

MARCH 2023

# A Deadly



# Divide



TB COMMITMENTS  
VS. TB REALITIES

— The Accountability Report of TB-affected Communities & Civil Society:

## Priorities to Close the Deadly Divide

Stop TB Partnership  
Community Delegation

Stop TB Partnership  
Developing Countries NGO Delegation

Stop TB Partnership  
Developed Countries NGO Delegation



Cover photo: © Stop TB Partnership

**This accountability report by TB-affected communities and civil society, hereon referred to as the Accountability Report, is dedicated to all people with, and affected by TB, their families, and the civil society that supports them.**

Every day, nearly 4,400 people die from a disease that is both preventable and curable, resulting in approximately 1.6 million lives lost yearly. As deaths from COVID19-decline, TB is reclaiming its title as the world's number one infectious disease killer. Too often, those who die are from our most vulnerable and marginalized communities. While there have been some advancements, the overall response to eliminate TB remains outdated, mired with complacency, and often at odds with basic human rights. This report is written by, and in solidarity with TB-affected communities and civil society to galvanize a transformative response to end TB.

**DEATHS FROM TB / DAY**  
4,400 people

**DEATHS FROM TB / YEAR**  
1.6 million people

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# Dedication

# Acknowledgements

This report would not have been possible without the contributions of 1,018 colleagues from 394 organizations in 91 countries, representing TB-affected communities, including people with TB and TB survivors, civil society constituencies, and allies to whom we are incredibly thankful (see **Annex**). Their collective experiences and perspectives serve as evidence of an escalated momentum to end TB. When the first Deadly Divide report was written in 2020, about 150 people in 61 countries participated, meaning engagement in this 2.0 effort has increased nearly ten-fold.

The steadfast efforts of regional community leaders, Meirinda Sebayang (Asia-Pacific), Olayide Akanni (Anglophone Africa), Bertrand Kampoe (Francophone Africa), Deliana Garcia (Americas), Timur Abdullaev (Eastern Europe and Central Asia), and Robyn Waite (high-income countries) is acknowledged with deep gratitude. With unwavering enthusiasm, they helped develop the methodology, spearhead outreach, and write this report together with Amrita Daftary (York University and SSHIFTB), Pushpita Samina, and Sheila Noriega-Mestanza (SSHIFTB). The Developing Country NGO Delegation, Developed Country NGO Delegation, and Community Delegation of the Stop TB Partnership Board of Directors are thanked for their vision, leadership, and commitment to amplifying the voice of the TB-affected communities and civil society as agents of change in the TB response. The efforts of all those who provided review, including Lucica Ditiu, Suvanand Sahu, Viorel Soltan, Brian Kaiser, Wayne Van Gemert, Caoimhe Smyth, Suhair Talab, Andrei Mosneaga, Janika Hauser, and Rhea Lobo, are highly appreciated.

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# Abbreviations


<b>ADPP</b>	Ajuda de Desenvolvimento de Povo para Povo	<b>DRAF-TB</b>	Francophone Africa Response Dynamics on Tuberculosis
<b>AI</b>	Artificial Intelligence	<b>DRC</b>	Democratic Republic of Congo
<b>AIDS</b>	Acquired Immunodeficiency Syndrome	<b>DRTB</b>	Drug-Resistant TB
<b>AMIMO</b>	Association of Mozambican Mineworkers	<b>DS-TB</b>	Drug Susceptible Tuberculosis
<b>AMR</b>	Antimicrobial Resistance	<b>EECA</b>	Eastern Europe and Central Asia
<b>BCF</b>	Bridge Consultants Foundation	<b>EGPAF</b>	Elizabeth Glaser Pediatric AIDS Foundation
<b>Bonela</b>	Botswana Network on Ethics, Law and HIV/AIDS	<b>FDCs</b>	Fixed-Dose Combinations
<b>BPaL/BPaIM</b>	Bedaquiline, Pretomanid, Linezolid/ Bedaquiline, Pretomanid, Linezolid Moxifloxacin	<b>FMR</b>	Foundation for Medical Research
<b>BRICS</b>	Brazil, China, India, Russia, South Africa	<b>GAVI</b>	GAVI, the Vaccine Alliance
<b>CAD</b>	Club des Amis Damien	<b>GCTA</b>	Global Coalition of Tuberculosis Advocates
<b>CAD</b>	Computer-Aided Diagnostics	<b>GloVax</b>	Initiative for Global Vaccine Access
<b>CBO/CSO</b>	Community Based Organization / Civil Society Organization	<b>GTC</b>	Global TB Caucus
<b>CCMs</b>	Country Coordination Mechanisms	<b>HBC</b>	High-Burden Countries
<b>CEPI</b>	Coalition for Epidemic Preparedness Innovations	<b>HCV</b>	Hepatitis C Virus
<b>CESI</b>	Global Fund's Community Engagement Strategic Initiative	<b>HIC</b>	High-Income Countries
<b>CFCS</b>	Challenge Facility for Civil Society	<b>HIV</b>	Human Immunodeficiency Virus
<b>CHW</b>	Community Health Workers	<b>ILO</b>	International Labour Organization
<b>CLM</b>	Community- Led Monitoring	<b>IMCI</b>	Integrated Management of Childhood and newborn Illnesses
<b>COVID-19</b>	Coronavirus Disease 2019	<b>IOM</b>	International Organization for Migration
<b>CR</b>	Community Relays	<b>KHANA</b>	Khmer HIV/AIDS NGO Alliance
<b>CRG</b>	Communities, Rights and Gender	<b>KHPT</b>	Karnataka Health Promotion Trust
<b>CSO</b>	Civil Society Organizations	<b>KNCV</b>	KNCV Tuberculosis Foundation
<b>CSTF</b>	Civil Society Task Force	<b>KVP</b>	Key and Vulnerable Population
<b>DAT</b>	Digital Adherence Technologies	<b>LAMP</b>	Loop-Mediated Isothermal Amplification
<b>DLB</b>	Delft Light Backpack	<b>LMIC</b>	Low- and Middle-Income Countries
<b>DOT</b>	Directly Observed Therapy	<b>MAF</b>	Multisectoral Accountability Framework
		<b>MPP</b>	Medicine Patent Pool
		<b>MSATBA</b>	Maharashtra State Anti-Tuberculosis Association

<b>MSF</b>	Médecins Sans Frontières	<b>SO</b>	Social Observatories
<b>MTB</b>	Mycobacterium Tuberculosis	<b>SAMA</b>	Southern African Miners Association
<b>NCD</b>	Non-Communicable Disease	<b>STP</b>	Stop TB Partnership
<b>NGO</b>	Non-Governmental Organization	<b>TAG</b>	Treatment Action Group
<b>NITHA</b>	Northern Inter-Tribal Health Authority	<b>TB</b>	Tuberculosis
<b>NFM4</b>	New Funding Model 4	<b>TIMS</b>	Tuberculosis in the Mining Sector in Southern Africa
<b>NSP</b>	National Strategic Plans	<b>TPT</b>	Tuberculosis Preventive Treatment
<b>NTP</b>	National Tuberculosis Program	<b>U-ASHA</b>	Urban Accredited Social Health Activists
<b>OGRA</b>	Foundation in Kenya	<b>UK</b>	United Kingdom
<b>PDL</b>	People Deprived of their Liberty	<b>UKAPT B</b>	UK Academics and Professionals to end TB
<b>PEER</b>	Partnership for Enhanced Engagement in Research	<b>UN</b>	United Nations
<b>PHF</b>	Philomera Hope Foundation	<b>UNICEF</b>	United Nations Children's Fund
<b>PLHIV</b>	People Living with HIV	<b>UNHLM</b>	United Nations High-Level Meeting
<b>POC</b>	Point of care	<b>UHC</b>	Universal Health Coverage
<b>PPE</b>	Personal Protective Equipment	<b>US</b>	United States
<b>PPPR</b>	Pandemic Prevention, Preparedness and Response	<b>USAID</b>	United States Agency for International Development
<b>PTLD</b>	Post-TB Lung Disease	<b>LON</b>	Local Organizations Network
<b>R&amp;D</b>	Research & Development	<b>vDOT</b>	Video-based Directly Observed Therapy
<b>REACH</b>	Resource group for Education and Advocacy for Community Health	<b>WFP</b>	World Food Programme
<b>SADC</b>	Southern African Development Community	<b>WHO</b>	World Health Organization
<b>SDGs</b>	United Nations' Sustainable Development Goals	<b>Wok</b>	Wellness on Wheels Keke
<b>SMART4TB</b>	Supporting, Mobilizing and Accelerating Research for Tuberculosis Elimination	<b>WRD</b>	WHO-recommended Rapid Diagnostics



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# Executive Summary



**We issue this Call to Action to demand social justice and awaken a transformative response to tuberculosis (TB), a disease that is preventable and curable, yet takes the lives of 4,400 people a day, including 700 children.**

**We want to ensure that those of us who are most impacted, namely TB affected communities and civil society, speak up so that our realities and priorities are understood, and our lives are saved.**

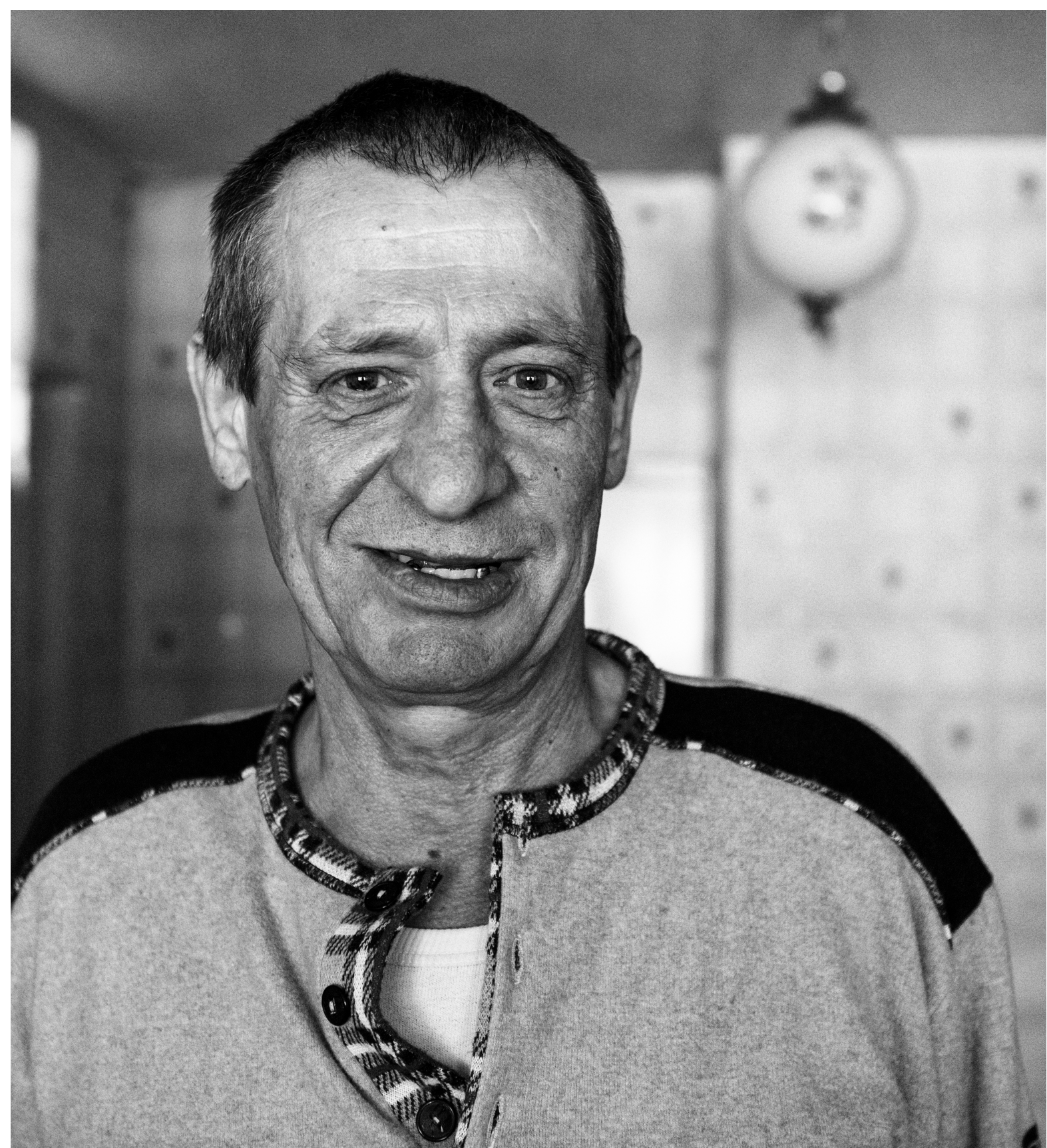




We feel it critical to emphasize that while TB can affect anybody, it does not impact everybody equally. The social determinants of health and inequities that are beyond a person's direct control can make some of us more vulnerable to TB and/or more likely to face barriers to accessing TB services. Those of us who are part of a key and vulnerable population (KVP) affected by TB deserve a just and inclusive response that recognizes and meets our different needs.

We recall the 2018 United Nations High Level Meeting (UNHLM) on TB and its targets and commitments, and the community progress report *A Deadly Divide: TB Commitments Vs TB Realities* released two years afterwards. Now, on World TB Day 2023, we reflect on progress made, success stories, as well as the shortcomings of our efforts in subsequent years. Today we look toward charting a course for the second UNHLM on TB in 2023 and beyond to end TB by 2030. We draw on the established road map of the *Global Plan to End TB 2023-2030* and, more significantly, the inspiration and learnings garnered from over 1000 TB-affected community and civil society partners from 90 TB-impacted countries who have provided rich and unique insights, including contributions to over 30 case studies of guidance and lessons learnt to enable progress in the TB response.

We affirm the 6 thematic calls to action as critical to ending the present-day pandemic of TB. They require us to prioritize and address three facts which have historically stagnated progress. First, we need TB to grab the political attention and ambition it deserves. It needs to be an economic and political priority addressed through a human rights and social justice lens. Second, we must make domestic and external financial resources immediately available to end TB. The funding gap must be closed, existing innovations and tools must be available and accessible for all, and TB research & development (R&D) needs to receive the investment levels we saw for COVID-19. Third, the empowerment of TB-affected communities and civil society partners has for too long been excluded. Our lived experience and distinct complementary expertise must be recognized, developed, and integrated into envisioning, planning, and financing for TB. Without these steps, progress will be derailed, lives will continue to be lost, and economies will continue to suffer the results of this neglect.



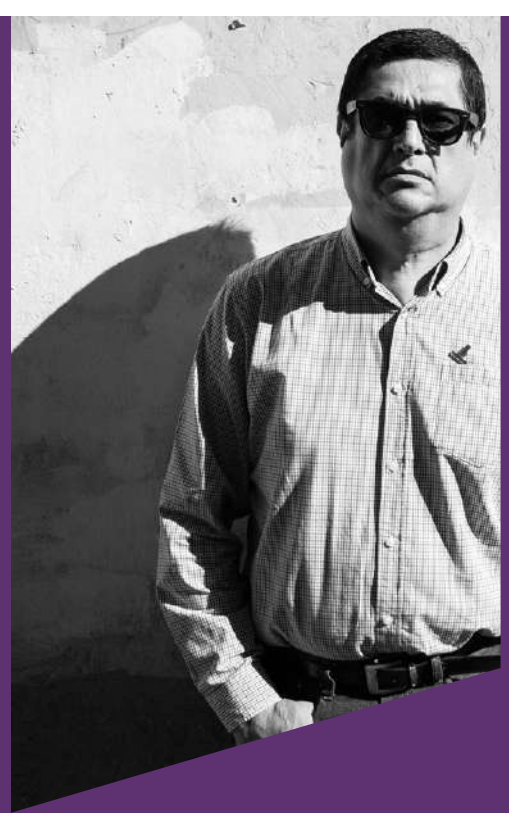
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# Calls to Action

# 01

## Close gaps in TB prevention, diagnosis, treatment and care by reaching all people with TB

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- Ensure WHO-approved rapid molecular diagnostics (wRMDs) are used as the initial test for TB.
- Ensure all people affected by TB, including TB infection and disease and drug-resistant TB (DRTB), and their contacts have affordable access to the newest prevention and treatment regimens.
- Develop and meet ambitious targets for TB prevention through contact tracing and coverage of TB preventive treatment (TPT), and also by addressing the social determinants of TB and urgently securing a new TB vaccine.
- Deliver quality people-centred, community-based and KVP-focused TB care to improve TB outcomes, including child-friendly services to improve outcomes of paediatric TB, through workforce training, attentiveness and resources to identify and overcome social and economic barriers to access.
- Ensure TB services are integrated with HIV, primary health care and/or occupational health services, using co-located models, to improve detection and treatment of TB in co-morbid conditions such as HIV, silicosis, malnutrition, and diabetes.
- Leverage the capacity of the private sector to improve access to TB services, particularly in countries with large private sector service providers.

# 2 Make the TB response equitable, gender-responsive, rights-based, and stigma-free, with TB-affected communities and civil society at the centre by 2025.

- Ensure Communities, Rights and Gender (CRG) and stigma elimination are prioritized in the UNHLM political declaration with specific targets, and explicitly integrated into National Strategic Plans (NSP) and TB Programme Reviews.
- Dedicate donor and domestic funding for TB community-led initiatives, including advocacy, monitoring and accountability efforts through the Stop TB Partnership (STP) Challenge Facility for Civil Society (CFCS), the Global Fund, and other technical support mechanisms.
- Ensure the meaningful participation of TB-affected communities and civil society as expert contributors in developing NSPs, planning TB Programme Reviews, as well as country proposal development processes for international grants in all high burden countries (HBCs), including through national networks of people affected by TB and empowerment and leadership of women and girls.
- Conduct CRG assessments, routine stigma measurement, and develop and implement costed TB CRG action plans in all HBCs that include community-led monitoring (CLM) of the TB response and of CRG in the TB response.
- Identify, conduct size estimations, and allocate funding to systematically attend to specific needs of TB KVPs, such as but not limited to people living with HIV, migrants, refugees and internally displaced people, people who use drugs, people deprived of their liberty, people with diabetes, the urban poor and people living in slums, miners and people with silicosis, indigenous peoples, and children, based on vulnerability and barriers to access.
- Strengthen social protection and security for people affected by TB, and ensure it includes income, health care, housing, nutritional support, mental health support, and legal aid.
- Update laws, policies, and programmes to promote and protect the rights of people affected by TB, combat inequalities and eliminate stigma and discriminatory practices, processes and language.

# 3 Accelerate the development, rollout of and access to essential new tools to end TB

- Develop and ensure the availability and accessibility of new TB vaccines to enable sharp reductions in disease incidence by 2025, with protected pipeline funding.
- Ensure all people affected by TB, including TB infection and disease and drug-resistant TB (DRTB), receive the latest shorter treatment regimens by the end of 2024.
- Develop novel point-of-care wRMDs, including those which are child-friendly and measure drug resistance to the latest and emerging treatment regimens, parallel to developing shorter treatment regimens for TB infection and disease that are based on new molecules.
- Strengthen utility and investment in digital technologies including digital portable X-ray, artificial intelligence-supported diagnostics and CLM mechanisms such as OneImpact.
- Accelerate rollout and market access of new and emerging tools - from design and adaptation through to adoption, demand creation and evaluation - with funded community advisory mechanisms, community-led campaigning and operational research.
- Coordinate efforts between developers such as through global alliances and not-for-profit product development partnerships to produce people-centred and accessible vaccines, diagnostics, treatments and digital technologies for TB, ensuring they are free from intellectual property or related industry or regulatory pricing barriers that inhibit access.



# 04

## Invest the funds necessary to end TB

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- Close the TB funding gap through investments of US\$ 210 billion between 2023 and 2030, including US\$ 40 billion for TB R&D to achieve the 6 calls to action.
- Support replenishment of global financing mechanisms such as the STP CFCS and TB REACH, the Global Fund and Unitaid, with proportionate allocations for TB and for TB-affected communities and civil society partners.
- Mobilize domestic resources for TB and integrate with health systems to leverage existing investments and reduce dependency on external funds.
- Eliminate catastrophic costs facing households affected by TB through multisectoral investments, coordination, and application of legal frameworks.
- Innovate financing to expand the pool of investors and to breed efficiency in TB spending.
- Ensure TB is recognized and included in investments in pandemic prevention, preparedness and response, antimicrobial resistance, and universal health coverage.

# 5

## Prioritize TB in pandemic prevention, preparedness and response (PPPR), antimicrobial resistance (AMR), and universal health coverage (UHC)

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- Ensure PPPR draws on experiences from and addresses present-day pandemics like TB and its role in future air-borne pandemics, with aligned funding.
- Ensure TB drug-resistance is featured in AMR surveillance and addressed in AMR strategic planning and aligned funding.
- Ensure TB screening, prevention, diagnosis, treatment, and care are included in national essential service packages for primary health care and UHC, and conversely ensure that all people affected by TB, including KVPs and family members, are enrolled and protected by national UHC schemes, thereby using TB as an indicator of progress towards UHC.
- Develop funded models for the meaningful inclusion of TB-affected communities and civil society as equal partners in PPPR (including the Pandemic Fund), AMR and UHC responses, with representation and voice within governance arrangements globally and at country level.



# 6 Commit to multisectoral action, decisive leadership and accountability



- Develop partnerships with journalists, parliamentarians, celebrities and other public figures to champion and implement the calls to action from this TB accountability report.
- Strengthen sector-wide collaboration and scale up adoption of the Multisectoral Accountability Framework (MAF) for TB, while developing additional mechanisms to hold all stakeholders to account for achieving commitments and targets.
- Apply CLM models to understand and address the realities facing TB-affected communities, including stigma, human rights violations, and to document community-led actions in addressing those barriers. Use these data to bolster national TB, PPPR and UHC responses and accountability for CRG.
- Engage Heads of State, high-level leadership and TB-affected communities and civil society in monitoring and review of national TB responses, multisectoral action and accountability mechanisms, and translating commitments on TB in PPPR, AMR and UHC to action, including at the 2023 UNHLM on TB.
- Request WHO to develop a timetable and transition plan for real time surveillance systems and data reporting.
- Mandate inclusion of TB-affected communities and civil society within Country Coordination Mechanisms (CCMs) and technical working groups related to monitoring and review of national responses, including support for STP Community and NGO Delegations to lead development of accountability reports in subsequent years.



# Introduction

Tuberculosis (TB) has lived with humanity for centuries. It is preventable, treatable, and curable, yet remains unconquered. In 2018, the first ever United Nations High Level Meeting (UNHLM) on TB catalyzed Member States to set out commitments to eliminate TB by 2030 under a Political Declaration on the Fight against Tuberculosis.<sup>1</sup> The Declaration affirmed the United Nations' Sustainable Development Goals (SDGs) for 2030<sup>2</sup>, the World Health Organization's (WHO) End TB Strategy for 2030<sup>3</sup>, and the Stop TB Partnership's (STP) Global Plan to End TB 2016–2020<sup>4</sup>, and set out targets for TB elimination at the global, regional and national levels.

It is now four years since the first UNHLM on TB and almost all targets remain unmet. Many targets also fall short of community priorities. The year 2021 saw 10.6 million people fall ill with TB and 1.6 million die from the disease.<sup>5</sup> This means, every day, about 29,000 people develop TB and 15% of them do not survive it. The COVID-19 pandemic reversed many gains that had been made in TB, leading to – for the first time in decades – an increase in TB incidence and mortality.<sup>5</sup> But even before the pandemic, TB was the leading cause of death from a single infectious agent. It threatens to maintain that position for the foreseeable future. Unless we act now.

In September 2023, a second UNHLM on TB will convene to set new commitments and targets for ending TB. This is a time of reckoning for those who are at the heart of this ongoing pandemic of TB. Communities affected by TB and civil society must hold political leaders to account for the promises they made in 2018 and, given the egregious gaps in progress achieved, demand the prioritization of decisive action and accountability to end TB, while remaining at the front and center of that response. With its roadmap of priority actions for people-centered care to end TB, including a detailed estimate of financial resource needs in TB R&D, implementation and infrastructure, The Global Plan to End TB 2023–2030 provides much-needed inspiration.<sup>6</sup>

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<sup>1</sup>The Global Plan to End TB 2016–2020 was later revised in light of the 2018 UNHLM on TB Political Declaration. The Global Plan to End TB 2023–2030 is referenced from hereon.

## Rationale for a Communities Report

Communities affected by TB and civil society are at the heart of the TB epidemic, no matter where TB emerges. They are the ultimate stakeholders and bearers of accountability in any effort to end TB. However, their voice has not been sufficiently prioritized.

The past five years reflect a seismic shift in community engagement and actions in TB, and this report is a timely reflection of that shift. A first Deadly Divide report was released in 2020, exposing major gaps between the targets endorsed by heads of state and governments, and the results achieved.<sup>7</sup> This second report builds on that endeavor with justifiable impatience.

TB-affected communities and civil society urge their meaningful engagement in decision-making to disrupt the status quo and help lead a transformative TB elimination response that is people-centered, equitable, rights-based, stigma-free, with investments on par with efforts for pandemic prevention, preparedness and response (PPPR), antimicrobial resistance (AMR), and universal health care (UHC). This report reflects their unapologetic voice in solidarity with people most directly affected by TB, including those who are frequently left out of conversations about when, where, and how to end TB. It commends community actions undertaken world over and, in providing crucial insights into preventable gaps, offers priority recommendations to facilitate action in six key areas, each driven by their purposeful involvement and leadership, and informed by their lived experience with TB. The report is designed to provoke political and multisectoral engagement in the persisting global crisis and awaken a response that is commensurate with the devastating rates of death, marginalization, disability and socioeconomic loss needlessly wreaked year upon year by TB.

## Definitions

For the purpose of this report, 'TB-affected communities and civil society' refers to:

- **People affected by tuberculosis (TB):** Any person with TB infection or TB disease or who previously had TB disease, as well as their caregivers and immediate family members, and members of key and vulnerable populations (KVP) affected by TB, such as children, health care workers, indigenous peoples, people living with HIV, people who use drugs, people in prison (people deprived of their liberty) and other closed settings, miners, mobile and migrant populations, women, and the urban and rural poor.
- **Community-based, civil society and non-governmental organizations and networks working to address TB** at local, national, regional, and global levels.

'TB survivors' is specifically used when referring to people who previously had TB disease. 'People with TB' or 'people affected by TB' is used when referring to people who have or previously had TB disease.



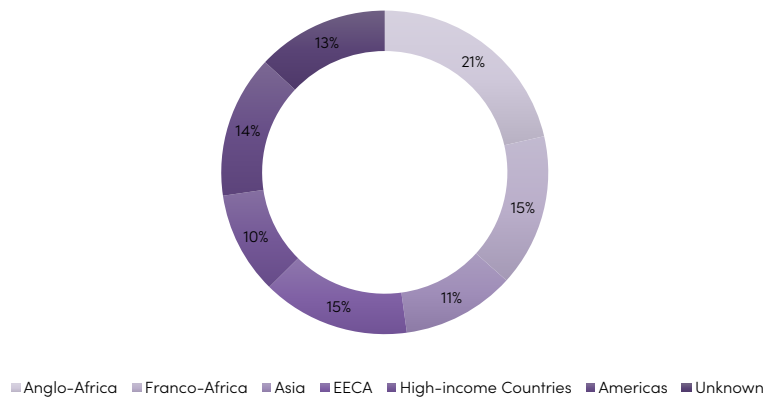
## Methodology

This report is based on the consolidated perspectives of 1,018 people engaged in the TB response from 394 organizations across 91 countries. The respondents are from Africa (Anglophone and Francophone Africa), Americas, Asia, Eastern Europe, and Central Asia (EECA), and High-income Countries (HIC) including people working at the global level (Figures 1-3). Their insights were captured via online surveys (n=860), interviews (n=158), and ongoing consultations facilitated by the TB-affected community and civil society leaders in each region, social science researchers, and coordinating organizations, as noted under Acknowledgements, between September 2022 and March 2023.

Approximately one-third of survey respondents self-identified as people with TB or TB survivors (n=295). Other respondents (n=565) identified as representatives of community-based organizations and civil society organizations, including non-governmental and not-for-profit organizations, and networks of TB survivors and KVP (75%); followed by technical experts including developers and funding body representatives (10%); academics or representatives of research institutions (8%); government representatives (3%); and journalists (1%). Most (90%) participants live and/or work in low- and middle-income countries (LMIC) impacted by TB.

