

# ASIA-PACIFIC TB AND HUMAN RIGHTS ADVOCACY STRATEGY

JOINTLY DEVELOPED BY APCASO, ACT! AP AND THE TB AND HUMAN RIGHTS CIVIL SOCIETY WRITING TEAM\*

## BACKGROUND

The adoption of the Political Declaration to Ending TB in 2018 has galvanized the global effort towards responding to the TB pandemic with a set of high-level political commitments that needs to be achieved by 2025 to end TB as a pandemic by 2030. This Political Declaration<sup>1</sup> reflects several targets set in the End TB Strategy and introduced new targets around prevention as well as in funding the global TB response.

Few of these targets have been on track in 2020. However, with the onset of the global COVID-19 epidemic, many of these tracks have been derailed. It is estimated that with the COVID-19 crisis, the plunge in detection rate of people with TB of between 25% to 50% over the period of three months will result to an additional 200,000 to 400,000 deaths in 2020 alone<sup>2</sup>. It was thus recommended that TB services are to be provided amid the COVID-19 pandemic and related lockdowns to ensure continuity of services for those affected by and currently treating for TB.

The 2018 Political Declaration has also recognized sociocultural barriers across the TB cascade, and the need to implement programs that respond to these barriers through “integrated, people-centred, community-based and gender-responsive health services based on human rights”<sup>3</sup>. However, no specific targets in the Political Declaration were adopted to properly measure this commitment. The TB accountability report, “A Deadly Divide: TB Commitments vs. TB Realities” has also found that investments in this area remains minimal<sup>4</sup>. While several initiatives have been implemented and

resources have been published by several organizations and funding mechanisms to promote a human rights-based response to TB, there is a need to consolidate these together to support the Asia-Pacific region towards a more human rights-based, people-centred TB response. Such shift will be crucial so that the systemic and structural challenges that hinder people affected by TB from accessing life-saving TB services are addressed, and that their rights are respected and protected.

## EXPERIENCES FROM THE RIGHT TO BREATHE PROJECT

APCASO, in partnership with the Activists Coalition on TB - Asia-Pacific (ACT! AP), as regional communities of advocates, has been implementing a project titled “Scaling Up Human Rights Advocacy and Accountability among People With and Affected by Tuberculosis in Asia-Pacific”, with support from the Stop TB Partnership. Referred to as the “Right to Breathe” Project, this aims to establish an Asia Pacific human rights advocacy agenda, which will provide a framework of advocacy priorities and strategies for APCASO and ACT! AP in engaging with regional and multilateral bodies, funders, stakeholders, and most importantly, national level government agencies and national TB programmes and advocate for a strengthened human rights-based response to TB in the region.

Over the course of its implementation since September 2020, the “Right to Breathe” Project has trained 21 community facilitators and trainers from 9 countries to roll out its Right to Breathe training manual for people living with and affected by TB in late 2020. These



## “RIGHT TO BREATHE” PROJECT OBJECTIVES

1. Support civil society, TB-affected communities, and TB survivors groups in the rollout of the TB and Human Rights Training Manual and in the implementation of their advocacy plans
2. Lead the development of a regional human rights advocacy agenda for the TB response
3. Advocate and influence inclusion of human rights agenda into the regional and national TB responses

community facilitators included country partners of APCASO and ACT! AP in three countries wherein in-country partners would conduct the country-level rollout as well as implement succeeding activities identified post-national trainings.

Corollary to this, APCASO supported 2 key population-led organizations and 1 civil society organization working on TB, namely Trisuli Plus (Nepal), Key Population Advocacy Consortium (Papua New Guinea), and SCDI (Viet Nam) to roll out national level TB and human rights trainings based on the Right to Breathe manual, and support succeeding activities that participants identified. This included sensitization and awareness building on the intersections of TB, human rights, and Community, Rights and Gender (CRG) concepts; meeting with national government representatives to promote the ongoing work on strengthening knowledge and capacity of communities on TB and human rights; and establishment of TB survivor groups.

