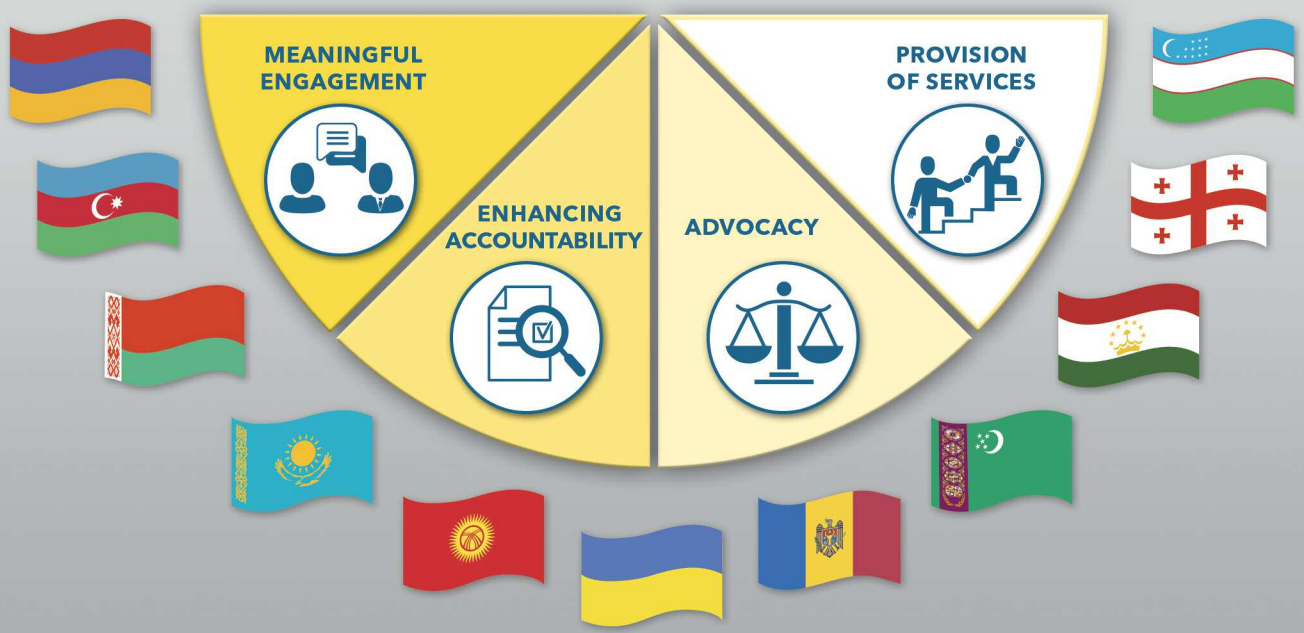

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Table of Contents

ACKNOWLEDGEMENTS
DISCLAIMER
TABLE OF CONTENTS 1
ABBREVIATION 2
EXECUTIVE SUMMARY 3
PREFACE 5
- Tuberculosis in EECA: Setting the Scene 6
- Epidemiological context 6
- Policy dimension 7
- Global, regional and national commitments to people-centred model of care 7
- Health systems context for TB services 9
- Roles and functions of CSOs and communities 10

CHALLENGES AND OPPORTUNITIES FOR STRENGTHENING THE ROLE OF CSO IN TB RESPONSE 12

STRENGTHENING THE ROLE OF CIVIL SOCIETY IN TRANSITION TO PEOPLE-CENTRED MODEL OF CARE IN EECA 14
- Objectives and expected outcomes 14
- Key actions 15
  - *Meaningful engagement of communities in decision making* 15
    - *Action 1: Understand the environment and identify opportunities for engagement* 15
    - *Action 2: Strengthen collaboration between CSOs, with NTP and other stakeholders and build strategic partnerships* 16
    - *Action 3: Foster adoption of innovative approaches to care* 16
    - *Action 4: Develop tools and instruments to help policymakers, healthcare providers, CSO and communities to enable a people-centred model of care* 17
  - *Monitoring and enhancing public accountability* 18
    - *Action 5: Promote community leadership and national accountability through community-based monitoring* 18
  - *Advocacy* 19
    - *Action 6: Address human rights, gender, stigma and discrimination barriers to TB Services* 19
  - *Service delivery* 19
    - *Action 7: Strengthen social contracting mechanism and budget advocacy to enable CSO participation in service delivery at the community level* 20
    - *Action 8: Define community/CSO -led services for tuberculosis at the national level* 21
    - *Action 9: Build capacity of CSOs as service providers* 21
    - *Action 10: Collaboration across three diseases: CSO and community-led response to TB, HIV, and viral hepatitis* 21

REFERENCES 23
SELECTED RESOURCES ON PEOPLE-CENTRED MODEL OF TB CARE 24

Abbreviation

CSO	Civil society organizations
EECA	Easter Europe and Central Asia
GF	The Global Fund
GHED	Global Health Expenditure database
HCV	Hepatitis C virus
HIV	Human immunodeficiency virus
NTP	National TB Program
OOP	Out-of-pocket payments
SGD	Sustainable Development Goals
TB	Tuberculosis
TBEC	TB Europe Coalition
UHC	Universal healthcare coverage
UN	United Nation
WHO	World Health Organization

EXECUTIVE SUMMARY

As a part of the project "Advancing People-centred Quality TB Care – From the New Model of Care Towards Improving DR-TB Timely Detection and Treatment Outcomes in Patients", TB Europe Coalition (TBEC) has supported civil society organizations (CSO) in 11 countries – Armenia, Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, the Republic of Moldova, Tajikistan, Turkmenistan, Ukraine, and Uzbekistan, through providing assessments/coaching visits for capacity building and has supported national dialogues between CSO groups, public authorities and other stakeholders, including National TB Programs (NTB) to highlight the role of CSO and support their active engagement in all stages of TB response efforts at the national level.

This document builds upon the materials developed with the technical assistance provided by TBEC within the TB-REP 2.0 project. This work supported intensification of the national dialogue and has produced number of materials to reflect outcomes of the process. This document summarizes the outcomes of the national dialogues from the prisms of regional and global approaches to advance the people-centred model of TB care. It identifies challenges faced by countries to switch to the people-centred model of care and challenges and opportunities for CSOs and community groups to be active engagement in this process.

Most of the countries in the region have explored key challenges they face and opportunities there for CSO engagement to support the TB elimination agenda.

Guided by the objective to identify key priority actions for TB communities and community leaders in the region, the document has identified 10 actions within four main blocks of priorities:

1. Meaningful engagement of communities in decision making

- **Action 1:** Understand the environment and identify opportunities for engagement.
- **Action 2:** Strengthen collaboration of CSOs with other stakeholders and build partnerships.
- **Action 3:** Foster adoption of innovative approaches to care.
- **Action 4:** Develop tools and instruments to help policymakers, healthcare providers, CSO and communities to enable a people-centred model of care.