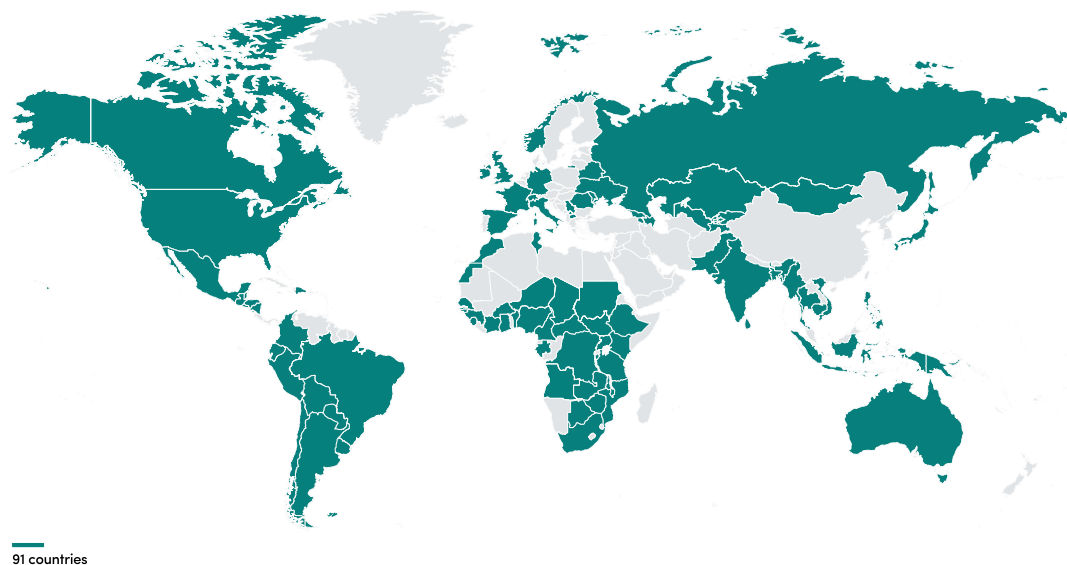
## Figure 1

Regional distribution of survey and interview respondents



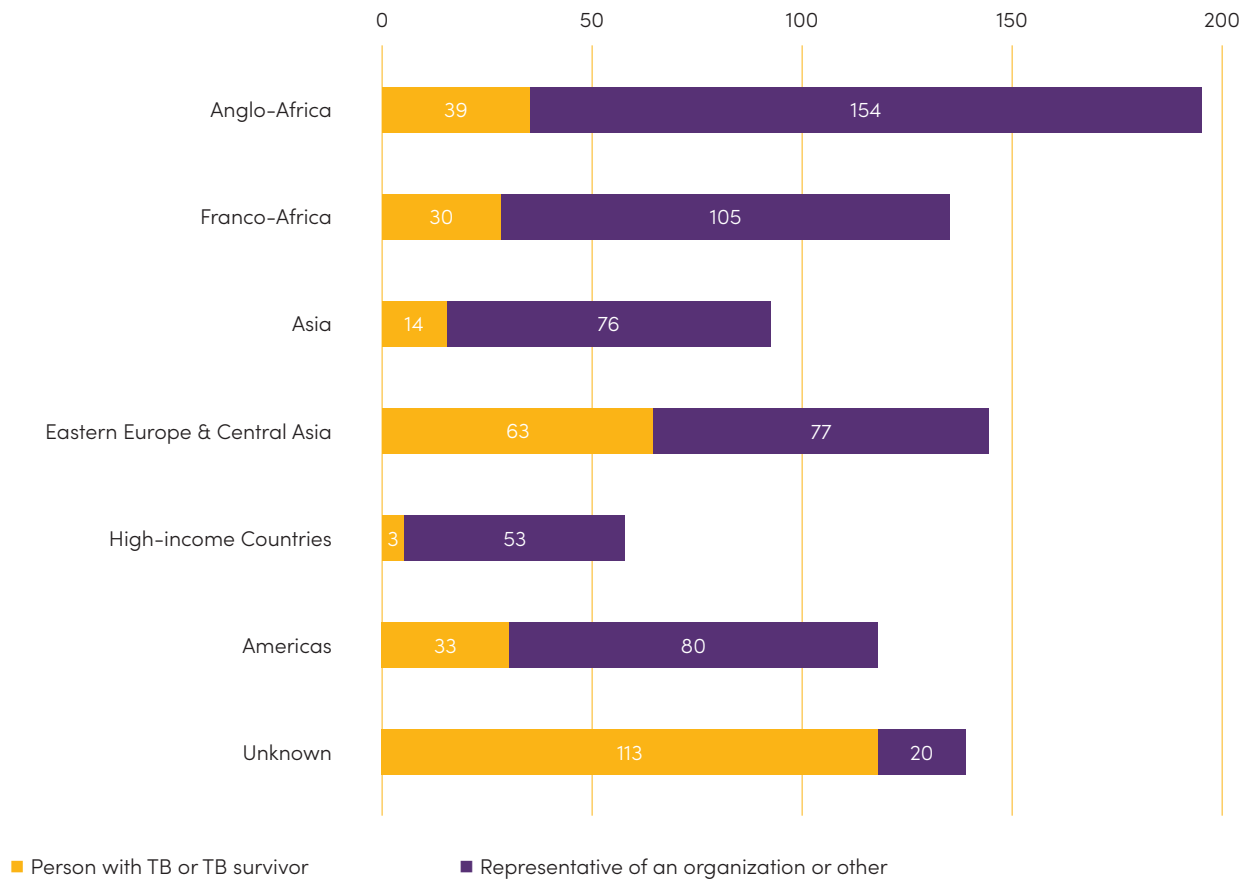
## Figure 2

Countries represented by survey and interview respondents



# Figure 3

## Profile of survey respondents



A community-led human rights framework<sup>8</sup> was applied to analyze data from respondents, contextualized with findings in the formal and grey literature. The current state of affairs from respondents' points of view, including a scorecard on progress achieved on the 2018 Political Declaration<sup>1</sup>, persisting challenges, and opportunities for transformative actions in the TB response are described across six priority areas. The scorecard constituted a quantitative assessment of progress achieved in each area, where categorical targets were committed to at the 2018 Political Declaration and where quantitative data were available, and/or a qualitative assessment of progress achieved, using traffic color code, where targets had not been specified. The scorecard also included relevant data from surveys, interviews, and the literature reviewed for this report.

Forty case studies exemplifying contributions by TB-affected communities and civil society in TB responses at the global, regional, national, and sub-national levels are highlighted, as evidence of their contribution and impact. These case studies represent only a handful of the laudable efforts undertaken world over and are by no means an exhaustive set.

The report is largely written in a narrative style, using explicitly stigmatizing language.<sup>9</sup> Quantitative evidence that is already well illustrated in documents produced by the TB scientific community is minimally repeated. Rather, the report provides a narrative basis to imagine the responses to TB that can close the persisting, preventable and deadly divide between promises made and progress achieved on TB elimination, and to spur more ambitious commitments and targets. The full methods, detailing the unprecedented level of participation and engagement of TB-affected communities and civil society, are available in the **Annex**.

### Case studies from TB-affected communities and civil society

Look for examples of community action and achievement throughout this report. Affected communities must be included at every level of the TB response. Investing in TB-affected communities and civil society = Investing in TB elimination.

## Targets for TB elimination

Targets for ending TB were set by the 2018 Political Declaration of the first UNHLM on TB (Table 1)<sup>i</sup>, in line with the UN SDG 3 to end TB by 2030 (based on TB incidence per 100,000 population) and the WHO's Global Plan to End TB Strategy (Table 2).

The 2018 Political Declaration targets and commitments are referred to throughout this report. Between then and now, that is, 2018 and 2023, many achievements can be celebrated such as the development of new shorter treatment regimens

for TB infection, disease and DRTB, including childhood TB, and the rollout of TB preventive treatment (TPT) for people living with HIV. However, we remain short of achieving nearly all targets.<sup>137i</sup> The current accountability mechanisms are also insufficient, woeful gaps in the fulfilment of political commitments and financial investments in the TB response. A number of Communities, Rights & Gender (CRG) related commitments that were, at the outset, devoid of indicators or targets failed to generate meaningful investments or action. The COVID-19 pandemic created a tremendous dent in efforts to eliminate TB, but we were behind in action even before 2020. We are therefore dealing with a widening deadly divide between commitments and the reality facing TB-affected communities on the ground.

## Table 1

### First UNHLM Political Declaration Targets and Commitments for 2022

First UNHLM on TB Political Declaration	Targets and commitments for 2022
<b>Reach all people by closing gaps on TB diagnosis, treatment and prevention</b>	<p>Treat 40 million people with TB, including 3.5 million children with TB.</p> <p>Treat 1.5 million people, including 115,000 children, with DRTB.</p> <p>Provide TPT to 30 million people, including 4 million children under five years of age, 20 million household contacts of people with TB, and 6 million people living with HIV.</p>
<b>Transform the TB response to be equitable, rights-based and people-centered</b>	<p>Remove laws, policies and programs that discriminate against people with tuberculosis.</p> <p>Protection and promotion of human rights and dignity.</p> <p>Recognize the sociocultural barriers to TB prevention, diagnosis, and treatment services, especially for KVP.</p> <p>Recognize the need to develop integrated, people-centered, community-based and gender-responsive health services based on human rights.</p> <p>End stigma and discrimination.</p>
<b>Invest funds needed to end TB</b>	<p>To increase overall global investments aimed at ending TB to at least US\$ 13 billion/year.</p> <p>To increase overall global investments in TB research to US\$ 2 billion, in order to close the US\$ 1.3-billion funding gap.</p>
<b>Accelerate development of essential new tools to end TB</b>	<p>Commit to delivering new, safe, effective, equitable, affordable vaccines, point of care and child-friendly diagnostics, drug sensitivity tests; safer, more effective and shorter drug regimens; innovation to strengthen health systems (for example, information and communication tools and delivery systems for new and existing technologies) to enable integrated people-centered prevention, diagnosis, treatment and care of TB.</p>
<b>Commit to decisive and accountable global leadership, including regular UN reporting and review</b>	<p>Request that the WHO Director General (DG) continue to develop the multisectoral accountability framework and implement it by 2019.</p> <p>Request the WHO Secretary General (SG) provide a progress report by 2020 to inform the next UNHLM on TB in 2023 for review by Heads of State and Government.</p>

From Political Declaration of the United Nations General-Assembly High-Level Meeting on the Fight Against Tuberculosis, 2018.<sup>1</sup>

<sup>i</sup> Reference out of sequence

## Table 2

### WHO End TB Strategy Targets for 2020 and 2030

WHO End TB Strategy	Targets
Reduce TB incidence	By 50% by 2025 and 80% by 2030
Reduce TB deaths	By 75% by 2025 and 90% by 2030
Eliminate catastrophic costs facing families affected by TB	To 0 by 2020

From WHO End TB Strategy, 2015.<sup>2</sup>

The primary indicators or measures of progress are the uptake of TB rapid tests and new drugs, coverage of TB treatment and preventive treatment, and treatment success, and catastrophic costs facing TB-affected households.

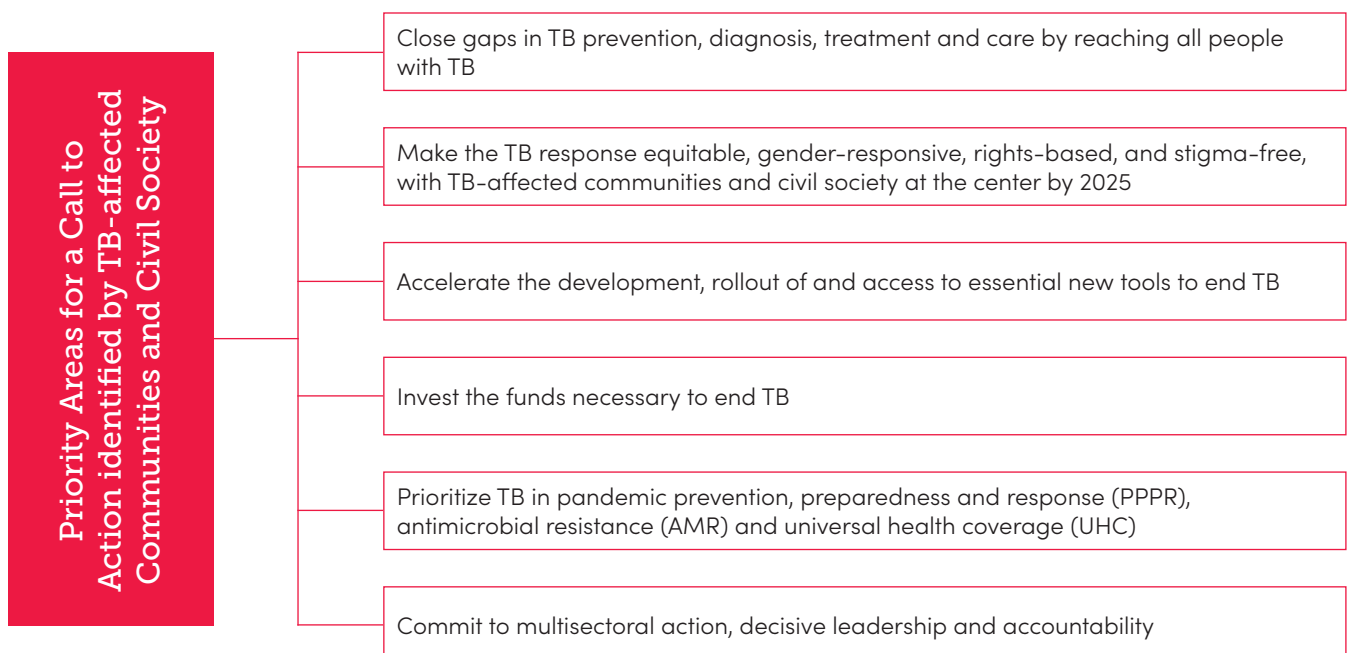
## Closing the divide

To close the deadly divide between promises made at the 2018 Political Declaration of the first UNHLM on TB and ground realities, TB-affected communities and civil society demand urgent and transformative action in six priority areas, ensuring they are meaningfully included and engaged in

every one of these areas (Figure 4). The progress achieved to date, barriers and challenges, as well as best practices undertaken by affected communities and partners in these areas are detailed in subsequent chapters, exposing persisting systemic inequities, limited investments, and the need for an expanded set of community-prioritized targets to govern decision-making in TB many of which are set out in the Global Plan to End TB 2023-2030<sup>6</sup>, as discussed ahead.

## Figure 4

### Areas for Action to close the divide between commitments and achievements



## Key and vulnerable populations (KVP) affected by TB

The imperative for greater recognition of, and targeted care for KVP cannot be understated, and their voice is presented in this report.

Though TB can affect anyone, people who have increased exposure to TB because of where they live or work, people who have limited access to quality TB and broader health care services, and people with biological behavioral factors are at elevated risk of developing TB, and facing poor clinical

outcomes and negative social consequences (**Table 3**).<sup>6</sup> Vulnerability to TB is also not just about disease incidence and prevalence. It stems from legal, human rights, socioeconomic, occupational and biological barriers that are experienced more by some people, often because of deep social and historical inequities.<sup>6</sup> Globally, and within regions, there can be huge variations in the people who represent KVP affected by TB. In line with the commitments related to “social inclusion” and “equity” in the 2018 Political Declaration<sup>1</sup>, responses to TB must include nuanced attention to the distinctive barriers facing KVP. Today, more countries have prioritized TB KVP in their National Strategic Plans for TB.<sup>10</sup>

# Table 3

## Key and vulnerable populations in TB

<b>People who have increased exposure to TB due to where they live or work</b>	<p>Prisoners, sex workers, miners, hospital visitors, health care workers and community health workers</p> <p>People who:</p> <ul style="list-style-type: none"> <li>• live in urban slums;</li> <li>• live in poorly ventilated or dusty conditions;</li> <li>• are contacts of individuals with TB, including children;</li> <li>• work in environments that are overcrowded;</li> <li>• work in hospitals or are health care professionals;</li> <li>• are in contact with or live with livestock;</li> <li>• live or work near cattle or ingest raw milk or blood.</li> </ul>
<b>People who have limited access to quality TB service</b>	<p>Migrant workers, women in settings with gender disparity, children, refugees or internally displaced people, illegal miners, and undocumented migrants</p> <p>People who:</p> <ul style="list-style-type: none"> <li>• are from tribal populations or indigenous peoples.</li> <li>• are homeless.</li> <li>• live in hard-to-reach areas.</li> <li>• live in homes for the elderly.</li> <li>• have mental or physical disabilities.</li> <li>• face legal barriers to access care.</li> <li>• are lesbian, gay, bisexual, or transgender.</li> </ul>
<b>People at increased risk of TB because of biological or behavioral factors that compromise immune function</b>	<p>People who:</p> <ul style="list-style-type: none"> <li>• live with HIV.</li> <li>• have diabetes or silicosis.</li> <li>• undergo immunosuppressive therapy.</li> <li>• are undernourished;</li> <li>• use tobacco;</li> <li>• suffer from alcohol-use disorders and/or inject drugs.</li> </ul>

From The Global Plan to End TB 2023–2030, Stop TB Partnership; p 104–105.<sup>6</sup>

## The Global Action Plan to End TB 2023-2030

The Stop TB Partnership (STP) in collaboration with the TB community at large produced a Global Plan to End TB 2023-30 (Table 4). The plan provides a road map with detailed budget estimates for ending TB by 2030, policy interventions to make people-centered care available to all, and guidance to address gaps in TB R&D, implementation and

infrastructure, and anticipate the approval and widespread availability of at least one new TB vaccine. This is a plan that is focused on TB-affected communities and civil society, and responsive to gender, rights and equity needs, taking into account mental health challenges and the interplay with different diseases like HIV/AIDS, among other factors. It has several TB CRG commitments, with a target for countries to complete a TB CRG assessment, develop a TB CRG costed action plan, integrate it into the NSP and implement/fully fund the plan. The calls to action that have resulted from this report have clear links to the Global Plan.

### Table 4

#### STP Global Plan to End TB 2030-2023 Priority Actions

Global Plan to End TB 2023-2030	Priority actions
<b>Ending TB through comprehensive investment packages implemented at scale</b>	<ul style="list-style-type: none"> <li>Invest in a comprehensive investment package.</li> <li>Scale up interventions to achieve key objectives and targets.</li> </ul>
<b>Scaling up TB diagnosis and care</b>	<ul style="list-style-type: none"> <li>Re-imagine TB care, delivering services through a people-centered approach. Scale up the use of modern diagnostics.</li> <li>Find the missing people with TB.</li> <li>Expand early diagnosis, including at subclinical stages.</li> <li>Develop and implement public communications strategies to raise TB awareness and promote early health seeking.</li> <li>Integrate TB screening and testing into other health services, with a focus on services that address common comorbidities or risk groups, depending on local epidemiological context.</li> <li>Provide support that enables people receiving TB care to complete a full course of treatment without an undue burden on them and their families, while avoiding catastrophic costs.</li> <li>Strengthen procurement systems and supply chains.</li> </ul>
<b>Scaling up TB prevention</b>	<ul style="list-style-type: none"> <li>Implement airborne infection prevention and control measures in health care settings and high-risk indoor places where people congregate.</li> <li>Provide TPT for those living with TB infection and who are at higher risk of progression to active TB disease.</li> <li>Deploy effective vaccines once such vaccines are officially recommended and available.</li> <li>Address TB risk factors and social determinants.</li> </ul>
<b>Partnering with key stakeholders: communities and the private sector</b>	<ul style="list-style-type: none"> <li>Increase funding support for engaging TB-affected communities in the TB response at least fourfold.</li> <li>Support community-based and home-based models for delivering TB prevention and care.</li> <li>Scale up public-private mix approaches to improve the quality of TB care, reduce out-of-pocket expenses and improve data reporting in the private health sector.</li> <li>Support a multisectoral TB response through stronger partnerships.</li> </ul>
<b>Ending TB through universal health coverage, pandemic preparedness and response, and socioeconomic actions</b>	<ul style="list-style-type: none"> <li>Expand access to TB services through universal health coverage initiatives.</li> <li>Position the TB response at the center of pandemic preparedness and response efforts.</li> <li>Invest in poverty alleviation and sustainable development.</li> </ul>



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**Human rights, stigma, gender, and key and vulnerable populations**

- Position universal human rights as the foundation of the TB response.
- Eliminate TB-related stigma and discrimination.
- Ensure that TB interventions are gender-sensitive and gender-transformative.
- Prioritize, reach and involve key and vulnerable populations.

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**Accelerating development of new TB tools**

- Invest, at minimum, US\$ 4 billion annually to accelerate the R&D of new TB diagnostics, medicines, and vaccines. Resources need to be mobilized from governments and philanthropies, increased engagement with the private sector, and innovative and sustainable financing.
- Develop a new TB vaccine by 2025.
- Accelerate the development of new tools to prevent, diagnose and treat TB by identifying innovative product-development pathways and improving collaboration among actors in product development.
- Invest at least US\$ 800 million annually in basic science research.
- Expand the use of operational research.
- Develop and implement digital tools.
- Create an enabling environment for TB R&D.
- Apply best practices in community engagement throughout the R&D process.
- Apply access principles in rolling out and optimizing the use of new tools.
- Strengthen advocacy for TB innovation.

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**Resource needs, return on investment, and cost of inaction**

- Mobilize US\$ 209.8 billion in funding between 2023 and 2030 for TB care and prevention, of which US\$ 52.6 billion is for vaccination once a new vaccine is available. The resources needed for care and prevention, excluding vaccination, total US\$ 157.2 billion, which averages to US\$ 19.65 billion per year.
  - Mobilize US\$ 40.18 billion in funding between 2023 and 2030 for TB R&D and basic science research through a more diversified funding base.
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From The Global Plan to End TB 2030–2023, Stop TB Partnership.<sup>6</sup>



# AREA FOR ACTION 1: Closing gaps in TB prevention, diagnosis, treatment and care by reaching all people with TB

## Introduction

As the TB community, we unapologetically declare that the right to access the best quality TB prevention, diagnosis, treatment and care is a fundamental human right for all people, irrespective of who they are, where they live and work, or how they identify. Short-course regimens and rapid molecular diagnostics are non-negotiables. It is only with enhanced political ambition that the rights of people affected by TB can be promoted and protected. In this chapter, we share TB-affected community and civil society perspectives about the achievements made, gaps encountered, and opportunities for scaling up delivery of the best available evidence-based tools for TB, including DRTB, childhood TB, and TB comorbidities. We begin with a view into the current state of affairs to situate the arguments presented and lead up to an ambitious call to action. This approach is replicated in each chapter.

## Current state of affairs

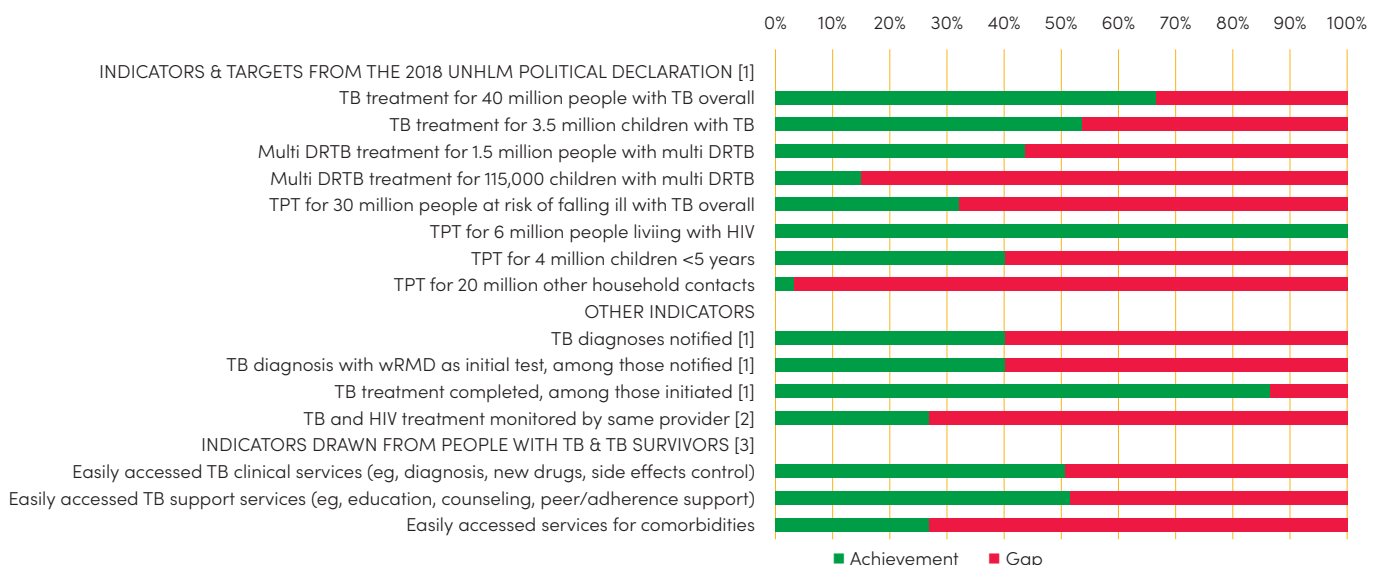
### Scorecard

There has been headway in closing gaps in TB prevention, diagnosis, treatment, and care with regard to relevant indicators from the 2018 Political Declaration. Between 2018 and 2022, 26.3 million people, including 1.9 million children, were treated for TB; and 649,000 people, including 17,700 children, were treated for DRTB. Overall, 12.5 million people were placed on TPT, including 10.3 million people living with HIV, 1.6 million child household contacts, and 600,000 other household contacts. These are laudable successes given the massive upheaval in TB responses in all countries on account of the COVID-19 pandemic. However, there remains a glaring shortfall (Figure 5) that demands urgent action, especially since — at the time of writing — TB is reclaiming its position as the world’s number one infectious disease killer.

Notably, in 2021, 4.2 million of the 10.6 million people living with TB were not diagnosed or notified<sup>5,11</sup>, and 60% of those notified did not receive a rapid molecular diagnostic test as the initial diagnostic test.<sup>11</sup> There are many other important indicators relevant to this area of action for which global data is not available. In the sections that follow, these achievements and gaps are reflected upon through the lens of the TB-affected community and civil society actors, including respondents from the TB scientific and technical community.

## Figure 5

Scorecard for closing gaps in TB prevention, diagnosis, treatment and care



[1] Based on 2021 data in the WHO Global TB Report 2022;  
 [2] Based on 2021 data in the UNAIDS Global AIDS Monitoring database;  
 [3] Based on 2022 survey data from people with TB/TB survivors.

## TB prevention

The approval of the new and shorter 1-3 month TPT regimens has been a breakthrough in TB prevention. The accelerated delivery of TPT to 10.3 million people living with HIV, surpassing targets of the Political Declaration, is also a major victory thanks to rapid updates made within the national guidelines of several countries (for example, Kenya, Ghana, South Africa, Malawi, and Zimbabwe) together with the collaborative efforts of communities and people affected by HIV. Targets for TPT coverage were, however, very conservative and HIV-negative people, particularly household and child contacts of people with TB, are continuously missed in TPT delivery. A commensurate level of advocacy and actions is needed to strengthen contact investigations and place contacts on TPT, to match rates achieved among people living with HIV. [Case study 1]

Respondents for this report argued that without confirmation of TB infection, people without symptoms of illness are – not unsurprisingly – loath to be placed on medicines, much less agree to have their children begin TPT, even if the regimen is short. The need for an accurate point-of-care test for TB infection cannot be understated. While new tests have been approved, they all have their limitations.<sup>12,13</sup>

Preventive actions in TB have also been very narrow, relying predominantly on pharmaceutical intervention. Airborne infection prevention and control measures, that are proven to reduce transmission, are lacking in most health facilities and congregate settings.<sup>14</sup> There has been little concerted attempt to address the root social determinants of TB, particularly the drivers of TB among KVP, such as poor and overcrowded living and work environments, and abating the risk for associated comorbid conditions such as under-/malnutrition, diabetes, silicosis and tobacco use.<sup>15</sup> Finally, the absence of an effective TB vaccine is a glaring gap, raised in Area for Action 3.

## TB diagnosis

The TB diagnostic gap in 2021 was estimated to be 40%.<sup>5,11</sup> While notifications declined dramatically during the COVID-19 pandemic lockdown, even before 2020 TB was missed in one out of every three people affected.<sup>5</sup> TB-affected communities and civil society await the release of the next Global TB Report to know whether some countries may have closed this gap.

Finding the missing people with TB requires escalating access to, and use of WRDs at point-of-care. Rapid molecular diagnostics have been on the market for over 12 years. While their use has gradually increased, especially through engagement of the private sector [Case study 2], respondents mirrored the findings of the WHO Global TB Report that these tests are heavily underutilized. In 2021, six of ten people notified with TB did not receive the best available WRDs.<sup>11</sup> The problem is that even the best available tests remain complex, costly, resource heavy and hence inaccessible to most people in need. Respondents shared that people with TB continue to be diagnosed via sputum smear tests and clinical examinations that are non-sensitive, non-specific, fail to pick up sub-clinical disease, and are tardy – forcing people under investigation to move between facilities and endure long waits. Modified RMDs<sup>16</sup> that may be used in power-deficient areas (for example, Truenat), with children (for example, stool sampling with GeneXpert), and among KVP exhibiting atypical disease such as people living with HIV (for example, TB LAM) are not yet available at scale.

The WHO standard for universal access to rapid TB diagnostics – released after data were collected for this report – includes 12 benchmarks to support the passage of people through the diagnostic cascade.<sup>138</sup> With the support of donors and civil society, we may see a narrowing of the TB diagnostic gap.

### Case study 1 Community-led TPT teams address childhood TB needs in Mozambique

The detection and follow-up of childhood TB in **Mozambique** is severely challenged by the lack of active screening at pediatric service entry points, missing information on child contacts, ineffective methods of pediatric test sampling and analysis, poor linkage between contact tracing and TPT, and weak follow-ups on TPT completion. In 2022, local NGO ADPP (Ajuda de Desenvolvimento de Povo para Povo) adapted a digital community-led monitoring (CLM) platform, Onelmpact, with an assisted model of outreach to put people, including children, at the heart of the TB response. Over three months of the intervention, barriers related to childhood TB among 504 people in Zambezia province were uncovered, specifically that the children of 88% of people were not initiated on TPT due to travel expenses, long commutes to the health facility and limited access to TPT medicines.

ADPP's local TB response activists, together with TB nurses and child health nurses at the health facilities concerned, carried out a campaign to link eligible children to TPT. The campaign included contact tracing and TB education within planned 'health fairs' in the community. 'TPT teams' visited 504 households and screened 1,157 contacts in their homes, leading to the diagnosis of 124 people with TB, including 77 children under 15 years. Another 320 children were identified as eligible and initiated on TPT.

By providing real-time insights into service gaps and opportunities, digital CLM served as an effective alert system for rapid, evidence-based community and health responses, supporting targets for childhood TB.



