

The role of civil society and TB-affected communities in preparation to the UN High-Level Meeting on TB: lessons learned and practical recommendations



Acknowledgements:

We extend our heartfelt gratitude to all partners and experts who generously shared their experiences, lessons learned, and recommendations gleaned from their invaluable participation in the preparatory processes for the UN High-Level Meeting on TB 2023.

Special thanks to Parvana Valiyeva, "Saglamliga Khidmat" Public Union; Safar Naimov and Ehson Tursunov, "Stop TB Partnership, Tajikistan"; Olya Klymenko, "TBPeopleUkraine" Charitable Organization and "Stop TB Partnership Ukraine"; Nurali Amanzholov, "Kazakhstan Union of People Living with HIV"; Nikoloz Mirzashvili, Network TBpeople Georgia; Natalia Shumskaya, AFEW in Kyrgyzstan; Oxana Rucsineanu, Moldova National Association of Tuberculosis Patients "SMIT".

The material was developed within the framework of the project "Addressing CRG barriers through data-driven evidence and monitoring of the UN HLM 2023 targets", supported by Round 11 of the Civil Society Challenge Facility of the Stop TB Partnership and implemented in the EECA region by the Center for Health Policies and Studies (PAS Center). The content of the material was developed by Aleksandra Vasylenko (consultant at the PAS Center) and coordinated by Cristina Celan (Program Coordinator at the PAS Center).

The views expressed in this publication do not necessarily reflect the views of the Stop TB Partnership.

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Abbreviations

CCM	Country Coordination Mechanism
CSO	Civil society organization
EECA	East Europe and Central Asia
NTP	National TB Program
TB	Tuberculosis
UN	United Nations
UN GA	United Nations General Assembly
UNHLM on TB	UN High-Level Meeting on Tuberculosis

INTRODUCTION

Civil society organizations and TB affected communities have traditionally played an important role in preparing countries to participate in the UN High-Level Meeting on TB (UN HLM) and have made significant contributions to improving the text of the Political Declaration on TB.

The active advocacy by civil society organizations (CSOs) and affected communities preceding the UN HLM, convened in New York on 22 September 2023, has contributed to:

- Promoting widespread recognition at the national level, including among the decision-makers, regarding the significance of engagement in the UN High-Level Meeting on TB and efforts to refine the Political Declaration on TB for the elimination of tuberculosis on a global, regional, and local scale;
- Involvement of a wide range of civil society representatives, TB-affected communities and other stakeholders in the processes of preparation for the UN HLM on TB at the country level, including the development of key asks for inclusion in the Political Declaration on TB;
- Inclusion in the final text of the [Political Declaration on TB](#) of measurable and time-bound targets for identifying, diagnosing and treating people with TB, financing the TB response and new developments, and country commitments to strengthen financial and social protection for people affected by TB;
- Include representatives of CSOs and TB-affected communities in national delegations to UN HLM on TB;
- Involvement of diverse representatives from civil society organizations and TB affected communities in the plenary session and two multi-stakeholder panel discussions of the UN High-Level Meeting on TB, alongside participation in associated events.

The Stop TB Partnership facilitated country-level collaboration via the Civil Society and TB Affected Communities Coordinating Hub in preparation for the 2023 UN High-Level Meeting on TB, alongside pertinent efforts from regional organizations. One pivotal event among them was the Summit on TB in Eastern Europe and Central Asia, organized by the PAS Centre in Dushanbe, Tajikistan. Following the Summit, [key asks from civil society and regional communities](#) were formulated and [dispatched to the President of the UN General Assembly](#). Additionally, a [Dushanbe Statement](#) was crafted and signed by 260 representatives from CSOs/communities, NTPs, parliamentarians, and other stakeholders. Moreover, the PAS Center devised the [EECA Regional Roadmap on advocacy for the preparations and post-accountability of the UN HLM on TB 2023](#), serving as the basis for the development of national advocacy roadmaps concerning the UN HLM on TB across the countries.

▶ Yet, it's noteworthy that during the advocacy efforts leading up to the UN HLM on TB, representatives of CSOs and affected communities encountered occasional barriers hindering their progress at various stages. However, it's crucial to acknowledge that many of these barriers could have been surmounted with foreknowledge.