2. Monitoring and enhancing public accountability

- **Action 5:** Promote community leadership and national accountability through community-based monitoring.

3. Advocacy

- **Action 6:** Address human rights, gender, stigma and discrimination barriers to TB Services.

4. Service delivery

- **Action 7:** Strengthen social contracting mechanism and budget advocacy to enable CSO participation in service delivery at the community level.
- **Action 8:** Define community/CSO -led service for tuberculosis at the national level.
- **Action 9:** Build capacity of CSOs as service providers.
- **Action 10:** Collaboration across three diseases: CSO and community-led response to TB, HIV, and viral hepatitis.

Implementation of these actions is expected to address the immediate needs of the TB response in EECA in the process of transitioning to people-centred model of care and to deliver the following outcomes:

- Speed up development of technical and communication solutions for implementation of people-centred services to end TB soon.
- Assure that TB response provides equal access to services with respect to rights and gender-oriented needs of people facing the problem of TB.
- Assure that all people who need it, have access to effective and up-to-date diagnostics, treatment and prevention of TB.
- Allocate funds and other kinds of support for the greater role of civil society in fighting TB.

PREFACE

Tuberculosis (TB) remains one of the most critical public health challenges globally and for countries in Eastern Europe and Central Asian (EECA) region. The strategic objectives set are ambitious and aim to end TB by 2030. However, as of 2020, TB-high priority countries in the WHO European Region are not on the track of achieving those targets. **Intensified efforts are needed by all parties engaged in TB response at the national and international level to realize commitments related to ending TB in the region.**

One of the approaches to support TB elimination is to redesign the national TB response system into an integrated and people-centred model. This model calls for intensive engagement of TB affected communities and civil society organizations (CSOs) representing those communities in the decision-making process, planning, and implementation of the TB response and monitoring the implementation process. The role of TB affected communities and civil society groups representing those communities have been defined in several high-level political documents, and strengthening their engagement and participation is set out to be a priority globally and for WHO European Region.

TB Europe Coalition (TBEC), which is a regional advocacy network of civil society organizations and individuals across the WHO Europe region has been engaged with TB-REP 2.0 project "Advancing People-centred Quality TB Care – From the New Model of Care Towards Improving DR-TB Timely Detection and Treatment Outcomes in Patients." It has supported CSOs in their advocacy for people-centred care at the national and regional levels. This work covers 11 countries: Armenia, Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, the Republic of Moldova, Tajikistan, Turkmenistan, Ukraine, and Uzbekistan. All those counties are high-priority countries for TB in the WHO European region.

As part of this project, TBEC has supported CSO at national level through providing coaching visits for capacity building and has supported a national dialogue between CSO groups and other public and medical stakeholders, such a National TB Programs (NTP) to highlight the role of CSOs and support their active engagement in all stages of TB response efforts at national level.

This document summarizes the results of technical assistance provided by TBEC and outcomes of the national dialogues from the prisms of regional and global approaches to advance the people-centred model of TB care. It identifies challenges faced by countries to switch to a people-centred model of care and challenges and opportunities for CSOs and community groups to be actively engaged in this process.

TB-REP 2.0 builds upon successes of the previous regional program – first TB-REP, which was implemented from 2016 to 2018 and focused on strengthening health systems for effective TB and DR-TB prevention and care in the same 11 high-priority countries. As a part of the first TB-REP program, a guide for adopting a people-centred model of TB care was developed and it had shaped the focus of the current program to support (i) enhanced participation of civil society in improving quality of care; (ii) further advances in health system strengthening interventions, with access to medicines as a key area of focus; and (iii) support for the implementation of the model of care with a focus on providers.

Tuberculosis in EECA: Setting the Scene

Ending the TB epidemic is part of the Sustainable Development Goals (SDG). The importance of this objective has been further reiterated in the Global Strategy to End TB, Political Declaration of the UN High-Level Meeting on the Fight Against Tuberculosis in 2018 and End TB Action Plan for Europe. However, TB remains a challenge globally and for the European region, which falls short of reaching regional and global targets, despite significant progress over the last two decades.

Global TB targets set in the SDGs, the End TB Strategy and the political declaration of the UN high-level meeting on TB, for the period up to the SDG deadline of 2030

SDG Target 3.3	By 2030, end the epidemics of AIDS, TB, malaria and neglected tropical diseases, and combat hepatitis, water-borne diseases and other communicable diseases
WHO End TB Strategy	80% reduction in the TB incidence rate (new and relapse cases per 100 000 population per year) by 2030, compared with 2015 *2020 milestone:* 20% reduction; 2025 milestone: 50% reduction
	90% reduction in the annual number of TB deaths by 2030, compared with 2015 *2020 milestone:* 35% reduction; 2025 milestone: 75% reduction
	No households affected by TB face catastrophic costs by 2020
UN high-level meeting on TB, 2018	40 million people treated for TB from 2018 to 2022, including: • 3.5 million children • 1.5 million people with drug-resistant TB, including 115 000 children
	At least 30 million people provided with TB preventive treatment from 2018 to 2022, including: • 6 million people living with HIV • 4 million children under 5 years of age and 20 million people in other age groups, who are household contacts of people affected by TB
	Funding of at least US$ 13 billion per year for universal access to TB prevention, diagnosis, treatment and care by 2022
	Funding of at least US$ 2 billion per year for TB research from 2018 to 2022

Epidemiological Context

Tuberculosis remains a public health challenge for the EECA region, particularly for 18 high-priority countries in the WHO European Region: **Armenia, Azerbaijan, Belarus, Bulgaria, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Moldova, Romania, the Russian Federation, Tajikistan, Turkey, Turkmenistan, Ukraine, and Uzbekistan.**

Despite having the fastest decline in TB incidence and mortality, these countries also have the highest rates of drug-resistant TB. Treatment success has been improving slowly over the years – from 75.7% to 77.1% and from 48.8% to 57.4% for DR- TB from 2015[1]; however, these rates remain below the regional targets of -85% and -75%, respectively. TB/HIV -coinfection rate is also on the rise in the region, with an estimated HIV infection rate of 18% among newly diagnosed people with TB in 2018. **DR- TB, TB/HIV -coinfection and underlying health system shortcomings are the main challenges that require urgent action in the region.**

[1] Report on the implementation of the TB Action Plan for Europe (unpublished draft)

Policy dimension

Tuberculosis Action Plan for the WHO European Region 2016–2020 was developed to assist the region and TB high priority countries in reaching SDG and End TB targets. **Integrated people-centred prevention and care is a key pillar of regional TB efforts.**

As we have approached the end of the implementation of the European region's action plan, the results are mixed and call for increased focus on TB is needed. While the region was able to attain a target for the decline in TB incidence, high MDR-TB burden and TB/HIV coinfections in the countries have undermined the achievement of the 2nd target on treatment success rates.