@Credit photo - TB PPM Network Pakistan

## Case study 2 Enabling access to TB services through engagement with private and informal providers

In many LMICs, two-thirds of people with TB symptoms initially seek care from providers outside the public sector.<sup>38</sup> The TB PPM Learning Network (tpppm.org) shows how private and informal providers are in a position to address issues of access, stigma, and inequality. In 2019–20, with funding from STP's TB REACH initiative, the OGRA foundation in Kenya implemented the Maliza TB Mashinani (Stop TB at the grassroots) initiative to engage formal and informal private providers in TB screening. Adolescent girls and young women, as Binta Balozis (community health volunteers), were trained and assigned to private facilities to assist staff in finding people with TB. Over 10 months, 45,003 people were screened, including household contacts, resulting in 250 confirmed diagnoses. The private providers were appreciative of the leadership demonstrated by the adolescent girls and young women.

At about the same time in **Pakistan**, Bridge Consultants Foundation (BHF) applied TB REACH funding to engage female private providers in TB screening. In four districts, 1,050 women with TB were notified, contributing a third of all notifications among women. Having female providers who initially focused on gynecological and pediatric problems lead the otherwise male-dominated clinical encounters helped overcome gender barriers. Community chest camps, women-empowering advocacy sessions and inclusion of male treatment supporters within families increased women's comfort to seek TB care.

In **India**, aligning with the Ministry of Health and Family Welfare's Jan Andolan theme of "Engaging Religious Leaders and Panchayati Raj Institutions", the Karnataka Health Promotion Trust (KHPT) launched the programme 'Keeping the faith in fighting TB'. With funding from USAID, KHPT engaged 154 religious leaders in four states in India and developed and shared 16 carefully curated video messages to allay community fears about TB, reduce stigma and link people to health care.

### TB treatment

Among people placed on TB treatment, success is trending upward. Treatment completion rates remained at 86% through the COVID-19 pandemic<sup>5</sup>, suggesting quality of care was sustained through the disruption, including through community-led responses. [Case study 3] Community leadership efforts are also helping to support continuity in TB care in conflict areas such as Ukraine. [Case study 4]

The WHO rapid approval of a new four-month safe and effective drug regimen for drug-susceptible (DS) TB heralds a turning point.<sup>17–19</sup> TB-affected communities and civil society welcome the promised impacts for people-centered treatment and care. However, an astounding 39% of people with TB do not approach health care facilities to begin treatment, much less access the new regimens.<sup>5</sup> Any successes in TB treatment must therefore be weighed against this gap, reported by respondents within HICs as well [Case study 5], and other reported challenges that have been validated through research, such as the catastrophic costs facing families affected by TB<sup>20</sup>, lifelong effects of post-TB sequelae such as post-TB lung disease (PTLD)<sup>21</sup>, and TB comorbid conditions including mental health challenges that are precipitated by TB.<sup>22,23</sup>

## Drug-resistant TB

WHO guidelines have shifted the standard of care for DRTB toward new safe and effective all-oral six-month treatment regimens.<sup>24</sup> Respondents frequently remarked that this has been a game changer for people with DRTB, and the WHO reports that by the end of 2021, 124 countries were using bedaquiline, 109 countries were using injection-free regimens, and 92 were using shorter regimens.<sup>5</sup> Many of these gains were achieved from the early advocacy efforts of TB-affected communities and civil society, which were reported in the first Deadly Divide report<sup>7</sup>. Among people on the latest DRTB regimens, treatment success rates have nearly doubled to 60%.<sup>5</sup> Even so, intellectual property protections are halting generic manufacture and slowing the pace of universal access in many settings.<sup>25</sup> India's recent decision to deny a second patent for bedaquiline, thanks in part to the lobbying efforts of TB survivors, comes as a relief to TB-affected communities and civil society.<sup>26</sup>

The rollout of new treatments for DRTB still needs to be matched with improved testing technologies and test practices. Data from 2021 shows that only 49% of people with rifampicin-resistant TB were tested for fluoroquinolone resistance, a marker for multi-DRTB, and only one in three people with DRTB were placed on treatment.<sup>5</sup> Challenges in innovation are highlighted in Area for Action 3.

## Case study 3 Community agents in Togo deliver TB treatment support at the height of the COVID19- pandemic

COVID-19 was identified in **Togo** in March 2020. As in many other countries, this led to a decline in general health seeking and, in the case of TB, a discontinuation of facility-based directly observed therapy (DOT). In response to this changing environment, the National TB Program (NTP) of Togo granted multi-month allocations of medications to people with TB. While the innovative move was welcomed, it also presented a heightened risk to treatment success.

The Togo NTP thus tested DOT-based treatment support relying on agents in the community, specifically community health workers (CHW) and community relays (CR). CHW and CRs were trained and compensated for their travel to visit and monitor people on TB treatment. Their tasks included daily observation during the intensive treatment phase, monthly observation during the continuation phase, appointment reminders for TB focal points, and awareness raising in the community. The project was evaluated among 182 participants equally split across intervention and control sites. At month two of treatment, the TB culture conversion rate was 89.01% in the intervention group versus 70.33% in the control group. Treatment outcomes in intervention versus control included (i) Therapeutic success: 93.41% vs. 78.02%; (ii) Lost to sight: 0% vs. 6.59%; and (iii) Death: 1.10% vs. 5.59%. Harnessing CHW and CRs for TB treatment monitoring proved successful.<sup>39</sup>

The documented gains and challenges from Togo's experience can be leveraged and built upon within the country and beyond its borders. The COVID-19 pandemic has also left an appetite for Togo and other countries to press on with new approaches to treatment monitoring and support beyond DOT.

## Case study 4 Responding to the challenges of war in Ukraine

War and armed conflict undermine access to essential services, including TB diagnosis and care. Russia's war against **Ukraine** has crippled the Ukrainian health infrastructure, including the energy grid. An investigation by human rights groups reports 700 attacks on hospitals, health workers, and other medical infrastructure in Ukraine since the start of the invasion.<sup>40</sup> Between February and December 2022, there were 292 attacks damaging or destroying 218 hospitals and clinics, 181 attacks on other health infrastructure such as pharmacies, blood centers, and dental clinics, 65 attacks on ambulances, and 86 attacks on health care workers leaving 62 killed and 52 injured. While data is not yet available, it is likely that the war has increased TB incidence and decreased notification, thus increasing the number of missing people with TB. People with TB now need resources for evacuation, essential life supplies such as dwelling and food, employment in the regions they are being relocated to, and psychological assistance.

Under these extraordinary circumstances, Ukraine and Ukrainians have mobilized an unprecedented public response. The Alliance for Public Health carried out an assessment of the need in TB screening and funding required to recover documents for internally displaced persons who have lost access to care. TB Europe Coalition coordinated TB screening for children and mothers at UNICEF's SPILNO Children Points, organized civilian evacuation from occupied territories, and procured and delivered medical supplies to health care facilities. TBpeople Ukraine as well as other organizations in Ukraine shifted focus to provide urgent humanitarian assistance, with some NGOs delivering medicines, food, water and personal care products to health care facilities and people in care in the occupied territories even amidst open fire. The exact numbers are not yet reported, but many volunteers transporting humanitarian aid have been wounded, killed and/or taken hostage.

The Public Health Center, together with the Ministry of Health of Ukraine, is providing leadership and coordination by developing the National Action Plan for the provision of medical assistance to people affected by TB in context of war; management measures to restore supply chain to ensure continuity of TB care; and monitoring of the needs of regional TB facilities for personal protective equipment (for example, body armor and helmets), medicines, and medical supplies.

TB affected communities and civil society are working at the frontlines in solidarity with TB KVP affected by the war, and must be supported and financed to continue this crucial work.



Source: (Destruction and Devastation: One Year of Russia's Assault on Ukraine's Health Care System. PHR, 2023).

## Case study 5 Barriers to accessing essential diagnostics and medicines extends to HICs

There may be a false assumption that people living in HICs have access to more dignified and state-of-the-art health care experiences. In many HICs, because TB impacts relatively fewer numbers of people, most of whom are marginalized or otherwise vulnerable, it is not as easily recognized as an issue by health care providers, the public, and politicians alike. People affected by TB end up encountering numerous challenges to a timely diagnosis. TB survivors in diverse HICs shared telling stories.

Attempts to access the best available treatments in HICs are similarly frustrating. Despite being listed on the WHO Model List of Essential Medicines<sup>41</sup>, rifapentine is inaccessible in many HICs such as **Canada** due to unjust corporate and domestic policies. Health Canada regulations, for example, state that medications can only be imported directly from the manufacturer, but Sanofi (sanofi.ca), the maker of rifapentine, has never submitted an application for regulatory approval in the country. This means providers must go through cumbersome administrative barriers with Health Canada's Urgent Public Health Need programme so that people with TB can access the latest short-course treatment regimens. A similar experience is shared with Europe, where Sanofi has never filed rifapentine for registration with the European Medicines Agency. By contrast, several other countries, especially LMIC and some HIC such as **Australia**, are utilizing the Global Drug Facility TB, coordinated by STP, to import essential new TB medicines. This has led to improved access to quality-assured and people-centered fixed-dose combination formulations (FDCs) in these countries, compared to the vast majority of HICs.

### Childhood TB

Children with TB can now access shorter, child-appropriate regimens to treat TB including DRTB. Likewise, child contacts of people with TB can also access shorter regimens.<sup>27</sup> Treatment success among children with TB has been stable at 88%, and TPT is 80%.<sup>5</sup> However, children under 15 constitute an unacceptable 14% of all TB-related deaths.<sup>5</sup> Between 2018 and 2021, less than half of all children estimated to have TB were placed on treatment, and only 15% of those with DRTB received treatment.<sup>5</sup> Coverage for TPT is also poor; only one of three under-5 child contacts of people with TB is identified through household contact investigations and placed on TPT.<sup>5</sup> Respondents expressed grave concern about the TB diagnostic gap in children as the primary driver of these abysmal outcomes. Far too many children with TB or at risk of developing TB are simply not being identified and hence not entering the care cascade.

TB-affected communities and civil society [**Case study 6**] are working hard to overcome barriers recorded previously<sup>28</sup>, such as lack of child-friendly RMTs, poor awareness and advocacy around the new shorter regimens, and resistance on the part of providers to implement childhood TB diagnostic algorithms and on the part of caregivers to place their children on TB treatment. Dedicated efforts for child-friendly DRTB formulations are to be applauded, but some respondents pointed to the continuing challenge of poor access in hard-to-reach areas.



### Case study 6 Women and girls raise their voice for childhood TB in Cameroon

In **Cameroon**, about 5% of people with TB are children below 14 years. The true burden of childhood TB is estimated to be higher but poor diagnostic capacity, gaps in provider knowledge, fear and stigma about TB, and poor integration of TB services into primary care are huge barriers. In 2020–21, the NGO For Impacts In Social Health Cameroon ([fiscameroun.org](http://fiscameroun.org)) implemented an advocacy campaign through an Elizabeth Glaser Pediatric AIDS Foundation's (EGPAF) Cap-TB Advocacy Small Grant Project. "Women voices on the issue of pediatric tuberculosis in Cameroon" sought to include pediatric TB into national guidelines and directives for the integrated management of childhood and new-born illnesses (IMCI) by:

1. Training women who had been affected by pediatric TB on leadership and effective communication.
2. Designing advocacy messages through focus groups with affected women and girls.
3. Mobilizing allies to support the advocacy campaign.
4. Engaging social networks and media (TV and radio).
5. Amplifying attention to pediatric TB in the IMCI through strategic meetings with the Ministry of Public Health.

The campaign mobilized 1,100 women who used multiple channels to demand better national leadership and accountability in the fight against pediatric TB. It showed that accountability and leadership in national goals for TB elimination can be built through beneficiary engagement and advocacy.

### Case study 7 Reaching KVP in Asia

Through community outreach, empowerment, capacity building, contact investigations and active support for people affected by TB, Asia is making progress towards TB elimination targets. Civil society organizations and communities are playing an active role. In Indonesia, 1.5 million people were reached for TB testing in 30 out of 34 provinces, thanks to the dedicated efforts of organizations such as PR Komunitas Konsorsium Penabulu-STPI ([tbckomunitas.id](http://tbckomunitas.id)). Communities also banded to promote TPT and contributed to 50% of the national TPT coverage. In Cambodia, the community work has contributed to the 20% reduction in incidence rates during the COVID-19 pandemic. Additionally, civil society organizations such as REACH and GCTA in **India**, KHANA in **Cambodia**, and ACHIEVE in **Philippines** have advocated for the recognition of human rights, and gender- and community-led monitoring in the national TB strategy and are providing community-based paralegal training and rights-oriented TB literacy to help people with TB uphold their human rights.

Despite best efforts, however, these community and civil society organizations face huge financial constraints, which prevent them from upskilling social workers and community workers or developing initiatives to cater to the needs of KVP, including their stigma-related challenges. TB is a much more complex disease for KVP, who, in the regional context, include people who work in mines, are malnourished, live with HIV, diabetes and other comorbid conditions, are children, belong to an ethnic minority, or are poor. Increased investments in community and civil society-based efforts are needed to reach those who are most marginalized and connect them to TB care.

## TB comorbidities

Between 15–60% of people with TB live with an underlying condition or comorbidity such as HIV, diabetes, undernutrition, silicosis, tobacco use, and/or substance use including use of alcohol or drugs.<sup>29–34</sup> Many of these conditions heighten the risk of TB, and many of the affected people represent KVP. [Case study 7] Integrated service delivery for TB and other health programmes, whereby multiple services can be provided within a single clinical interaction, can help find missing persons with TB, link them to treatment and care for both conditions, and alleviate multimorbidity.<sup>35</sup>

Improved linkages between TB and HIV programs have greatly improved outcomes for both infections, but coordination across other programs is very limited.<sup>35</sup> Even in the TB–HIV sphere, there are persisting gaps. In 2021, almost one in two people living with HIV who developed TB was not diagnosed or reported with TB, and approximately one in three AIDS-related deaths was related to TB. In a vast majority of countries, TB and HIV treatments continue to be provided at distinct facilities and monitored by different health care providers.<sup>29</sup> Co-located and integrated approaches to TB comorbidities can support people-centered programming, as has been evidenced through a systematic review<sup>36</sup>, particularly at the level of primary care. They can also contribute to the realization of universal health coverage (UHC), as highlighted in Area for Action 5.

## Cross-cutting barriers

The goal to reach all is stymied by cross-cutting barriers (Figure 6). Respondents from diverse settings shared how access to TB services, tools and technologies was fraught with operational challenges including resource and technical constraints, lack of TB services in settings where affected people lived and worked (that is, insufficient decentralization), poor training of the health workforce; and socioeconomic challenges including misperceptions about TB, stigma and discrimination, and economic hardship coupled with lack of socioeconomic protection, especially for KVP, as raised in Area for Action 2. Several technical experts and larger organizations cautioned that the TB response is not adequately linking itself with ongoing movements in global public health; this is raised in Area for Action 6. Gaps in innovation including the absence of a point-of-care diagnostic test and a vaccine, raised in Area for Action 3, were seen as fundamental challenges in finding missing people with TB and eliminating the disease.

# Figure 6

## Cross-cutting barriers to reaching all for TB diagnosis, treatment and prevention



## To reach all, the TB response must be reimagined

With TB incidence only decreasing by 10% of the global target — half of what was envisioned for 2022 — and mortality decreasing by only 6%<sup>5</sup>, it is clear that the current response is insufficient. KVP constitute the greatest proportion of people affected by TB.<sup>37</sup> This is not a coincidence. It is a result of narrow decision-making and systemic unjust practices that continue to neglect the most underserved members of our community, who are the hardest, and hence most expensive to include. [Case study 8]

To reach all, a far more bold and compassionate approach is needed that harnesses the effectiveness of available tools (including digital technologies); places TB as a global and national funding priority; meaningfully engages stakeholders within and outside of the traditional actors of the TB community; and espouses authentic mechanisms of accountability for the commitments made to ensure available tools and emerging technologies are accessible, acceptable and equitably delivered with explicit attention to those on the social periphery. For such a shift to be realized, donors, funders, developers, technical partners and national programs must be empowered with an enhanced appetite for risk and disruptive innovation. The robust engagement of affected communities and civil society in the design, delivery and evaluation of each of these processes is imperative to generate market demand, cinch acceptability, and ensure that no one is left behind. These imperatives are elaborated in subsequent chapters.



### Case study 8 TB care for the hardest-to-reach communities

Medical Impact is an NGO based out of **Mexico** City that is exemplifying socially innovative methods to deliver health care in conditions of extreme marginalization. It is continually refining its methods to support vulnerable, forgotten, and unprotected populations through humanitarian service-oriented well-being and comprehensive care. With modest support from the National TB Program, and volunteers including physicians, nurses, mental health practitioners, physical therapists, and child development specialists, it runs 7- to 15-day missions to bring BCG vaccination, TB testing and treatment, as well as prevention education, to the hardest-to-reach communities across the country. Many of their supplies are gifted.

The commitment to the vulnerable, forgotten, and unprotected communities of Mexico is a force to be reckoned with, and an example to celebrate in the region.

## CALL TO ACTION

### Close gaps in TB prevention, diagnosis, treatment and care by reaching all people with TB

- Ensure WHO-recommended rapid diagnostics (WRDs) are used as the initial test for TB.
- Ensure all people affected by TB, including TB infection and disease and drug-resistant TB (DRTB), and their contacts have affordable access to the newest and best prevention and treatment regimens.
- Develop and meet ambitious targets for TB prevention through contact tracing and coverage of TB preventive treatment (TPT), and also by addressing the social determinants of TB, and urgently securing a new TB vaccine.
- Deliver quality people-centered, community-based and KVP-focused TB care to improve TB outcomes, including child-friendly services to improve outcomes of pediatric TB, through workforce training, attentiveness, and resources to identify and overcome social and economic barriers to access.
- Ensure TB services are integrated with HIV, primary health care and/or occupational health services, using co-located models, to improve detection and treatment of TB in co-morbid conditions such as HIV, silicosis, malnutrition, and diabetes.
- Leverage the capacity of the private sector to improve access to TB services, particularly in countries with large private sector service providers.



# AREA FOR ACTION 2: Making the TB response equitable, gender-responsive, rights-based, and stigma-free, with TB-affected communities and civil society at the center by 2025

## Introduction

Ending TB is a matter of social justice. TB-affected communities, KVP, and civil society universally assert that equity, gender-responsiveness, human rights, and freedom from stigma and discrimination need to underlie every aspect of the TB response. This includes the design, planning, testing, implementation, rollout, monitoring, evaluation and governance mechanisms of TB programs, policies, and decisions related to financing and accountability. The distinct complementary expertise of TB-affected communities and civil society needs to be recognized, financed and capacitated, and integrated into mainstream efforts without delay; no longer can we be bystanders to what is decided for us and what happens to us. We need country targets included in the 2023 UNHLM on TB Political Declaration, and dedicated funding mechanisms to support this work. In this chapter, we outline advancements made in these areas, as also the crucial gaps and opportunities to accelerate progress.

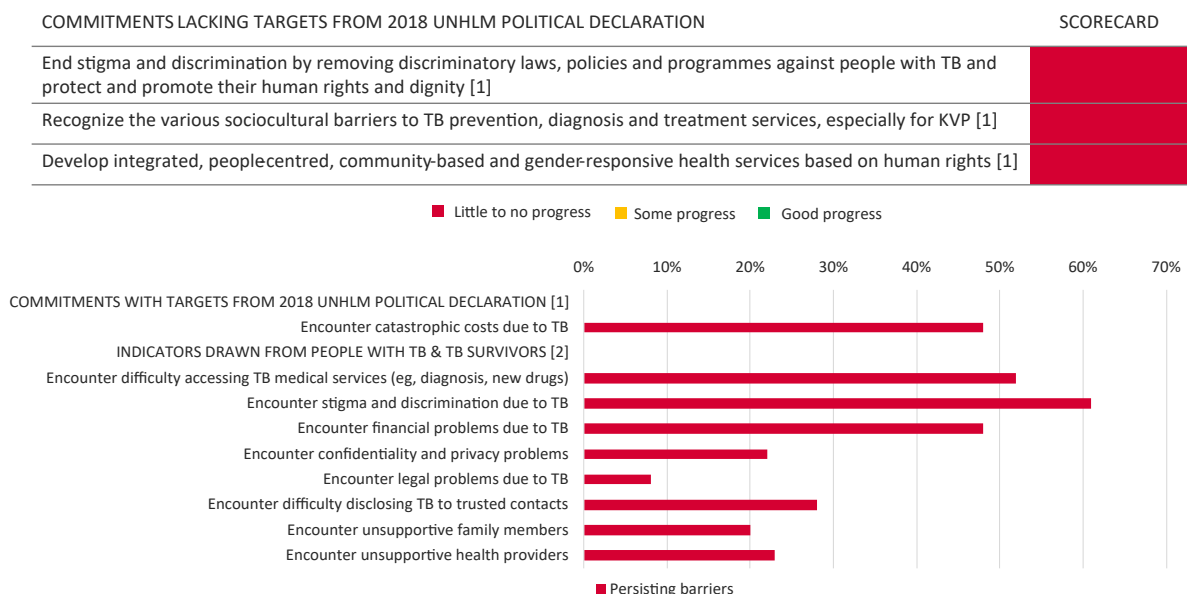
## Current state of affairs

### Scorecard

The 2018 Political Declaration included several commitments relevant to making the TB response equitable, gender-responsive, rights-based, and stigma-free, with TB-affected communities and civil society at the center.<sup>1,42</sup> It was an opportunity to elevate attention to root social barriers to TB elimination and galvanize actions for people-centered and community inclusive approaches to TB service delivery, research and innovation, and decision-making. But without clear targets, these commitments remained inadequately addressed and unfulfilled (Figure 7). Responses from the TB-affected persons and TB survivors who contributed to this report cite stigma and discrimination as leading challenges encountered during TB care, followed by financial problems that worsen inequities, and difficulties disclosing to contacts who are normally trusted. Privacy and confidentiality breaches, absence of support from health providers as well as family members, and legal problems are also all too common. It is essential that TB responses, no matter the biomedical or technological intervention, uphold the principles of equitable, gender-responsive, community- and rights-based, and stigma-free care.

# Figure 7

## Scorecard for making the TB response equitable, gender-responsive, rights-based, and stigma-free, with TB-affected communities and civil society at the center



[1] Based on qualitative assessments of progress made on commitments (and absence of targets), drawing on the results of CRGand stigma assessments and data collected for this report; [2] Based on 2021 data in the WHO Global TB Report 2022; [3] Based on survey responses of people with TB/TB survivors.

## Challenge Facility for Civil Society

The Challenge Facility for Civil Society (CFCS), coordinated by STP, has emerged as the leading grant and technical support mechanism for pushing forward a CRG agenda in TB.<sup>43</sup> Strengthening the capacity of community and civil society actors to engage with and lead a TB response that is grounded in human rights and gender equality, so that no one gets left behind, is imperative to its mission. Several CFCS grantees interviewed for this report felt uniquely empowered by the opportunity to win funds and lead projects that would normally be reserved for researchers and technical experts. Since 2007, across 11 cycles, the CFCS has awarded US\$ 24.5 million – amassed in particular from USAID, The Global Fund TB Strategic Initiative, and Eli Lilly – to support 351 grants to community, civil society and grassroots organizations to undertake activities that respond to CRG commitments. [Case study 9] In the previous Deadly Divide report, we called for more countries to contribute to this mechanism, and we are delighted to hear that the Government of France intends to become a supporter. We call on more countries to follow suit.

Among other accomplishments, CFCS grants have spearheaded 39 countrywide CRG assessments, including a number of stigma assessments, and uncovered major gaps in Asia, Africa and EECA.<sup>44</sup> They include limited access to quality services for people affected by TB; gender-related barriers; poor recognition and inclusion of KVP; neglect of gender- and rights-centered policymaking and law enforcement; stigma and discrimination at the level of the community, health system and household; and poor engagement with TB-affected persons – all of which are echoed by the data collected for this report (Figure 8). It has also supported the formation and strengthening of TB survivor networks, the transition of TB community organizations to Global Fund Principal Recipient and Sub Recipient, and the increase in TB survivors on Country Coordinating Mechanisms (CCMs). [Case study 10]

The results of several CRG and stigma assessments have been integrated into NSPs for TB, fueling the development of 16 costed CRG action plans in countries such as Benin, Bangladesh, the Democratic Republic of Congo, Nigeria, and Pakistan.<sup>10,44</sup> Together with projects supporting CLM, as discussed in Area for Action 6, the CFCS is shaping an equity- and people-centered agenda at the country level, with opportunities for scaling up funding.

## Figure 8

### CRG and stigma assessments reveal critical neglected barriers to TB elimination



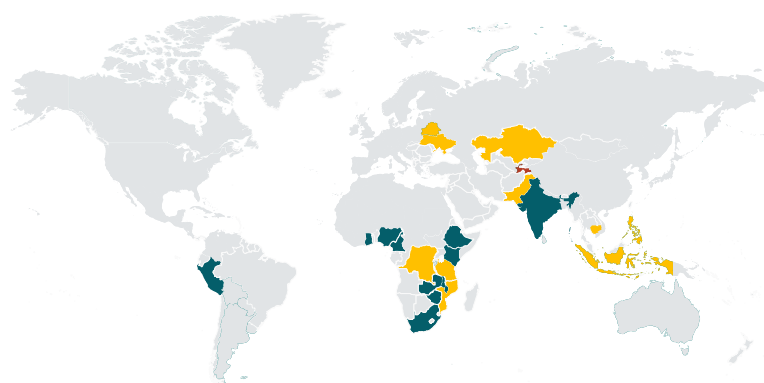
## Case study 9 The Challenge Facility for Civil Society grant mechanism enables Community, Rights & Gender in the TB response

The preferred and dominant model of TB care, which targets biomedical interventions, indicates that while CRG in the TB response is valued in rhetoric, it is often overlooked in practice. The CFCS is uniquely enabling action on CRG by identifying and mitigating barriers to access and care, and building advocacy and accountability in the TB response. An investment of US\$ 24.5 million over 11 rounds of the CFCS has enabled the achievement of many CRG-related actions <sup>44,51</sup>:

- **Increased investments, political will and institutionalization of CRG to overcome barriers to access in 20+ countries.**
  - 22 countries have completed national CRG assessments, with findings and recommendations to overcome barriers to access.
  - Nine countries have either completed or are in the process of implementing TB stigma assessments to measure the levels and impact of TB stigma.
  - Six countries have completed national CRG action plans, which are contained within NSPs.
  - The remaining country CRG action plans are under development.
  - TB Legal and Human Rights Scorecard developed and currently are being piloted in Kenya, Ghana, and Pakistan by civil society partners.
- **Prioritizing KVP to focus the TB response on finding the most vulnerable and marginalized populations.**
  - 22 countries, through the CRG assessments, have prioritized TB KVP to enable strategic targeting of TB interventions for KVP.
  - A new tool for prioritization and size estimations has been developed for country-level utilization.
- **The establishment of global, regional, and national TB community networks for community-led advocacy and leadership in TB.**
  - Three global networks;
  - Seven regional TB networks;
  - Several national networks in Cambodia, Cameroon, Democratic Republic of Congo, Ethiopia, Georgia, Ghana, India, Indonesia, Malawi, Mozambique, Nigeria, Pakistan, the Philippines, and Tajikistan, among other countries (see case study 11).
- **CLM for accountability in TB.**
  - The STP OneImpact CLM approach is now being implemented in 26 countries; an innovative, rights-based approach to enhance community participation, and accountability in TB.

Essential and unique to the CFCS grant mechanism is the possibility of technical assistance and documentation of best CRG practices for ongoing investments and scale-up. Being a UN organization with a mandate to cultivate and forge partnerships, the STP continually links CFCS grantees to strategic national and international partners, thereby ensuring continuity and institutionalization of CRG.

CRG-related barriers impact outcomes in TB, and the CFCS supports a high return on investment. Sustaining and expanding the CFCS will enable meaningful ways of addressing the persisting barriers to TB care.



**First pilot (Tajikistan) 2017**  
**First adopting countries 2017-2020**  
**New countries 2020-2022**

## Case study 10 Poor quality of care and stigma bar access to TB services in Mali

Barriers in access to care are not well understood in **Mali**, where the incidence of TB is 50 per 100,000 and TB treatment coverage is about 66%.<sup>55</sup> In 2022, ARCAD Santé PLUS ([arcadsanteplus.org](http://arcadsanteplus.org)) in collaboration with the National TB Program undertook a structured CRG assessment of the national TB response, including a document analysis to assess historical and current point of view, surveys with 408 people living with TB and 153 TB caregivers, and interviews/discussions with members of the TB-affected community and program stakeholders. The following results were uncovered:

1. There is poor ability to provide quality TB care in the country, driven by an absence of TB screening during routine consultations in most health facilities.
2. The approach to TB care is not people-centered, especially for vulnerable populations.
3. There is a lack of trained personnel for TB activities and limited continuous training in TB care.
4. The high level of stigma is having deleterious effects on the quality of life of people with TB.
5. There is insufficient knowledge about protective laws and the rights of people with TB at all levels (institutions, health personnel, community agents, and the general population).
6. There is little interest in gender aspects of TB and related care among institutions.

This CRG assessment illuminated the barriers to access of prevention and quality care for TB, and allowed for their documentation at the national level. The results will serve as the basis for the implementation of interventions in 2023 and for the new cycle of Global Fund funding requests.

## Figure 9

### Toolkit to measure and monitor CRG, stigma and CLM in the TB response



Courtesy: The Stop TB Partnership, Geneva

### Tools to monitor progress on TB CRG and stigma

Many of the CFCS's accomplishments have been facilitated by a suite of tools developed and championed by STP together with people affected by TB, digital innovators, researchers and national TB programs (Figure 9). These tools enable cross-country comparisons and measurement of changes from baseline on CRG and stigma, and CLM of responses to TB.<sup>45-47</sup> The Stigma Measurement tool is now accepted by The Global Fund and informs its performance framework.<sup>48</sup> At the time of drafting this report, a TB Legal and Human Rights Scorecard and a TB Key and Vulnerable Populations Size Estimation tool were also ready for piloting. The 2022 Words Matter language guidance for destigmatizing TB communication adds to the growing list of CRG-friendly resources.<sup>9</sup> All of these tools can help establish a tangible set of indicators for commitments in CRG, stigma and equity, and in guiding actions and monitoring progress.