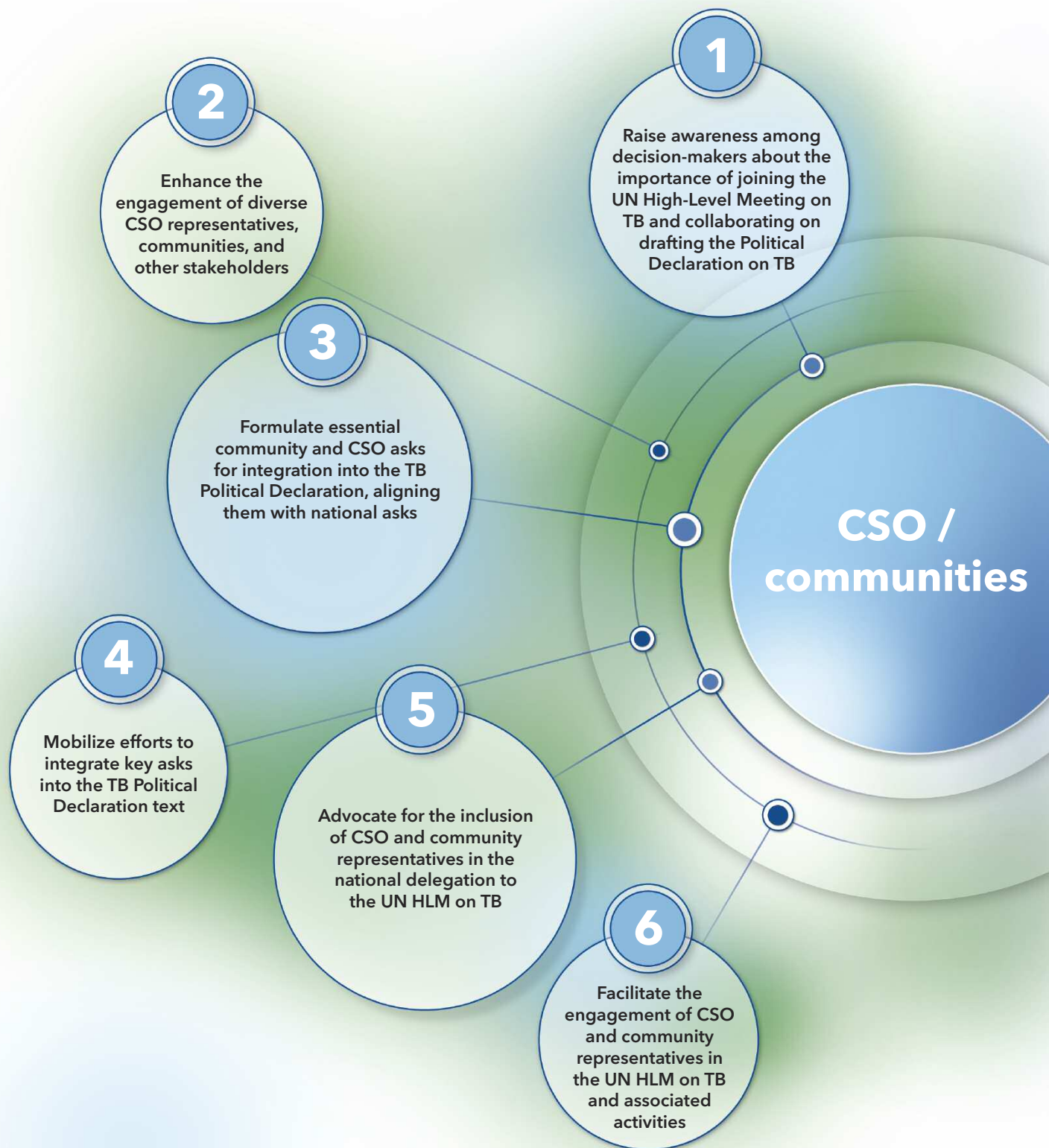
Thus, learning lessons from the UN HLM on TB preparations can be extremely useful in enhancing the meaningful engagement of CSOs and affected communities in the processes related to the next UN HLM on TB in 2028 or other relevant UN HLMs. With timely response planning and appropriate responses to potential barriers, and by applying successful practices that have proven themselves in the preparations for the 2023 UN HLM on TB, CSOs

and communities in countries can significantly enhance their engagement and expand the scope of attainable outcomes.