Little is known about the financial burden of TB care to individuals and families affected by TB in the region. As of 2018, only Armenia has reported out-of-pocket expenditures for health services for TB.[2] However, other countries have not measured a level of TB-related expenditure to provide such information.

Global, Regional and National Commitments to People-centred Model of Care

The importance of engagement of civil society and community groups in TB response is now widely acknowledged. The TB Action Plan for Europe has a designated objective for community systems and civil society engagement, which calls all member states to design actions to systematically include affected communities and civil society representatives in program planning, design, and implementation and coordinate their advocacy and communication strategies with those groups.

The importance of civil society engagement in TB response was first stressed in 2007 in the Berlin Declaration. This message has been then taken forward in the number of key and high-level political declarations and commitments:

- In 2015, the Riga declaration, **the engagement of civil society and affected communities in the design, implementation and monitoring of national TB response as well as service delivery was stated as essential to strengthening the work with vulnerable populations.**
- Moscow Declaration 2017, as well as Estonian Senior-level Policy Dialogues in 2017 state that civil **society and community involvement can ensure that the collective response is informed by the realities of those most affected** populations.

Those commitments are supported by high-level global strategies such as **Sustainable Development Goals, End TB Strategy and Political declaration of the UN General-Assembly High-Level Meeting on the Fight Against TB (2018).**

[2] Out-of-pocket payments are direct, private payment to the healthcare provider. This type of payment is a leading cause of catastrophic (impoverishing) healthcare expenditures.

Similarly,

- The Global Fund, which remains the key donor for TB response activities in the EECA region, has reiterated the importance of directing its funding to work with key populations through civil society and community representatives.
- Roadmap to implement the Tuberculosis Action Plan for the WHO European region 2016–2020 also stresses the importance of involving communities and civil society groups (Point 2E)

Making TB a part of universal health coverage agenda is an important step forward, which was once again reiterated as UN High-Level Meeting (UN HLM) on Universal Health Coverage (UHC) in 2019.

In 2017, a framework for People-centred model of TB care (Blueprint) was developed within the TB-RER project and the WHO adopted the framework. It serves as a guidebook to redesign TB services with a purpose to shift an increasing share of TB-related activities to an outpatient setting, to support the integration of TB services into the existing healthcare system and increase the availability of community-based services. Those require profound changes in TB service delivery in our region. This new model – a people-centred model of care, is "focused on and organized around the health needs and expectations of people and communities rather than on patients or disease."[3], or (to add) the way current health and medical systems function.

In 2021, WHO developed the ENGAGE-TB approach in response to the need to operationalize commitments on CSO engagement in TB prevention, diagnosis and care. It explains the policies and programmes that are needed to support CSOs to integrate TB into their community-based work, even if they have been working in the fields such as maternal, newborn and child health (MNCH), HIV care, primary health care (PHC), education, agriculture and livelihoods development programmes. It also outlines how NTPs, NGOs/CSOs can collaborate on community-based approaches. Although not a policy document, the set of ENGAGE-TB tools help countries to operationalize some aspects of CSO engagement in TB response.

TB is strongly associated with biological and behavioural factors that weaken the immune system- (including -HIV infection, diabetes and the use of tobacco, alcohol, and illicit drugs), as well as with social, economic, and environmental determinants that increase vulnerability and exposure to TB (such as poverty, unemployment, imprisonment, and migration). **Ending TB requires concentrated efforts which will tackle not only the medical aspect of TB but also behavioural aspects and social determinants contributing to increased TB burden. Civil society organizations and affected communities play an essential role in ensuring that TB care is people-centred – they reach vulnerable populations, are available closer to their homes, and address complex social determinants and behavioural risks of the diseases.**

A number of countries have committed to improve CSOs and community engagement in the national TB response, and to broader principles of people-centred model of care. Those commitments are reflected in the national strategic plans.

[3] https://www.euro.who.int/__data/assets/pdf_file/0004/342373/TB_Content_WHO_PRO_eng_final.pdf

Health Systems Context for TB Services

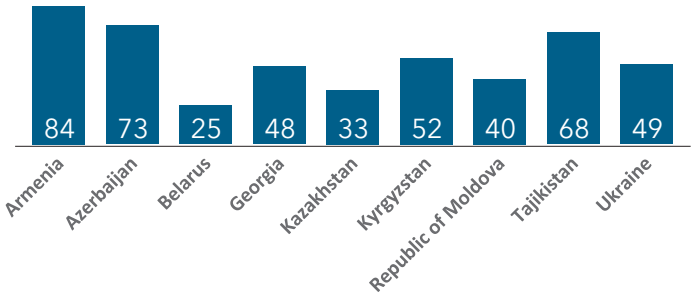
Low and middle-income countries in the WHO European Region are making fast progress towards universal health coverage (UHC). However, most of the high-TB priority countries in the region suffer from shortcomings of the healthcare system, which is focused on in-patient treatment and is underfunded from public sources; this is expressed in (i) high level of hospital bed capacity, which consumes significant share of current expenditures for TB, (ii) high out-of-pocket expenditures, which create significant barriers for seeking care, and (iii) limited focus on people affected.

A people-centred model of TB care calls for focusing on comprehensive needs of people, bringing services closer to the homes of patients and focuses on outpatient models, rather than lengthy in-patient treatment. This is supported by the innovations in TB treatment, such as shorter and fully oral treatment regiments, rapid diagnostics, and remote (video-supported) directly observed therapy.

Several health systems factors held back this transformation. Some of those from financing, service delivery and human resources perspective are listed below, although this list is by far not an exhaustive:

! High out-of-pocket expenditures deter patients from seeking needed medical care or delay their contact with the healthcare facility. Countries in the TB-REP project do not report having out-of-pocket expenditures for TB except Armenia and Georgia.[4] However, given the high share of OOP for other medical services, it is highly possible that potential OOP can force TB patients to forego needed medical care. In 9 EECA, the share of out-pocket-payments varies from 84% (Armenia) to 25% (Belarus).[5]

Household out-of-pocket payment
% Current health expenditure (CHE)



This variation of OOP among those countries, also signify different health systems context in the region. This includes a mix of public and private providers, as well as funding schemes used by the government. Those factors affect TB service delivery and funding as well: countries with predominantly public provision of services, mechanisms to contract non-public providers, such as CSOs, could be less developed, while in countries with limited funding of healthcare, funds could be an issue.