### Community voice and leadership

The TB-affected community today is much more vibrant, listened to, and recognized in all of its strength and diversity compared to before. Its voice is louder, bolstered by the establishment and expansion of networks of people affected by TB at the regional and national levels [Case study 11], and inclusion within the structure of key institutions such as the STP (Community and NGO Delegations<sup>49</sup>) that recently scaled

up representation of TB KVP and affected community at the governing board level, and WHO (Civil Society Task Force on TB50), and via the CFCS.<sup>51</sup>

The Global Fund's Community Engagement Strategic Initiative (CESI)<sup>52</sup> is also actively working to increase its focus on TB and the positioning of TB-affected communities in national, regional, and global decision-making processes through inclusion in country processes and working groups tasked with advocating for the needs of KVP, such as youth councils and CRG advisory groups. The CESI has also supported four regional TB networks as part of its engagement in Global Fund processes. Unitaid has a community delegation on its board.<sup>53</sup> Several other global actors such as FIND and TB Alliance are priming structures to engage affected communities in strategic agency decisions. With the support of leading health and advocacy organizations, commitment to CRG is gaining momentum at the global level and as introduced earlier, is evident in the outcomes of CFCS grants.

TB-affected communities and civil society appreciate and applaud the significant support received from the Global Fund TB Strategic Initiative on Finding the Missing People with TB, which leverages CFCS and the US\$ 1.5-million contribution to CFCS.<sup>54</sup> However, they expressed the need for sustained and scaled-up investments to ensure their inclusion in the TB response. They seek dedicated funding to build capacity for sustained CRG work, organizational infrastructure, and for TB survivor networks. [Case study 12] Indeed, grassroots

organizations have especially limited technical capacity to compete for funds, though they are often best acquainted with affected community needs. Partnerships with actors working at the regional and global levels can lead to opportunities for funding. [Case study 13] Consultations for this report also point to a demonstrable divide in TB CRG between countries that have received support through CFCS and those that have not (currently 29 countries are supported under CFCS Round 11). Ensuring eligibility for this technical support and increasing the funding mechanism can help address the gap. Given that CFCS is proving to be the most effective mechanism for building a strategic, coordinated movement to end TB, the TB community calls for donors to directly support this mechanism and for The Global Fund to continue its support of CFCS and leverage partner strengths and existing mechanisms, including direct contribution to CFCS from CESI.

### Case study 11 TBpeople Global strengthens country networks of people affected by TB

Networks of people affected by TB are lacking in many countries and those that exist often struggle to become meaningfully engaged in national TB responses. The absence of seed funding prevents informal groups from organizing themselves and becoming officially registered. Young networks also do not have sustainable resources to build their capacity for implementation. Recognizing these barriers and to enable linkages within and across countries, in 2018 TBpeople Global (tbpeople.org) created country chapters for national networks of people affected by TB. Over five years, 11 national chapters have emerged, with six more in the making. Several country chapters (for example, in **Ukraine** and **Kyrgyzstan**) have grown sufficiently to become sub-recipients of national Global Fund grants and recipients of CFCS grants, demonstrating that even modest support groups of people affected by TB can grow quickly to become important partners in their country's TB response.

As TBpeople works to formalize the system, funding has emerged as a huge challenge. The number of groups seeking to benefit from small grants considerably exceeds the number of grants available. Donors are reluctant to support global and regional networks, despite evidence demonstrating their success in supporting community groups to get organized, registered, win grants, grow in capacity, and implement projects.

### Case study 12 TB Champions pave the way for people-centered TB care in India

Since 2017, not-for-profit organization REACH or Resource group for Education and Advocacy for Community Health (reachindia.org.in), **India**, has trained TB survivors to become 'TB Champions' with the support of USAID. TB survivors participate in interactive three-day workshops to gain knowledge and skills in TB by drawing on their personal, lived experiences. They go on to engage in a six-month mentorship programme to work with their communities as educators and peer supporters for people receiving TB treatment. They provide treatment literacy, psychosocial support, counselling to families, and help mitigate stigma. Today, several thousand TB survivors have been engaged and trained and constitute a network spanning 15 states, including five legally registered organizations.

Over an 18-month period, more than 3,000 TB Champions reached out to over 25,000 people through the rollout of a community accountability framework on quality of TB care. The NTP has committed to scale up efforts to train 15,000 TB Champions to facilitate India's goal to end TB by 2025. The motivation for this work is stated by one TB champion: "I do not want anyone else to suffer like I did". The significance was captured in the India Joint Monitoring Missions recommendations: "Move from passive community engagement to full community participation and ownership, with reliance on TB Champions and TB Survivors working alongside programme staff in advocacy, planning, implementation, and monitoring of the local, state, and national TB response. Invest in local TB forums, which are effective change agents able to work at reducing/eliminating stigma and a human rights response framework."

The adoption of this community-led effort by the Indian NTP promises a major shift in the direction of people-centered TB care.

### Case study 13 Stronger community systems for stronger TB responses in Indonesia

To ensure people-centered care the TB response must be led by empowered people affected by TB. In **Indonesia**, the national network of TB survivor organizations, Perhimpunan Organisasi Pasien TB or POP TB (poptbindonesia.org), is now the Global Fund sub-recipient leading activities on CRG. However, just 12 months prior to taking on this role, POP TB was not registered, nor did it have organizational systems in place. This was set right through a CFCS grant to STP Indonesia, which helped POP TB to legally register, develop organizational systems, develop a strategic plan, and build capacity in TB CRG.<sup>56</sup>

Now, in 2023, POP TB, together with STP Indonesia, is a leader in TB CRG in Indonesia, mobilizing national partners to up TB CLM and finalizing a TB CRG costed action plan. A member of POP TB's national network, Rekat (rekat.or.id), an Indonesian women-led DRTB survivors' organization, has gone on to receive its first grant in TB CRG through the CFCS mechanism. With these small grants and support packages, TB survivors can be the catalysts for transforming and building sustainable community-led national TB responses.

Finally, though affected communities and civil society are engaging in CCMs, respondents wanted their representation, capacity and participation to be built further and extended to neglected KVP. Despite a nod to CRG within many NTPs, TB community and civil society actors are still vying to be recognized as government allies. Their roles are often restricted to service provision, such as through social contracts, but have little say in decisions or planning for financing, monitoring, and accountability; this is raised in Areas for Action 4 and 6. A few community groups also struggle with polarized framings of their activities. On a positive note, though, community organizations that have implemented CRG tools in collaboration with NTPs noted that the process helped enhance their partnership, credibility, and legitimacy with the government.

*“Advocacy is not a sprint, it’s a marathon, takes time, energy and requires a lot of resources.”*

**Mayowa Joel, Stop TB Partnership Board and Stop TB Partnership Nigeria**

## Key and Vulnerable Populations affected by TB

TB KVP need nuanced responses to their nuanced needs. Case studies show that affected communities and civil society are often the only actors with access to the hardest-to-reach KVP and can meet their distinct needs. [Case study 14] With dedicated investments, community-engaged and community-led actions have opened opportunities for the provision of people-centered, equitable TB care for groups that may otherwise be neglected. [Case study 15] The gains achieved through the self-determining actions of historically marginalized groups affected by TB in select settings are also lending hope to KVP elsewhere. [Case study 16]

But many KVP groups remain undercounted, underrepresented, and therefore insufficiently engaged or funded in the TB response. The growing scale and depth of involvement of people living with HIV, women, and youth in response to TB needs to be met with country-level representation of other KVP groups such as people living in slums, migrants [Case study 17], refugees, and mobile populations such as miners, internally displaced people, and people deprived of their liberty. There is a need to recognize and address the barriers faced by women, men and gender non-binary individuals in order to fill the gaps in gender-responsiveness.

## Social protection

As stated in Area for Action 1, nearly half of all families affected by TB and over three-quarters of families affected by DRTB incur direct and indirect medical costs, as well as opportunity costs due to loss in livelihood, which exceeds 20% of their household income.<sup>20</sup> TB-affected communities and civil society respondents have cited unemployment, housing and food insecurity, legal status precarity, and scarce access to mental health support as accompaniments to the clinical course of TB. A human rights framework for TB mandates addressing these social morbidities, and sustained commitments from government sectors within and outside of health, as discussed in Area for Action 6.

## CRG approaches must underline every aspect of the TB response

Making the TB response rights-based, equitable and stigma-free, with communities at the center, is fundamental to reaching global targets for TB elimination. Without exposing and correcting discriminatory practices, policies, and laws, we risk violating the fundamental human rights of people affected by TB. Without attending to TB stigma and its insidious drivers, we risk alienating affected people from TB care and many others before they even enter the health system. And without placing TB-affected communities at the heart of the TB response we are set up to exclude the most vulnerable populations affected by TB and fail in the goal to reach all.

Systemic biases and neglect of community voices have been recognized and addressed in other infectious diseases such as HIV and must be further championed for TB at all levels. This neglect is at the heart of the deadly divide upon which this report is constructed. While there has been some headway towards meaningful engagement of communities at the global level, much more sustained investment is needed, especially at the national and sub-national levels. CRG can serve as the backbone of the TB response, but it remains one of the least funded areas. Global actors must use their diplomatic voice and funding influence to carve out dedicated space for the inclusion of affected communities and civil society in country proposals and national decision-making, backed by a dedicated wallet to strengthen community-led infrastructures for CRG in TB.

### Case study 14 People deprived of their liberty gain access to care in Paraguay

Incarceration heightens vulnerability to TB. Central and South America are experiencing the highest increases in rates of incarceration. People deprived of their liberty (PDL) now represent 11% of all people with TB even though they comprise only 1% of the population.<sup>57</sup> Despite these numbers and recognition of PDL as KVP at the global level, the incidence of TB among PDL is not reported within global documents, and PDL are not recognized as a priority by most NTP plans.<sup>58</sup>

In **Paraguay**, the NTP has significantly increased activities dedicated to PDL, in large part from the sustained efforts of Alvida (Alientos de Vida/Breaths of Life), a civil society organization and sub-recipient of The Global Fund. Alvida has dedicated itself to working with the NTP to support people living with TB and their families with an emphasis on PDL as well as indigenous populations. Its efforts have been critical in securing the inclusion of community leadership development work in the National Action Plan for the Sustainability of HIV and TB in Paraguay 2021–25. In 2022, in collaboration with several prisons and NTP support for molecular diagnosis and treatment, Alvida trained teams of PDLs as volunteer community health workers to aid in the detection of active TB and identification of other PDL in need of TB testing services.

KVP affected by TB can be effectively engaged in efforts to address their unique barriers and find people with TB who may be otherwise missed.

## Case study 15 Building cross-border protections for miners in southern Africa

Miners in southern Africa's gold mines have the highest rates of TB in the world. Every year, half a million men travel across the region to work in South Africa's mines and, in doing so, contract TB.<sup>59</sup> This pattern of migration – men arriving at the mines to work, becoming infected with TB and returning home again – has created an enormous regional crisis.

More than a decade ago, heads of states from the Southern African Development Community (SADC) signed a Declaration on TB in the Mines with mandates for the SADC ministers of health, finance, migration, local government, labor, and mining.<sup>60</sup> Since then, several partners have supported country efforts to address TB in the mines such as The Global Fund TB in the Mining Sector in Southern Africa (TIMS) grant and USAID TB Local Organizations Network (TB LON). Ex-miners who are TB survivors have also been mobilized under the coalition of the Southern African Miners Association (SAMA). In **Mozambique**, for example, the partner organization, Association of Mozambican Mineworkers (AMIMO, amino.org), celebrates the establishment of two occupational health centers to support TB screening among ex-miners.

AMIMO and other organizations such as the Jointed Hands Welfare Organization (jointedhands.org) in **Zimbabwe** share the need for mobilize and scale-up of TB detection at community levels, cross-border referral systems that harmonize treatment for miners on the move, and attention to artisanal and small-scale miners who could be missed in ongoing interventions. SAMA is working to secure policy changes that address these gaps, and to sustain and grow the political will to end the public health crisis among miners and their associated communities.

## Case study 16 The latest Canadian TB Standards centers the rights of Indigenous Peoples

TB among Indigenous Peoples in **Canada** is inextricably linked to a history of colonization and associated trauma.<sup>61</sup> The eighth edition of the Canadian TB Standards was published in March 2022 and centers, for the first time, the rights of Indigenous Peoples.<sup>62</sup> A chapter dedicated to providing “An introductory guide to tuberculosis care to improve cultural competence for health care workers and public health professionals serving Indigenous Peoples of Canada” details the specific epidemiology of TB, and its historical and cultural context as it relates to each of the three Indigenous groups in Canada – Inuit, First Nations, and Metis.<sup>63</sup> To uphold their values, needs and priorities when it comes to TB prevention, diagnosis, treatment and care, seven asks are made of all people providing services on Indigenous lands and/or working with Indigenous Peoples for TB-related work. This includes education about the unique history and epidemiology of TB in the community, accessibility barriers related to climate and geography, cultural safety including respect toward cultural differences, specific social determinants and inequities affecting distinct indigenous groups, acknowledgement of the role of ongoing colonization, personal and systemic racism and privilege, promotion of self-resilience, self-advocacy and empowerment by respecting the rights of Indigenous Peoples, and understanding that each Indigenous group is historically and culturally distinct, and may have unique TB needs.

The impacts of colonization, historical trauma, and systematic inattention to the upstream social determinants of health have shaped TB epidemics in indigenous populations around the world. The ground-breaking effort of the Indigenous Peoples in Canada can serve as inspiration for all national TB programs.



## CRG approaches must underline every aspect of the TB response

Making the TB response rights-based, equitable and stigma-free, with communities at the center, is fundamental to reaching global targets for TB elimination. Without exposing and correcting discriminatory practices, policies, and laws, we risk violating the fundamental human rights of people affected by TB. Without attending to TB stigma and its insidious drivers, we risk alienating affected people from TB care and many others before they even enter the health system. And without placing TB-affected communities at the heart of the TB response we are set up to exclude the most vulnerable populations affected by TB and fail in the goal to reach all.

Systemic biases and neglect of community voices have been recognized and addressed in other infectious diseases such as HIV and must be further championed for TB at all levels. This neglect is at the heart of the deadly divide upon which this report is constructed. While there has been some headway towards meaningful engagement of communities at the global level, much more sustained investment is needed, especially at the national and sub-national levels. CRG can serve as the backbone of the TB response, but it remains one of the least funded areas. Global actors must use their diplomatic voice and funding influence to carve out dedicated space for the inclusion of affected communities and civil society in country proposals and national decision-making, backed by a dedicated wallet to strengthen community-led infrastructures for CRG in TB.

### Case study 17 TB among migrants crossing the Northern Triangle

Migration from the Americas has long been motivated by economic need due to widespread poverty. Many leave looking for employment, a better standard of living, better work conditions and remuneration, and, in extreme cases, because of rising levels of violence. Guatemala is both an expulsive country and a transit for migrants from other countries in the Northern Triangle (**Guatemala, Honduras, and El Salvador**) who are moving towards the United States via Mexico.<sup>64</sup> Though the national rate of TB is relatively low, the burden is much greater among migrating worker populations that are predominantly indigenous and depart and return to isolated and underserved communities. Their migration through Mexico, which has much higher rates of TB disease and infection than the Northern Triangle, combined with the conditions under which migrant people are forced to travel and wait to enter the United States are prime factors for the development of TB infection and active disease.

In 2016, the Guatemalan congress approved a Migration Code with an eye on human rights. Migrants are now recognized as holders of rights, bestowing access to medical attention, shelter, work, and education from the Guatemalan state. The legislation addressing TB and the broader health needs of migrants as KVP was a product of a partnership between civil society and government and may serve as an example for other countries that fall along migratory corridors.

## CALL TO ACTION

**Make the TB response equitable, gender-responsive, rights-based, and stigma-free, with TB-affected communities and civil society at the center by 2025.**

- Ensure Communities, Rights and Gender (CRG) and stigma elimination are prioritized in the 2023 UNHLM on TB Political Declaration with specific targets, and explicitly integrated into National Strategic Plans (NSP) and TB Program Reviews.
- Dedicate donor and domestic funding for TB community-led initiatives, including advocacy, monitoring and accountability efforts through the Stop TB Partnership (STP) Challenge Facility for Civil Society (CFCS), the Global Fund, and other technical support mechanisms.
- Ensure the meaningful participation of TB-affected communities and civil society as expert contributors in developing NSPs, planning TB Program Reviews, as well as country proposal development processes for international grants in all high burden countries (HBCs), including through national networks of people affected by TB and empowerment and leadership of women and girls.
- Conduct CRG assessments, routine stigma measurement, and develop and implement costed TB CRG action plans in all HBCs that include community-led monitoring (CLM) of the TB response and of CRG in the TB response.
- Identify, conduct size estimations, and allocate funding to systematically attend to specific needs of TB KVP, such as but not limited to people living with HIV, migrants, refugees and internally displaced people, people who use drugs, people deprived of their liberty, people with diabetes, the urban poor and people living in slums, miners and people with silicosis, indigenous peoples, and children, based on vulnerability and barriers to access.
- Strengthen social protection and security for people affected by TB, and ensure it includes income, health care, housing, nutritional support, mental health support, and legal aid.
- Update laws, policies, and programmes to promote and protect the rights of people affected by TB, combat inequalities and eliminate stigma and discriminatory practices, processes and language.



## AREA FOR ACTION 3: Accelerate the development, rollout of and access to essential new tools to end TB

### Introduction

TB-affected communities and civil society recognize the substantial headway made in TB R&D since the first UN HLM on TB but are quick to note the TB toolkit is still far from full. Practical, efficient, effective, and resource-light solutions that can be scaled up in communities most impacted by TB are urgently needed. Above all other innovations, they voice the need for a vaccine. In this chapter, we return to achievements and gaps in innovation and rollout that were introduced in Area for Action 1, to catalyze bolder and more effective approaches to TB R&D. Funding R&D efforts is taken up in the next chapter.

### Current state of affairs

#### Scorecard

TB-affected communities and civil society hugely applaud the development and approval of safer and shorter drug regimens for TB infection and TB disease, including DRTB and childhood TB. They recognize digitization as an important health system innovation. And they celebrate the monumental investment in TB R&D, amounting to nearly US\$ 1 billion.

However, they also point to crucial gaps. They lament the persisting absence of TB vaccines, WRDs that operate at point-of-care and are child-friendly, and rapid drug susceptibility tests that predict resistance to the latest suite of drugs. They argue that the scale-up of many emerging and existing tools is woefully slow. As raised in *Area for Action 1*, over 50% of TB-affected persons, including TB survivors, surveyed for this report faced challenges accessing TB services including drugs, diagnostics, and other supports. Ultimately, while there are examples of innovative approaches to TB service delivery, the efforts are piecemeal. There has been no major disruption to the status quo.

## Figure 10

### Scorecard on accelerating the development, rollout of and access to essential new tools to end TB

#### Targets 2018 – 2022

#### Scorecard

Treat 40 million people with TB, including	66%	
3.5 million children with TB	54%	
1.5 million people with multi DRTB	43%	
115,000 children with multi DRTB	15%	
Place 30 million people at risk of falling ill with TB on TPT, including	31%	
6 million people living with HIV	172%	
4 million children <5 years	40%	
20 million other household contacts	3%	

■ Little to no progress   ■ Some progress   ■ Good progress

## Vaccine R&D

We need an effective and accessible vaccine, if not many. The COVID-19 pandemic demonstrated that, with sufficient investments, vaccines can be developed and implemented at scale at record-breaking speed without compromising on scientific rigor. The 2021 Global Roadmap for R&D of TB vaccines outlines how this can be achieved for TB, identifying key barriers, ways to overcome them, and a shared set of priorities to guide R&D activities.<sup>65</sup> As has been seen with dozens of infections, including smallpox and polio, a vaccine is the one (and only) innovation that can halt an epidemic. TB-affected communities are becoming well-prepared to roll out a vaccine as soon as one becomes available, but progress is hampered by lack of protected investments, as is raised in the next chapter.

## Drugs and diagnostics

The assortment of new, safe, effective and shorter treatment regimens for TB infection and disease, including DRTB and childhood TB, signifies the greatest achievements of the TB response since the 2018 UNHLM on TB – if not in the history of TB response – and provides much awaited relief to TB-affected communities and civil society. DSTB can now be treated in four months, DRTB in as little as six months without injections, and TB infection can be treated – and disease prevented – in 1-3 months<sup>19,24,27</sup> [Case study 18] These new regimens promise to enhance treatment acceptability, health system and program feasibility, and support people-centered approaches to TB prevention, treatment and care.

That said, there is substantial room for innovation in biomedical R&D. On the diagnostics side, TB-affected communities need a WRD that can be used at scale in resource- and power-deficient areas to obtain results within minutes. Point-of-care tests for TB infection and sub-clinical TB, and markers to assess the risk of progression to TB disease are also lacking. On the treatment side, technical experts consulted for this report note that new treatment regimens still rely on old drugs. New molecules are needed so that TB can be prevented and cured in even less time, to accelerate reductions in incidence and mortality, and counter new strains of drug-resistance.

In all these innovations, breastfeeding and pregnant women, children, and adolescents benefit inequitably; most R&D pipelines, by design, are exclusionary of these groups.<sup>66</sup> TB-affected communities and civil society seek to ensure the gains of TB R&D can be enjoyed by KVP and others who have been historically neglected. Technical experts consulted for this report emphasize that research into the safety and efficacy of BPaL/M DRTB regimens and rifapentine-based TPT regimens in pregnant/breastfeeding women, premenopausal women requiring contraception, and children under two years, as well as people living with HIV (for example, those receiving dolutegravir) must be prioritized, undertaken and/or finalized; it is among these key groups that the impacts of TB are often the most severe.

## Case study 18 BPaL/BPaLM heralds hope for people with DRTB

Between 2018 and 2020, since the introduction of bedaquiline, all-oral regimens for DRTB have become standard of care. In 2022, BPaL/BPaLM became the newest safer, cheaper, shorter, and more effective all-oral regimen, supported by phase III data from the TB PRACTECAL, ZeNix, and Nix-TB trials.<sup>77</sup> BPaL/BPaLM comprises bedaquiline (B), pretomanid (Pa), linezolid (L) and/or – depending on resistance to fluoroquinolones – moxifloxacin (M). This is a game changer for people with DRTB, who will need to take only 3-4 pills a day for six months! Treatment success is over 80%, signifying a tremendous lifesaving advancement in TB R&D. WHO guidelines approving the use of BPaLM and BPaL in December 2022<sup>24,78</sup> means that countries around the world can start making the regimens immediately available to people affected by DRTB. The regimens will also be substantially cost-saving compared to longer, toxic treatments that require more intensive monitoring and follow-up.<sup>79</sup>

## Uptake and accessibility of tools

As introduced in Area for Action 1, new and emerging tools must reach TB-affected communities in order to have impact. Countries are steps behind in their uptake of many WHO-approved tools that have come to market over the last decade. This lethargy is particularly evident in the slow adoption of WRDs such as GeneXpert which, notwithstanding its limitations, is the best available tool to detect TB. Likewise, shorter treatment regimens are not yet accessible to all; remote hard-to-reach and underserved areas are at a persistent disadvantage. TPT scale-up, other than in people living with HIV, is abysmal with many governments delaying authorization or lacking access to rifapentine.<sup>67</sup> The 1/4/6x24 campaign – recently launched by a coalition of TB survivors, researchers, clinicians, activists, and civil society professionals from around the world – is now gearing up to ensure that the best available drug regimens reach those who need it the most in the fastest time possible.<sup>68</sup> [Case study 19]

Mobilizing access to new tools requires operational research and market shaping to facilitate contextual adaptation and adoption, as well as price negotiations.<sup>25</sup> Respondents shared that many of their countries contend with affordability challenges, unused supplies of old tools, and regulatory hurdles to accommodate importation of new ones, making the adoption of new tools difficult. Infrastructure barriers are also pervasive – there are supply chain issues with TB testing and cloud storage issues with the rollout of digital technologies. At the facility level, there is a lack of technical guidance on best practices and, within communities, lack of demand from people directly affected by TB because of poor access to information. Community-driven campaigns are essential for raising awareness and advocacy to overcome these hurdles to access. [Case study 20]

## Case study 19 Portable AI-CAD is finding people affected by TB in the places where they live and work

Artificial intelligence-based computer-aided detection (AI-CAD) products offer an opportunity to automate and standardize the interpretation of digital chest X-rays and expedite pathways for TB screening and finding people with TB. Several projects funded by the STP's TB REACH initiative demonstrate the impacts of bringing portable AI-CAD innovations to otherwise hard-to-reach communities.

Dopasi Foundation (dopasi.org), a not-for-profit community organization, implemented AI-CAD in three coal mining districts in **Pakistan** using Fuji Film Xair, consisting of a compact, lightweight, solar-powered digital X-ray machine linked to a computer-aided reading software, Lunit INSIGHT CXR.<sup>60</sup> The districts had sparse to no health facilities, electricity or transport infrastructure. Between 2019 and 2021, 117 screening camps were conducted, 150,242 coal miners and their families were screened for TB, including 12,495 screened using X-ray, and 429 people diagnosed with TB were provided with treatment leading to a 77.5% increase in TB detection in the project areas. Typical quality concerns regarding image resolution were not encountered, and low radiation was confirmed by the nuclear and radiology authority. Challenges included low battery capacity and overheating of the device during extremely hot weather.

Similarly, PATH (path.org), an organization that works with public and private actors, also helped accelerate TB diagnosis among residents of informal settlements in the city of Nagpur, **India**, using the AI tool qXR, developed by Qure.ai, and working closely with the local association of radiologists to earn their support.<sup>61</sup> During 2019–20, 10,481 people were referred for free chest X-ray read by AI, leading to TB diagnosis in 197 people. About 13% of diagnoses were missed by human readers but identified by AI. Both projects, alongside others, are showcased at Stop TB's Focus Group on AI-based Imaging for TB (FG-AITB), which serves as a global knowledge-sharing platform to connect implementers, facilitate south-south connections, and provide technical support for scale-up.

## Digital innovations

Digital technologies have come to the forefront of the TB response, amid a marked growth in health system innovation. WHO-approved portable computer-aided diagnostics (CAD), coupled with artificial intelligence (AI) apparatus<sup>13</sup>, promise a sea change in TB diagnostic algorithms, especially the pace of TB screening, with potential benefits to resource-poor areas that lack health facilities and qualified providers. [Case study 21] Multiplex technologies may be able to tap into TB from primary care and other areas to increase notification rates.<sup>69,70</sup> Respondents shared how digital adherence technologies (DAT) are altering how people on TB treatment are monitored, and streamlining the workflow among service providers. Research reviews of video-based directly observed therapy (DOT) provide evidence that digitizing DOT is reliable, acceptable, and associated with improved adherence compared to standard DOT; this has supported video DOT or vDOT in several HICs.<sup>71</sup> As TB-affected communities open up opportunities for virtual service delivery, prompted by

## Case study 20 Accelerating scale-up of new regimens through the 6/4/1x24 campaign

Few people have access to the best available evidence-based tools in TB. Demand generation is needed to promote their accessibility, availability, acceptability, and quality. The 1/4/6x24 campaign is generating much needed demand to make sure the latest innovations reach people fast.<sup>68</sup> The campaign calls on and works with global donors and health actors to accelerate the introduction and scale-up of new shorter TB treatments, including by committing to time-bound targets for the adoption of new WHO guidelines, and to ambitious, innovation-forward NSPs and funding proposals.

The campaign's name comes from its central demand: that countries and other duty bearers take action to implement the shortest available regimens – 1 month or once-weekly for TB prevention, 4 months for drug-sensitive TB, and 6 months for drug-resistant TB – by the end of 2024. The campaign is already gaining the attention and commitment to action of key TB actors, including STP, WHO, The Global Fund and USAID, and is demonstrating the power of a shared goal and rallying advocacy campaign in equipping and mobilizing community advocates to hold duty bearers to ambition and account. This must include mitigation and removal of human rights- and gender-related barriers to services that inhibit access to innovations in TB.

# 1/4/6x24



COVID-19 lockdowns, they also hope this will shift reliance away from DOT to community empowerment – where people with TB have the information and support they need to complete prescribed treatments (also see case study 3).

Digital platforms are gradually reforming the TB surveillance infrastructure, allowing countries to use real-time data.<sup>72</sup> Respondents see this as an opportunity to strengthen advocacy, and mitigate barriers to care and inequities for people affected by TB. For health systems, they can expedite referrals, diagnosis and treatment monitoring, and defray costs and capacity constraints. The OnelImpact CLM tool is uniquely enabling several affected communities to monitor and respond to gender- and rights-related barriers to TB care, form peer connections, and monitor local responses to TB.<sup>73</sup>

## Case study 21 Campaigning to bring down the cost of emerging new tools

Product patents and high costs impede universal access to emerging TB drugs and diagnostics. Organizations representing and comprising people affected by TB are using ingenious approaches to counter these bottlenecks and support product availability, accessibility, acceptability, and adaptability.

Since 2019, Médecins Sans Frontières' (MSF) Access Campaign has coordinated a 'Time for \$5' campaign to halve the price of the GeneXpert MTB/RIF test, given that the manufacturer, Cepheid, has maintained the test price at nearly \$10 for over a decade. The Access Campaign is also advocating to drive down the price of the latest BPaLM regimen for DRTB to below \$500. The eighth edition of their DRTB Drugs Under the Microscope report calls for loosening the restrictive terms of drug patent licensing between Johnson & Johnson and the not-for-profit organization TB Alliance to support the entry of generic versions of the latest regimens, and boost their affordability and accessibility in countries that need it the most.<sup>25</sup>

A new agreement between the Global Fund, STP, and Molbio Diagnostics is taking this a step further. WHO-approved Truenat® assays (MTB, MTB Plus and MTB-RIF Dx) will be available at a reduced price in all countries supported by the Global Fund, STP and USAID; Truenat® is especially helpful for the diagnosis and subsequent detection of rifampicin resistance in adults and children with signs and symptoms of pulmonary TB, and for use in power-deficient areas. The partnership will include global standard service-level agreement to ensure commitment to service and maintenance, and with potential to extend similar pricing to public and private sector buyers.<sup>82</sup> This price reduction should be the beginning of a conversation, one that continues to bring down price barriers until they are removed completely.