This document summarizes the challenges encountered by CSOs and community representatives in the Eastern Europe and Central Asia region during their preparations for the UN HLM on TB 2023, along with the recommendations they offer from the advocacy endeavors and the effective practices they've employed to attain their advocacy objectives leading up to the UN HLM on TB.



STAGES OF CSO/COMMUNITY PARTICIPATION IN UN HLM ON TB PREPARATORY PROCESSES



LESSONS LEARNED FROM THE PARTICIPATION OF EECA CSOs/COMMUNITIES IN THE PREPARATORY PROCESSES FOR THE UN HLM ON TB 2023

Despite the notable achievements of CSOs and affected communities in the preparation for the 2023 UN HLM on TB (such as the incorporation of numerous key community and civil society asks into the final text of the Political Declaration on TB, as consolidated by the Stop TB Partnership and endorsed in various countries, the inclusion of four civil society and community representatives in the national delegations of EECA region countries, the integration of issues pertaining to the UN HLM on TB preparation into the political agenda of countries, and extensive civil society engagement in the preparation process), several challenges were encountered. While certain challenges were contextual to specific countries, the majority shared common features across the EECA region.

▶ A preliminary understanding and possible removal of most of these barriers in the future will help ensure the maximal involvement of CSOs and communities in the preparation and participation processes of the UN HLM, (including the 2028 UN HLM on TB). This effort can also lead to the expansion of the list of community and civil society asks incorporated into the resulting Political Declaration on TB.

After the UN HLM on TB in 2023, the Centre for Health Policies and Studies (PAS Center) conducted interviews with representatives of civil society organizations and TB-affected communities from countries in the EECA region who were actively engaged in advocacy efforts in preparation to the UN HLM on TB.

Drawing from these interviews, valuable lessons learned and effective practices were identified, leading to the formulation of practical recommendations. These insights and recommendations will prove beneficial to CSO and community representatives as they prepare for the next UN HLM on TB.

For ease of reference, the lessons learned are outlined as distinct barriers encountered, accompanied by relevant practical recommendations intended to address them at each stage of participation for CSOs and affected communities from the EECA region in the preparatory processes for the UN HLM on TB 2023.

Step 1. Raise awareness among decision-makers about the importance of joining the UN High-Level Meeting on TB and collaborating on drafting the Political Declaration on TB



Barrier: Low awareness and interest in the UN High-Level Meeting on TB among decision makers.



Recommendation: CSOs and community representatives can proactively arrange meetings and negotiations with officials from the Ministry of Health, National TB Programs (NTP), Ministry of Foreign Affairs, and other stakeholders to elucidate the significance of the event for TB control, underscore opportunities to shape the final text of the Political Declaration on TB, and establish a cohesive country preparation plan while jointly delineating the roles of each stakeholder.



Barrier: CSO and community representatives face limitations in capacity and knowledge to undertake advocacy tasks.



Recommendation: Actively participate in activities organized by regional and international organizations to equip CSOs and communities for engagement in the UN High-Level Meeting on TB. Utilize letter templates crafted by these organizations when reaching out to decision makers. Seek guidance from regional organizations to formulate a step-by-step plan tailored to your country's needs. During cross-country gatherings, share insights, achievements, and obstacles encountered in preparing for the UN High-Level Meeting on TB, and glean valuable lessons from counterparts in other nation.



Barrier: Representatives from NTPs and/or Ministry of Health overseeing TB control may not always receive timely and comprehensive updates on high-level policy developments. At times, during the initial phases of country preparation, their understanding of the UN High-Level Meeting on TB processes and its implications for TB control might be incomplete.



Recommendation: Arrange an inter-ministerial and cross-sectoral meeting with mandatory attendance from representatives of the Ministry of Foreign Affairs, with the aim to thoroughly inform all stakeholders about the preparatory stages for the UN High-Level Meeting on TB, including the ongoing work on drafting the Political Declaration on TB.





Barrier: Government authorities may lack confidence in the information provided by CSO/community representatives regarding the UN High-Level Meeting on TB.



Recommendation: Collaborate with regional and international leaders to collectively engage with national government authorities, involve and inform parliamentarians through the Global TB Caucus in advancing country-level preparations for the UN High-Level Meeting on TB, which include fostering effective communication with representatives from the Ministry of Health, NTP, Ministry of Foreign Affairs, and other relevant stakeholders.