! Countries still have excess TB bed capacity: TB high burden countries covered in the project report that countries have excess TB bed capacity. Given that TB beds, in most of the cases, are fully or partially funded from the public budget independent of utilization (number of patients), this, on the one hand, consumes a large share of the budget available

[4] Armenia reported 1 million US out-of-pocket expenditures for TB in 2018 in WHO Global Health Expenditure Database (GHED) – https://apps.who.int/nha/database; Georgia does not report such spending in GHED. However, health utilization and expenditure survey carried out in 2016 revealed such spending for TB.
[5] 2018 reports in GHED https://apps.who.int/nha/database

for TB, and on the other hand, create incentives within the system to admit and retain patients without clear medical need.

Lack of qualified human resources to make TB diagnostic, treatment, and care more accessible for the population, given that the countries historically have had a highly vertical TB service provision model and integrating those services with general healthcare services is a challenge for the system.

Another important aspect is how those countries view healthcare and adjunct services. According to the GF, community roles can be formally included within the healthcare sector, partially included or entirely outside of the system.[6] Community health workers and integrated community case management can be part of the formal healthcare system (e.g., staff employed in a healthcare facility is responsible for delivering the service), while community health education, health commodity distribution and adherence support and home care could be only partially included in the health system. Community-led social accountability system and addressing social determinants are also essential services for TB response but are outside the healthcare sector.

Roles and Functions of CSOs and Communities

Several high-level documents have already stressed the pertinent role of TB affected communities and CSOs in TB response activities and accelerating achievement of set global targets. Communities and CSOs are resources and recipients of TB response measures, and they can serve different roles and functions.

TB Action Plan for WHO European Region calls for **greater involvement of civil society in the design, development, implementation and monitoring and evaluation of TB response.** Based on the review of WHO and the Global Fund strategic documents and guidance, as well as the vision of TB-CSOs in the EECA region, this includes:

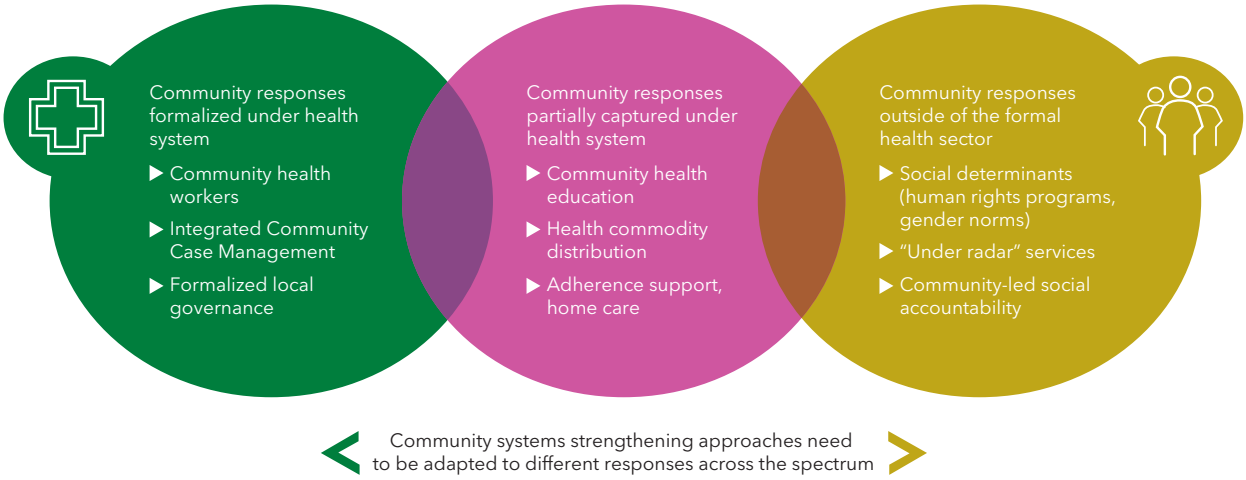
- Support to patients in continuing their treatment, thus improving treatment adherence and outcomes.
- Creating and maintaining a public awareness of TB, destigmatizing patients, and strengthening community involvement in treatment and care.
- Reaching and mobilizing people – including those who are most vulnerable and affected by TB.
- Providing psychosocial support to patients and their families.
- Make sure that TB interventions are informed and respond to changing needs and concerns of the community.
- Advocating for enabling environment and programming to reduce human rights and gender-related barriers to accessing services.

As this list can be expanded further, those are achieved through four main streams of community/CSO activities:

- Meaningful engagement of communities in decision-making process.
- Monitoring and enhancing public accountability.

[6] https://www.theglobalfund.org/media/8464/publication_communityresponses_focuson_en.pdf

- Advocacy.
- Service delivery.



CHALLENGES AND OPPORTUNITIES FOR STRENGTHENING THE ROLE OF CSO IN TB RESPONSE

Ending TB requires the comprehensive challenges related to the diseases to be addressed. An effective TB response requires robust health systems to accelerate the achievement of universal coverage of TB prevention and care services. **Integrated people-centred prevention and care is a key pillar** of regional TB efforts, which are aligned with the United Nations Political Declaration of the High-level Meeting on Universal Health Coverage, adopted by the United Nations General Assembly on 23 September 2019.

High-level political support to meaningful engagement of CSO and communities at global, regional and national level provides an opportunity for CSOs. Those commitments need to be operationalized at the local level and while countries define their approaches as a part of national strategic planning process, other TB-related policy development, programming or implementation, CSOs have opportunities to influence those decisions for the best interests of vulnerable groups, affected communities and patients.

As the countries in the WHO European Region commit to shift to this new model of care, several issues arise, including with respect to the role and function and CSO/community groups:

- Roles, functions, and responsibilities of those groups to provide essential non-medical services to TB patients, their families and TB prevention services to the broader group of the society.
- Definition of those services (service standards) and their costs.
- How those services will be funded through sustainable sources, such as domestic or local budgets.

and finally,

- As the whole system – medical and non-medical system tries to change, to voice the needs of TB affected communities and protect their best interests (advocacy). This includes the role of CSOs as a spokesperson for TB affected communities at high-level decision-making platforms in the national or sub-national level.

Throughout the continuum of TB care, CSOs and community groups can play a vital role in addressing TB specific and non-specific behavioural risks, as well as social determinants for health and ensuring timely access to medical services.

Addressing those medical and non-medical needs requires actions on multiple levels: from engagement in policy and decision-making processes to monitoring, advocacy and service delivery.

Meaningful engagement in policymaking and decision-making processes: In most of the countries, CSOs and community organizations engagement with the national TB response process is relatively nascent and only accounts for the past three to five years. Therefore, organizations face several challenges. Those include systematic challenges pertinent to the

way health and social care systems are functioning in EECA countries, as well as to epidemiological challenges and TB care model prevalent in the region.