Several outcomes have been noted by our three country partners in implementing their respective projects:

- Knowledge and capacity of TB-affected communities about TB and their rights are built and enhanced
- Convening of stakeholders working in TB such as district health offices and national TB program managers together with TB-affected communities, TB survivors, which was a first in their country ([Nepal and Papua New Guinea](#))
- Development of community-led monitoring tools that will act as feedback mechanisms between TB-affected communities and respective stakeholder

e.g. health facilities ([Papua New Guinea and Viet Nam](#))

- Formation of 10 TB survivor groups in 10 high-burden districts ([Nepal](#))
- Influence in proposal writing for the Global Fund TB Request ([Nepal](#))

Building on this progress to advance rights-based approaches to TB in Asia-Pacific while at the same time learning from these experiences and outcomes from the 3 countries, and based on the outcomes of the regional Training of Trainers (TOT), APCASO in partnership with ACT! AP and Stop TB Partnership organized a regional community and civil society consultation that aimed to develop a regional community-led advocacy strategy on TB and human rights. Initial discussions have been facilitated by APCASO and ACT! AP among 45 community and civil society participants during the Asia-Pacific TB and Human Rights Advocacy Strategy Consultation (report [here](#)), and a writing team has been formed to finalize the advocacy strategy.

This regional advocacy strategy aims to provide a pathfinder for Asia Pacific as a region and for the countries in this region towards a more human rights-based, people-centered TB response. This regional advocacy, developed by TB-affected communities and civil society working on TB themselves, with the facilitation of APCASO and ACT! AP, include key priority objectives and interventions that will aim to accelerate the achievement of a human rights-based TB response in the region.

# THE REGIONAL TB AND HUMAN RIGHTS ADVOCACY STRATEGY

**GOAL: TO TRANSFORM TOWARDS A MORE RIGHTS-BASED TB RESPONSE IN ASIA-PACIFIC WITH TB-AFFECTED COMMUNITIES AT THE CENTRE**

## OBJECTIVE 1:

Increase knowledge and awareness of TB-affected communities both in TB infection and disease, as well as on entitlements and human rights

## ALIGNED WITH UN HIGH-LEVEL COMMITMENT PARAGRAPH 38:

"Commit to providing special attention to the poor, those who are vulnerable, including infants, young children and adolescents, as well as elderly people and communities especially at risk of and affected by TB, in accordance with the principle of social inclusion, especially through **ensuring strong and meaningful engagement of civil society and affected communities** in the planning, implementation, monitoring and evaluation of the TB response..."

Steps / initiatives	Challenges	Responding to these challenges
<ol style="list-style-type: none"><li>Enhanced and effective public communication among people affected by TB about TB as well as their rights of people affected by TB</li><li>Gather voices and narratives of various populations affected by TB and TB survivors, particularly those who are highly vulnerable such as women and children, indigenous peoples, migrants, refugees, internally displaced people, people living in situations of complex emergencies, prisoners, people living with HIV, people who use drugs, miners, urban and rural poor, undernourished people, individuals who face food insecurity, ethnic minorities, people living with diabetes, people with mental and physical disabilities, people with alcohol use disorders, and people who use tobacco</li><li>Rights literacy among TB-affected communities</li></ol>	<ol style="list-style-type: none"><li>COVID-19 lockdown poses difficulty to gather voices and stories</li><li>Language and literacy can be an issue especially when published information on posters and brochures are not accessible by everyone</li><li>Issues and conditions of people affected by TB are multi-layered (other co-morbidities, self-stigma, caste)</li></ol>	<ol style="list-style-type: none"><li>Civil society and communities to work together collaboratively (not tokenistic)</li><li>Ensure that public communication materials employ language that is easily understandable by the communities, including use of visuals if needed</li><li>Make sure that referral mechanisms are in place to be able to refer people affected by TB who may experience intersecting issues</li></ol>

## OBJECTIVE 2:

Strengthen the capacity of the legal community and private healthcare sector about TB and human rights

### ALIGNED WITH UN HIGH-LEVEL COMMITMENT PARAGRAPH 33:

**"Commit to developing community-based health services through approaches that protect and promote equity, ethics, gender equality and human rights in addressing tuberculosis"**

Steps / initiatives	Challenges	Responding to these challenges
<ol style="list-style-type: none"><li>1. Develop strategic information about the rights of people affected by TB (referring to the 2019 Declaration of the Rights of People Affected by TB) and sharing this information among legal community and the private healthcare sector</li><li>2. Build and strengthen human rights literacy and capacity-building on advocacy among the legal and justice community and private healthcare sector</li><li>3. Involve TB-affected communities as paralegal service provider and/or service point provider in the private sector</li><li>4. Creation of legal and paralegal redress mechanisms and linking with TB-affected communities</li><li>5. Forming consortium of private medical associations</li><li>6. Advocate for inclusion of diagnostics / procedures of sampling collections into the national health coverage</li></ol>	<ol style="list-style-type: none"><li>1. Private healthcare sector are not aware of the rights of TB-affected communities</li><li>2. Private healthcare sector provides subpar medications to people with TB without any reprimand</li><li>3. Medical associations are not sensitized about TB and about human rights of people affected by TB</li><li>4. Many non-medical workers such as security guards within private healthcare facilities are the primary barriers to clients affected by TB returning for treatment</li></ol>	<ol style="list-style-type: none"><li>1. Integrate rights literacy activities into the periodic medical education of private healthcare service providers, including non-medical healthcare facility staff</li><li>2. Partner with various medical associations and work with the federation of medical associations (if existing) and national associations of lawyers to ensure immediate rollout of rights literacy education activities</li></ol>