Step 2. Enhance the engagement of diverse CSO representatives, communities, and other stakeholders



Barrier: Limited interest in the UN High-Level Meeting on TB among TB-affected individuals and CSOs, particularly in remote areas/regions of the country.



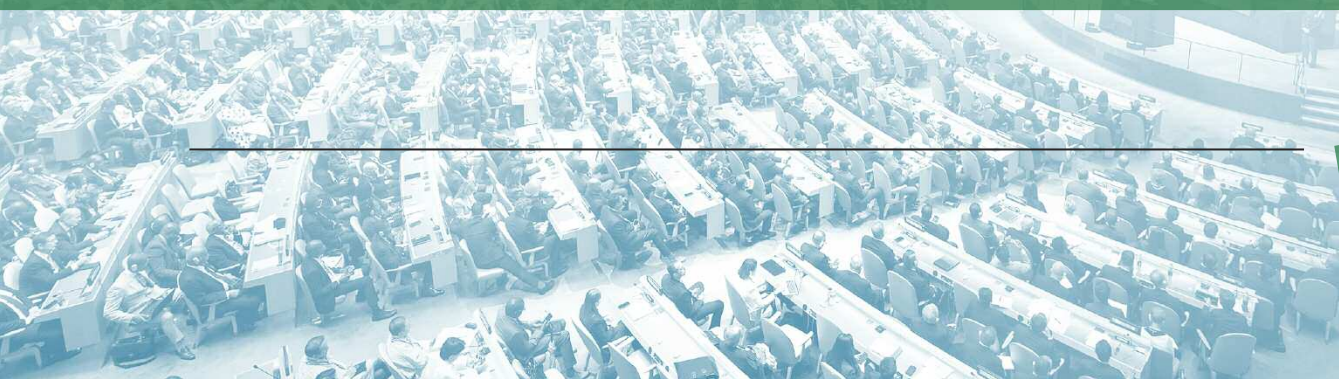
Recommendation: Ensure that communication and information materials regarding the UN High-Level Meeting on TB utilize are delivered in and straightforward language, with consideration for local linguistic nuances. Emphasize the correlation between the UN High-Level Meeting on TB and the provisions outlined in the Political Declaration on TB, highlighting their role in enhancing the TB situation and addressing the needs of individuals affected by TB.



The effective practices

Kyrgyzstan

In conjunction with the active involvement of people affected by TB in developing key asks and information campaigns across the country, AFEW Kyrgyzstan organized a media training on TB control and the UN HLM on TB. This educational event was attended by media representatives, the Advisor to the Minister of Health of the Kyrgyz Republic, spokespersons from the Ministry of Health, the National Center for Phthysiology, other relevant government agencies, as well as CSO and community representatives. The purpose of the media training was to raise participants' awareness not only about the disease in general but also about the significance of the High-Level Meeting on TB for ending TB in the country and globally. Participants learned about the importance of systematic and accurate public information on TB issues, and areas that need more mainstream media coverage were presented. Additionally, they were informed about the possibility of live streaming the UN HLM on TB on the UN website. As a result of the media training, journalists became more interested in TB response and regularly request stories of people with TB to cover the topic.





Barrier: *Community representatives lack confidence that the country's leadership will uphold its commitments regarding the TB Political Declaration.*



Recommendation: To alter perceptions regarding the government's dedication to enforcing the provisions of the TB Political Declaration, it's essential to elucidate the significance and status of United Nations General Assembly (UNGA) resolutions within the health sector. Specifically, emphasis should be placed on the "soft law" status of the TB Political Declaration and the significance of advocacy endeavors by communities and CSOs.



The effective practices

Georgia

TBpeople Georgia together with its partners developed a roadmap for the country's preparation for the UN HLM on TB. The document was prepared taking into account the recommendations of the EECA Regional Roadmap on advocacy for the processes of preparation for the UN HLM on TB in 2023 and accountability after it, as well as the key asks of civil society and communities in the region developed at the Summit on TB in Eastern Europe and Central Asia in Dushanbe. One of the most important steps in the preparation of civil society and communities for the UN HLM on TB was the development of key asks, which were presented to a wide range of national stakeholders at the Country Coordinating Mechanism meeting. The minutes of the CCM meeting, attended by 11 representatives of the Government, highlighted the high priority of the UN HLP on TB issues in the national political process.