Limited access to financial resources needed to engage CSOs in (i) service delivery and (ii) maintain advocacy work: Countries do not provide sufficient domestic funding for community-led/based services for TB and only a handful of organizations receive such funds. In many cases, public funding system has limited capacity to provide such funding, or services are not well-defined to be funded from public sources. In addition, public budgets do not provide funding for advocacy work, which is often directed at the public sector itself.

Currently, the primary source of funding for CSOs and community organizations in the region is the Global Fund. Those funding streams are available through national grants to regional grants that provide more focused funding for advocacy work. **The gradual transition** from the Global Fund funding may create a gap in the availability of already scarce financial resources.

Service Delivery: timely access to affordable and acceptable services is essential to the prevention, timely detection, treatment, and care for people with TB and TB affected communities. Health and social care system in TB high priority countries are not conducive to address complex clinical, social, and economic needs of people affected with TB, leading to suboptimal results.

The newly emerged **COVID-19** pandemic has negatively impacted TB response resulting potentially 20% increase in TB-related mortality[7] among people with TB due to deferral of care and diagnostics. Potentially, it has also exhausted available financial resources in the countries[8] and has stagnated TB service delivery by affecting TB hospitals, as well as health labour workforce for TB.

Shrinking space for collaboration between CSOs and governments have been identified as one of the impacts of COVID-19 and its control measures. This included regulations regarding freedom of speech and expression.[9]

Impact of the COVID-19 may be more profound in the long term by deterring resources and efforts from TB, especially for TB vaccine and new drug development, to that of SARS-2-COV. On the other hand, this might be an opportunity to highlight the importance of ending this disease, which cause such a significant social disruption.

The pandemic has also demonstrated the profound role that communities and CSOs play in addressing needs of people and patients even in the situation of a global health crisis. CSOs have demonstrated their flexibility in responding to changing context and their capacity to serve as reliable additional resource to healthcare workers in TB response.[10]

[7] https://www.theglobalfund.org/en/covid-19/news/2020-06-17-global-fund-survey-majority-of-hiv-tb-and-malaria-programs-face-disruptions-as-a-result-of-covid-19
[8] For examples, the government of Georgia has reported that there will be over 80% decline due to COVID-19
[9] http://afew.org/wp-content/uploads/2020/10/COVID-impact-survey-report-AFEW-International-3.pdf
[10] https://reliefweb.int/sites/reliefweb.int/files/resources/solidarity-in-the-time-of-covid-19_en.pdf

STRENGTHENING THE ROLE OF CIVIL SOCIETY IN TRANSITION TO PEOPLE-CENTRED MODEL OF CARE IN EECA

Based on the global, regional, and national vision, TB affected communities and CSOs should be engaged at all levels of the national TB response – planning, implementation, and monitoring. Those organizations may take different functions and roles depending on their organizational setup, country context, and country's needs.

Objectives and expected outcomes

Strengthening the role of CSOs and communities is needed to support the transition to a people-centred model of care and to achieve better outcomes for TB prevention and care. This model assures comprehensive pursuance of TB response goals in a way that puts people at the centre of the model and assigns key role to CSOs and communities in TB response planning and service provision.

CSOs, which work with and represent TB affected communities, are one of the key players in TB response activities at the national level. By acting as link between people affected with TB and medical services within the National TB Program, CSOs are important players to assure intensification of finding people with TB, early diagnosis and successful treatment. To make a meaningful contribution to this process, CSO engagement in the national TB response activities needs to become informed with evidence, and capable of addressing the needs of TB communities. In contrast, the national health system should create an enabling environment for such actions.

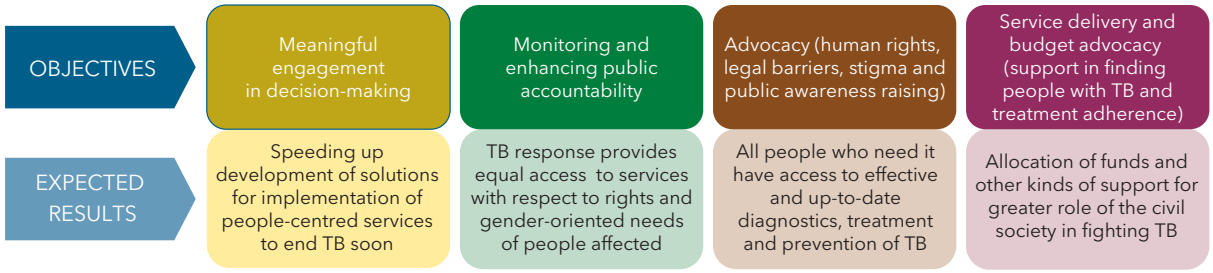
The objective strengthening of the role of CSOs in the transition to a people-centred model of care in EECA are to:

- Meaningfully engage in decision-making,
- Monitor and enhance public accountability,
- Advocate to include budget advocacy and advocacy for human rights and elimination of legal barriers for vulnerable communities, awareness raising and de-stigmatization of services, and finally,
- Deliver community based services to support finding people with TB and treatment adherence.

Realizations of those objectives is expected to assure:

- Speeding up development of technical and communication solutions for implementation of people-centred services to end TB soon.

- TB response provides equal access to services with respect to rights and gender-oriented needs of people facing the problem of TB
- All people who need it have access to effective and up-to-date diagnostics, treatment and prevention of TB
- Allocation of funds and other kinds of support for greater role of the civil society in fighting TB



TBEC has developed a diagnostic tool to help CSOs conduct a situational assessment to monitor achievement of those objectives based on the proposed set of expected changes within the system – "ANALYSIS OF THE CURRENT STATE OF THE NATIONAL RESPONSE TO TB EPIDEMIC AND THE CIVIL SOCIETY ROLE" (can be found HERE).

Key Actions

Achieving these objectives requires decisive action from the CSOs and TB communities in the EECA region. Some organizations have already engaged in a national dialogue to collaborate with NTP and other stakeholders and have developed action plans; others are in the process of formulating their approaches to pursue those key objectives.

Based on those plans, as well as regional and global strategic documents and guidance, the following actions are suggested for strengthening the role of civil society in transition to a people-centred model of care in selected countries in EECA.

Meaningful engagement of communities in decision making

Action 1: Understand the environment and identify opportunities for engagement

TB communities and CSOs are not always well engaged in TB response activities at the national level. Understanding of status of the current state of the national TB response, the role of CSOs in this process is essential to identify venues where CSO engagement is needed and possible.