Campaigning against unfair product patents and pricing can help overcome major barriers to accessing TB care.

Most digital innovations aiding diagnostics, treatment monitoring, and surveillance are however not yet scaled up. Consultations for this report suggest that many countries continue to report on paper – a disappointing finding that has also been documented by the WHO<sup>74</sup> – and that while digital tools would be valued to fill gaps in data, abridged, simpler tools would be appreciated. Ultimately, country adoption of these innovations will require government buy-in beyond donor-driven projects. This is an opportunity for developers to work with TB-affected communities and civil society, as well as local innovators.

### Approaches to innovation

Over a dozen actors are engaged in the development of new tools for TB, and many more are in the digital space. With a few exceptions, they work in silos and sometimes in competition, leading to a fragmented response to innovation where one new tool is playing catch-up to another.

For example, the rollout of new TB treatments could be strengthened by commensurate innovations in diagnostic technology. Current WRD tests for DRTB convey sensitivity profiles for only a fraction of drugs, leaving communities ill-prepared to prevent, detect and respond to potential resistance to the latest regimens. Innovators must synergize efforts to develop WRDs that are responsive to the full slate of drugs available on the market as well as those poised for phase II/III trials.

Another limitation is that too few innovators work hand-in-hand with TB-affected communities to co-create tools and collaborate on their rollout. TB-affected communities and civil society express concern that developers come in with a prepared tool, attempting to then convince them of its value. As a result, innovations are seldom developed with an eye to equity and they fail to reach their full potential. TB-affected communities must be able to articulate their needs and inform the design of new tools. To do this there is a need to build knowledge and capacity among them, and provide funding and space. Their early and meaningful engagement is critical to seize buy-in, acceptability and, ultimately, impact. [Case study 22]

## Case study 22 The Global TB Community Advisory Board (TB CAB) as an agent of change in TB R&D

The Global TB CAB is a group of research-literate community activists from TB networks in Asia, Europe, Africa, and North and South America that advises research and product sponsors engaged in the development, evaluation and introduction of new TB treatment, diagnostic and preventive technologies. It advocates for a more inclusive TB R&D agenda in terms of trial design as well as the types of evidence that get prioritized in TB decision-making. In recent years, it has leveraged clinical trial protocol reviews to advocate for the inclusion of key groups in TB research, including children and pregnant persons. Thanks in large part to their efforts, the TB field has shifted with a number of studies and initiatives taking a more progressive and inclusive approach – for example, the endTB and endTB-Q trials allow people who become pregnant during the study to decide whether or not to continue<sup>83,84</sup>; the BEAT Tuberculosis trial in South Africa includes children down to age 6 and pregnant people as eligible participants<sup>85</sup>; and the USAID-funded Johns Hopkins University-led Supporting, Mobilizing and Accelerating Research for Tuberculosis Elimination (SMART4TB) consortium is planning to prioritize these populations in its research<sup>86</sup>, taken forward under the project, including through partnership with CFCS grantees.

The TB CAB is concurrently working to contribute to, and improve the collection, rigor and consideration of TB affected community perspectives in the decision-making processes that guide TB R&D agendas, funding priorities and policies. By elevating the preferences and perspectives of people with lived experience of TB, the TB CAB is enabling the priorities of people affected by TB to hold more weight in major decision-making for TB research and policy. An independent evaluation of the Global TB CAB spotlights its role in promoting scientific advocacy, elevating community perspectives, and serving as agents of change in the TB R&D landscape.<sup>87</sup>

The need for coordination with government actors and regulatory systems is raised in [Area for Action 6](#), and vital to the success of emerging innovations. The Global Drug Facility affords opportunities to overcome regulatory barriers and supply shortages that are often implicated in the slow rollout of many new tools.<sup>75</sup> Access-oriented voluntary licensing interventions such as those enabled by the Medicine Patent Pool (MPP) – and which have met with success in HIV and HCV – can also help save costs, and lives, by instituting safeguards early in the R&D process to ensure access to products that prove to be efficacious at later stages.<sup>76</sup>

## Demand creation for the development and rollout of TB innovations

The pace of TB innovation is clearly not enough to keep up with the pace of the present-day TB pandemic. An unprecedented movement of funds is needed to accelerate

access to emerging tools and fill the R&D funding gap, which is raised in the next chapter. Pooled efforts from developers – and far more generous public and private investors – working with TB-affected communities and civil society at the outset, are needed to stimulate market demand for existing and the next generation of tools – especially a vaccine. HICs can challenge for-profit models of pharmaceutical companies by negotiating in the interest of the public at home and abroad, and increasing investments in not-for-profit models such as product development partnerships.

Innovation in TB has also suffered a myopic frame, focused on marketable products stemming from biomedical and technological advancements. Operational research, social research, and community-based research are needed to enable their uptake, counter barriers, and achieve fruition. [[Case study 23](#)] There is opportunity to expand conceptualizations of innovation to include interventions that address the social, economic, and legal drivers of TB, especially CRG barriers, beyond its pathogenic and epidemiological determinants.

### Case study 23 Evaluating the preparedness of urban ASHA workers to deliver TB services in India

The Urban Accredited Social Health Activists (U-ASHA) are incentivized community health workers of the National Urban Health Mission of **India** who link the community to health services by functioning as health educators, service providers, and health activists. In 2022–23, the Foundation for Medical Research (FMR, [fmrindia.org](http://fmrindia.org)) implemented pilot research in two cities, Mumbai and Pune, involving over 300 U-ASHA workers and other relevant stakeholders to understand their preparedness for delivering TB services to the last mile in urban poor communities, and for facilitating community engagement in seeking timely and regular TB care. The project was carried out under the Partnership for Enhanced Engagement in Research (PEER) programme of the National Academy of Sciences, with co-funding from Godrej Industries and the support of the Maharashtra State Anti-Tuberculosis Association (MSATBA).

U-ASHAs were found to have great potential in identifying people who may be affected by TB, counselling people with TB and their families for mental support and nutrition, infection control, primary management and referral of adverse drug reactions, and reducing stigma through community awareness and attention to confidentiality. To build them an enabling ecosystem, support from the community and health system is needed. Current approaches to training devote just a half day to TB, leaving little room for U-ASHAs to learn about the essentials of TB, the programme, and the key components of people-centered care such as TB stigma, nutrition, family involvement, or interventions for the elderly and people with diverse other needs. There is also little attention given to structural support such as U-ASHA payment schemes, workload balance and workflow supervision, and opportunities for continued learning and advancement. The pilot research uncovered important gaps as well as opportunities to strengthen community-based TB programming and reach all.

## CALL TO ACTION

### Accelerate the development, rollout of and access to essential new tools to end TB

- Develop and ensure the availability and accessibility of new TB vaccines to enable sharp reductions in disease incidence by 2025, with a protected pipeline of funding.
- Ensure all people affected by TB, including TB infection and disease and drug-resistant TB (DRTB), receive the latest shorter treatment regimens by the end of 2024.
- Develop novel point-of-care WRDs, including those which are child-friendly and measure drug resistance to the latest and emerging treatment regimens, parallel to developing shorter treatment regimens for TB infection and disease that are based on new molecules.
- Strengthen utility and investment in digital technologies including digital portable X-ray, artificial intelligence-supported diagnostics, and CLM mechanisms such as OnelImpact.
- Accelerate rollout and market access to new and emerging tools – from design and adaptation through to adoption, demand creation and evaluation – with funded community advisory mechanisms, community-led campaigning, and operational research.
- Coordinate efforts between developers such as through global alliances and not-for-profit product development partnerships to produce people-centered and accessible vaccines, diagnostics, treatments and digital technologies for TB, ensuring they are free from intellectual property or related industry or regulatory pricing barriers that inhibit affordability and access.

# AREA FOR ACTION 4: Invest the funds necessary to end TB

## Introduction

The need for greater financial investments to support TB elimination reverberated across all consultations for this report. TB-affected communities and civil society assert that TB deserves an R&D investment akin to that of COVID-19. During 2020 and 2021, COVID-19 took the lives of 2.65 million people<sup>88</sup>, many of whom would have been affected with TB. In this same period, TB took the lives of no less than 3 million people.<sup>5,89</sup> Whereas billions of dollars were pumped into COVID-19 responses and recovery efforts, barely a shadow of those investments were seen in responses to TB from either domestic or external sources. It is an egregious injustice that the lives of people affected by TB should matter less. This chapter lays bare the TB funding gap, and the unacceptable cost of inaction.

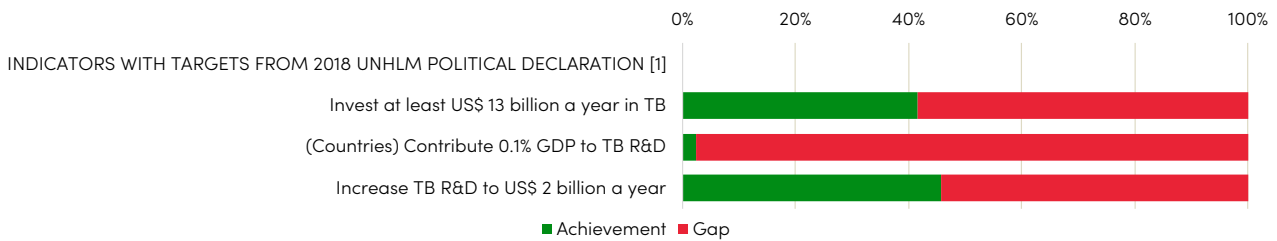
## Current state of affairs

### Scorecard

Investments in TB care grew in the years preceding 2019 but fell in 2020, largely due to a diversion of resources to support the COVID-19 pandemic response. They appear to have stabilized in 2021, when TB financing reached US\$ 5.4 billion, and R&D financing reached a record high of US\$ 915 million. These are monumental amounts, but the TB response is still grossly underfunded. TB-affected communities and civil society lament that we are not even halfway to achieving the financial security promised in the 2018 Political Declaration (Figure 11).<sup>1,42</sup> Compared to investments that address other infectious diseases and major health issues, funding for TB is still disproportionately low. What is more, many investments are not tied to targets that support people-centered care such as CRG, stigma, attention to KVP, and equitable access to the best available tools.

# Figure 11

## Scorecard on investing the funds necessary to end TB



# Table 5

## Funding needed to accelerate achievement of TB elimination by 2030

	2023	2024	2025	2026	2027	2028	2029	2030	Total
Global funding need <sup>1</sup>	15.7	17.6	20.3	21.9	33.1	32.8	33.6	34.9	209.8

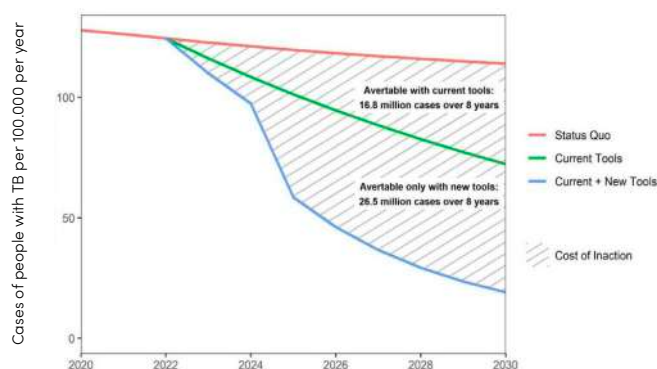
<sup>1</sup> in billion US\$  
From The Global Plan to End TB 2023-2030, Stop TB Partnership; p. 166

That said, even though we are behind in achieving UN targets, The Global Plan to End TB 2023-2030 shows that it is possible to end TB if sufficient financial, and related political investments are made. An estimated US\$ 210 billion – nearly four times the current investment – can help us achieve the goal of TB elimination over the next seven years (Table 5).<sup>6</sup> The return on investment is estimated to be huge – with a

US\$ 40 cost saving on the dollar by the year 2050, going as high as US\$ 60 in LMIC, and 16-27 million people escaping developing TB. The cost of inaction, on the other hand, is unacceptable: nearly US\$ 1 trillion with millions of lives lost (Figure 12).<sup>6</sup> Without sufficient and sustained financing of the TB response, progress will be stalled in every area of action.

## Figure 12

The potential human cost of failing to implement the Global Plan 2030–2023



Courtesy: Stop TB Partnership, Geneva

### International funding

About three-quarters of all international financing for TB comes from multilateral funding via The Global Fund.<sup>5</sup> The seventh replenishment of The Global Fund amounts to US\$ 15.7 billion, a monumental amount.<sup>90</sup> However, only 18.6% of the funds are allocated to TB<sup>91</sup>, despite the annual mortality from TB outweighing that from HIV or malaria.<sup>92</sup> [Case study 24] Several countries are also seeing drastic cuts in allocations, due in part to economic growth<sup>91</sup>; most do not yet have sufficient domestic capacity to cover the shortfall.

The United States of America is the highest bilateral contributor to the TB response, covering 50% of international funding for TB, including contributions to The Global Fund, followed by France and the United Kingdom.<sup>5</sup> Very few other countries have a vested stake in TB. [Case study 25]

### Domestic investments

The widening political profile of TB has led to its increased visibility and spurred expressions of commitment, as represented in the Political Declaration at the regional (for example, Common Africa Position<sup>93</sup>) and national (for example, BRICS5,<sup>94</sup>) levels. The BRICS countries collectively cover two-thirds of all TB funding arising from domestic sources. India has shown some of the steadiest increases in TB funding in recent years, and investments from other TB-impacted countries such as Bangladesh, Cambodia and Zambia have also increased.<sup>5</sup> Most TB-impacted countries, however, continue to be supported through international donors. Domestic investments in TB also plummeted over the past three years due to COVID-19, as stated earlier.<sup>5</sup>

### Case study 24 Community-driven campaigns for The Global Fund's latest replenishment – a record falls short of the need

Amidst a climate of severe financial pressure, The Global Fund secured a record-breaking final investment of US\$ 15.7 billion for 2023<sup>90,91</sup>, in large part due to the rallying of advocates around the world towards the #FightForWhatCounts campaign. Despite this remarkable achievement, the amount raised falls short of needs, especially for TB. The Global Fund needed at least US\$ 18 billion to reclaim gains lost during the pandemic.<sup>103</sup>

Some donor countries stepped up more than others. Early ambition and leadership from the **United States of America**, which set the bar high for all donors to increase on their last pledge by 30%, was critical to empowering advocates to be bold. Countries like **Germany** and **Japan** made early 30% increase pledges, which likewise provided significant momentum to support advocates among other traditionally “large” donors like **Canada** and the **European Commission**, whose leaders ultimately announced 30% increases in New York. Nineteen countries met the target of a 30% increase from their last pledge, including seven implementing countries. **South Korea** made a remarkable pledge with its 300% increase from US\$ 25 million to US\$ 100 million. The **United Kingdom** forfeited its long-held leadership role in international development, by cutting its pledge from previous years by almost 30%.<sup>104</sup>

TB-affected community groups and civil society organizations can be proud of the many 30-plus% pledges secured through global collaborative efforts and coordination amongst one another, but will need to maintain a laser focus on mobilizing resources to end the pandemic once and for all. Despite recent small wins in The Global Fund disease split, TB continues to receive the least in comparison to HIV/AIDS and malaria, and TB has a massive funding gap of over US\$ 7 billion. We can learn from the successes and challenges of the #FightForWhatCounts campaign to secure the resources needed to #EndTB.<sup>104</sup> Given the increasing use of “set asides” by Global Fund donors, there is hopefully an immediate opportunity to see an increase in TB funding directly from these sources, which the TB community must explore.



## The most neglected areas

### R&D

The Treatment Action Group's (TAG) annual report breaks down the US\$ 915 million record investment in TB R&D in 2021.<sup>95</sup> Contributions came from public funds (70%), philanthropic donors (14%), the private sector (10%), and multilateral actors (6%). Most funds were from northern governments and a handful of agencies such as the Bill & Melinda Gates Foundation, US National Institutes of Health, UNITAID, USAID. Contributions from private and philanthropic actors as well as middle- and high-income countries, including many G7 countries, were very low, not unlike previous years. Only three out of 215 TB-impacted countries — Ireland, the Philippines and South Africa — met the benchmark for TB R&D funding, defined as 0.1% of overall R&D.<sup>5</sup> Investments into drugs and vaccines from the pharmaceutical industry were especially poor<sup>95</sup>; TB is not seen to yield a strong return on investment despite evidence to the contrary.<sup>96</sup> Other multilateral funders such as GAVI, the Coalition for Epidemic Preparedness Innovations (CEPI), and development banks have also not contributed significant resources to support innovations in TB. This is in stark contrast to the support shown for COVID-19.

About 35% of TB R&D funding goes toward drugs research, 17% to basic science research, 16% to operational and epidemiological research, 15% to diagnostics research, 12% to vaccines research, and 5% to research infrastructure and unspecified projects.<sup>95</sup> Compared to previous years, 2021 saw increased investments into TB drugs, diagnostics, and operational and epidemiological research, but these gains were countered by reductions in pediatric-specific research and flattened funding for vaccines.<sup>95</sup> The lack of protected funding to develop an effective vaccine for a disease that has lived with humanity for centuries and continues to be one of the leading causes of death due to an infectious agent should be an embarrassment to our broader community. To put things in perspective, in the first year of the COVID-19 pandemic, US\$ 51 billion was invested in the development of a COVID-19 vaccine and, within a year, not one but three new vaccines were available on the market.<sup>97</sup> In 2021, by contrast, no more than US\$ 120 million was spent on TB vaccine R&D.<sup>95</sup>

Technical experts and researchers consulted for this report state that the TB R&D funding gap cannot be underestimated. It is at the root of the TB innovation gap. Between 2023 and 2030, the STP's Global Plan to End TB estimates, US\$ 40 billion is needed to accelerate the R&D for new TB medicines and treatment regimens, diagnostics, and vaccines.<sup>6</sup> There are also untapped opportunities to leverage investments in COVID-19 to support TB R&D, an issue that is highlighted in the next chapter.

### Case study 25 Chronic under-investment in TB in Western and Central Africa

The African continent is home to 17 of the 30 countries with a high burden of TB. Many countries have low rates of TB detection, exacerbated during the pandemic. For example, **Gabon** experienced an 80% drop in notifications in 2020, compared to 2019. According to the WHO Regional Office of Africa, detection is significantly impacted by the underfunding of national TB programs. WHO Regional Director for Africa Dr Matshidiso Rebecca Moeti stated in 2022, "we must end the chronic under-investment that keeps the TB burden high, leaves huge numbers of people undetected, and undermines prevention and treatment".<sup>105</sup> This is especially the case in Central and Western Africa, compared to the rest of the continent. **South Africa**, for example, is steadily increasing domestic funding to fight TB, up to 81% in 2020. In **Cameroon**, by contrast, domestic investments in TB decreased by nearly 40% between 2019 and 2020.<sup>106</sup>

French-speaking respondents from Africa who took part in the Deadly Divide 2.0 online survey also identified funding gaps as a major problem, stating TB was a low priority for domestic governments, which relied heavily on external donors. In 2023, Expertise France/L'Initiative launched 'The Accelerator', a new modality to help address these challenges, with opportunities for action based on the expression of needs by countries and partners. Providing tailored support for civil society and community-based organizations was part of the recommendations of their external evaluation, supported by French civil society organizations on the steering committee.

### CRG and stigma reduction

The success of the CFCS, introduced in Area for Action 2, is a seminal achievement in moving the needle on community inclusion and empowerment, and attention to CRG in TB. The 11th round of CFCS funding in 2022 reached a record US\$ 10.5 million — over 20 times the funding garnered in 2007 when it first launched — and is supporting 100 organizations in 29 countries (**Figure 13**). It remains the main grant mechanism, placing power in the hands of community, civil society and grassroots actors to undertake activities that address CRG. The results demonstrate that TB-affected communities can meaningfully advance the TB agenda, manage larger-scale investments, and, with the technical support of STP, aid the institutionalization of CRG in countries to find missing people with TB. [**Case study 26**] Alongside the CFCS, there is also increasing expectation to address gender within Global Fund, USAID, and TB REACH proposals, as also in TB R&D more broadly, particularly epidemiological and operational research.



Within the TB financing architecture, however, funding for CRG and stigma reduction is negligible. On average, despite exponential growth, the CFCS has only been able to meet 25% of the demand from a limited number of countries. This is evidence of a growing demand from local partners to do CRG-related work and that there is significant opportunity for the growth of the CFCS. In the face of the competing goals for PPPR and UHC, and squeezed allocations<sup>98</sup>, catalytic funding for strategic initiatives that would normally support CRG in TB may be the first to be erased from donor agendas. Unless we amplify funding for the CFCS and expanding support to all countries impacted by TB, there is no safety net to support community priorities that are instrumental in finding the missing people with TB. USAID has been championing the cause of addressing community priorities and local ownership through the CFCS, among other initiatives. Global Affairs Canada has also made meaningful contributions, for example, through the TB REACH Initiative. Countries of the European Union can follow this lead and help close this critical gap.

### Case study 26 Scaling up funding for CRG in the Democratic Republic of Congo

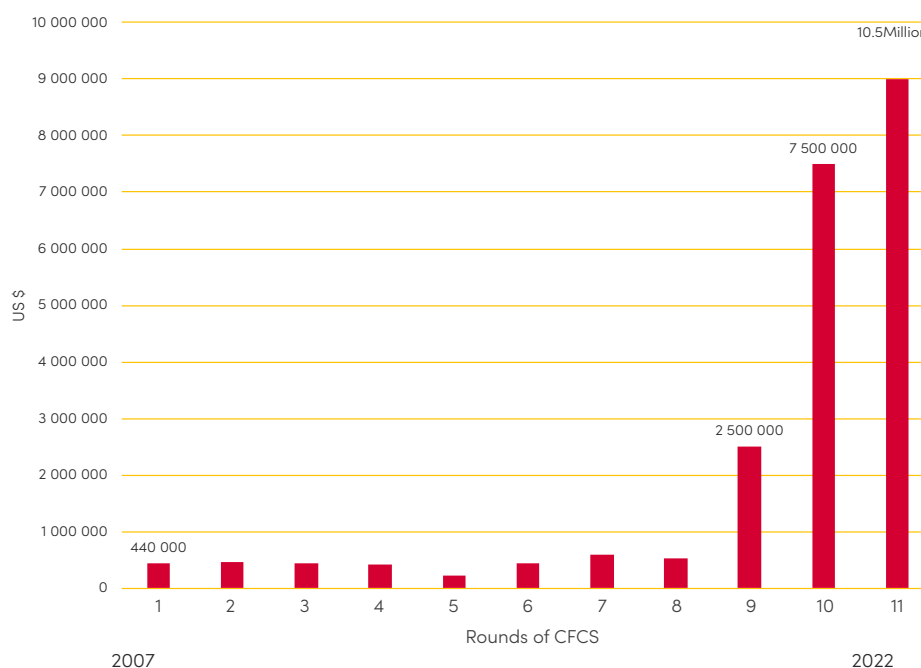
The **Democratic Republic of Congo** (DRC) is among 30 countries with a high burden of TB, TB/HIV, and multi DRTB. It is also one of 13 countries in the world that account for 75% of missing people with TB.<sup>5,55</sup> To assess human rights and gender-related barriers faced by KVP, in 2018 the DRC NTP and an organization led by people affected by TB, Club des Amis Damien conducted a CRG assessment. Support was received from the STP under a Global Fund Initiative to find missing people with TB. The NTP went on to develop a three-year CRG action plan (PA-CRG 2021-2023) with assistance from CAD.<sup>107</sup>

To inform decision-making for The Global Fund's Grant Cycle 7 NMF4 funding request, the NTP commissioned a thorough review of the PA-CRG 2021-23 from STP to ensure CRG was included and prioritized in the NSP for TB 2024-2028 and written into the NMF4 funding request. As a result of these efforts, interventions in DRC's successful GC7 included several foci on CRG: mitigating and overcoming TB CRG barriers; scaling up TB CLM; promoting and protecting human rights; advancing gender-sensitive programming; and integrating TB CRG in TB service delivery.

Funding requests of The Global Fund offer significant opportunities for NTPs to scale up investments in TB CRG. Countries can use the STP's Community Support Package in identifying, mitigating, and overcoming CRG barriers in the TB program and find and treat missing people with TB.

## Figure 13

Growth of the Challenge Facility for Civil Society over 11 rounds, 2007-2022



Courtesy: Stop TB Partnership, Geneva

## Catastrophic costs facing TB-affected families

Funding for the social, including economic and legal, protection of people affected by TB is nearly non-existent. There is no wallet supporting the global target to eliminate catastrophic costs faced by families affected by TB. Investments into economic protections for TB-affected communities require multisectoral and legal recourse, and dedicated financing to support those interventions. As it stands, most countries have no budget allocated to other sectors through which people affected by TB can access social security or other benefits; this is raised in Area for Action 6.

## Urgent need for greater, sustained, and diverse financing

There is an urgent need to close the TB funding gap through far more generous and sustained investments, and a greater diversity both in terms of funders and funding priorities.

Right now, the TB response relies heavily on one multilateral donor (The Global Fund) and a very small group of bilateral donors (primarily from the United States). Investments from other bilateral sources and from the private sector are needed to breed a vested interest in TB and to fund creative solutions that could be missed through multilateral mechanisms, especially for KVP-related challenges that are region- or country-specific. In 2020, countries of the G20, for example, which represent 50% of the global TB burden, had a collective GDP of US\$ 66 trillion, projected to be US\$ 99 trillion in 2026. The STP estimates that mobilizing only 0.01% of this collective GDP would make an additional US\$ 6 billion available per year for the fight against TB now, and US\$ 10 billion per year by 2026.<sup>99</sup>

There are emerging new sources of funding on the horizon, such as PPPR/COVID-19 funding, World Bank loan buy-downs by The Global Fund, and crowdfunding.<sup>100-102</sup> Going forward, these new sources of funding need to be explored to strengthen opportunities for domestic investments into TB, and use PPPR and UHC funding to end TB. Not only will this enhance the allocative and technical efficiency of the funds available to countries, it will also save lives across the board.

Borrowing on the successes achieved in other areas of health, innovative funding models can also attract new investors in TB. Social contracting, social impact bonds, low-cost debt financing, pooled donor trusts, and related models can pave the way for sustainable high-impact programs as well as those that may be led by affected communities and civil society. Joint financing schemes can help mobilize resources across programs, such as in primary care, to mitigate costs even before free services can be accessed (for example, before TB screening and diagnosis). People-centered care and local ownership must be at the core of any sustainable investment, coupled with trust building among investing stakeholders and CLM to hold donors accountable for commitments made. [Case study 27]

Diversifying the funding mandate is also critical. Many community-prioritized activities are consistently underfunded. CRG-related hardships, including catastrophic costs borne by families affected by TB, can be addressed — and commitments within the Political Declaration achieved — by developing funding schemes to provide

## Case study 27 Social contracting engages civil society organizations in TB responses in Botswana

Social contracting occurs when civil society organizations (CSO) receive government funding through grants, contracts or cooperative agreements, to deliver public services such as disease prevention, treatment, care and support services. Social contracting is indicative of government recognition of the role of civil society actors, including their outreach skills, community credibility, and innate knowledge of community contexts and priorities.

The Ministry of Health and Wellness and the National AIDS & Health Promotion Agency of the Government of **Botswana** routinely implement social contracts to CSOs. The Botswana Network on Ethics, Law and HIV/AIDS (Bonela, bonela.org) has successfully implemented education and communication campaigns; provided TB, HIV and related care services; trained health workers including on KVP; developed strategies for stigma reduction; advocated for gender equity and legislative changes to address human rights violations; and undertaken a TB CRG assessment. To sustain the progress achieved, it identified several recommendations for inclusion in social contracting mechanisms and guidelines: performance-based funding, predictable funding, clear and common funding guidelines (across all government sectors), simplified reporting, transparency on social contracts awarded, and CSO inclusion and engagement in health financing, monitoring and evaluation of social contracts. These will support CSOs to be more meaningfully engaged in national TB responses and promote greater accountability in the national TB response.

and promote social, legal and economic protections for people and families affected by TB, and scaling them up through regional and multisectoral efforts. Equality markers that are now expected of Global Fund proposals may help elevate attention to these community priorities. A community annex within Global Fund proposals can ensure that these community priorities get integrated into funding schemes and recognized within national budgets. That said, the CFCS has already proved to be an effective mechanism to support CRG in the TB response. Amplified funding expanded to all countries affected by TB can accelerate its impact and help achieve the goal of TB elimination by 2030.

TB R&D has a role to play in this diversification. USAID's upcoming SMART4TB program promises \$200 million in investments to build research capacity and evaluate new, transformative approaches to prevention, diagnosis, treatment and care, and translating research to policy and practice. It will be one of the largest investments into TB research by any donor agency, and there are priorities within to include focus on women and children.<sup>66</sup>

It cannot be understated that unprecedented events such as the COVID-19 pandemic, and the war in Ukraine, will incur major setbacks to TB financing globally and/or in specific regions. Funds earmarked for TB are not always ring-fenced and are easily diverted, without being recouped. Political attention and investment are also now split, with renewed energy and mechanisms for PPPR threatening to leave TB out — despite alignment in agendas. Even so, the

COVID-19 pandemic response shows that with wide-scale pooled investments and multisectoral action, an airborne infectious disease that, in many ways, overlaps with TB can be overcome. Indeed, funding for TB, including TB R&D, can be leveraged through greater alignment with PPPR, UHC, and AMR to mobilize resources and help advance elimination efforts everywhere. These issues are raised in the next chapter.