Step 3. Formulate essential community and CSO asks for integration into the TB Political Declaration, aligning them with national asks



Barrier: *Limited understanding of the suitable format and concepts for formulating key asks.*



Recommendation: Utilize the key asks articulated by community and civil society that have been collectively prepared at the international level (including those curated by the Stop TB Partnership prior to the UNGA Multi-stakeholder Hearing ahead of the UN HLM on TB 2023) and engage in comprehensive discussions within a wide civil society country platform to identify the most pertinent asks for the nation. If needed, adapt these asks to align with the national context. You can also get ideas for key asks from [the Stop TB Partnership's Deadly Divide report](#), [all available country reports on CRG and TB stigma](#), [TB Key and Vulnerable Populations Size Estimation](#), [Legal Environment and Human Rights Scorecard](#), etc.



Barrier: Lack of clarity regarding the process for formulating and endorsing key asks.

Recommendation: Key asks from community and civil society groups carry significant weight, as they represent essential elements that CSOs and communities consider for inclusion in the TB Political Declaration text. At the national level, it's crucial to establish a comprehensive civil society platform to identify and prioritize the key asks for the country. To kick start this initiative, leveraging internationally developed community and civil society asks can serve as a foundation. These asks should undergo thorough review to ensure alignment with the country's specific needs (with adjustments made as necessary). Subsequently, the selected key asks should be presented to governmental bodies for potential inclusion in a unified national position (comprising consolidated country asks). This presentation and dialogue can occur through cross-sectoral meetings, including platforms like the Country Coordinating Mechanism (CCM), or via formal correspondence channels.



Barrier: Government entities may overlook and fail to incorporate essential asks from communities and CSOs into the state's consolidated position.



Recommendation: Alongside sending official correspondence outlining the key community and civil society asks to the Ministry of Health, NTP, and Ministry of Foreign Affairs (with a request for dissemination to the country's UN mission), it would be beneficial to present these asks at a comprehensive cross-sectoral meeting. This meeting could be facilitated by CSO and community representatives, and would aim to harmonize community and civil society asks with the country's consolidated position. Furthermore, launching an extensive information campaign involving communities and CSOs to disseminate key asks through diverse communication channels and media platforms can prove highly effective.



The effective practices

Tajikistan

To sensitize decision-makers to the UN HLM on TB, the Stop TB Partnership organized a cross-sectoral advocacy event "From Intent & Reality to End TB". Tajikistan organized a cross-sectoral advocacy event 'From Intent & Reality to End TB'. During the event, key civil society and community asks were presented to a wide range of national partners, which got the attention of the Minister of Health and Social Protection. He also expressed interest in the results of community-led monitoring and the practice of engaging national celebrities in the TB awareness to change public opinion and decrease TB stigma. The event resulted in agreements on direct collaboration between the Minister of Health and Social Protection and CSO/community representatives.

Step 4. Mobilize efforts to integrate key asks into the TB Political Declaration text



Barrier: *Limited comprehension of the procedure for integrating key asks into the text of the TB Political Declaration.*



Recommendation: The initial chance to voice or submit written statements outlining essential community and CSO asks for incorporation into the zero draft of the Political Declaration on TB is by participating in the UNGA Multi-stakeholder Hearing, typically scheduled in May. Following the hearings, the UNGA releases a zero draft of the Political Declaration on TB a few weeks later, which is then circulated to the country's Ministry of Foreign Affairs for assessment via its missions to the UN.

Further negotiations to finalize the text of the Political Declaration on TB are undertaken by country missions to the UN. Therefore, the country's consolidated position, incorporating key asks from communities and CSOs, is transmitted from the Ministry of Foreign Affairs to the mission representatives. Subsequently, these representatives engage in advocacy efforts to include these asks in the TB Political Declaration text.

To enhance the mission representatives' understanding of the country's key asks, particularly those from communities, and to bolster their advocacy for inclusion in the TB Political Declaration text, the practice of conducting introductory meetings between CSO and community representatives (including those from international and regional organizations) and country mission representatives at the UN has proven beneficial. Typically held offline in New York a few days before or after the UNGA Multi-stakeholder Hearing preceding the UN High-Level Meeting on TB, these meetings provide a platform for CSO and community representatives to articulate TB issues, key challenges, and country asks, including those from communities and civil society. Continued communication with mission representatives facilitates the improved integration of asks into the TB Political Declaration text.



