A Deadly Divide:
TB Commitments vs. TB Realities

A Communities Report on Progress Towards the UN Political Declaration on the Fight Against TB and a Call to Action to Close the Gaps in TB Targets

November 2020

Stop TB Partnership Affected Community Delegation
Stop TB Partnership Developing Countries NGO Delegation
Stop TB Partnership Developed Countries NGO Delegation

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Dedication

This *Communities Report* is dedicated to all people with and affected by tuberculosis (TB) (affected communities), their families, and civil society who support them.

Every day, some 4,000 people die from a disease that is both preventable and curable. That totals around 1.4 million people a year, every year. Too often, those people are from our most vulnerable and marginalised communities. For too long, decision-makers have accepted a response to TB that is not only outdated, but inhumane. We do not accept this. It is time to change and this 'Communities Report' is part of that process.

DEATHS FROM TB / DAY
4,000 people

DEATHS FROM TB / YEAR
1.4 million people

Acknowledgements

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Contents

Abbreviations

ACT!	African Coalition on TB
ACT! AP	Activists' Coalition on TB Asia-Pacific
ACT-A	Access to COVID-19 Tools Accelerator
API	Active Pharmaceutical Ingredient(s)
CAB	Community Advisory Board
CaP TB	Catalysing Pediatric TB Innovations
CCM	Country Coordinating Mechanism
COWLHA	Coalition of Women Living with HIV and AIDS
CRG	Community, rights and gender
DR-TB	Drug-resistant TB
DS-TB	Drug-Susceptible TB
DRAF TB	Dynamique de la Repose d'Afrique sur la Tuberculose
EANNASO	Eastern Africa National Networks of AIDS and Health Service Organisations
EECA	Eastern Europe and Central Asia
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
FACT	Facilitators of Community Transformation
GCTA	Global Coalition of TB Activists
GDF	Global Drug Facility
Global Fund	The Global Fund to Fight AIDS, Tuberculosis and Malaria
GNP+	Global Network of People Living with HIV
IMPAACT4TB	Increasing Market and Public health outcomes through scaling up Affordable Access models of short Course preventive therapy for TB
IPT	Isoniazid Preventive Therapy
LAM	lipoarabinomannan
LTBI	Latent TB infection
MAF-TB	Multisectoral Accountability Framework for TB
MDR-TB	Multi drug-resistant TB
MENA	Middle East and North Africa
NGO	Non-governmental organisation
PAS	Center for Health Policies and Studies
PEPFAR	President's Emergency Fund for AIDS Relief
PLHIV	People living with HIV
POC	Point-of-care
R&D	Research and development
RMD	Rapid Molecular Diagnostics
SANAC	South Africa National AIDS Council
SDG	Sustainable Development Goal
TB	Tuberculosis
TB-REP	Tuberculosis Regional Eastern Europe and Central Asia Project
TPT	TB preventive treatment
TRIPS	Agreement on Trade-Related Aspects of Intellectual Property Rights
TRP	Technical Review Panel
UHC	Universal Health Coverage
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNSG	United Nations Secretary General
WHO	World Health Organization
WTO	World Trade Organization
xPOCT	Multiplexed point-of-care testing

Introduction

Background to Communities Report

Today, tuberculosis (TB) remains the world's biggest infectious killer. Each year, some 10 million people fall sick with the disease and an estimated 1.4 million die,[1] including 230,000 children – more than 50% of whom are below the age of five. This is despite TB being both preventable and curable.

On 16 September 2018, the first-ever United Nations (UN) High-Level Meeting on TB was held.[2] This led to the *Political Declaration on the Fight against Tuberculosis* (the '*Political Declaration*'), which set out commitments to be met by Member States to eliminate the disease by 2030.[3] The *Declaration* reaffirmed existing global targets – as stated in the Sustainable Development Goals (SDGs)[4]; the *End TB Strategy*[5] *and the Moscow Declaration to End TB*[6] – whilst also establishing new ones.

As an accountability yardstick of progress towards the targets committed to in the *Political Declaration*, the United Nations Secretary General (UNSG) requested a Progress Report in 2020 that provides a status update on the targets at the national, regional and global levels. This Progress Report, as prepared by with support from the World Health Organization (WHO), was published in September 2020.[7] It reinforces recommendations for Member States and will inform a further High-Level Meeting addressing TB in 2023. A key recommendation in the *Progress Report* is the need for active investment in TB-affected communities and civil society, and to ensure their meaningful engagement in all aspects of the TB response.

Purpose of Communities Report

Affected communities and civil society – as defined in B*ox 1* – were actively engaged in the lead-up to and the duration of the UN High-Level Meeting on TB in 2018. This included through the TB-affected Community and Civil Society Advisory Panel and the Civil Society Hearing. For these stakeholders, the 2018 UN High-Level Meeting represented an unprecedented opportunity to profile TB, agree commitments and mobilise a TB-affected response.

The resulting *Political Declaration* represented important progress for the entire TB community. It affirms, amongst other issues, that all people with and affected by TB should have access to people-centred prevention, diagnosis, treatment and care, as well as psychosocial, nutritional and socioeconomic support; affected communities/civil society should be meaningfully involved in the TB response; and decisive and accountable leadership on TB should be provided that is TB-affected and inclusive of affected communities/civil society.