## OBJECTIVE 3:

Create an enabling environment for a rights-based TB advocacy in the region

### ALIGNED WITH UN HIGH-LEVEL COMMITMENT PARAGRAPH 37:

"Commit to...promote and support and end to stigma and all forms of discrimination, including by removing discriminatory laws, policies, and programmes against people with TB"

Steps / initiatives	Challenges	Responding to these challenges
<ol style="list-style-type: none"><li>1. Inclusion of rights-based activities into the TB response</li><li>2. Invest in, develop, and adopt community-led monitoring tools into national TB strategic information systems</li><li>3. Support the TB survivor and TB-affected community movements by investing in mobilization activities</li><li>4. Inclusion of and investing in sensitization across various stakeholders</li><li>5. Build solidarity with HIV movement, mainly key population-led organizations, and support the inter-movement mobilization (e.g. Global Fund C19RM process</li><li>6. Undertake national TB stigma assessments</li></ol>	<ol style="list-style-type: none"><li>1. Buy-in of NTPs</li><li>2. Mobilization and engagement of civil society are sometimes a tick in the box in multistakeholder meetings.</li></ol>	<ol style="list-style-type: none"><li>1. Promotion of this advocacy strategy and outcomes of national rollouts</li><li>2. Institutionalize the participation of civil society and affected community engagement such as through provision of seat within decision-making tables, and supporting consultations</li></ol>

## OBJECTIVE 4:

Support the immediate adaptation of WHO Guidelines into national guidelines, and support initiatives in addressing barriers in accessing affordable medicines

## ALIGNED WITH UN HIGH-LEVEL COMMITMENT PARAGRAPH 19:

“Commit to **promote access to affordable medicines, including generics, for scaling up access to affordable tuberculosis treatment**...to promote public health and, in particular, to promote access to medicines for all”

Steps / initiatives	Challenges	Responding to these challenges
<ol style="list-style-type: none"><li>1. Treatment literacy among people affected by TB and TB survivors</li><li>2. Support the creation of TB Technologies Task Force<sup>5</sup></li><li>3. Review and develop a national strategy to identify and eliminate systemic barriers in accessing affordable medicines</li><li>4. Identify price, intellectual property and trade barriers to access of different TB tools</li></ol>	<ol style="list-style-type: none"><li>1. Engagement with big pharma needs to be laid out</li><li>2. Challenge ever-greening of patents</li><li>3. Ask for transparency in setting of prices/demand price control on essential drugs</li></ol>	<ol style="list-style-type: none"><li>1. Work with government agencies and TB national coordinating mechanisms (e.g. through TB Technologies Task Force) and advocate for accessing generics</li><li>2. Work with lawyers to file interventions against wrongful grant of patents on TB drugs</li><li>3. Work with drug price control authority to identify TB drugs that should come under price control</li><li>4. Engage with trade unions and groups to identify potential impact of bilateral and multilateral treaties on access to medicines</li></ol>

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## **ENDNOTES**

- <sup>1</sup> <https://www.who.int/tb/unhlmonTBDeclaration.pdf>
- <sup>2</sup> <https://www.who.int/publications/m/item/overview-progress-towards-achieving-global-tuberculosis-targets-and-implementation-of-the-un-political-declaration-on-tuberculosis>
- <sup>3</sup> <https://www.who.int/tb/unhlmonTBDeclaration.pdf>
- <sup>4</sup> [http://www.stoptb.org/assets/documents/communities/The%20Deadly%20Divide\\_TB%20Commitments%20vs%20TB%20Realities%20FINAL%20HLM%20Report.pdf](http://www.stoptb.org/assets/documents/communities/The%20Deadly%20Divide_TB%20Commitments%20vs%20TB%20Realities%20FINAL%20HLM%20Report.pdf)
- <sup>5</sup> [http://www.stoptb.org/assets/documents/communities/Activating%20A%20Human%20Rights%20Based%20Tuberculosis%20Response\\_Policy%20Brief%20\(2020\).pdf](http://www.stoptb.org/assets/documents/communities/Activating%20A%20Human%20Rights%20Based%20Tuberculosis%20Response_Policy%20Brief%20(2020).pdf)



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