Barrier: *Ministry of Health and/or NTP not receiving the initial draft of the TB Political Declaration in a timely manner for review and the subsequent formulation of necessary improvement recommendations (key country asks).*



Recommendation: Expedite the delivery of the zero draft of the TB Political Declaration to the Ministry of Health and/or NTP by the Ministry of Foreign Affairs, ensuring ample time for them to prepare and submit recommendations for document enhancement, incorporating key country asks. Early collaboration with representatives from the Ministry of Foreign Affairs and the country's UN mission is advisable to streamline this process.



Barrier: *According to the discussions among country missions to the UN, the draft Political Declaration on TB does not include key asks from communities and civil society.*



Recommendation: Launch a regional or international advocacy initiative aimed at raising awareness among the UNGA President regarding the significance of integrating key community and CSO asks into the Political Declaration text. This campaign could partner with decision-makers in various countries and enlist diverse representatives of civil society and communities to maximize its impact. Additionally, if further negotiation rounds are scheduled among country missions to the UN to deliberate on the draft Political Declaration on TB, it would be beneficial to correspond with national foreign ministries and country missions to the UN to garner increased support for advancing key community and CSO asks.



The effective practices

Ukraine

Thanks to the initiative of civil society and communities, the national partners managed to establish reliable cooperation with representatives of the Ministry of Foreign Affairs and the country's mission to the UN, which created the necessary conditions for successful work on improving the text of the Political Declaration on TB. After a working meeting with the Ministry of Foreign Affairs on participation in the UN HLM on TB, representatives of TBPeopleUkraine and the "Stop TB Ukraine", the TB European Coalition, as well as the NTP, received the necessary information on the algorithm of the country's preparation for the UN HLM on TB and work on the draft Political Declaration on TB. Having received assistance from the Ministry of Foreign Affairs in communication with the mission of Ukraine to the UN, representatives of civil society and communities held a working meeting with the leadership and staff of the mission in New York. Subsequently, key asks from CSOs/communities and the country as a whole were jointly developed and submitted to the Ukraine Mission to the UN for inclusion in the draft Political Declaration on TB. According to the Stop TB Partnership Ukraine, of the 55 revisions prepared by CSOs/communities to the zero draft of the Political Declaration, 23 were adopted verbatim or substantively in the final text of the document.

Step 5. Advocate for the inclusion of CSO and community representatives in the national delegation to the UN HLM on TB



Barrier: The procedure of forming the national delegation remains inaccessible to the public.



Recommendation: In the event of a closed process for forming the national delegation, CSO and community representatives should take initiative to communicate with the Ministry of Health and the Ministry of Foreign Affairs through official correspondence, highlighting candidates selected from broad civil society forums. The fact that the participation of these candidates in the national delegation will not necessitate budget allocations, as funding will be provided by international or regional organizations (subject to securing support from such entities), may also be crucial.



Barrier: *Government representatives assert that the participation of CSO/community representatives in the national delegation is not feasible.*



Recommendation: If the national regulatory framework does not explicitly forbid the involvement of CSOs/community representatives in national delegations representing state interests at the UNGA, advocacy efforts may be worthwhile. This could entail sending official letters to the Head of Government and/or Ministers of Foreign Affairs and Health, referencing the UNGA President's recommendations regarding the inclusion of representatives from affected communities and civil society in national delegations to the UN High-Level Meeting on TB. Typically, such recommendations by the UNGA President are outlined in the UNGA Resolution titled "Scope, modalities, format, and organization of the high-level meeting on the fight against tuberculosis," adopted at the onset of the year of the UN High-Level Meeting on TB.



Barrier: *Previous assurances from relevant governmental bodies to include CSO/community representatives in the national delegation have not been honored.*



Recommendation: To prevent recurrence of such situations, it's advisable to submit the decision regarding the participation of CSOs/community representatives in the national delegation to a cross-sectoral country platform, such as the Country Coordinating Mechanism (CCM), for formalized recommendation/decision-making. This ensures a transparent process and provides a basis for further advocacy on this matter.



Barrier: *CSO/community representatives, selected as candidates for the national delegation and coordinated with relevant government agencies, faced challenges in obtaining visas to enter the United States due to prolonged decision-making processes.*



Recommendation: To address this issue, select candidates from CSOs/communities for the national delegation well in advance and commence advocacy with relevant government agencies as early as possible (e.g., post-Multi-stakeholder Hearing). For countries where citizens are eligible for multi-year U.S. visas, consider including possession of a valid U.S. visa as an asset for selecting CSO/community candidates.