Since 2018, communities/civil society have continued to play a pivotal role in monitoring the implementation of the *Political Declaration* and holding stakeholders to account. Affected communities and civil society have also actively carried out interventions aimed at filling in existing gaps within national TB responses. This *Communities Report* is part of that accountability process. It aims to complement the 2020 UN Secretary General's Progress Report by providing an alternative and complementary view of the status of the Declaration's targets and commitments, specifically through the lens of affected communities and civil society.

Box 1

Who are affected communities/civil society?

In this Report, 'affected communities and civil society' refers to the constituencies of the Civil Society Delegation to the Board of the Stop TB Partnership. These include:

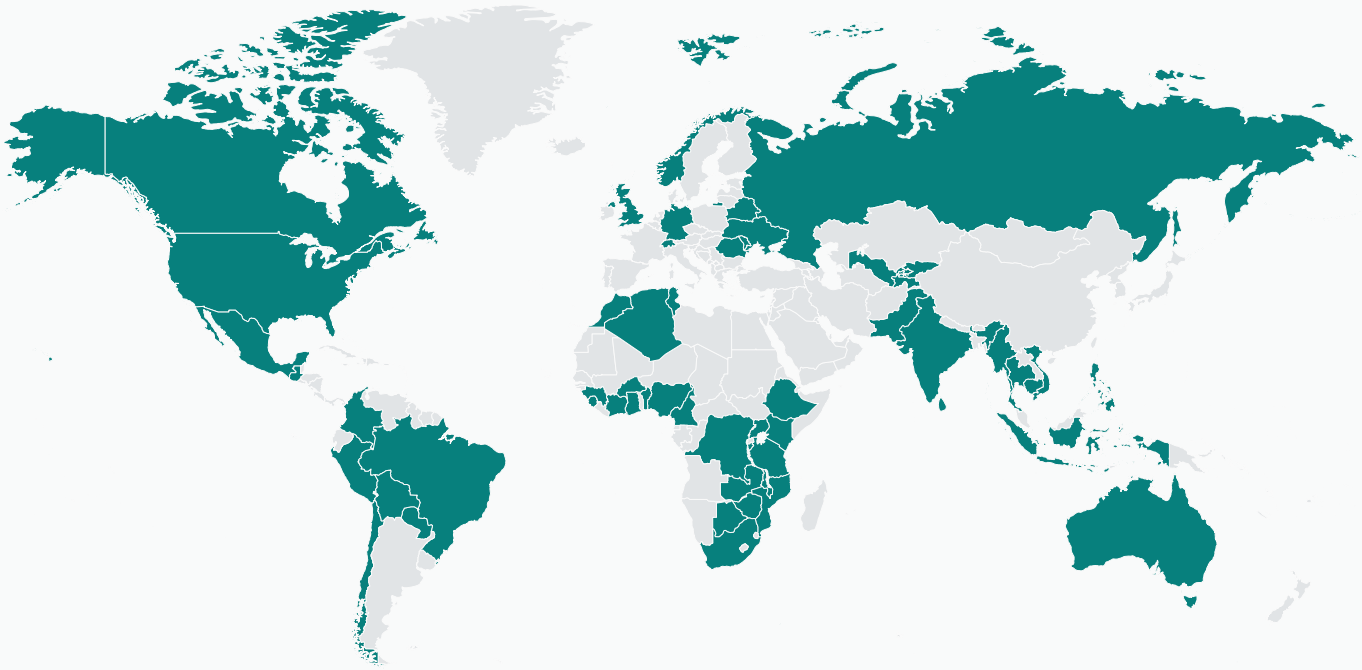
- **People affected by TB:** Any person with TB disease or who previously had TB disease, as well as their caregivers and immediate family members; members of TB key and vulnerable populations, such as children, healthcare workers, indigenous peoples, people living with HIV, people who use drugs, people in prison and other closed settings, miners, mobile and migrant populations, women and the urban and rural poor.
- **Community-based organisations, non-governmental organisations and networks** at local, national, regional and global levels.

This Report gives a voice to those most directly affected by TB – people who are often left behind.

It offers the affected communities' perspective on the people-centred delivery of TB programmes, including updates related to the promotion and protection of human rights and provision of gender-responsive and equitable TB programmes, driven by meaningful community engagement.

Figure 1

Community & Civil Society Engagement in *A Deadly Divide*



Participant

Methodology for Communities Report

This *Communities Report* has been produced by the three civil society Delegations to the Board of the Stop TB Partnership (Affected Community Delegation, Developing Country NGO Delegation, and Developed Country NGO Delegation).[8] Each of these Delegations represents the voice of affected communities and civil society in global TB governance.

This report was developed through an extensive combination of participatory methodologies, including surveys, interviews and desk reviews. The process engaged a large and diverse range of stakeholders from the constituency of the three civil society Delegations and other sectors at country, regional, and global levels. This included over 150 people spanning 61 countries from 8 regions, who were consulted through surveys, interviews and email exchanges. This process contributed to the country and regional action-orientated community engagement best practice case studies. Further details are provided in Annex 1.