## CALL TO ACTION

### Invest the funds necessary to end TB

- Close the TB funding gap through investments of US\$ 210 billion between 2023 and 2030, including US\$ 40 billion for TB R&D, to achieve the six calls to action and deliver on the Global Plan to End TB.
- Support replenishment of global financing mechanisms such as the STP CFCS and TB REACH, the Global Fund and Unitaaid, with proportionate allocations for TB and for TB-affected communities and civil society partners.
- Mobilize domestic resources for TB and integrate with health systems to leverage existing investments and reduce dependency on external funds.
- Eliminate catastrophic costs facing households affected by TB through multisectoral investments, coordination, and application of legal frameworks.
- Innovate financing to expand the pool of investors and to breed efficiency in TB spending.
- Ensure TB is recognized and included in investments in pandemic prevention, preparedness and response, antimicrobial resistance, and universal health coverage.



## AREA FOR ACTION 5: Prioritize TB in pandemic prevention, preparedness and response (PPPR), antimicrobial resistance (AMR), and universal health coverage (UHC)

### Introduction

The 2018 Political Declaration's commitment to transform the TB response to be equitable, rights-based and people included commitments to related improvements in advancing universal health coverage (UHC) and antimicrobial stewardship.<sup>1,42</sup> In 2020, the world was faced with the COVID-19 pandemic, giving way to a ubiquitous focus on pandemic prevention, preparedness and response (PPPR). The converging impact of all three movements – PPPR, UHC and AMR – on responses to TB was recognized in the 2020 Progress Report on the Political Declaration.<sup>108</sup> Countries were implored to safeguard TB prevention and care in the context of COVID-19 and other emergent threats, monitor and review the pandemic's impact on the TB response, including with community and civil society engagement, and "build back stronger" by drawing on lessons learned from the pandemic response, improving TB program resiliencies, implementing recovery plans to catch up to targets, and capitalizing on new digital technologies. They were also recommended to advance UHC to enable access to affordable quality care for all people affected by TB, and to include DRTB within national strategies and planning for antimicrobial resistance (AMR).

TB-affected communities and civil society therefore emphasize the prioritization of TB in PPPR, UHC and AMR efforts not only to safeguard the TB response but also potentiate synergies for all (Figure 14).

### PPPR must prioritize the ongoing pandemic of TB

The global response to the world's latest pandemic has outpaced anything seen in the history of the oldest unconquered pandemic. The greatest lesson is that with sufficient political will and funding, scientists, innovators, government and non-government actors, as well as affected communities and civil society can unite to confront a crisis. They can overcome differences and regulatory hurdles, execute rigorous research, create market demand, accelerate access to tools and services, and radically transform the pace of action to generate impact.

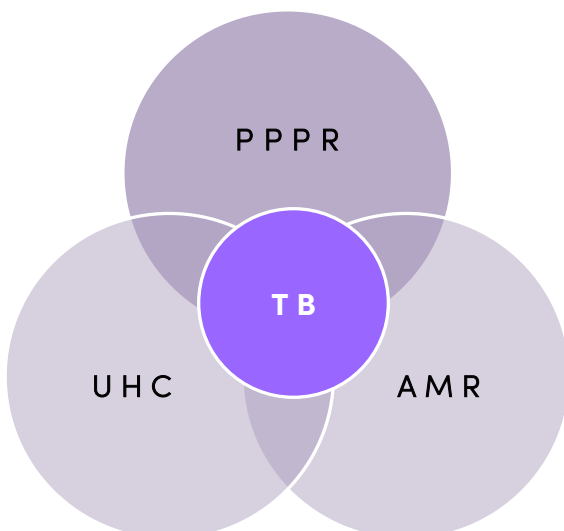
That said, the COVID-19 response was also laden with flaws. It exposed huge inequities and gaps in vaccine rollout, drew attention to the catastrophic costs faced by affected communities – for example, over 150 million people were pushed into extreme poverty by 2021 – human rights violations, and long-term and mental health effects.<sup>109,110</sup> Respondents for this report shared how people with TB were unduly confined and some arrested while collecting TB medications, and KVP were disproportionately affected.

TB, a pandemic in its own right, has ample offerings as responses to current and future pandemics.<sup>111</sup> Indeed, the initial response to COVID-19 was built on the expertise, infrastructure and experience of TB programs, which were quickly translated to support screening, contact tracing, stigma reduction, peer support, community-led monitoring, bidirectional diagnostics, human resources, and medical facilities for people affected by COVID-19. During COVID-19 lockdowns and restrictions, TB-affected communities and civil society developed innovative approaches to maintain continuity of care for people on TB treatment, as also TB screening and testing in communities they knew to be heavily impacted by both infections, even leveraging resources for COVID-19 to reach people for TB. [Case study 28] They uncovered CRG barriers that can inform the development of PPPR more broadly. [Case study 29] They were also instrumental in The Global Fund's COVID-19 Response Mechanism (C19RM), funded and engaged in developing the funding request, which then helped ensure representation of TB and TB community priorities.<sup>112</sup>

It is time for the TB community to bring to the PPPR table the wealth of intellectual expertise borne out of decades of work in TB, draw on the observations and lessons learned from COVID-19 to safeguard investments in TB, leverage investments devoted to pandemic recovery to mount an accelerated response to TB, and address CRG barriers affecting communities in times of crisis. [Case study 30]

## Figure 14

Ensuring prioritization of TB in PPPR, AMR and UHC



There can be no conversation on PPPR minus the commitments and actions to end TB. The Financial Intermediary Fund for PPPR, commonly referred to as the “Pandemic Fund”, is a collaborative partnership involving donor governments, co-investor countries, foundations, civil society organizations, and international agencies, supporting long-term funding for critical PPPR. Hosted by the World Bank, and with WHO as technical lead, the fund has just approved a first round grant of US\$ 300 million for LMICs.<sup>113</sup> Funding to combat current pandemics such as TB must be built into these PPPR schemes, learning from the public health and infection control methods of past and current pandemics, and the synergistic efforts between programs seen over the last three years.

### Case study 28 Leveraging COVID-19 vaccine acceleration to find missing people with TB in Nigeria

In December 2021, USAID launched an Initiative for Global Vaccine Access (GloVax) to intensify COVID-19 vaccine implementation and scale-up in sub-Saharan Africa.<sup>122</sup> Seeing that the COVID-19 pandemic had reduced rates of TB detection in many countries, KNCV TB Foundation **Nigeria** (kncvnigeria.org) – an implementer of a USAID TB LON project and recipient of the GloVax grant, seized the opportunity to ramp up TB screening alongside COVID-19 vaccinations in seven states in the country.<sup>123</sup> “Leveraging on the COVID-19 grant, we looked at what we can do to contribute to [finding people with] active TB and strengthen our TB interventions,” explained Dr Bethrand Odume, KNCV Nigeria’s Executive Director.

How did this play out with TB- and COVID-19-affected communities? With GloVax funding, KNCV Nigeria acquired tricycles, which they branded as the ‘Wellness on Wheels Keke’ (WoK). These were reconfigured and equipped with portable digital X-ray machines (DLB), Truenat, and TB LAMP devices to support TB detection while concurrently improving COVID-19 screening, and vaccine uptake and acceptance. From markets to homes to distant and hard-to-reach communities, WoK transported health workers together with trained community volunteers to screen for COVID-19 and TB, record results, and vaccinate against COVID-19. The project also used funds from the GloVax grant to procure additional digital X-ray machines.

KNCV Nigeria used screening for TB as well as screening and treatment provision for chronic illnesses such as hypertension and diabetes as an “incentive” to engage communities in COVID-19 responses and dispel the myths that were fueling COVID-19 vaccine hesitancy. Many communities more familiar with TB became open to conversations about COVID-19 and vaccination when incentivized in this way. Within a three-month period, the project was able to vaccinate over 1 million people and provided screening for TB, hypertension, and diabetes. Results from one state showed that 4,076 persons were screened for TB, leading to a TB diagnosis in 35 persons over a four-week period. KNCV’s key learning from this intervention is that, by leveraging various health interventions through an integrated health service delivery approach to increase TB screening coverage, TB notifications and linkages to treatment can be improved.

### Case study 29 Lessons learned for CRG in TB and PPPR, from community-led activities during COVID

As many health systems have prioritized the COVID-19 response, community-led innovations became critical to ensuring continuity of care for people affected by TB, especially through the support of TB Champions, peer supporters and other community health workers (CHW). The Global Coalition of TB Advocates (gctacommunity.org), KHANA (khana.org.kh), STP Kenya (stoptbkenya.org), and STP Indonesia (stoptbindonesia.org) studied the community service delivery models in **Cambodia, India, Indonesia** and **Kenya**, and gleaned lessons with implications for CRG- centered service delivery for pandemics of today and tomorrow.<sup>124</sup>

1. Most CHWs, including TB Champions, are not well compensated despite carrying out promotional, logistical and clinical work. All cadres of CHWs must be professionalized and fairly compensated in line with international labor and human rights laws. This includes financing to deploy telephone-based services and access PPE to minimize occupational risks.
2. Even as digital innovations can flourish and enable access to care for many, inequities may grow among particular groups such as the elderly and people without smartphones who miss out on online support interventions, experience greater social isolation, and thus experience compromised care. The digital divide must be overcome as part of PPPR.
3. KVP such as people with co-occurring vulnerabilities and comorbidities will have distinct diagnostics, treatment, economic and social needs during pandemic lockdowns. People-centered, equitable approaches must be planned to cover needs such as home/self-testing, monetary support, and food security.
4. Nutritional support cannot be underestimated as an enabler of adherence to TB treatment. Countries must budget for nutritional support to prevent CHWs from dipping into their own pockets to meet the needs of the people they serve.
5. Affected community groups need to be involved at all levels, including through representation and meaningful consultation presentation as technical experts in national decision-making bodies such as the Pandemic Fund, the upcoming WHO future medical countermeasures platform, and diagnostics policy groups.

The insights of TB-affected communities and civil society who were engaged in TB responses during the COVID-19 pandemic can be tapped to ensure future responses to both TB and other pandemics remain rights-based, gender-responsive, and community-centered.

## Case study 30 Innovative responses to TB amidst disruptions sparked by COVID-19

TB services were adversely affected in many countries by the COVID-19 pandemic. With the support of affected communities, countries implemented a number of approaches supporting continuity of TB care, including reduction in the frequency of healthcare provider visits to people with TB for treatment and support, increasing the supply of anti-TB drugs at each visit to one month or more, and expanding the use of remote advice and digital tools. The WHO also documented examples of best practices in 2021 to disseminate the new knowledge and lessons learned from community-supported adaptations to TB care.<sup>125</sup> For example:

In **India**, TB laboratory personnel were deployed to the COVID-19 response, leaving gaps in TB diagnostic care. The community organization Innovators in Health, Bihar, purchased an additional GeneXpert machine and hired laboratory staff, using cartridges supplied by the district. Government-employed community health workers supervising people on TB treatment additionally covered services along the entire pathway of TB care and supported early detection. The Xpert MTB/RIF testing capacity of the TB program increased by 67% and improved the testing for two comorbidities, HIV and diabetes, by utilizing private laboratories allowing the project to meet targets despite the pandemic.

In **Myanmar**, The Union adapted its socioeconomic support package for people with DRTB by providing tele-counselling at the time of TB testing and using a digital cash-transfer payment (Wave Money) so that more than 95% of people with DRTB received monetary support. These interventions reduced hardship and suffering for people with DRTB and their contacts.

In **Pakistan**, districts supported by the organization Mercy Corps saw a 39% reduction in TB notifications due to COVID-19 lockdown, stigma, health worker shortages, and gaps in community referrals. To counter the drop, they implemented public-private interventions to improve TB diagnostic and treatment services through targeted projects in clinics, private hospitals and “outreach chest camps” for vulnerable populations; self-referrals through interactive voice calls; engagement of female health workers; transport of sputum specimens by community riders; and awareness-building forums. As a result, 98% of people with TB were able to continue treatment without interruption in supported districts.

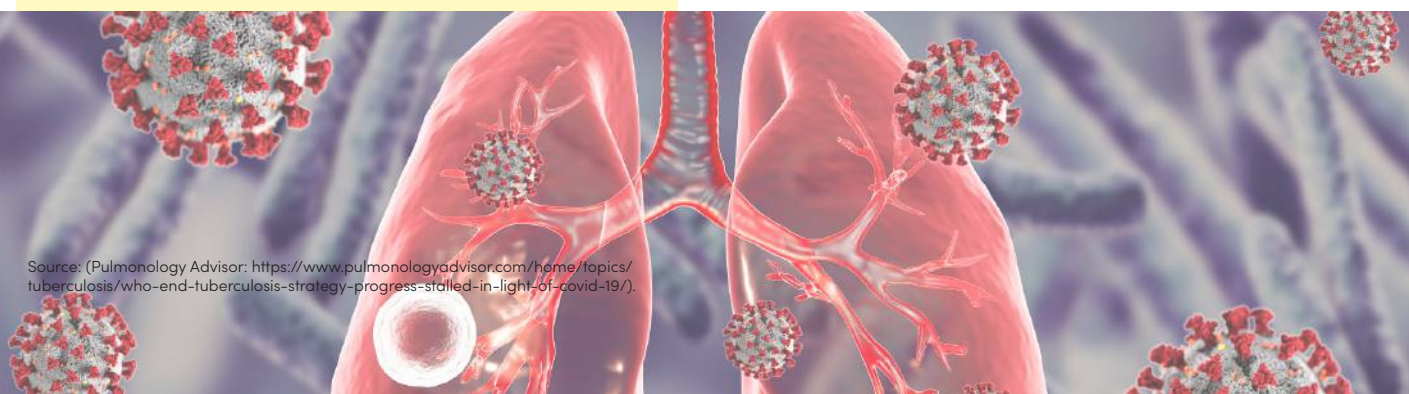
In times of crisis, TB-affected community and civil society actors working at sub-national levels can find acceptable and accessible ways to innovate and adapt while maintaining a high quality of care. Their creativity and success, stemming from a deep understanding of community norms and values, should be harnessed to support strategies for PPPR.

## TB must be a part of the global AMR response

TB is one of the deadliest and most debilitating infectious diseases. The TB bacillus is prone to drug resistance. Each year, half a million people develop rifampicin/multi DRTB, and less than one-half are successfully treated; only one-third of people with extensively drug-resistant disease are cured. Deaths due to DRTB constitute an estimated one quarter of all deaths due to AMR bacteria. Yet, in global iterations of planning for AMR responses, TB is repeatedly and inexcusably overlooked. It is excluded from major AMR funding schemes, much less accorded any priority.<sup>114</sup>

Global strategic priorities on AMR<sup>115</sup> target its key determinants, including antimicrobial misuse and overuse, poor diagnostics, inappropriate treatments and prescribing practices, and poor infection prevention and control, through multisectoral coordination and strengthened surveillance. These determinants are evident in the emergence of DRTB and multisectorality is vehemently expressed in responses to DRTB. There is an obvious synergy to be gained if AMR were entwined into the TB response and vice versa.<sup>116</sup> Akin to any other bacterial disease, TB too is in need of shorter treatment regimens, new molecules, and rapid diagnostics. Advancements in TB drug susceptibility testing and surveillance of DRTB can support efforts in AMR, and wider multisectoral efforts in AMR can deeply benefit global and national responses to TB. TB-affected communities and civil society can inform advocacy efforts in AMR more broadly, given the successes in securing access to the newest antimicrobial regimens for people affected by DRTB. However, TB remains a footnote in the widely publicized WHO priority list for AMR pathogens (despite having a chapter devoted to it in the main report)<sup>115</sup> and still excluded from the Global Database for Tracking AMR.<sup>117</sup> This blindness towards TB needs correction. The language and tenets of an AMR approach could be adopted when vying for resources in TB.

Given that almost 50% of all TB diagnoses and deaths come from G20 nations, which have the financial capacity to mount an effective response, there is an opportunity to call on members of the G20 to match their commitment towards addressing multi DRTB, as part of the global AMR response, with the necessary actions and investments. In 2022, a Call to Action on Financing for TB Response was drafted by the Indonesian G20 Presidency in consultation with G20 members, in collaboration with WHO, STP, Global TB Caucus, Global Fund, USAID, World Bank, and STP Indonesia to spur investments; promote TB within One Health multisectoral approaches to combat AMR; and include multi and extensive DRTB in the implementation of AMR activities.<sup>118</sup> In 2021, the AMR Accelerator | Innovative Medicines Initiative contributed 9% of all public R&D spending on TB drugs. TB-affected communities and civil society therefore hope to see greater integration of TB into mainstream AMR strategies, including AMR accelerator research on TB and AMR.



## TB and UHC

UHC represents the goal of people receiving essential healthcare services without suffering financial hardships, which is in line with the sentinel goals of the TB response.<sup>119</sup> [Case study 31] In developing an index of essential health services from which progress towards UHC can be measured, the WHO identified 16 tracer indicators, one of which is coverage of TB treatment.<sup>120</sup> Modelling studies show that TB is indeed an important indicator of overall UHC service coverage, especially in LIC.<sup>121</sup> This is not surprising as TB disproportionately affects poor and marginalized populations,

### Case study 31 Alignment between visions for responses to UHC and to TB among affected communities and civil society

The Global Fund Advocacy Network Asia-Pacific Region and APCASO (apcaso.org) convened the Asia-Pacific community and civil society UHC caucus to articulate a UHC model that would respond to the priorities and needs of affected communities and civil society<sup>126</sup>:

- **People-centered UHC**, attending to people and communities as opposed to diseases and with a focus on holistic, equitable and destigmatizing care. Healthcare is affected and determined by people's multiple social identities and may therefore require differentiated and tailored approaches.
- **Equitable and rights affirming UHC**, which recognizes inequities and prioritizes access to health for the most excluded communities. This includes removal of punitive laws against key populations based on their sexual orientation, gender, identity or expression, drug use, engagement in sex work, or HIV, migrant and other statuses, and inclusion of sexual reproductive health and rights as core to the right to health.
- **UHC that meaningfully engages community and civil society participation**, as equal partners of government and development partners in design, budgeting, review of health policies and plans, with sufficient resourcing, legal enablement, and inclusion of KVP.
- **Effectively and sustainably financed UHC**, which ensures access to services without financial hardship, by drawing on global solidarity and calling on governments and international donors to increase investments, remove user fees for essential drugs and services, improve technical and allocative efficiency in health spending, earmark funds for community mobilization and leadership, and ensure resources are allocated to marginalized communities.
- **Accountability mechanisms to achieve the "UHC that [they] want"**, which are transparent, recognize the primary role and accountability of governments, and meaningfully engage community and civil society.

The UHC caucus recognizes that SDG targets related to UHC and TB (and malaria and HIV) are interdependent. The overlap between community-centered ideas for UHC and the calls to action articulated by TB-affected communities in this report give way to natural opportunities for synergistic advocacy and action in UHC and TB.

and if we do not reach them, then we do not achieve UHC. Given this reality, TB can, and should be the entry point for efforts to strengthen UHC and is an optimal indicator for the achievement of UHC. TB screening and diagnosis, treatment (including preventive treatment) and care must be included in every national essential service package for UHC. Not only would this move the agenda for UHC forward, but it would also ensure sustainability of the TB response. [Case study 32]

### Case study 32 Gaps in UHC implementation shape poor TB outcomes in Chad

In many African countries, with **Chad** in particular, large proportions of the population live in conditions of extreme poverty. Diverse crises prevent countries from providing minimum coverage of social and health services. In 2015, a National Strategy for Universal Health Coverage was adopted in Chad and implemented through the promulgation of Law No 035/PR/2019 in 2019.<sup>127</sup> Despite the political will displayed to improve financing, accessibility and quality of care, in particular free care including access to essential medicines, funding remains very weak and UHC is not being realized. Underserved, isolated communities are unable to enjoy their right to health, impeded by communication and infrastructure barriers. They have very limited access to TB screening, diagnosis, treatment, and follow-up care services, which may explain the poor results of the country's TB response. In 2020, 43% of people with TB were missed in notifications and 5,600 people died of TB.<sup>106</sup> The barriers to access essential healthcare services, including for TB, are poorly understood.

Four years after the promulgation of the UHC Law and despite support from various technical partners, Chad still faces governance, structural and financial problems. CRG and catastrophic cost assessments could allow the NTP to reorient its National Strategy to approach the objectives of achieving UHC and ending TB by 2030.

### TB-affected communities can strengthen linkages to PPPR, AMR and UHC

Models involving affected communities and civil society as equal partners are needed not only for TB but also PPPR, AMR and UHC, with equal voting rights and seats in governance arrangements – globally and at the country level – and with funding for implementation arrangements and accountability mechanisms. TB-affected communities and civil society have demonstrable experience to contribute to these conversations. In 2023, UNHLMs will be held not only on TB but also UHC and PPPR. There is no better time than now to ensure the visibility and prioritization of TB at each of these critical events so that TB elimination stays high on the agenda of political leaders and investors during those conversations. TB-affected communities and civil society must be supported in having a voice on these platforms to safeguard attention and investments toward ending TB, and to contribute to broader efforts in health that will, no doubt, improve the lives and wellbeing of communities affected by TB.



## CALL TO ACTION

### **Prioritize TB in pandemic prevention, preparedness and response (PPPR), antimicrobial resistance (AMR), and universal health coverage (UHC)**

- Ensure PPPR draws on experiences from and addresses present-day pandemics like TB and its role in future airborne pandemics, with aligned funding.
- Ensure TB drug-resistance is featured in AMR surveillance and addressed in AMR strategic planning and aligned funding.
- Ensure TB screening, prevention, diagnosis, treatment, and care are included in national essential service packages for primary health care and UHC, and conversely ensure that all people affected by TB, including KVP and family members, are enrolled and protected by national UHC schemes, thereby using TB as an indicator of progress towards UHC.
- Develop funded models for the meaningful inclusion of TB-affected communities and civil society as equal partners in PPPR (including the Pandemic Fund), AMR and UHC responses, with representation and voice within governance arrangements globally and at country level.



## AREA FOR ACTION 6: Commit to multisectoral action, decisive leadership and accountability

### Introduction

Given that TB is inextricable from its social determinants and impacts, responses to it cannot be contained within the domain of NTPs or health ministries. Siloed approaches serve as obstacles to reaching all for TB prevention, diagnosis treatment and care; innovating and ensuring access to new tools in TB care, or achieving the complementary goals of counter-responses in PPPR, AMR and UHC.

Leadership and accountability in the TB response are enshrined within this critical call for multisectorality. Political leadership and multi-stakeholder accountability at levels beyond ministries of health, funding bodies, and technical actors; and independent, transparent evaluations of the TB response are essential to accelerate action and build systems of answerability. The ultimate accountability bearers of any response to TB are people affected by TB and civil society. We must be firmly present at decision-making and planning tables that determine what happens to us, how, and whom we can hold to account when promises are not fulfilled.

This final chapter focuses on commitments, critical gaps, and opportunities for clarifying and strengthening multisectoral action, decisive leadership, real-time data and accountability in the TB response.

### Current state of affairs

#### Scorecard

In 2019, the WHO released a multisectoral accountability framework for TB (MAF-TB) and provided technical guidance to countries and stakeholders to adapt and implement MAF-TB. It was crafted together with other UN agencies including the International Labour Organization (ILO), International Organization for Migration, UN High Commissioner for Refugees (UNHCR), World Food Programme (WFP), UN Children's Fund (UNICEF), WHO Civil Society Task Force (CSTF), and civil society and community organizations. The four components of MAF-TB are global/political commitments relevant to TB, in particular, in the 2018 Political Declaration, SDGs, and End TB Strategy; operationalizing multisectoral action; monitoring and reporting processes to track national TB responses; and periodic reviews of national responses with high-level leadership, multisectoral perspectives, and stakeholders including TB-affected communities and civil society.<sup>128</sup> By 2021, baseline assessments of MAF-TB, using checklists, were completed in 45 countries. They revealed major gaps in implementation (Table 6).<sup>74</sup>

## Table 6

### Progress achieved on multisectoral action and accountability

<b>1. Translation of commitments to policies</b>	67% have translated commitments to national policies.
<b>2. Multisectoral actions</b>	56% NSPs align with multisectoral action (integration with primary care, HIV). 33% have national multisectoral coordinating bodies; <50% address other social determinants of TB (for example, undernutrition, poverty).
<b>3. Monitoring and reporting processes</b>	89% have strong TB surveillance systems; 53% have other national data (for example, costs, DRTB); 51% have sub-standard reporting on childhood TB; 50-plus% do not have digital surveillance; 20% engage TB-affected communities and civil society in monitoring and reporting.
<b>4. Periodic reviews</b>	80% have no review by high-level political leadership; 50% have no stakeholders beyond the health sector; No indicators to measure performance of accountable stakeholders; No budget for TB-specific activities by accountable stakeholders.
	33% countries have all four components in place.

From WHO MAF-TB: progress in adaptation and implementation<sup>74</sup>

In 2020, following up on commitments made within the Political Declaration, the WHO Director-General released a report on progress towards achieving global TB targets and implementation of the Political Declaration, stating that while there has been some progress, “urgent and more ambitious investments and actions are required to put the world on track to reach targets, especially in the context of the COVID-19 pandemic”.<sup>108</sup> TB-affected communities and civil society sense a palpable urgency to mobilize action at the 2023 UNHLM on TB, and this is reflected in calls to action in this report.

**Engagement of health and non-health sectors**  
Non-health sectors remain largely unengaged in the TB response. Only 50% of NTPs connect to sectors outside of health (Table 6).<sup>74</sup> Without multisectoral linkages, and financial investments to support them, targets for TB elimination will remain out of reach (Figure 15). For example, the smooth procurement and importations of essential TB diagnostics and drugs requires high-level buy-in by the Ministries of Trade, Finance and Customs. Tackling the social and economic barriers facing TB-affected communities requires coordination between Ministries of Urban Planning, Housing, Labor, and Social Protections.

Even within health sectors, as suggested by MAF-TB baseline assessments, TB-affected communities and civil society report poor coordination. There are weak to no linkages between TB programs and those which address child and maternal health, long-term/post-TB related disabilities, and comorbidities beyond HIV. There is also, overall, insufficient coordination with the private sector, despite evidence suggesting 60% of people in TB-impacted countries access initial care in the private sector.<sup>129</sup> Collaboration with other health programs and sectors outside of health are essential for TB care, to ensure visibility for TB in conversations about PPPR, AMR and UHC.

## Figure 15

An effective TB response requires comprehensive actions across all sectors



## Engagement of TB-affected communities and civil society

In many countries, TB-affected community and civil society groups, including TB survivor-led groups and social observatories, are establishing and strengthening country and regional advocacy platforms for multisectoral action and accountability. [Case study 33] [Case study 34] Survey responses show that many respondents are engaging with TB affected communities and civil society, especially people affected by TB and TB survivors, NTPs and other health sectors, other community/civil society organizations, and political and social leaders outside of national ministries (Figure 16). This suggests there is an appetite for multisectoral coordination and action. However, the lack of funding – also raised in Area for Action 4 – is cited as a major impediment. TB affected communities and civil society also have to contend with a history of their exclusion in TB responses, which many countries are yet to address despite the extraordinary shifts in some other settings; this is raised in Area for Action 2. Several respondents noted that momentum around community engagement and empowerment that are observed at the global and regional levels are not always translated within countries and local communities. Indeed, most respondents (36%) who stated engaging with different sectors described these encounters as consultations about specific projects as compared to formal partnerships, much less tied to an accountability mechanism.

### Case study 33 Networks of people in high income countries engage in advocacy

Networks of people committed to ending TB in high-income country settings are mobilizing with renewed energy. For example, in 2020 the advocacy organization Results UK (results.org.uk), **United Kingdom**, helped to develop and sustain a new network of UK Academics and Professionals to end TB (UKAPTb, ukaptb.org), which is now campaigning, advocating, and educating the general public, public servants, and politicians to improve UK policies on TB and devote more resources to TB research. Likewise, in **Denmark**, the Global TB Caucus, AIDS Fondet and MSF have come together to convene a new TB/HIV caucus in parliament. Lastly, in **Canada**, alongside committed allies, Results Canada has helped to reinvigorate Stop TB Canada (stoptbcanada.com) to promote policy actions, create public awareness, and mobilize communities affected by TB. This led to the launch of TBpeople Canada (stoptbcanada.com/tbpeoplecanada), the country's first supportive community for people who have or had TB, and their family members, friends, and caregivers.

Despite being volunteer-run and supported by bootstrapped start-up budgets, many of these networks are playing crucial roles in building political will towards ending TB in their countries. The relationships and capacity being built are priming advocates and parliamentarian champions to engage in the fight to end TB, now and into the future.

*"Thanks to my role with Stop TB Canada – it has launched me into platforms where I can create awareness using my professional and personal experiences with TB, having worked in several remote Indigenous communities."*

**Tina Campbell, Stop TB Canada Co-Chair and TB Advisor for the Northern Inter-Tribal Health Authority (NITHA).**



When community leadership has been harnessed to enable multisectoral action and bridge sectors, the gains have been profound for people affected by TB. [Case study 35] The CFCS has also enabled TB-affected communities to branch out and make connections with journalists, celebrities, and other public figures to champion their cause – as raised in Area for Action 4. The emergence of parliamentary caucuses devoted to addressing TB, with the support of TB-affected communities and civil society, has helped raise awareness and build demand for domestic resource mobilization in support of global TB elimination targets. [Case study 36] Thanks to the efforts of the Global TB Caucus, for example, TB is now referenced in every G20 Ministers of Health and Heads of State declarations.<sup>130</sup> However, WHO reports show that only 41% of countries are engaging TB-affected communities and civil society in national responses.<sup>74</sup> This suggests we are still not achieving the omnipresent goal.