Step 6. Facilitate the engagement of CSO and community representatives in the UN HLM on TB and associated activities



Barrier: *Lack of funds for travel.*



Recommendation: Plan budgets ahead for 2028 initiatives to accommodate travel expenses for a community representative/CSO to New York to attend the UN High-Level Meeting on TB. Reach out to regional and international organizations to request financial assistance for participation in the UN HLM on TB and its associated events.



The effective practices

Azerbaijan

Thanks to an international inter-sectorial conference organized by the Saglamlıga Khidmat Public Association in Baku, the issues of participation in the UN HLM on TB were put on the political agenda and attracted the attention of decision-makers and the media. During the event, information exchange on the UN HLM on TB and the draft Political Declaration on TB was established between representatives of the Ministry of Health, NTP, Ministry of Foreign Affairs, President's Administration, parliamentarians, as well as relevant communication between ambassadors of other countries. At the conference, the participants agreed on many important issues. In particular, the country position on the Political Declaration on TB was agreed upon, and as a result of official correspondence with the Ministry of Foreign Affairs, a decision was made on the participation of a civil society representative in the official country delegation to the UN HLM on TB. The participants of the event, including the Deputy Minister of Health, signed the "Baku Declaration", which outlined the country priorities – key asks of the UN HLM on TB.



Barrier: Organization failed to register for the UN HLM on TB on the official UN website within the deadline.



Recommendation: Stay vigilant about deadlines for organization registration for the UN HLM on TB and disseminate this information widely among fellow CSOs/communities. It's advisable to register even without confirmed funding for travel to New York, as closer to the event, regional or international organizations may free up resources to support the participation of community representatives/CSOs. However, note that the registration process closes several months prior to the event.



Barrier: Inability to participate in the UN High-Level Meeting on TB due to delays in registering on the lists for organizations with consultative status with the Economic and Social Council of the United Nations (ECOSOC). While registration for organizations without ECOSOC status occurs earlier, organizational deficiencies with the report to ECOSOC have resulted in the organization's status being inactive, rendering it impossible to register under this category for the UN High-Level Meeting on TB.



Recommendation: It is advisable for organizations with ECOSOC status to verify their status well in advance of the registration deadline to confirm their eligibility for ECOSOC registration. If such verification is not feasible, registering the organization under the CSO and community-wide registration is recommended to prevent missing the opportunity to participate in the UN High-Level Meeting on TB.



Barrier: A CSO/community representative, as part of the national delegation, could not attend the UN HLM on TB due to registration process glitches.



Recommendation: National delegation members are typically registered for the UN HLM on TB by the country's UN mission representatives, in coordination with relevant government bodies. This registration occurs several weeks prior to the event, after registrations for other participant categories (such as various CSOs/communities and organizations with ECOSOC status) have closed. To avoid instances where CSO/community representatives within the delegation are inadvertently excluded from participation due to documentation errors, it's crucial to pre-register your organization during the broader registration period for CSOs and communities. Additionally, it's imperative to ensure timely registration of the CSO/community representative within the UNGA's delegation registration deadline, by cross-checking with the Ministry of Health, Ministry of Foreign Affairs, or the country's UN mission.

CONCLUSION

This material, developed by the Centre for Health Policies and Studies (PAS Centre) with funding from the Stop TB Partnership, will prove invaluable to representatives of civil society organizations and communities impacted by TB, along with other stakeholders engaged in preparations for the 2028 UN High-Level Meeting on TB and similar high-level gatherings.

Leveraging lessons gleaned from CSOs and communities during advocacy efforts leading up to the 2023 UN HLM on TB will enable you to navigate numerous challenges encountered at each stage of this endeavor, thereby amplifying the role of civil society and affected communities in global TB policy initiatives.

For a more in-depth look at the algorithm guiding CSO and community engagement in preparation for the UN HLM on TB, consider reviewing the [TB Europe Coalition's resource](#), supported by the Stop TB Partnership.



A row of flags from various countries, including the United Kingdom, Australia, Canada, and the United States, flying against a blue sky with clouds. The flags are arranged in a line, with the United Kingdom flag on the far right and the United States flag on the far left. The flags are flying in the wind, and the sky is a clear blue with some light clouds.