This *Communities Report* is structured around the same five key 'asks' that were made by affected communities and civil society as part of advocacy around the 2018 UN High-Level Meeting on TB. Underscoring the current challenge the world is facing, a sixth 'ask' related to COVID-19 has been added.

Progress towards the *political declaration*

Overview

This *Communities Report* describes how, two years after the *Political Declaration*, important progress has been achieved. Countries and stakeholders have embraced it, including translating its commitments into national targets[9], revising National TB Strategic Plans, and developing contextually-relevant TB-affected Accountability Frameworks.

However, this *Report* also argues that, since 2018, momentum generated by the *Political Declaration* has lessened, alongside that for the global response to TB more widely. **There is a major – and deadly – divide between the commitments (what was promised in the Declaration) and the reality (what has been delivered on the ground). The world has taken its eye off TB – a situation exacerbated significantly by COVID-19. There is a need to re-galvanise global action.**

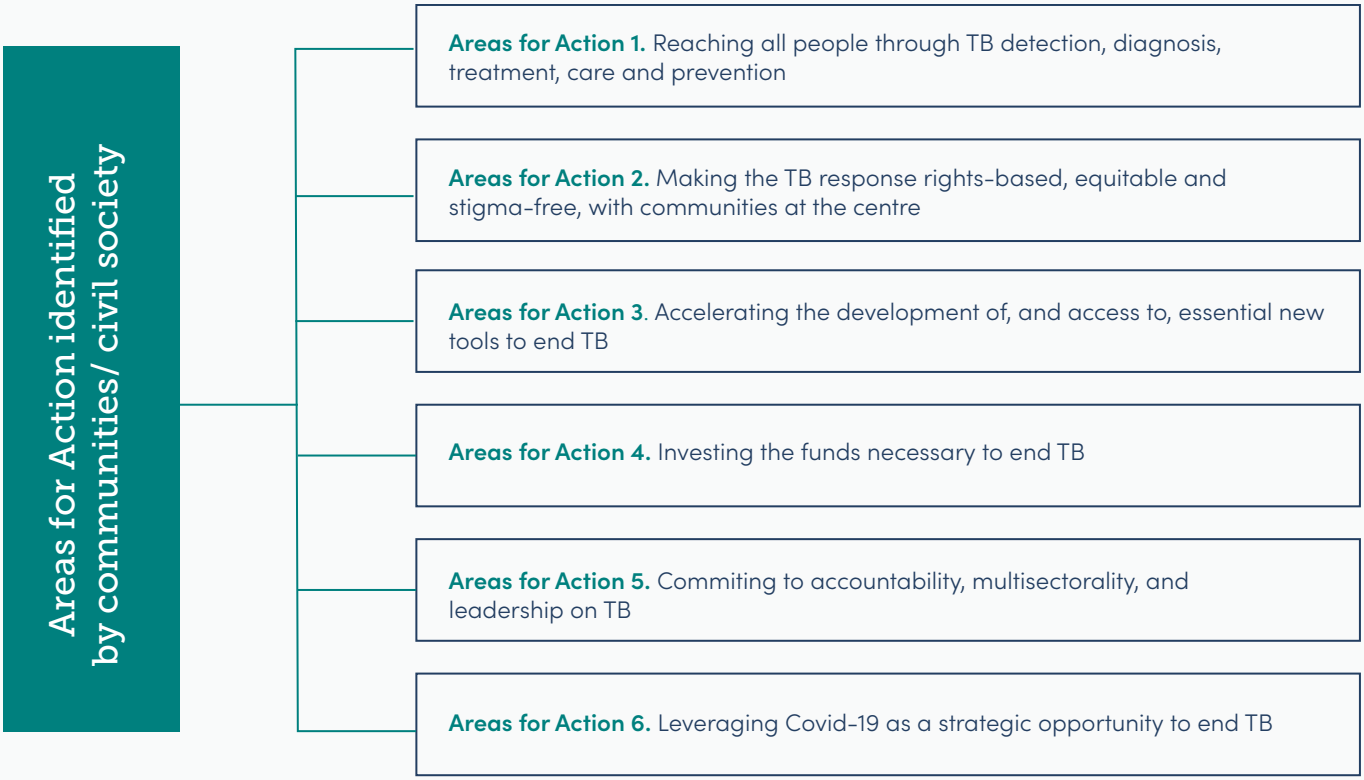
This *Communities Report* explores six key *Areas for Action* which require immediate attention and urgent measures (*see Figure 2).* Under each of these *Areas for Action*, snapshots will be provided of the targeted commitment(s) as per the *Political Declaration*; progress thus far during the period under review; reported contextual and systemic barriers and challenges noted under each Area of Action; as well as documented community response(s) to the challenges, as well as best practices.

Target checks

Target checks are provided throughout this report, comparing the 2020 status of the response to TB with the commitments set out in the *Political Declaration*. They are referenced from the UN Secretary General's *Progress Report*, prepared with support from WHO and released during the United Nations General Assembly in September 2020.

Figure 2

Areas for Action identified by TB-affected communities/civil society



Area for Action 1: Reaching all people through TB detection, diagnosis, treatment, care and prevention

Diagnosis, treatment, care and prevention

In 2018, the *Political Declaration* provided an ambitious set of commitments for TB diagnosis, treatment, care and prevention.[10] These commitments underscore those of Sustainable Development Goal 3.3: By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases.