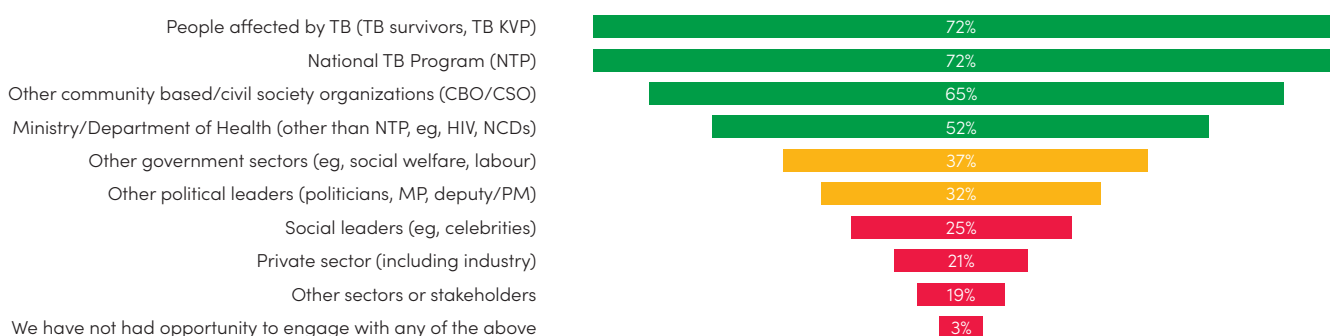
## Case study 34 National Stop TB Partnership chapters

Presently, there are 30 active national Stop TB Partnership (stoptb.org) platforms in both donor and implementing countries, and 16 of them are supported through grants and technical assistance (with a further two envisaged for 2023). These platforms have brought together a range of stakeholders to support multisectoral actions. Some of their achievements in enabling progress on community priorities related to human rights, stigma and KVP are listed below:

- **Cambodia:** Broad media engagement in press and talk shows, mainstreaming discussions on ending TB.
- **Democratic Republic of Congo:** Mapping of seven key and vulnerable populations and facilitation of the representation of each group in national TB governance.
- **Indonesia:** Promoting TB as part of the G20 agenda during the Indonesian presidency while acting as Global Fund co-Principal Recipient.
- **Kenya:** Mobilizing celebrities and communities in a national TB human rights campaign on ending TB stigma and discrimination, and access to services.
- **Nigeria:** High-level advocacy for increased domestic resource mobilization; engagement of political elites, the media, and celebrities; established and supporting Nigeria Parliamentary TB Caucus and TBpeople Nigeria, a national network of TB survivors and people affected by TB.
- **Pakistan:** High-level dialogue with President Dr Arif Alvi and national leaders on ending TB.
- **Tajikistan:** Engagement of popstars and celebrities as TB champions to increase the visibility and profile of TB.
- **Tanzania and Uganda:** Engagement of political leaders at the highest level possible to control TB and ensure commitments to end the disease by 2030.
- **Ukraine:** Social mobilization for ending TB in the country. After the beginning of the war, the partnership has been facilitating coordination among civil society's humanitarian efforts.
- **Zambia:** Active TB case detection in several provinces and TB awareness programs.

## Figure 16

### Multisectoral engagement among survey respondents



## Case study 35 Parliamentarians form the backbone of advocacy in the Global TB Caucus

The Global TB Caucus (GTBC, [globaltbcaucus.org](http://globaltbcaucus.org)) is a unique international network of political representatives. It gathers over 2,500 members and has helped launch 56 National TB Caucuses, four regional networks (Africa, Americas, Asia Pacific, Europe), and a linguistic network (Francophone) to mobilize parliamentarians to become TB champions who promote legal environments that support equitable, people-centered human rights-based and gender-transformative TB responses. Members adhere to the principles outlined in the founding document, the Barcelona Declaration: “to work across geographical and political divides in a non-partisan and inclusive fashion; to engage with civil society and all other stakeholders involved in the fight against the TB epidemic; and to confront stigma and social isolation associated with the disease.”<sup>132</sup>

The GTBC is making significant strides in raising political interest and momentum at the regional level. The GTBC of the Francophone region, for example, is seeing a steady increase in the number of parliamentarians engaged in the TB response in **Chad, Cameroon, Gabon, Niger, and Côte d’Ivoire**. In 2021, the Caucus joined efforts with DRAF TB, the Regional TB umbrella network in Francophone Africa, for a baseline assessment of achievements under 2018 UNHLM targets. This led to the production of five videos featuring parliamentarians from Chad, Senegal, DRC and Mauritius to amplify a united voice and a call for greater domestic investments and resources to support the fight against TB.

Several regional efforts are also having national impacts. In **EECA**, for example, the Caucus piloted Annex 4 of the multisectoral accountability framework to accelerate progress to end TB (MAF-TB) to assess the level and extent of parliamentary engagement on country-level responses and to define the role of parliamentarians in the MAF-TB process. This involved organizing a TB Legislation workshop in 2022 and the subsequent development of a report on ‘People-Centered, Rights-Based TB Legislation in Eastern Europe and Central Asia’. The report outlined the current state of TB-related legislation in the EECA region, together with 15 essential recommendations to promote people-centered, rights-based TB legislation. The recommendations are now being used to guide TB legislation review in **Moldova**.

## Leadership and accountability

As one of its first recommendations, the 2020 Progress Report on the 2018 Political Declaration urges action toward multisectoral collaboration and accountability under the leadership of Heads of State or Government. But most countries are still not engaging sectors other than health in matters related to TB (**Table 6**).<sup>74</sup> The absence of indicators for TB-specific activities in non-health sectors, and the lack of financing for TB-specific activities in any other sector – much less to engage TB-affected communities and civil society – is stalling action. [**Case study 37**]

Leadership and accountability in the TB response, therefore, remains largely under the purview of NTPs and ministries

## Case study 36 Social observatories – a regional mobilization of civil society

A mechanism termed ‘social observatories’ (SO), intending to mobilize civil society, as well as support social surveillance and political influencing, was successfully launched in 2022 by Socios en Salud and the TB Coalition of the Americas with support from the Global Fund.<sup>133</sup> SOs are designed to support implementation of PAHO Engage-TB strategy, based on integrated community-based TB prevention, diagnosis, treatment, and care. It is a space for the convergence of civil society that makes visible the problem of the disease and promotes and strengthens civil society participation in national and regional control strategies against TB. Each SO is structured to include:

1. A General Assembly of interested members of civil society.
2. A Technical Secretariat, which is generally a non-governmental organization (NGO) with more than five years of experience working on TB in the community and serving as a host for the administration of the observatory.
3. An to study the impact of the SO at various levels of completion.

The General Assembly of each SO determines the areas of work to be undertaken. In the Americas, the areas identified included public policy, human rights, vulnerable populations, community monitoring, syndemics, capacity building, monitoring, advocacy and research, case management, psychosocial aspects, and social protections. SOs have become an important space for promoting the CRG framework, cultural relevance, and differential focus for the most vulnerable communities.

of health at the country level, who also remain answerable to donor agencies, and WHO at the global level. This may be problematic on many fronts. First, NTPs and the global TB program rely on a narrow set of indicators to monitor progress, almost entirely clinical and agnostic to the wider realities and challenges facing people affected by TB. Though gender disaggregated data is beginning to be reported, as well as comorbid risks associated with TB, nowhere are the other social, economic and rights-related indicators captured – which are prioritized by affected communities and implicated in their engagement (or disengagement) in care. Second, programs delivering services – or those that chart guidance on service delivery – cannot reasonably be held answerable for their own progress or the lack thereof. The bearers of accountability in the TB response – TB-affected communities and civil society actors – must be integrated into the monitoring and performance evaluations of TB responses, and through channels that are unencumbered by social service delivery contracts to support independent, transparent accountability. MAF-TB baseline assessments suggest that among countries that engage TB-affected communities and civil society in national responses, only a half engage communities in program monitoring and review processes.<sup>74</sup> This type of guarded inclusion borders on tokenism, and could threaten the accountability process. Third, without high-level leadership and governance, there will be difficulties in coordination, resource mobilization and answerability between other government sectors. The COVID-19 pandemic has shown that the engagement of political leaders is one of the most crucial forces needed to accelerate progress.

## Case study 37 Elevating multisectoral accountability in Francophone Africa

The Francophone Africa Response Dynamics on Tuberculosis (DRAF TB, [draftb.org](http://draftb.org)) is committed to measuring progress made toward the Political Declaration in Francophone West and Central Africa. With support from the CFCS, DRAF TB undertook a baseline assessment of the implementation of multi-sectoral accountability frameworks in 12 countries – **Benin, Burkina Faso, Burundi, Cameroon, Chad, Congo, DRC, Gabon, Guinea, Côte d'Ivoire, Niger, and Senegal** – including interviews with representatives of National TB Programs.<sup>134</sup>

While all countries were found to align their NSPs for TB with the UN SDGs and the WHO End TB Strategy, none had owned the Moscow Declaration of the WHO Global Ministerial Conference on the Elimination of TB (2017) or the Political Declaration of the UNHLM on TB (2018). These delays were reflected in the 2020 Progress Report of the Secretary General of the UN and the WHO where the Africa region was noted to be a focal TB setting – with 25% of all people with TB; and in the 12 countries assessed, 78,000 people had died, including 24,000 with HIV.<sup>135</sup>

The assessment concluded that global commitments are being weakly implemented in all 12 countries. Priority areas in need of special attention include high-level leadership; establishment of multisectoral accountability frameworks; sufficient and sustainable funding; research and innovation; and considering the role that determinants such as poverty, vulnerability, and gender inequality play in the epidemic.

## Community-led monitoring

NTPs face significant challenges of service availability, accessibility, and quality, commodity supply and distribution, and other human rights barriers that negatively affect health outcomes and program targets, as was echoed by respondents and are raised in other chapters of the report. CLM is an intervention that serves to fill the data gaps around these challenges.<sup>73</sup> Under CLM, TB-affected communities systematically and routinely report and analyze data on service provision and quality, as well as stigma and human rights violations from service delivery sites and along the pathway of care. This information can provide deep and unique insights on the service delivery gaps, human rights and stigma barriers preventing access, and on the targeted action needed to improve services and the experience of people affected by TB, resulting in better health outcomes for individuals and the broader community. CLM is therefore an intervention that can overcome the service delivery and human rights barriers that negatively affect health outcomes and program targets. Importantly, CLM is complementary to national health management information systems (HMIS) and, together, these data can also inform national strategic and operational planning for TB programs to improve overall implementation and mitigate programmatic risks.<sup>73,131</sup> [Case study 39] Nearly two-thirds (64%) of representatives of TB affected community and civil society organizations who responded to survey questions about CLM had been

## Case study 38 Community-led monitoring (CLM) enables tangible changes in TB service delivery

Using the OnelImpact tool for CLM, community and grassroots organizations funded by the CFCS were able to systematically document key barriers to service delivery and catalyze action for changes to TB protocol and practices in diverse settings.

In the **Democratic Republic of Congo**, Club des Amis Damien highlighted drug stockouts, unauthorized user fees and high levels of TB stigma in health facilities in Kinshasa and Kongo Centrale provinces. This led to a memorandum of understanding with the NTP to alert them about drug stocks from a community perspective, the issuance of letters prohibiting health facilities from charging unauthorized fees, and the central decision to undertake a nationwide TB stigma assessment. In **Pakistan**, the Association for Social Development in Nankana Sahib District uncovered acceptability challenges facing women seeking care from male doctors. Medical consultation protocols were thereby changed, including an increased presence of female doctors. In **Uganda**, Philomera Hope Foundation used CLM-generated data to combat stigma, advocate for gender-sensitive programming, and expand mobile testing for TB at four clinics in the remote island community of Kalangala through an agreement with the telecom provider Airtel. In **Ukraine**, TBpeople highlighted high levels of discrimination among people with TB, which led them to advocate for the development of a TB law to protect and promote the rights of people affected by TB.

CLM can therefore be a gateway to community engagement and mobilization, capacity building, real-time data driven responses, overcoming human rights barriers with community-led solutions, and strengthened partnerships between NTPs and TB-affected communities. These country examples help bolster credibility in CLM, both in terms of its process and impact.



Images – Airtel #UgNeedsMoreofU

engaged in CLM of the TB response in varying capacities, expressing hope for greater investments in this area. They saw immense added value in the opportunity to engage in reviews of the TB response together with NTPs and other partners, capture perceptual, gender- and rights-related barriers and enablers to accessing TB services, and contribute to elevating affected community priorities and accountability in the TB response.

### Case study 39 Expanding access to social protection and health insurance for households affected by TB in Djibouti

MAF-TB baseline assessments undertaken with the technical guidance of WHO uncovered many gaps in multisectoral action to address the social determinants and impacts of TB, and insufficient engagement of TB-affected communities and civil society. However, there were also important success stories that can serve to generate demand for investments in multisectoral coordination.<sup>74</sup>

In **Djibouti**, the World Food Programme (WFP) complemented the national social protection program, Programme National de Solidarité Famille (PNSF), with a cash transfer program to help protect the most vulnerable households affected by HIV and TB during the COVID-19 pandemic. WFP also advocated for PNSF to include these households into their ongoing family support program. WFP, with the support of non-governmental organizations, Le Réseau and Solidarité Féminine, and in collaboration with the Ministry of Health and Ministry of Social Affairs and Solidarity (MASS), delivered cash to HIV- and TB-affected households for nine months. Beneficiaries were also enrolled in the national social registry managed by MASS, in the same way as other PNSF beneficiaries, to help mitigate barriers related to stigma and discrimination. Once enrolled, beneficiaries were automatically eligible for health insurance under the Programme d'Assistance Sociale de Santé (PASS).<sup>74,136</sup>

Community actors not only serve as key gatekeepers to the community, but they can also help mediate and propel coordination between government and non-government actors in TB responses.

OnelImpact Community-led Monitoring, introduced in Area for Action 2, is the innovative, rights-based approach to community participation, and accountability in TB, endorsed by global, regional and national TB communities. It leverages technology to optimize community engagement, data collection and analysis, responses, and systems for a rights-based response to TB. Built on the principles of community leadership, country ownership, people-centeredness, institutionalization, and evolution, the OnelImpact CLM approach has been designed, led, and implemented by affected TB communities, with strategic guidance, support, and continuous engagement from NTPs for accountability. It draws on six years of implementation experience across 26 countries.<sup>73,131</sup> [Case study 40]

### ONE IMPACT COMMUNITY LED MONITORING (CLM)

OnelImpact is a digital platform that operationalizes community engagement, community empowerment and community-led monitoring solution for the TB response. It was developed by the Stop TB Partnership together with affected communities and civil society, and Dure Technology, and comprises three connected components:

- Downloadable mobile application, providing people affected by TB with on-the-go information on TB, their rights, TB care, support services, and virtual connection to peers to report and rapidly resolve challenges.
- First responder dashboard, allowing responders to track, coordinate, and mobilize responses to reported challenges.
- Accountability dashboard, allowing community advocates to monitor and analyze trends in the challenges reported, and generate CLM reports for advocacy, action, and programmatic change.

Since 2017, OnelImpact has been applied in over 26 projects/countries to support CLM and related community actions.

### Case study 40 Human Rights and Accountability — Scorecard development in the Philippines

In the **Philippines**, there have been several initiatives to garner information from health service users. This includes piloting TB community-led monitoring (CLM) and the development of an accountability scorecard.

In 2022, the Scorecard initiative, led by ACHIEVE, represented a significant contribution of TB-affected community and civil society to national accountability. It also uncovered some interesting findings. Overall, people with TB disease and TB survivors rated TB services in the Philippines 4.25 out of 5, which shows there are many strengths in the Philippines TB program. However, further analysis shows that a focus on getting people with TB cured may overshadow the gaps they experience while accessing services. Gaps that were identified reflect findings from the country TB CRG Assessment and includes:

- Inadequate communication between doctors and people affected by TB, which results in the latter not understanding anything about their treatment;
- Insufficient medical staff relative to number of people requiring medical services; and
- Inadequate access to treatment.

CLM in TB can yield important insights into the functioning of national programs, including positive aspects and those that would benefit from immediate attention to enhance the quality of care and address the CRG-related barriers facing TB-affected communities.

# TB COMMUNITY REPORT:

What do TB-affected communities say about TB programs and services?



A community scorecard is a tool for reviewing and assessing service delivery and ensuring accountability of the government to its mandates and its people.

In 2022, ACHIEVE and PASTB through the support of USAID developed the Community Humanrights Scorecard to capture TB-affected people's feedback on TB services.

The TB Scorecard was rolled out in seven (7) pilot areas from September to November 2022.



SCORE OF **4.25 out of 5** **OVERALL TB EXPERIENCE**

The scorecard respondents gave this rating which was mostly characterized by the statement, "*Okay na rin, ang importante, gumaling*" (It's fine, the most important is to get cured).

*Libre ang gamot pero masikip nga lang ang facility.*  
*Kulang sa doctor's assistance. Minsan walang doctor.*  
 This rating reflects the appreciation of respondents to the program, but also their inclination to look past the gaps in TB services – gaps that need to be filled in towards a TB-free PH.



## MAJOR AREAS

### Diagnosis

**59.7%**

(604 out of 1,012) of respondents said that they paid for their x-ray (~PhP150 to 400).

**60.5%**

reported going through TB contact tracing, and said that other household members were screened for TB (83.8%). However, among those screened, only 77.6% reported being tested, and out of this, only 25.7% received TB Preventive Therapy.

### Treatment

**Start of treatment, side effects:**

5.3% waited to start treatment after diagnosis.

76.7% reported having experienced side effects, but 6.3% of them said that these were not addressed.

**15.9%**

said that the facility location is not very accessible because transportation is costly (91.3%).

**93.3%**

reported that there were enough facility staff to respond to their needs, however, 4% felt they were not friendly and accommodating.

## CATASTROPHIC COSTS

While TB treatment is often provided at no cost to patients, additional expenses incurred by TB-affected households can have a negative impact on finances and their wellbeing.

The scorecard found that those who paid for their x-ray were mostly treated in public health centers.



**P150-P400**

is the cost of x-ray paid by almost 60% of the respondents



60.8% percent of those who paid for x-ray in public health facilities reported being unemployed.

## STIGMA AND DISCRIMINATION

**13.7%**

reported being discriminated in the workplace

**10.4%**

reported difficulties applying for a job

**9.1%**

reported being terminated due to having TB.

## COVID-19 PANDEMIC



of the total respondents were diagnosed with TB during the pandemic.

**14.6%**

reported the facility they were treated at to be inaccessible (mahirap puntahan)



## Real-time data

Among its other findings, MAF-TB assessments also show that over %50 of countries still rely on paper-based surveillance for TB, which is prone to errors and delays and altogether ignores or, at best, inconsistently captures CRG-related barriers.<sup>74</sup> A recent assessment of digital TB surveillance systems, undertaken by STP and The Global Fund, found huge variations in the maturity of systems used in 19 highly impacted countries.<sup>72</sup> Technical, human resource and infrastructure constraints were rife, including poor Internet connectivity, IT capacity, advanced analytics such as AI to guide data-driven action, systems to monitor people with TB from screening to treatment completion, or standardized approaches to capture granular data on community barriers.

TB responses must be informed by real-time data. The WHO Global TB Report stands as the most robust global surveillance platform for annual reporting; in 2020, it matured to include monthly reporting of national TB notifications. This is still insufficient and behind the surveillance systems adopted in the monitoring of other epidemics and pandemics. If we ever needed a reminder of the need to prioritize real-time data, then presenting an update on global TB data — in the midst of a pandemic — using data from before the pandemic is the strongest possible example.

## Conclusion

Today, five years after the first UNHLM on TB, almost no targets of the 2018 Political Declaration have been achieved. Indeed, we were set to miss targets even before the COVID19- pandemic. What are the consequences of an unsuccessful outcome? Who can be held to account and how? This cannot be the accountability system that TB-affected communities deserve. As we applaud the stakeholders and systems that have enabled important victories in the last five years, those of us who live with TB and face the risks of developing TB are no longer content to quietly rationalize the losses where crucial targets were missed. As we build a reimagined response to TB – with the calls to action expressed through the consolidated voice of TB-affected communities and civil society contributors to this report – we urge a more frank and fearless approach to building accountability at the 2023 UNHLM on TB. As demonstrated through the testimony shared within the 40 case studies contained in this report, which represent only a handful of community-led actions around the world, TB-affected communities and civil society have immense capability to inform a more comprehensive TB response. As consumers of public services, they are already continually engaging with multiple sectors of the government. Given their innate knowledge about the lived experience of TB, there is no better ally to propel progress in this priority area.

## IMMEDIATE ASKS FOR THE 2023 UNHLM ON TB

To secure multisectoral action, decisive leadership and accountability for TB — a disease that affects us deeply and that kills our loved ones every day — we implore **Heads of State** to attend, participate and pledge increased commitments to the TB response at the 2023 UNHLM on TB; for civil society to feature in all country delegations; that the UHC and PPPR calls to action in this report are integrated into briefings for the respective UNHLMs that are also taking place in 2023.

We also ask for the **UN President of the General Assembly**, along with co-facilitators, WHO and STP, to partner with TB-affected communities and civil society in determining concepts, agendas and speakers for the Multi stakeholder Hearing and the UNHLM. We want to ensure TB gets the attention it deserves, it is not sidelined, deprioritized or consumed by the busy agenda of the UN General Assembly and health HLMs.

## CALL TO ACTION

### Commit to multisectoral action, decisive leadership and accountability

- Develop partnerships with journalists, parliamentarians, celebrities, and other public figures to champion and implement the calls to action from this TB accountability report.
- Strengthen sector-wide collaboration and scale up adoption of the Multisectoral Accountability Framework (MAF) for TB, while developing additional mechanisms to hold all stakeholders to account for achieving commitments and targets.
- Apply CLM models to understand and address the realities facing TB-affected communities, including stigma, human rights violations, and to document community-led actions in addressing those barriers. Use these data to bolster national TB, PPPR and UHC responses and accountability for CRG.
- Engage Heads of State, high-level leadership and TB-affected communities and civil society in monitoring and review of national TB responses, multisectoral action and accountability mechanisms, and translating commitments on TB in PPPR, AMR and UHC into action, including at the 2023 UNHLM on TB.
- Request WHO to develop a timetable and transition plan for real-time surveillance systems and data reporting.
- Mandate inclusion of TB-affected communities and civil society within Country Coordination Mechanisms (CCMs) and technical working groups related to monitoring and review of national responses, including support for STP Community and NGO Delegations to support the development of accountability reports in subsequent years.



# Annex: Methodology

## Overview

Data collection instruments for this report were adapted from those developed for the first Deadly Divide report. Surveys were posted online and made publicly accessible; they were completed in English (54.9%), Russian (16.3%), French (15.7%), and Spanish (13.1%). Interviews were conducted in private, virtually, in these and other regional languages based on respondents' preferences. All questions within the survey and interview were optional. Respondents were given a choice to withhold or disclose their name, organization and/or country and distinctly asked permission to share any or all of that information in an ensuing report. Documents from the gray and published literature were gathered to substantiate points raised within surveys and interviews.

Regional analyses were drafted based on survey and interview data emerging from Asia, Anglophone Africa, Francophone Africa, Eastern Europe and Central Asia, the Americas, and high-income countries. Data from interviews with individuals working globally were narratively synthesized. The raw data, regional analyses, and global synthesis were iteratively analyzed. Six main chapters were developed to highlight key achievements, gaps and opportunities related to the priority areas of action identified by TB-affected communities and civil society; a scorecard in relation to the Political Commitment emanating from the first UNHLM on TB in 2018, WHO End TB Strategy and TB-affected community and civil society priorities; case studies of community best practices and challenges; and reference to related guidelines, reports, publications and resource materials, including those recommended by survey and interview respondents.

The data collection, analysis and writing stages of this endeavor took six months, though community engagement and planning began months prior. Surveys and interviews were completed between November and December 2022. Analysis and writing were completed between December 2022 and March 2023. The coordinating organizations of this report were Afro Global Alliance and the Stop TB Partnership. Data were collected by regional leads, representatives of TB-affected communities and civil society – Meirinda Sebayang (Asia), Olayide Akanni (Anglophone Africa), Bertrand Kampoer (Francophone Africa), Timur Abdullaev (Eastern Europe and Central Asia), Deliana Garcia (Americas), Robyn Waite (high-income countries), and global social science TB researcher Amrita Daftary. Data were consolidated regionally by each lead and analyzed together with global data by the researcher and her team – Pushpita Samina and Sheila Noriega-Mestanza. A first draft of the report was prepared by Amrita Daftary, and widely shared with all leads, coordinating organizations, technical personnel, and a design team for review and feedback.

Anyone seeking to learn more about the methods and process is invited to contact [info@stoptbdevelopingngo.org](mailto:info@stoptbdevelopingngo.org)

## Supplementary tables

### Table 7

#### Survey respondents

	Person with TB, including TB survivor <sup>1</sup>	Representative of an organization <sup>1,2</sup>	Total
Asia	14	76	90
Africa	69	209	328
(Francophone)	(30)	(105)	(135)
(Anglophone)	(39)	(104)	(193)
Americas	33	80	113
Eastern Europe and Central Asia	63	77	140
High-Income Countries	3	53	56
Unknown <sup>3</sup>	113	20	133
Total	295	565	860

<sup>1</sup> Self-identified

<sup>2</sup> Community-based, civil society or other organizations, including journalists, researchers, technical experts, funders and government or parliament representatives

# Table 8

## Interview respondents

Name	Country <sup>1</sup>	Primary affiliation
<b>AFRICA</b>		
<b>Anglophone Africa, Francophone Africa</b>		
Abedola Adams	Nigeria	TB Voices
Alberto Manhique	Mozambique	Association of Mozambican Mineworkers (AMIMO)
Anicet Diguï	Cameroon	For Impacts In Social Health (FIS Cameroon)
Bertrand Odume	Nigeria	KNCV Tuberculosis Foundation
Carol Nawina	Zambia	Community Delegation to the Stop TB Partnership Board
Cecilia Senoo	Ghana	Hope for Future Generations (HFFG)
Daniel Ogbuabor	Nigeria	University of Nigeria Nsukka (UNN)
Deborah Ogwuche Ikeh	Nigeria	Global TB Caucus
Dembele Mathurin	Burkina Faso	National TB Program, Burkina Faso
Donald Denis Tobaiwa	Zimbabwe	Jointed Hands Welfare Organisation
Endalkachew Fekadu	Ethiopia	Volunteer Health Services
Evaline Kibuchi	Kenya	Stop TB Partnership Kenya
Fitsum Lakew Alemayehu	Ethiopia	WACI Health
Fourati Rachid	Tunisia	National TB Program, Tunisia
Gisèle Badoum	Burkina Faso	The Union
Ingrid Schoeman	South Africa	TB Proof
Jerry Amoah-Larbi	Ghana	National TB Voice Network
Jorge Mucambe	Mozambique	Association of Mozambican Mineworkers (AMIMO)
Joseph Kayira	Uganda	Philomera Hope Foundation
Kambou Edouard	Côte D'Ivoire	Alliance Nationale pour le Développement et la Santé en Côte D'Ivoire (Alliance Côte D'Ivoire)
Koffi N'guessan Blaise	Côte D'Ivoire	Aide Internationale pour le Développement Durable (AIDD)
Kouassi Koffi Anicet	Côte D'Ivoire	Collectif des Organisations de Lutte contre la Tuberculose et les Maladies Respiratoires en Côte d'Ivoire (COLTMR)
Lourenco Zunguene	Mozambique	Association of Mozambican Mineworkers (AMIMO)
Lynette Mabote	South Africa	UNITAID
Mahoumbou Jocelyn	Gabon	National TB Program, Gabon
Manefoue Fotsa Joséphine	Cameroon	TBpeople Cameroon
Mayowa Joel	Nigeria	Stop TB Partnership, Stop TB Partnership Nigeria
Mbitikon Olivia	Central Africa Republic	Independent
Moises Uamusse	Mozambique	Association of Mozambican Mineworkers (AMIMO)
Mombo Guy	Gabon	Réseau National pour la promotion de la santé sexuelle et Reproductive des Adolescents et des Jeunes en population et Développement (RENAPSAJ)

Nana Gleeson	Botswana	Botswana Network on Ethics, Law and HIV/AIDS (BONELA)
Olivier Rusumba	Democratic Republic of Congo	Ambassadeurs de la Lutte contre la TB
Oluseyi Kadiri	Nigeria	Centre for Positive Health Organisation
Paulino Lai	Mozambique	Association of Mozambican Mineworkers (AMIMO)
Pedro Cumbane	Mozambique	Association of Mozambican Mineworkers (AMIMO)
Peter Ngola Owiti	Kenya	Stop TB Partnership Community Delegation
Pierre Claver Ndayizeye	Burundi	Alliance Burundaise contre le SIDA et pour la Promotion de la Santé (ABS)
Rhoda Igweta	Kenya	Elizabeth Glaser Pediatric AIDS Foundation (EGPAF)
Rodrick Mugishagwe	Tanzania	Tanzania TB Community Network (TTCN)
Roger Paul Kamugisha	Uganda	Kuboesha - Africa Limited
Rosemary Mburu	Kenya	WACI Health
Sekouna Sélavie	Guinea	TBpeople Guinea
Thokozile Phiri Nkhoma	Malawi	Facilitators of Community Transformation (FACT)
Timothy Wafula	Kenya	Kenya Legal & Ethical Issues Network on HIV and AIDS (KELIN)
Watara Yahaya	Ghana	Community Delegation to the Stop TB Partnership Board
Yahaya Kasimu	Nigeria	TB Voices