A tool developed by the TBEC – "ANALYSIS OF THE CURRENT STATE OF THE NATIONAL RESPONSE TO TB EPIDEMIC AND THE CIVIL SOCIETY ROLE" is a situation mapping instrument which also aids discussion of possible questions about improving coordination and involvement of all partners in response to the epidemic of TB. The tool can be used

routinely to monitor and observe changes. It is advisable to apply the tool and to build strategic objectives for improved CSO participation upon the outcomes of the analysis.

- Conduct situation assessment.

Action 2: Strengthen collaboration between CSOs, with NTP and other stakeholders and build strategic partnerships

All high-level policy documents support and state the need for increased community and CSO engagement. In addition, the Global Fund grant requirements create a conducive environment for this process through national dialogues and country coordination mechanisms. This opportunity should be harnessed to make CSOs and communities a fundamental part of the TB-related decision-making process.

As relatively nascent organizations, they still need to build partnerships with other stakeholders – NTP, government, medical communities and other CSOs, to develop their internal capacity to be meaningfully engaged in the local and central level decision making processes.

NTPs in the EECA region are mostly highly verticalized and medical care focused systems. Therefore, they often overlook the opportunities to increase detection among high-risk population and to support patients during treatment and prevent loss to follow-up. CSOs can help TB controls by creating such opportunities. Within a TB REP 2.0 project, a model Memorandum of Understanding (MoU) has been developed to aid formation of collaborative working processes between NTPs and CSOs. The template of the MoU can be found HERE.

In places where multiple TB-focused CSOs are working, a coordination body might also be needed to assure that efforts of those organizations are aligned with each other. This type of coordination helps with collaboration with NTP, where engagement with different individuals and CSOs could be a challenge.

- Identify and know key stakeholders through the development of stakeholder maps.
- Become a partner with NTP by signing MoU.
- To achieve meaningful engagement and representation of TB CSOs and community groups should be represented in central and local level decision-making bodies, where decisions relevant for people vulnerable to TB are made;
- Actively engage in the development of the National Strategic Plan for TB. CSOs and community leaders should be equipped to make a significant contribution to the process by representing the needs and values of the communities.

Action 3: Foster adoption of innovative approaches to care

TB treatment is changing, as well as how medical services are delivered and used by patients. More effective drugs and faster diagnostics are invented, or patients are provided with tools that improve their professional quality. At times, those innovations may cost more upfront. Still, if the evidence supports that they are more effective, those investments may be validated.

Ending TB using old-fashioned approaches is not possible. Globally investments are made to develop new drugs, vaccines, diagnostics, or treatment solutions. New treatment regimens are now recommended by WHO as they shorten treatment duration and improve the treatment success rate for drug resistant TB. In contrast, new diagnostic tools assure a faster and improved quality of diagnosis, which is important for timely starting of the treatment with the right regiments. In addition, tools are being made available, which gives patients more autonomy and the possibility to take treatment closer to home. Health systems should be investing in developing more innovative approaches to solving existing challenges.

However, innovations are not always integrated into the system. The speed might be slow, or they might have limited (geographic) availability. Those challenges are related to finances – countries not being able to allocate funding within NTP to scale up the access, as well as to rigidity of the system to accept and introduce innovations. In another case, CSOs and communities have a significant role to play to inform decision-makers regarding innovative approaches, provide evidence, and advocate for their implementation.

- Advocate and support resources mobilization process for improved access to new treatment and diagnostic services, including for latent TB infection, without discrimination.
- Promote and increase acceptance of the innovative solutions among users/TB patients.
- Introduce and advocate for the uptake of Video Supported Treatment.

Action 4: Develop tools and instruments to help policymakers, healthcare providers, CSO and communities to enable a people-centred model of care

People-centred model of care calls for a dramatic shift in the focus of TB response activities and modification of existing healthcare service delivery models. Traditionally, TB care in EECA was a specialized vertical system, with little to no integration with the remaining healthcare delivery. This has resulted in delays in patient diagnosis and treatment, the treatment being structured around the needs of the system, rather than that of patients, and the need of people vulnerable of TB not being considered in the system.

In 2017, a Blueprint for the new model of care had been developed within the TB-REP project with the participation of experts, communities, and leaders from the WHO European region. However, uptake of those recommendations requires focused and diligent efforts from the national governments, NTPs, and communities. Civil society and international organizations developed and produced tools, which are aimed to support national governments in the process of integrating TB services, developing more people-centred interventions, and improving quality in this process.

- Develop and advocate for the adoption of service standards for community-based supportive services for patients and people.
- Monitor the needs of TB affected population and support assist the government in addressing those through incentive and social assistance schemes, such as food and transportation vouchers.
- Work with primary care service providers to ensure that TB service integration is effectively taking place.

- Develop tools to monitor and improve the quality of care received by TB patients and communities.
- Advocate for service delivery models, which bring services closer to the home, such as community-supported DST.

  Conduct and advocate for patient-pathway analysis to generate evidence on existing bottlenecks in the TB cascade.

Monitoring and enhancing public accountability

Action 5: Promote community leadership and national accountability through community-based monitoring

Community-based monitoring is a powerful tool to generate evidence, identify community needs and ensure that the implementation of services is addressing community needs. It is powerful also in the sense that CSOs that hold data are more respected, and their statements have more values. According to the Global Fund "working with community-based organizations (CBOs) and other civil society groups in this area is vital to recognize and respond to human rights and gender barriers that weaken programmes and systems."[11]

CSOs and communities play a fundamental role in all components of accountability related to tuberculosis as it is acknowledged in the Sustainable Development Goals, the End TB Strategy, the Moscow Declaration and the Political declaration of the UN General-Assembly High-Level Meeting on the Fight Against TB (2018). This position is carried in the WHO's Multisectoral Accountability Framework To Accelerate Progress To End Tuberculosis By 2030, where section III on Monitoring and Reporting specifically includes reports and audits produced by CSOs.[12]

Community-based monitoring is promoted by the Global Fund within national grants. Innovative platforms such as "OneImpact" developed by Stop TB Partnership, allow communities and CSOs to collect evidence on treatment quality and human rights issues, participate in the decision-making process, and to inform patients. Several other tools support the identification of needs of communities and patients, and the collection of information of existing quality challenges; such tools are also enabled by national and local legislation and regulations, which allow public/community participation in the public decision-making process through hearings, council or committee meetings or others. Similarly, several tools and case studies for community-based monitoring developed within the Global Fund programs (LINK).

A specific challenge for most of the TB high priority countries in EECA is an ongoing transition from the Global Fund support. This means that donor support for TB is declining, and it is important that domestic budgets allocate resources for TB services; moreover, actions are needed to ensure that community-based and community-led advocacy, services and monitoring efforts receive the support needed for their continuation.