The key target areas include; (i) reduced TB incidence; (ii) reduced TB deaths; (iii) increased treatment completion; (iv) increased TB preventive treatment (TPT); and (v) increased TB funding (for the response as a whole and specifically for research and development). These are summarised in *Box 2.* While some headway has been made in some areas during the period under review, and some governments are stepping up; overall progress remains unsatisfactory.

Based on scientific innovation and putting policy into practice, the past two years have seen important advances in some aspects of the global response to TB, including among affected communities and civil society. Examples include the scale up of rapid molecular diagnostics (as the initial test for TB); accessible tools for diagnosing TB in people living with HIV (PLHIV); shorter, all oral drug-resistant TB (DR-TB) regimens, and short-course TB preventive treatment (TPT).

Box 2

Status of Political Declaration global targets for TB[11]

Original source of target	Target	Target check	
		Target	2020 Status
End TB Strategy	80% reduction in TB incidence by 2030 (compared with 2015)	20% reduction in 2015–2020	9% reduction in 2015–2019
	90% reduction in the number of TB deaths by 2030 (compared with 2015)	35% reduction in 2015–2020	14% reduction in 2015–2019
	No people with TB disease and their households face catastrophic costs by 2020	Zero by 2020	49% face catastrophic costs
UN Political Declaration on the Fight Against TB	40 million people treated for TB from 2018–2022, including:	40 million people in 2018–2022	14.1 million people in 2018 and 2019
	3.5 million children	3.5 million children in 2018–2022	1.04 million children in 2018 and 2019
	1.5 million people with drug-resistant TB, including 115,000 children	1.5 million people, including 115,00 children, in 2018–2022	333,000 people, including 9,000 children, in 2018 and 2019
	At least 30 million people provided with TB preventive treatment from 2018–2022, including:	30 million people in 2018–2022	6.3 million people in 2018 and 2019
	6 million people living with HIV	6 million people living with HIV in 2018–2022	5.3 million people living with HIV in 2018 and 2019
	4 million children under 5 years of age and 20 million people in other age groups who are household contacts of people affected by TB	4 million children and 20 million other contacts in 2018–2022	783,000 children and 179,000 other contacts in 2018 and 2019
	Funding of at least $13 billion per year for universal access to TB prevention, diagnosis, treatment and care by 2022	$13 billion annually by 2022	$6.5 billion in 2020
	Funding of at least $2 billion per year for TB research from 2018–2022	$2 billion annually by 2018–2022	$900 million in 2019.

These developments are supported by the commitments in the *Political Declaration* and actively promoted through updated, normative guidance from WHO.

Where countries have made strides in aligning their domestic TB responses to the global guidance, progress can be seen. In terms of TB incidence, the *Progress Report* states that a total of 78 countries are on-track to reach the 2020 milestone (of a 20% reduction between 2015 and 2020).[12] This includes seven countries with high TB burdens that have already reached this milestone (Cambodia, Ethiopia, Kenya, Namibia, Russian Federation, South Africa and United Republic of Tanzania), and three other countries with high TB burdens that are on course (Lesotho, Myanmar and Zimbabwe). However, while the TB Stigma Assessment is available, the progress on the commitment to end TB-related stigma remains largely unknown. This must receive further attention in all future TB accountability reporting.