## AMERICAS

Ana Carolina Gaillard	Argentina	TB Caucus of the Americas
Claudio Marte	Dominican Republic, Bolivia	TB Caucus of the Americas
Danytza Machado	Bolivia	Observatorio Social de Bolivia
Deccy Gonzalez	Colombia	Observatorio Social de Colombia
Emmanuel Carmona	Mexico	TB Caucus of the Americas
Eva Limachi	Bolivia	TB Caucus of the Americas Focal Point
Fatima Leticia Luna Lopez	Mexico	National TB Program, Mexico
Félix Ajpi	Bolivia	TB Caucus of the Americas
Francisco Olivares	Chile	TB Caucus of the Americas Focal Point
Franklin Ysaías Peña Villalona	Dominican Republic	TB Caucus of the Americas
Giorgio Franyuti	Mexico	Medical Impact
Hector Javier Sanchez Perez	Mexico	El Colegio de la Frontera Sur
Ignacio Ibarra	United States of America	Pan American Health Organization (PAHO)
Jaime Argueta	El Salvador	TB Caucus of the Americas
Juan Luis Castro	Chile	TB Caucus of the Americas
Kathy Britto	Dominican Republic	TB Caucus of the Americas
Leonid Lecca	Peru	Socios en Salud, TB Caucus of the Americas Focal Point
Luis Enrique Gallo Cantera	Uruguay	TB Caucus of the Americas
Luis Sanchez	Guatemala	TB Caucus of the Americas Focal Point
Marcia Leao	Brazil	Observatório Social do Brasil, TB Caucus of the Americas Focal Point
Marta Angelica Pineda de Navas	El Salvador	Australia-Japan Foundation

Myriam Caballero	Paraguay	Altervida
Noe Flores	Honduras	TB Caucus of the Americas Focal Point
Pastor Vera Bejarano	Paraguay	TB Caucus of the Americas
Pedro Avedillo	United States of America	Pan American Health Organization (PAHO)
Rasel Antonio Tomé Flores	Honduras	TB Caucus of the Americas
Sandra Patricia Escandon Moncaleano	Colombia	TB Caucus of the Americas Focal Point
Sarita Aguirre	Paraguay	National TB Program, Paraguay
Soledad Tamayo	Colombia	TB Caucus of the Americas
Sonia Marina Gutierrez Raguay	Guatemala	TB Caucus of the Americas
Victor Castillo	Panama	TB Caucus of the Americas
Zulma Unzain	Paraguay	Alvida, TB Caucus of the Americas Focal Point

## ASIA

Achut Sitaula	Nepal	Trisula Plus
Akramul Islam	Bangladesh	BRAC
Andrew Codlin	Vietnam	TB Help
Ani Hernasari	Indonesia	REKAT
Blessina Kumar	India	Global Coalition of TB Advocates (GCTA)
Budi Hermawan	Indonesia	Perhimpunan Organisasi Pasien (POP) TB Indonesia
Choub Sok Chamreun	Cambodia	KHANA
Elvi Siahaan	Indonesia	Yayasan Menara Agung Pengharapan Internasional
Heny Prabaningrum	Indonesia	PR Consortium STPI-Penabulu
Iman Abdurrahma	Indonesia	Jaringan Indonesia Positif
Khuat Thi Thai Oanh	Vietnam	Center for Support Community Development Initiatives (SCDI)
Luan Nguyen	Vietnam	TB Relief
Lukman Hakim	Indonesia	Stop TB Partnership Indonesia
Mara Quesada	Philippines	ACHIEVE Philippines
Masaki Inaba	Japan	Global Africa-Japan Forum
Prashant Warier	India	Qure.ai
Priyanka Aiyer	India	Global Coalition of TB Advocates (GCTA)
Rachel Forse	Vietnam	Friends for International TB Relief (FIT)
Ramya Ananthkrishnan	India	Resource group for Education and Advocacy for Community Health (REACH)
RD Marte	Thailand	Asia Pacific Council of AIDS Service Organizations (APCASO)
Shilpa Karvande	India	Foundation for Medical Research (FMR)
Subrat Mohanty	India	NGO Delegation to the Stop TB Partnership
Thea Hutanamon	Indonesia	Stop TB Partnership Indonesia
Vidula Purohit	India	Foundation for Medical Research (FMR)

## EASTERN EUROPE & CENTRAL ASIA

Alesia Matushevich	Ukraine, Portugal	Global TB Caucus
Cristina Celan	Moldova	Centre for Health Policies and Studies (PAS Center)
Dilshat Khaitov	Kyrgyzstan	TBpeople Kyrgyzstan
Elena Rzhepishevskaya	Ukraine, Sweden	TBnet
Jamshed Murtazakulov	Tajikistan	Parliament of Tajikistan
Nikoloz Mirzashvili	Georgia	TBpeople Network
Olya Klymenko	Ukraine	TBpeople Ukraine
Safarali Naimov	Tajikistan	Stop TB Partnership Tajikistan
Yuliia Kalancha	Ukraine	TB Europe Coalition

## HIGH INCOME COUNTRIES

Amanda Banda	Switzerland	Médecins Sans Frontières (MSF)
Bertie Squire	United Kingdom	Liverpool School of Tropical Medicine
Caoimhe Smyth	Switzerland	Stop TB Partnership
Cheri Vincent	United States of America	U.S. Agency for International Development (USAID)
Clarisse Veylon-Hervet	France	French Ministry of Foreign Affairs
Colin Smith	United States of America	Results US
Draurio Barreira	Switzerland	UNITAID
Erick Fleutelot	France	Expertise France/L'initiative
Erika Arthun	United States of America	Bill & Melinda Gates Foundation
Fifa A Rahman	United Kingdom	Global Matahari Solution
Francesca Belli	Italy	Global Health Advocates
Gang Sun	Switzerland	Joint United Nations Programme on HIV/AIDS (UNAIDS)
Gilles Cesari	Switzerland	The Global Fund to Fight AIDS, Tuberculosis and Malaria
Hannah Monica Dias	Switzerland	World Health Organization Global TB Programme
Himanshu Patel	Canada	TBpeople Canada (+ 2 persons)
Hyeyoung Lim	Switzerland	Stop TB Partnership
Islam Tauhidul Islam	Switzerland	World Health Organization Global TB Programme
Jacqueline Huh	Switzerland	Stop TB Partnership
James Malar	Switzerland	Stop TB Partnership
Karishma Saran	Switzerland	FIND: Global Alliance for Diagnostics
Kate O'Brien	United States of America	We are TB (+ 3 persons)
Kate Thomson	Switzerland	The Global Fund to Fight AIDS, Tuberculosis and Malaria
Katherine Horton	United Kingdom	The Union Working Group on Gender Equity in TB
Kavindhran Velen	Switzerland	FIND: The global Alliance for Diagnostics
Kelly Collins	United States of America	Dimagi
Kerry Millington	United Kingdom	LIGHT Research Consortium
Kobto Koura	France	The Union
Lana Syed	Switzerland	World Health Organization Global TB Programme

Lasha Gogvadaze	Switzerland	International Federation of Red Cross and Red Crescent Societies (IFRC)
Laurel Sprague	Switzerland	Joint United Nations Programme on HIV/AIDS (UNAIDS)
Lindsay McKenna	United States	Treatment Action Group (TAG)
Lucica Ditiu	Switzerland	Stop TB Partnership
Nuccia Saleri	Switzerland	The Global Fund to Fight AIDS, Tuberculosis and Malaria
Olive Mumba	Switzerland	The Global Fund
Patricia Waterous	Canada	Dimagi
Priya Amin	Canada	Stop TB Canada
Rhea Lobo	India, Denmark	Community Delegation to the Stop TB Partnership Board
Suvanand Sahu	Switzerland	Stop TB Partnership
Tereza Kasaeva	Switzerland	World Health Organization Global TB Programme
Véronica Nosedá	France	Expertise France/L'initiative
Vinny Wooding	United Kingdom	Results United Kingdom
Viorel Soltan,	Switzerland	Stop TB Partnership
Wayne Van Gemert	Switzerland	Stop TB Partnership

<sup>1</sup> Regional classification is based on location of work and/or residence, although many respondents live and work in multiple countries/regions and/or globally. The writers of this report apologize for any errors.

## Table 9

### Organizations represented in surveys and interviews

100 Percent of Life, Ukraine	Community Advocacy Against Poverty, Ghana	Khmelnytsky National University Training Center for Distance Education, Ukraine	Réseau Accès aux Médicaments Essentiels (RAME), Burkina Faso
Act for Involvement, Moldova	Community Consortium STPI-Penabulu, Indonesia	Khulna Mukti Seba Sangtha (KMSS), Bangladesh	Réseau Ivoirien des organisations de personnes vivant avec le VIH-SIDA (RIPPlus), Cote d'Ivoire
Action against AIDS, Germany	Community Delegation to the Stop TB Partnership Board	KNCV Indonesia (YKI), Indonesia	Reseau National des Associations de lutte contre la Tuberculose et la Co-infection TB/VIH ALT, Centrafrique
Action des jeunes pour la lutte contre la tuberculose (AJLTB), Chad	Community Empowerment for Peace and Health Initiative (CEPI), Nigeria	KNCV Tuberculose Foundation, The Netherlands	Réseau Nigérien des Personnes vivant avec le VIH/Sida (RENIP+), Niger
Action for Health Initiatives, Inc. (ACHIEVE), Philippines	Community Humanitarian Inter-livelihoods and Emergency (CHIEF), South Sudan	Kuboresha-Africa Limited, Uganda	Respiratory Society of Kenya (ReSoK), Kenya
Action for Peace, Education and the Defense of Human Rights (APEDH), Democratic Republic of Congo	Concern Health Education Project (CHEP), Ghana	Latin American and Caribbean Network of Environmental Fund (RedLAC), Ecuador	Respiratoires en Cote d'Ivoire, Cote d'Ivoire
Advocacy Network Africa (AdNetA), Kenya	Convictus Ukraine, Ukraine	Leiden University Medical Center (LUMC), The Netherlands	Resource Group for Education and Advocacy for Community Health (REACH), India
Advocates for Health and Development Initiative (AHDI), Nigeria	Corporacion Casa de Amigos con Alcance, Colombia	Lesotho Country Coordinating Mechanism (LCCM), Lesotho	RESULTS United Kingdom
Advocates of Hope for Community (AHFCO), Eswatini	Corresponsales Clave, Peru	LHL International Tuberculosis Foundation Norway	RESULTS United States
AIDS Foundation East West-Kyrgyzstan (AFEW), Kyrgyzstan	Country Coordinating Mechanism, Belarus	Liga Antituberculose Colombiana, Colombia	Rhodapomak Lifeskills Foundation
Affirmative Action, Cameroon	Damien Foundation, Nigeria	LIGHT Research Consortium, United Kingdom	Roots Link Africa
Afric'Mutualite, Benin	Debriche Health Development Centre, Nigeria	L'Institut National de Recherche en Santé Publique (INRSP) Mauritanie, Mauritania	Rural Health Advocacy Project, South Africa
Africa Biodynamic Centre (ABC), Ghana	Délégation Régionale de la Santé Publique du Centre, Cameroon	Liverpool School of Tropical Medicine, United Kingdom	SAFI, Tajikistan
Africa Coalition on Tuberculosis (ACT!), Nigeria	Department of Health and Family Welfare, India	London School of Hygiene and Tropical Medicine, United Kingdom	Saglamliga Khidmat, NGO, Azerbaijan
Africa Global Alliance	Descom Global Care Initiative	MAD Consulting, Kazakhstan	SCDI, Vietnam
Africa University FACT Partnership	TB Network Anambra Chapter, Nigeria	Makueni ExTB TB networking support group, Kenya	SCORE TB Ghana
Afrihealth Optonet Association, Niger	Dimagi Inc., United States	Malawi-Liverpool-Wellcome Clinical Research Programme (MLW), Malawi	Seek To Save Foundation, Ghana
Afro Global Alliance, Ghana	Disaster and Environmental Management Trust, Zimbabwe	Media for Social Change and Development, Nigeria	Service de Pneumologie Hôpital Fann / Task Force recherche opérationnelle tuberculose, Senegal
AGBB	Diversity and Solidarity Trust, Sri Lanka	Medical Impact, Mexico	SHDEPHA+ Network, Tanzania
Aide Internationale pour le Développement Durable (AIDD), France	Dopasi Foundation, Pakistan	Médecins Sans Frontières (MSF)	Shepherd for Health Environment Advocacy and Development Centre, Nigeria
AIDS-Fondet, Denmark	Dream Weaver Organization, Ghana	Medicines Patent Pool (MPP), Switzerland	SID, Lebanon
Aisha Buhari Foundation, Nigeria	Dynamics of the Francophone Africa Response to Tuberculosis (DRAF TB), Cameroon	Melita Matiso Multipurpose Centre, South Africa	Sir HN Hospital and Research Centre, Mumbai, India
Ajuda De Desenvolvimento de Povo para Pova (ADPP), Angola	Eastern Africa National Network of AIDS and Health Service Organization, Tanzania	Menara Agung Pengharapan (MAP) Foundation International, Indonesia	Society for Family Health, Nigeria
Albergue las Memorias A.C., Mexico	Eden Spring of Hope, Ghana	Mesa Tem tica de VIH y Derechos Humanos (MCP-ES), El Salvador	Society for Positive Atmosphere and Related Support to HIV and AIDS (SPARSHA) Nepal
Alliance Burundaise contre le SIDA et pour la Promotion de la Santé (ABS), Burundi	EKB, Ukraine	Methadone Family Against Drug Abuse, Tanzania	Socios En Salud, Peru
Alliance Burundaise pour la Lutte contre la Tuberculose, la lèpre et les autres Maladies (ABTL), Burundi	Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), Kenya	Middle East and North Africa Harm Reduction Association	SORAK Development Agency, Uganda
Alliance for Public Health, Ukraine	Enable the Disable Action (EDA), Democratic Republic of Congo		SOS Tuberculosis and Respiratory Diseases (SOS TBMR), Morocco
Alliance Myanmar, Myanmar	Facilitators of Community Transformation (FACT), Malawi		Sous-direction lutte contre le VIH, Senegal
ALVIDA, Paraguay			
Amoru AIDS Support Community Initiative, Uganda			
Andres Soriano Foundation,			



Inc., Philippines	Family Support Centre, Ukraine	(MENAHRRA), Lebanon	South Africa Miners Association (SAMA), South Africa
Antenne Régionale Abengourou, Côte d'Ivoire	Family Welfare Foundation, Tanzania	Middle East and North Africa International Treatment Preparedness Coalition (MENA ITPC), Morocco	Southeastern National TB Center Southern, United States
Aramis, Congo	Faol, Uzbekistan	Ministry of Health, Saudi Arabia	Southern African Miners Association (SAMA), South Africa
Asia Pacific Council of AIDS Service Organization (APCASO)	Federal University of Sciences Otukpo, Nigeria	Ministry of Health, Somalia	SPIN Plus, Tajikistan
Asociacion Benefica Ser Humano, Spain	FIND: The Global Alliance for Diagnostics, Switzerland	Ministry of Health Isiolo, Kenya	Sportsmen / Women Fighting HIV and TB (SPOFA), Kenya
Asociación Salvadoreña Para La Formación Y Capacitación Integral Sostenible, El Salvador	Focus Droits et Acces-asbl (FDA), Democratic Republic Congo	Monde des Enfants pour l'Atténuation de la Pauvreté du Frère Rural au Togo (MECAP FR TG), TOGO	Social Science and Health Innovation for Tuberculosis (SSHIFTB), Canada
Association Chabab El Borj, Morocco	Fondation femme plus (FFP), Democratic Republic of Congo	Mongolian Tuberculosis Coalition, Mongolia	STEPS Tanzania
Association Affiliate Network, Kyrgyzstan	For Impact in Social Health (FIS), Cameroon	Movement Against TB, HIV/AIDS and Malaria in Nigeria (MATHAMAN), Nigeria	Stop TB Partnership
Association des Anciens Patients Tuberculeux du Bénin, Bénin	Foundation for Environmental Watch (FEW), Ghana	Multidimensional Resource Centre Nepal, Nepal	Stop TB Partnership Canada
Association des Femmes Actives pour le Développement, Guinée	Foundation for Medical Research, India	Murna Foundation, Nigeria	Stop TB Partnership Ghana
Association de Mozambican Mineworkers (AMIMO), Mozambique	Fraser Health Region, Canada	Mwitikio wa Kudhibiti Kifua Kikuu na Ukimwi Tanzania (MKUTA), Tanzania	Stop TB Partnership Indonesia
Association For Promotion Sustainable Development, India	Fraternité, Cote d'Ivoire	Nari Maitree, Bangladesh	Stop TB Partnership Kenya
Association for Rural Area Social Modification, Improvement and Nestling (ARASMIN), India	Free Zone, Ukraine	National Alliance for Development and Health in Cote D'Ivoire, Cote D'Ivoire	Stop TB Partnership Mozambique
Association for Social Development, Pakistan	French Ministry of Foreign Affairs, France*	National Autonomy University of Mexico, Mexico	Stop TB Partnership Tajikistan
Association Health Mission, Serbia	Friends for International TB Relief (FIT), Vietnam	National Centre for Infectious Diseases, Singapore	Stop TB Partnership Ukraine
Association of Brothers and Sisters United (AFSU), Cameroon	Frontera Sur School (ECOSUR), Mexico	National Collaborating Centre for Infectious Disease, Canada	Strategic Coalition against Tuberculosis, Cameroon
Association of Former Tuberculosis Patients (ASSAP), Benin	Fundación Grupo Efecto Positivo (FGEP), Argentina	National Collective of General Practitioners of Morocco (MG Maroc), Morocco	Sustainable Development and Cooperation of Sweden in Bolivia (ASDI), Bolivia
Association of People Affected by Tuberculosis (ASPAT), Peru	Gender Perspective and Social Development Centre (GPSDC), Nigeria	Nacional Federico Villarreal University, Peru	Synergie des Organisations de la Société Civile pour la promotion des droits humains et de l'environnement, Democratic Republic of Congo
Honduran Association Against Tuberculosis in Honduras, Honduras	Georgetown Global Health LLC, Cameroon	National Institute for Research in Tuberculosis, India	Tanzania Advocacy Centre for Development (TACEDE), Tanzania
Association rêve de vivre positive (ARV Positive), Algeria	Ghana Health Service, Ghana	National Organization of Peer Educators (NOPE), Kenya	Tanzania Health Promotion Support (THPS)
Australia Japan Foundation (AJF), Japan	Ghana HIV & AIDS Network, Ghana	National Pirogov Memorial Medical University, Ukraine	Tanzania STP Co/Health Promotion Tanzania (HDT), Tanzania
Association des Volontaires pour le Triomphe des Initiatives de Développement à la Base (AVOTRIDEB), Benin	Global Africa-Japan Forum, Japan	National Reference Tuberculosis Laboratory, Portugal	Tanzania TB Community Network, Tanzania
B Control Program, Pakistan	Global Alliance for Human Rights, India	National Research Center for Phthiisopolmonology, Kazakhstan	TB Caucus of the Americas
BAK-AIDS BAKWATA, Tanzania	Global Alliance of National Human Rights (GANHRI), India	National TB Elimination Programme, India	TB Caucus of the Americas Focal Point, Chile
Bangladesh Garments Manufacturers and Exporters Association (BGMEA), Bangladesh	Global Fund Advocates Network Asia Pacific (GFAN AP), Singapore	National Tuberculosis and Leprosy Control Program, Uganda	TB Coalition, Azerbaijan
Be Glad Care and Support Foundation, Nigeria	Global Health Advocates, Italy	National TB Control Program, Pakistan	TB Coalition Americas, Colombia
Bill & Melinda Gates Foundation*, United States	Global TB Caucus - EECA Region	National TB Program, Burkina Faso	TB Help, Vietnam
Blossom Trust, Virudhunagar,	Global Coalition of TB Activists (GCTA)	National TB Program (PNLT), Chad	TB HIV Care, South Africa
	Government of Tajikistan, Tajikistan	National TB Program (PNLT), Gabon	TBnet Sweden
	Great Lakes Agency for Peace and Development Africa (GLAPD), Australia		TBnet Ukraine
	Greater Life Empowerment Access Initiative, Nigeria		TBpeople Canada, Canada
	Guinean Alliance for Civil Society (AGUISOC), Guinée		TBpeople Global, United Kingdom
	Guinéenne Émancipées pour le Progrès et la Citoyenneté (GEPC), Guinée		TBpeople Network, Georgia
			TBpeople Philippines Organization Inc., Philippines
			TBpeople-Kyrgyzstan, Kyrgyzstan
			TBpeople-Ukraine, Ukraine
			TB Proof, South Africa
			TB Relief, Vietnam

- India  
Botswana Network on Ethics, Law and HIV/AIDS (BONELA), Botswana  
BRAC, Bangladesh  
Bridge Consultants Foundation, Pakistan  
Buzurg, Tajikistan  
Cambodian Health Committee (CHC), Cambodia  
Campaigns in Global Health, United Kingdom  
Catholic Relief Services (CRS), Cameroon  
Cavite Positive Action Group  
The Jch Advocacy Inc., Philippines  
Centre Cinématographique Marocain (CCM), Morocco  
Centenary Institute, Australia  
Center for Development of Community Health Initiatives (C&E), Vietnam  
Center for Support Community Development Initiatives (SCDI), Vietnam  
Center Imkon, Uzbekistan  
Centers for Disease Control and Prevention (CDC), United States  
Centre de Recherche et d'Éducation Pour le Développement (CREPD), Cameroon  
Center for Community Health and Poverty Alleviation (CHEPA), Nigeria  
Centre for Healthworks Development and Research Initiative (CHEDRES), Nigeria  
Centre for Infectious Disease Research in Zambia (CIDRZ), Zambia  
Centre for Positive Health Organization (CEPHO), Nigeria  
Solidarity and Social Action Centre (SAS), Cote d'Ivoire  
CEPVV Foundation, Ecuador  
Cercle d'Entraide et d'Assistance des Mères (CEAM), Cameroon  
Chernihiv Network, Ukraine  
Chernivsti Regional Clinical Tuberculosis Dispensary, Ukraine  
Child Health Foundation, Ghana  
Civil Association Angel Azul, Peru  
Civil Society for the Eradication of Tuberculosis in Nigeria, Nigeria (TB NETWORK)  
Civil Society for HIV/AIDS in Nigeria (CiSHAN), Nigeria  
Civil Society in Malaria Control, Immunization and Health and Development Alliance (HEAD), Cambodia  
HOMES Fountain, Ghana  
Honorary Commission for the Fight against Tuberculosis and Prevalent Diseases (CHLAEP), Uruguay  
Hope and Life, Uzbekistan  
Hope for Children and Youth Foundation Trust, Zimbabwe  
Hope for Future Generations (HFFG), Ghana  
Hope Givers Care and Support Organisation, India  
Hospital Barros Luco, Chile  
Humana People To People India, India  
Ifakara Health Institute, Tanzania  
Infervision, Germany  
Innovations for Community Health, Philippines  
Innovations for Development (I4DEV), Uganda  
Inspire Trans Movement Uganda, Uganda  
Institut Pasteur, France  
Institut pour la gouvernance et éducation électorale, Congo  
Institute of Allergy and Clinical Immunology of Bangladesh (IACIB)  
Institute of Lung Diseases and Tuberculosis, North Macedonia  
Integrated Development in Focus, Ghana  
International Association of Solidarity for Development (AISD), Benin  
International Centre for Diarrheal Disease Research (ICDDR,B), Bangladesh  
International Federation of Red Cross and Red Crescent Societies (IFRC), Switzerland  
International pour le développement de l'ingénierie conseil (IDEV-ic), Senegal  
International Union Against Tuberculosis and Lung Disease, France  
IRNIB, Azerbaijan  
Health Authorities Mexico (ISESALUD), Mexico  
Janna Health Foundation, Nigeria  
Jaringan Indonesia Positif, Indonesia  
Jeunesse Actions Développement Solidarité (JADES), France  
Joint United Nations Programme on HIV/AIDS (UNAIDS), Switzerland  
Jointed Hands Welfare National Tuberculosis Program, Kenya  
National TB Program, Paraguay  
National TB Program (PNLT), São Tomé and Príncipe  
National TB Voice Network, Ghana  
National Youth Network for Sexual and Reproductive Health Issues (RENAP/SAJ), Gabon  
Network for Empowerment in Rural Areas and Townships (NERAT), Nigeria  
Network of AIDS Service Organization (NASOSS), South Sudan  
Network of People Living with HIV and AIDS in Nigeria (NEPWHAN), Nigeria  
New Vector, Georgia  
Observe TB Colombia  
Majlisi Oli, Tajikistan  
ONGAWA, Senegal  
Organisation pour la Protection de l'environnement et la Sauvegarde des Valeurs Traditionnelles (OPESVaT), Benin  
Pan American Health Organization (PAHO)  
Paradiso TB Patients Trust, Malawi  
Partners in Health, Kazakhstan  
Centre for Health Policies and Studies (PAS), Moldova  
Patients Friend Foundation, Ghana  
Peace Heritage Foundation, Nigeria  
Penabulu Foundation, Indonesia  
Pennsylvania Department of Health, United States  
Perhimpunan Dokter Paru Indonesia (PDPI), Indonesia  
Perhimpunan Organisasi Pasien (POP) TB Indonesia  
Philomera Hope Foundation, Uganda  
Pijet, Cameroon  
Pinnacle Health Foundation, Indonesia  
Pitambara jan kalyan Trust, India  
Positive Effect Group Foundation, Argentina  
Prevention Relief Organisation Congo (OCPS), Congo  
Prakruthi Social Service Society, India  
Precious Life Foundation, Nigeria  
Prisma, Peru  
Programa departamental TB Social Observatory of Bolivia (OSTB), Bolivia  
TB Social Observatory of Brazil (OSTB), Brazil  
TB Social Observatory of Colombia (OSTB), Colombia  
TB Social Observatory of Guatemala (OSTB), Guatemala  
TB Social Observatory of Mexico (OSTB), Mexico  
TB Voices, Nigeria  
TB Women Global  
The Global Fund to Fight AIDS, Tuberculosis and Malaria, Switzerland  
The Union, France  
The Union Working Group on Gender Equity in TB, United Kingdom  
Total Care Foundation, Ghana  
Transgender Equality, Uganda  
Translational Health Science and Technology Institute (THSTI), India  
Treatment Action Group (TAG), United States  
Trisula Plus, Nepal  
Tuberculosis Research and Prevention Center, Armenia  
Tupambane na Kifua Kikuu na UKIMWI (TUKIKIZA), Zanzibar  
Turkana Bio Aloe Organization (TUBAE), Kenya  
Ubunye Foundation, South Africa  
Uganda Catholic Medical Bureau, Uganda  
Union fait la force de kolaboui, Guinea  
UNITE, Global (Argentina)  
University of El Salvador, El Salvador  
University of Zaragoza, Spain  
University Hospitals Birmingham, United Kingdom  
University of California, USA  
University of Nigeria Nsukka (UNN), Nigeria  
University of Sheffield, United Kingdom  
University of Zimbabwe, Zimbabwe  
U.S. Agency for International Development (USAID), United States  
V. N. Karazin Kharkiv National University, Ukraine  
Veremsiz Heleja Dogri, Azerbaijan  
Vladimir TB Centre, Russia  
Volunteer Health Services, Indonesia  
WACI Health, South Africa  
We are TB, United States  
Willing & Caring Hands

Nutrition (ACOMIN), Nigeria  
 Civil Society Movement  
 Against Tuberculosis in Sierra Leone, Sierra Leone  
 Clinic of Pulmonary Diseases, Romania  
 Club des Amis Damien, Republic of Congo  
 Civil Society Coalition Nigeria (CONISOC TB), Nigeria  
 Civil Society in Malaria Control, Immunization and Nutrition (ACOMIN), Nigeria  
 Coalition of Women Living with HIV and AIDS in Malawi (COWHLA), Malawi  
 Codea, Democratic Republic of Congo  
 Collectif des Organisations de Lutte contre la Tuberculose et les Maladies (COLMTR), Cote d'Ivoire  
 College of Agriculture and Animal Science Bakura Zamfara State, Nigeria  
 Communities, Alliances & Networks (CAAN), Canada  
 Organisation, Zimbabwe  
 Justice Development and Peace Caritas, Nigeria  
 Karnataka Health Promotion Trust (KHPT), India  
 Kazakhstan Association of Phthisiopulmonologists, Kazakhstan  
 Kazakhstan Union of People Living with HIV (PLHIV-Kat), Kazakhstan  
 Kenko Foundation, Cameroon  
 Kenya Legal & Ethical Issues Network on HIV and AIDS (KELIN), Kenya  
 Kenya Malaria Youth Army, Kenya  
 Kenyan Citizens 4 Good Governance, Kenya  
 Key Interventions to Develop Systems and Services for Orphans and Vulnerable Children (KIDSS), Cameroon  
 Khadija Mahmood Trust Hospital, Pakistan  
 Khmer HIV/AIDS NGO Alliance (KHANA), Cambodia  
 de control de la Tuberculosis Santa Cruz, Bolivia  
 Provincial TB Control Program Punjab, Pakistan  
 Psy d'Afrique, Republic of Congo  
 Public Union for Development and Welfare, Azerbaijan  
 Punjab Bar Council, Pakistan  
 Pyi Gyi Khin (PGK), Myanmar  
 Quire.ai, India  
 REACH Ethiopia  
 Real Opportunities Network, Ghana  
 Red Crescent Society, Azerbaijan  
 Red Latinoamericano por el acceso a medicamentos (RedLAM), Argentina  
 Regional Expert Group on Migration and Health (REG), Georgia  
 Rekat Peduli Foundation, Kenya  
 Rekat Peduli Indonesia (REKAT), Indonesia  
 Foundation (WICAF), Nigeria  
 Women and Development Network in North Kivu (REFED-NK), Democratic Republic of Congo  
 Women with Dignity, Tanzania  
 World Bank, United States  
 World Health Organization (WHO), Switzerland  
 World Health Organization (WHO), Europe office, Denmark  
 World Health Organization (WHO) Global TB Programme, Switzerland  
 Youth AID Initiative Ghana, Ghana  
 Youth Development Foundation (YDF), Cameroon  
 Youth Gate Zimbabwe Trust, Zimbabwe  
 Zatumbe Entertainment Youth Group, Kenya  
 Zimbabwe National Network for People Living with HIV, Zimbabwe

Organization names were drawn from survey and interview responses. Duplicate entries were removed. Country networks/chapters of global organizations are listed and counted as a collective. The writers of this report apologize for any errors.

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