- Introduce and actively use tools like OneImpact for ongoing monitoring and evidence generation.
- Actively engage with NTPs in order to inform key stakeholders about the findings and data collected through community-based monitoring and studies and to utilize those findings to inform decisions on TB policies and programs.

[11] https://www.theglobalfund.org/media/9632/crs_2020-02cbmmeeting_report_en.pdf
[12] 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

- Engage in transition planning and monitoring.
- Develop tools and indicators to monitor CSO-based/community-led activities for TB and advocate for inclusion of such targets in the national monitoring frameworks for TB Response.

Advocacy

Advocacy is a set of strategic actions to influence the decisions government/public sector makes. It represents, and voices the needs and position of vulnerable groups, and leads to changes. Advocacy may be directed to elimination of human rights violations, and removing legal barriers.

Action 6: Address human rights, gender, stigma and discrimination barriers to TB Services

Adhering to the principles of human rights, gender aspects and eliminating other types of barriers such as stigma and discrimination are the key to ending TB. Unfortunately, those barriers prohibit many to seek TB services and lead to worsened outcomes. Active communication campaigns are needed with community engagement to foster a positive image of TB treatment and reduce the associated stigma. Some countries have documented those barriers by conducting designated studies and identifying barriers faced by the most vulnerable groups of population (Regional CRG Overview HERE).

Several tools are available for identification of stigma and discrimination, as well as documenting human rights and gender barriers to services (e.g. Stop TB CRG Assessment Tool HERE). A technical brief (LINK) developed by the Global Fund, also provides a broader view of human rights and gender perspective for TB services.

- Engage with the government sector and NTPs in active communication campaigns to reduce stigma and address discrimination of TB affected populations.
- Document existing human rights and gender-based barriers to TB services; where possible, develop strategies to address comprehensive needs of most vulnerable groups of the population through inter-disciplinary approaches, case management and peer-driven interventions.

Service delivery

Action 7: Strengthen social contracting mechanism and budget advocacy to enable CSO participation in service delivery at the community level

Social contracting is a collection of mechanisms that allows public sector – central or local governance bodies to provide funds to private, or CSO-based services. This is essential to ensure that community, supportive services are funded in the country. Even if now funding is provided through donors, this funding is not sustainable, and it is an ultimate responsibility of the government to cover interventions for TB response in the country.

Countries have different legal and regulatory mechanisms around public procurement and public participation in the budgeting process. Within TB-REP 2.0, TBEC has developed

several case studies and resources on how different countries approach this issue, what legal changes are needed to create an enabling environment for the social contracting and to engage in budget advocacy effectively (those can be found HERE).

- Identify legal and regulatory barriers for social contracting and devise an advocacy strategy to address those barriers.
- Monitor effective implementation of social contracting schemes (whether publicly stated commitments are materialized, or not).
- Engage in budget analysis to devise budget advocacy strategy and engage in budget advocacy work.

Action 8: Define community/CSO -led services for tuberculosis at the national level

Engagement of communities and CSOs in service provision needs regulations that countries might not have in place. Such regulations include a definition of what services are to be provided, in which settings, and how to assure qualification of personnel. Although, ethical aspects like patient confidentially and respect to personal dignity also come into play. This might as well include standards and tools on how service budgets and reimbursement policies will be defined.

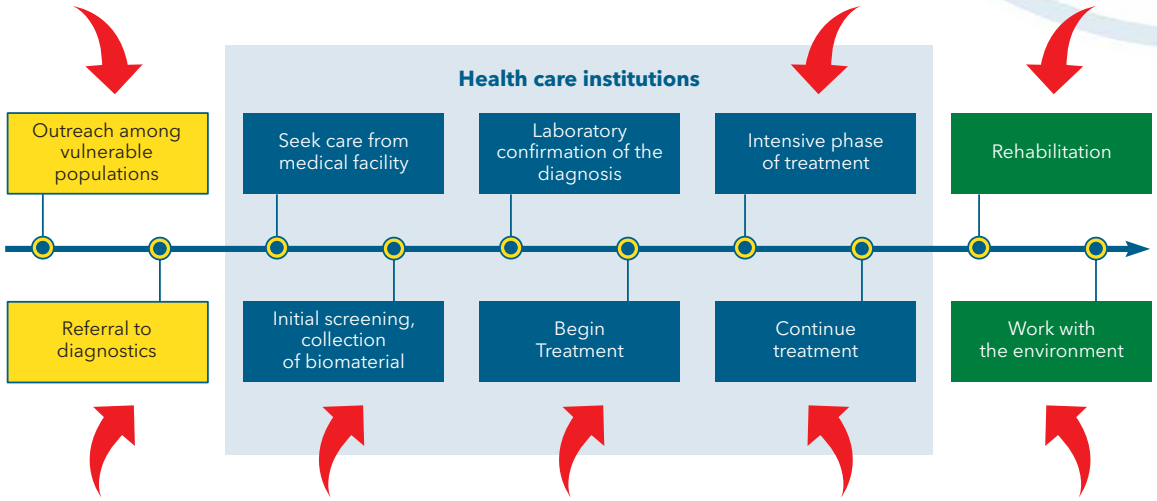
The model below presents services provided to TB affected communities and patients on the continuum of TB care to identify where engagement of CSOs is justified and can deliver the best results. This includes:

- Testing initiation through outreach and community mobilizations/awareness raising.
- Working with individuals seeking medical attention for TB symptoms (presumptive people with TB) in primary healthcare to assure timely referral, patient support and contact identification.
- Supporting patients who are on treatment.
- Facilitating post-treatment rehabilitation and integration.

Those CSO-led interventions in TB care continuum are shown with red arrows.

Successful implementation of those services depends upon the **cooperation with primary healthcare and NTPs,** and **conducive environment for TB supportive services,** which are addressed in the previous sections of the document.

Model: CSO intervention in TB care continuum



The model developed by Mikhail Volyk, TBEC consultant

In many countries, CSO-led services have been funded by donor organizations. However, as the dependence on national sources of financing increases, is it important that those services become an integral part of the national health and social care systems. This integration is also essential for patients and populations served, in order to assure that they are referred to the necessary services provided by CSOs and from CSOs to relevant medical providers within the general healthcare system.

EECA countries often do not have special regulations for CSO-provided services. Within TB-REP 2.0, TBEC and PAS Center have worked with a team of experts to design a set of essential supportive services to be provided by the community organizations, including costing tools to calculate the cost of those services in each setting.

- Define a set of national standards on CSO/Community-led service provision jointly with government and NTP and assist government sector and CSO groups in forming a contract and starting service provision.
- Monitor implementation of those standards.
- Become a service provider and follow the standards and community needs (if that is the focus of the organization).