Systemic barriers and challenges

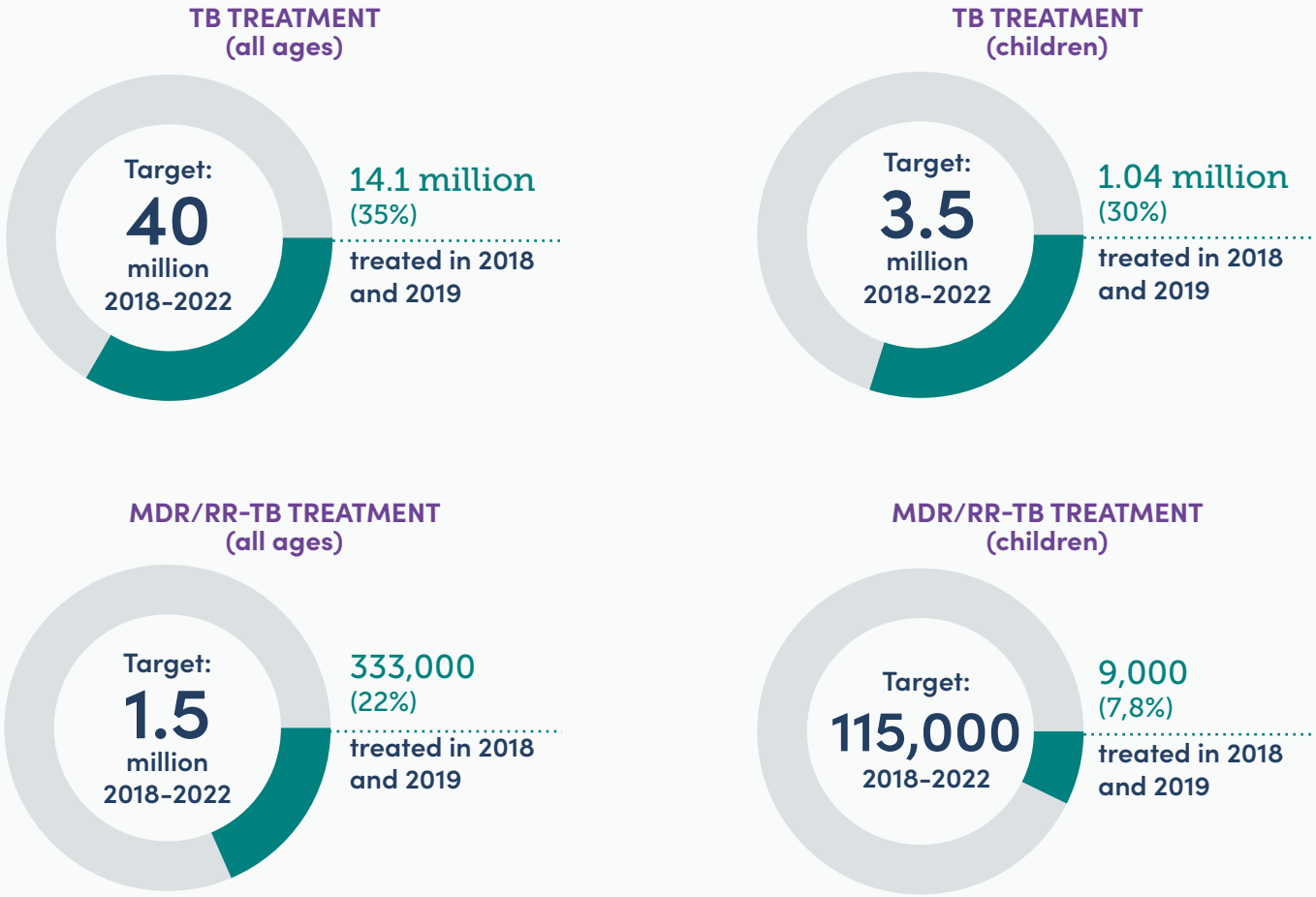
Affected communities and civil society report that many responses to TB are severely off-track. It is worrisome that out of a target of 80% reduction in TB incidence by 2030, there was only a 9% reduction in TB incidence between 2015 and 2019. Another area where progress should be accelerated is TB treatment. As shown in Figure 3,[13] just 35% of the overall target for 2022 is being achieved. The rates are even lower in specific categories, such as for people and children with drug-resistant or multi drug-resistant TB (DR/MDR-TB) (22% and 7.8% respectively).

Target checks Incidence, deaths and treatment

- 14% reduction in TB deaths 2015–2019, compared to a target of 35% for 2015–2020
- 9% reduction in TB incidence 2015–2019, compared to a target of 20% for 2015–2020
- 14.1 million people were treated for TB in 2018 and 2019, compared to a target of 40 million people 2018–2022

Figure 3

Provision of treatment to people with TB in 2018 and 2019



Source: Report of the Secretary General Progress towards the achievement of global tuberculosis targets and implementation of the political declaration of the high-level meeting of the General Assembly on the fight against tuberculosis, 2020

Progress towards targets

The Progress Report reiterates that the world is "a long way from reaching the End TB Strategy targets".[14] The gaps noted are due to a wide range of structural, political and economic barriers. Some of these gaps are noted at programmatic level, with most countries still using archaic case detection and diagnostic practices. Efforts to find the 'missing millions' have been met by the growing push for improved TB case detection. Stop TB Partnership, in collaboration with WHO and through the Strategic Initiative, developed a set of *Field Guides* to help TB programmes and partners plan, design and monitor these different interventions. [15] These include differentiated approaches to case finding, and linkages and improved access to TB services – especially by key and vulnerable populations.

Another area of grave concern is the limited investment in scaling up access to accurate to decentralised diagnostics, despite evolved WHO guidance for diagnosing TB. A decade after the introduction of rapid molecular diagnostics (RMD), in 2020, countries are starting to welcome RMD as the initial diagnostic test for all people with signs and symptoms ('RMD-for-all').[16] Unfortunately, policy has not always translated into practice, leading to overreliance on microscopy and as a result significant diagnostic gaps in both TB and DR-TB.

A periodic report produced by *Médecins Sans Frontières* and the Stop TB Partnership, entitled *Step Up for TB 2020*, analyses the policies on TB diagnosis, treatment, prevention and drug procurement in 37 high-burden countries, representing 77% of the global TB incidence.[17] It concludes that too few national TB programmes are consistently and rapidly updating their national policies in line with WHO guidelines. As a result, the products of innovation are taking too long to reach those who need them, minimising their impact. The report provides a checklist of the key policies that need to be adopted and implemented by every country in order to meet the targets of the *Political Declaration* (*see* Annex 1).

Affected communities and civil society across all regions report major gaps between the commitments, policies and practice of their respective TB responses. Examples include scenarios whereby:

- equipment for rapid molecular diagnostic testing for TB is available in health centres, but unused due to a lack of health infrastructure, such as laboratory capacity.[18]
- periodic stock-out of TB drugs – another crippling factor – affecting successful treatment completion. Between 2019 and 2020, Stop TB Partnership's Global Drug Facility (GDF) observed drug stock-outs in 27 countries in Africa, Asia, and EECA regions.[19] The DR Congo CRG Assessment also noted this challenge.[20]

Figure 4

Global TB diagnosis gap

Approximately

7 MILLION PEOPLE

were diagnosed with TB disease and notified to WHO in 2019

... leaving nearly

3 MILLION PEOPLE*

with TB disease who were not diagnosed or notified to WHO

*people were either undiagnosed and thus unable to seek treatment, or were diagnosed, but not notified to WHO

= 1 million people

Community actions and responses

However, affected communities and civil society also report that – where prioritised, scaled up and resourced – evidence-based interventions demonstrate the potential to transform action on TB. Examples are provided at country level (such as Vietnam, see Communities case study 1)[21] and in international collaborations (such as the *Strategic Initiative To Find the Missing People with TB*). The latter is resourced by the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund) and implemented by the Stop TB Partnership and WHO, in partnership with affected communities and civil society.[22] For every year from 2018 to 2020, the Initiative aimed to find 1.5 million more 'missing people' with TB – in particular amongst key and vulnerable populations – in the 13 countries that account for 75% of such cases globally.[23] Progress so far indicates that the gap between TB notifications and incidence fell from 49% in 2014 to 33% by 2018, and continues to reduce.

The biggest declines are seen in some of the countries with the highest TB burden in Asia (Bangladesh, India, Indonesia and the Philippines). It is noteworthy to highlight that this was the situation documented *before* the impact of COVID-19.

"TB is a disease of poverty, and economic distress, vulnerability, marginalisation, stigma and discrimination are often faced by people affected by TB"
— **UNSG TB Progress Report, 2020**

Communities case study 1: Collaborating to eliminate TB – Vietnam

In 2019, the Government of Vietnam established an inter-ministerial National Commission to End TB as part of a Prime Ministerial decree to consolidate the systems for prevention and control, and to fulfil the targets of the *Political Declaration*. The Commission is chaired by the Deputy Prime Minister and aims to coordinate implementation of the National Action Plan through engagement of multiple sectors - including communities/civil society – in line with the WHO Multisectoral Accountability Framework for TB. Sector roles will be defined in the National TB Strategic Plan for 2021–2025, while a revised national law on infectious diseases, including TB, is being formulated. To support the country's strategy, a consortium of communities/civil society organisations – including Interactive Research and Development Viet Nam and Friends for International Tuberculosis Relief – collaborated with provincial authorities to implement SWEEP-TB. This initiative uses population-wide screening for both TB disease and infection, and was the first in the country to roll out the replacement of smear microscopy with Xpert rapid molecular diagnostics and chest X-ray (a key element of Vietnam's new National TB Strategic Plan). The results of the work, funded through Stop TB Partnership's TB REACH, have included increased case identification in communities (almost 500/100K) and the enrolment of hundreds of people on TPT.

Key and vulnerable populations

Affected communities and civil society welcomed the Political Declaration's commitment to prioritising and supporting people from key and vulnerable populations.[24]

However, stakeholders express strong concern about shortfalls in progress towards the *Political Declaration*, with community members who are most in need being the hardest hit. Examples of key and vulnerable populations include: migrants, people who use drugs, indigenous peoples, homeless people, children, miners, people deprived of their liberty, and people affected by conflict or natural disasters. This scenario is most notable at country level, where limited national key and vulnerable population data results in them being left behind.

Systemic barriers and challenges

A series of ongoing challenges has been documented relating to key and vulnerable populations. These include:

- Identification and prioritisation of key and vulnerable populations in National TB Strategic Plans
- Developing and scaling up differentiated TB interventions that are linguistically and culturally appropriate, especially for migrants, refugees and indigenous people (see Communities case study 3)
- Addressing sociopolitical barriers, such as harmful laws
- Programming to reduce stigma and discrimination, including in health services and communities. There are glaring data gaps in population size estimates in most countries
- Lack of disaggregated, real-time and nuanced data on size estimates, vulnerabilities and TB needs of TB key and vulnerable populations
- Access to services while crossing international borders, particularly mobile and migrant populations, refugees, nomadic and indigenous peoples.

Community actions and responses

Affected communities/ civil society have been able to contribute to efforts to address the data gaps. This has informed targeted and differentiated TB programming by national TB Programmes, while gathering evidence to secure sustainable funding to cater for these populations.

During the period under review, affected communities/ civil society have scaled up efforts to inform national-level key and vulnerable population size estimates, to support data-driven TB responses. Numerous interventions have been supported by the Global Fund and Stop TB Partnership Community, Rights and Gender (CRG) programme. In a number of countries – including countries in Asia Pacific (see Communities case study 2)[25] – 'Data for Action' processes have been conducted to identify priority key and vulnerable populations.[26]

Communities/civil society in other regions, including the Americas and Middle East and North Africa, that also face significant economic, political and humanitarian challenges, would particularly benefit from increased support for this kind of intervention.