Action 9: Build capacity of CSOs as service providers

Provision of service to populations and management of donor or government funding requires a set of organizational systems and capacities for TB CSOs. This includes knowledge about regulations, proper and transparent accounting system, management of processes and human resources, and many more. To become a service provider, CSOs need to demonstrate that they can provide services, report to funders, maintain records and protect the confidentiality of patients.

TBEC has designed approaches to coach CSOs and help them identify existing gaps and needs. This approach should engage all the CSOs working in the country, especially the ones working in remote, rural areas.

In addition, NTP and medical doctors should be better informed on what services are offered by CSOs and how those services benefit patients. This is important because doctors should know when to refer their patients to those community-based services and should have trust that those services would be beneficial for their patients.

- Design a mechanism to identify capacity building needs for CSOs and jointly address those needs through actions such as technical assistance, coaching, and mentorship.
- Raise awareness of medical staff and NTP on services offered by CSOs and the benefits of those services to patients and communities.

Action 10: Collaboration across three diseases: CSO and community-led response to TB, HIV, and viral hepatitis

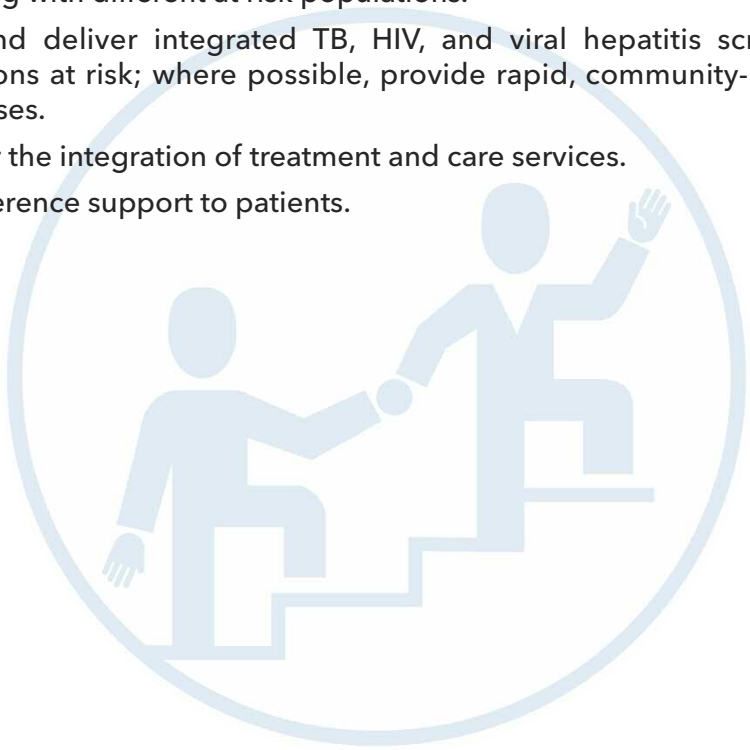
TB, HIV, and viral hepatitis share the risk factors and mitigations strategies. Comorbidities adversely affect outcomes for patients, while prevention strategies have many similarities. Clinical outcomes for TB/HIV remain to be a major concern for the region, and patients with those comorbidities are most likely to suffer terminal outcomes of the disease. Similarly, viral hepatitis, which significantly affects the population in the EECA region impacts the

treatment process and outcomes for TB patients. Since 2019, a Regional Collaborating Committee on Accelerated Response to Tuberculosis, HIV and Viral Hepatitis (RCC-THV) has been supported by WHO Regional Office for Europe to guide and assist member states in intersectoral actions against those three diseases and the Committee also serves as a high-level platform, where CSO representatives from the region can corroborate in political decisions in the region.

CSOs in the EECA region have long been collaborating across those three diseases, especially for TB and HIV. Similarly, national TB policies also include activities for TB and HIV testing, integration of treatments and measures to improve treatment outcomes. Similar integration is weaker for viral hepatitis. In addition, people at risk or living with those three priority diseases, often have other healthcare needs, such as mental health services, substitution treatment for people who use drugs, and reproductive and sexual health services and integration and continuation of those services is also a priority to maintain the focus on the needs of people.

Important aspect of collaboration includes collaboration of CSOs working with different high risk groups including prisoners, migrants, and vulnerable populations such as women and youth. Given the diversified needs of those populations, they might seek services with different organizations, and it is important to integrate TB prevention activities in the services, which are available through different organizations. ENGAGE-TB is a toolset by WHO, which helps to build capacity of CSOs to deliver TB specific activities.

- Ensure integrated community mobilization activities for TB, HIV, and viral hepatitis by working with communities, especially with groups at risk to raise their awareness and motivation for early screening/detection, including partnership and collaboration with CSOs working with different at risk populations.
- Advocate and deliver integrated TB, HIV, and viral hepatitis screening services for populations at risk; where possible, provide rapid, community-based screening for the diseases.
- Advocate for the integration of treatment and care services.
- Provide adherence support to patients.



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14. Towards a Common Understanding of Community-based Monitoring and Advocacy. The Global Fund. 2020. LINK
15. Towards people-centred health systems: an innovative approach for better health outcomes. WHO Regional Office for Europe; 2013. LINK

Selected Resources on People-centred Model of TB Care

Key guiding and strategic documents:

1. UN high-level meeting on TB: Key targets and commitments. LINK
2. Political declaration of the UN General-Assembly High-Level Meeting on the Fight Against TB (2018). LINK
3. End TB Strategy. LINK
4. Tuberculosis action plan for the WHO European region 2016–2020. LINK
5. Roadmap to implement the tuberculosis action plan for the WHO European Region 2016–2020. LINK
6. Technical Brief: Tuberculosis, Gender and Human Rights. The Global Fund. 2020. LINK

People-centred model of TB Care:

7. A people-centred model of tuberculosis care: A blueprint for Eastern European and Central Asian countries, 1st edition (2017) ("Blueprint"). LINK

Tools and instruments available as a part of the Blueprint:

- Bed forecasting tool.
- Hospitalization criteria.
- Current provider payment mechanisms in 11 TB-REP countries.

Evidence collection and monitoring tools:

8. Community-based monitoring: An Overview. The Global Fund. 2020. LINK
9. Patient Pathway Analysis Tool. LINK
10. OneImpact tool. LINK

Service delivery:

11. Supportive service standards (to be published soon).

Budget Advocacy:

12. Budget Advocacy Briefing guide. LINK

Role of Communities and CSOs:

13. Template of MoU with NTP. LINK
14. Analysis of the Current State of the National Response to TB-epidemic and the Civil Society Role. LINK
15. The Crucial Role of Communities: Strengthening Responses to HIV, Tuberculosis and Malaria. The Global Fund (2018). LINK