"Children are specifically vulnerable to TB disease, particularly if they are malnourished and/or HIV positive."
— **WHO 2020 TB Progress Report**

Communities case study 2: Identifying TB key and vulnerable populations – Asia Pacific

By conducting 'Data for Action' processes, countries can identify and address gaps in data for TB key and vulnerable populations, to inform National TB Programmes and the design of interventions. The process fosters national dialogue on the gaps, how to address them, and how to meaningfully engage key and vulnerable populations in service planning, implementation and monitoring at national and local levels. As examples, the following populations were identified as priorities in countries in Asia Pacific:

- Pakistan – people living with HIV, transgender people, men who have sex with men, people with HIV/TB co-infection, people who inject drugs, people in prisons and other closed settings, poor people in urban areas and health workers
- Philippines – people in prisons and other closed settings, people who smoke, elderly people, people with diabetes, people who live in slums, people who live on the streets, and people who use drugs,

Communities case study 3: Recognising vibrant indigenous voices to end TB – Canada

As the highest rates of TB in Canada are amongst Indigenous Peoples, a project called *Recurrent Tuberculosis* is working to translate whole genome sequence insights into best public health practices to strengthen the TB response. This project is working in the province of Saskatchewan, building reciprocal relationships between local indigenous leaders, communities and health providers. At the heart of the project is a recognition that Indigenous cultural norms and protocols are fundamental and foundational to sharing circles and relationship building with First Nations partners.

Funded by the Canadian Institutes of Health Research, they are differentiating relapse from reinfection of TB in Canada and ensuring culturally-appropriate approaches are reaching Indigenous peoples most at risk of TB. This project uses an Integrated Knowledge Translation Approach that applies the principle of cultural safety, and is an approach that may help inform the tailoring of programmes to reach indigenous peoples in other contexts. The onus is on the individual with the actual or perceived power in the working relationship to establish a relationship that recognises the strengths and vibrancy of Indigenous Peoples, while respecting and upholding Indigenous voices, ways of knowing, ancestral understandings, Elders, and knowledge keepers.

Children

Among key and vulnerable populations, children are among those hardest hit by the gaps in progress on TB targets – with 230,000 deaths in 2019.

Progress towards targets

In 2019, children represented 12% of all people who developed TB.[27] Whilst estimates of DR-TB amongst children range from 25,000 to 32,000 per year, only 8,986 children had access to DR-TB treatment in 2018 and 2019.[28] It is disturbing to note that, where children are concerned, progress lags behind that of other age groups, and despite significant improvements in treatment options in recent years.

The Progress Report noted improved access to child-friendly treatment. By 2019, 1.1 million treatment courses for children with drug-susceptible TB were provided by the GDF since these were first introduced in 2016. The GDF currently provides 13 child-friendly DR-TB formulations to 62 countries, with projections that all child-friendly DR-TB medicines will be made available in 2021. The period under review notes progress in terms of strengthened high-level TB-affected collaborations and commitments from WHO, STOP TB Partnership, donors and pharmaceutical manufacturers (both in diagnostics and drugs) through the Rome 5 Paediatric HIV and TB Action Plan in 2020.[29]

Target check: Children

- 1.04 million children were treated for TB in 2018 and 2019, compared to a target of 3.5 million for 2018–2022
- 9,000 children were treated for DR-TB in 2018 and 2019, compared to a target of 115,00 for 2018–2022
- 783,000 children under 5 years of age who are household contacts of people affected by TB were provided with TPT in 2018 and 2019, compared to a target of 4 million for 2018-2022

Systemic barriers and challenges

The major challenges reported by affected communities/civil society include:

- Case detection gaps which resulted in under-reporting of the number of children on treatment annually. This is attributable to a lack of access to affordable point-of-care (POC) diagnostic tools (including sample collection methods)[30]
- A paucity of child-friendly drug formulations and initiation of children (under 5 years of age) on TPT, where they are household contacts of bacteriologically confirmed pulmonary TB cases
- Lack of systematic TB screening, which is attributable to poor coordination across health programmes and between TB and children's programmes (including those for maternal and child health and social services).
- Lack of prioritisation in budgeting for paediatric TB programmes within National TB Strategic Plans and in Global Fund funding requests
- Lack of visibility of childhood TB in some key global initiatives.

The impact of COVID-19 on childhood TB highlights the grim outlook for children, especially with increased levels of malnutrition and decreased levels of immunisation.

Community actions and responses

Affected communities and civil society stakeholders observe that, despite WHO's *Roadmap Towards Ending TB in Children and Adolescents*[31] and improved treatment options, access to these remains a challenge. Poor and detrimental practices – such as the programmes 'cutting up' of adult TB drugs for children[32] – persist on the ground. To support TB programmes to eradicate such practices, and in order to support the proliferation of child-friendly TB formulations, the Global Drug Facility has delivered more than 1.1 million treatment courses of the appropriately-dosed, child-friendly, fixed-dose combination products for DS-TB since these were first introduced in 2016.[33]

Communities case study 4: Identifying priorities for children and TB – Kenya

In Kenya, a communities/civil society consultation in June 2020, held to strategise on the Global Fund allocation cycle for 2021–23, resulted in a *Civil Society Children Priority Charter*. This identifies four priorities for paediatric TB, each supported by actions to inform national advocacy:

- **Priority 1**: Paediatric TB active case-finding and scaling up diagnosis – including actions on rapid and expanded diagnosis of childhood TB and intensified country capacity to find children with TB.
- **Priority 2**: TB prevention – including actions on shorter regimens for TPT and latent TB infection testing and contract tracing.
- **Priority 3**: TB treatment (including MDR-TB) – including actions on highly efficacious TB treatment for children and treatment monitoring by healthcare workers and community health volunteers.
- **Priority 4**: Equipping healthcare workers and communities to address childhood TB – including actions on policy and political leadership for community action on TB and demand creation for TB testing.

Although progress is slow, there are rays of sunshine. Affected communities and civil society are proving to be essential allies in ensuring children access the care they deserve. Examples include: development of a Civil Society Children Priority Charter in Kenya (see Communities case study 4)[34] and Catalysing Paediatric TB Innovations (CaP TB), a 2017–21 collaboration between the Elisabeth Glaser Pediatric AIDS Foundation (EGPAF) and Unitaid.[35] The latter focuses on integrating children's TB services into maternal and child health programmes in India and nine Sub-Saharan African countries.[36] It includes capacity building for communities/civil society, and the use of a pioneering budgeting tool on childhood TB.[37]

Drug-resistant and multi drug-resistant TB

The *Political Declaration* committed to addressing the "grave risks to individual and public health" presented by the escalating threat of drug-resistant (DR) and multi-drug resistant TB (MDR-TB). [38]

Target check: DR/MDR-TB

- 333,000 people were treated for DR-TB in 2018 and 2019, compared to a target of 1.5 million people 2018-2022

Progress towards targets

According to the Progress Report, in 2019, 57% of people diagnosed with TB had their infections bacteriologically confirmed – an increase of just 2% from 2018.[39] In turn, the percentage of people with bacteriologically confirmed TB who were tested for rifampicin resistance was just 61%. Both statistics are far short of the global targets.

The period 2018–2020 has witnessed significant progress in terms of scientific advancements and the policies and practices needed to address DR-TB, as articulated in *WHO's Consolidated Guidelines on Drug-Resistant Tuberculosis Treatment*.[40] This guidance addresses important developments in terms of effective rapid molecular testing, such as GeneXpert and TrueNAT; the introduction of shorter and safer 'all-oral' drug regimens; price reductions to drugs such as bedaquiline (as negotiated by the Global Fund and Stop TB Partnership); and an emphasis on people-centred approaches – thereby promoting decentralisation of DR-TB treatment initiation to primary healthcare facilities. Amidst these advancements, there remains overwhelming concern around the Global Fund's transitioning out of some of the DR-TB high-burden countries, including some of those in Eastern Europe and South America.

Systemic barriers and challenges

Whilst welcoming scientific innovations, affected communities/civil society report that in many contexts DR-TB remains an acute – and worsening – health crisis, especially for key and vulnerable populations. This is the same for people in the households of those with DR-TB, who also face disproportionate social and economic impacts, including catastrophic costs. Due to programmatic inefficiencies, costs related to diagnostics, treatment and care for DR-TB remain crippling in most regions, with estimates of around $5,000 per person. This is also largely because of routine hospitalisation. Other challenges noted include:

- Limited scale up of improved DR-TB diagnostics
- Contexts where short course 'all-oral' treatment for MDR-TB is cited as the national standard, but not yet rolled out (with outdated and less-safe injectable treatments still being used)
- Sluggish scale up of the 'all-oral' DR-TB regimens, primarily because these patented DR-TB drugs are too expensive and currently have no generic equivalent
- Low levels of targeted psychosocial support before, during and after treatment results in poor management of side-effects and therefore less than desirable programming outcomes.

People-centred decentralised treatment at primary healthcare facilities provides growing cost-effective programmatic model options.

Community actions and responses

In response, communities/civil society are playing a central role in mobilising and implementing action in this critical area. The sector's work has ranged from the production of key resources, such as the *Activists Guide to Drug Resistant TB* by the Treatment Action Group,[42] to the implementation of programmatic interventions (for example, in Azerbaijan, see Communities case study 5)[43] and participation in national advocacy (for example, in Zimbabwe, see Communities case study 6.[46]

Communities case study 5: Reducing drug resistant TB among people in prisons in Azerbaijan

In 2018, Azerbaijan saw increasing levels of DR-TB among people in and being released from prison. In response, Saglamliga Khidmat Public Association, a civil society organisation, developed a package of social and clinical support. For people with TB in prison, this included food packages, awareness sessions and peer-to-peer training, including for six months after completion of treatment. For those released from prison, it included follow-up support, with monthly visits, educational sessions, the delivery of TB drugs and collection of samples. The initiative supported over 800 prisoners and saw levels of DR-TB decrease significantly, including among people released into the wider community.

Communities case study 6: Advocating for better regimens for drug resistant TB in Zimbabwe

In 2020, Zimbabwe joined the few African countries that have introduced a shorter, highly-effective and all-oral regimen for Rifampicin-resistant TB treatment, as recommended by WHO. This resulted from combined efforts, including strong advocacy by affected communities, civil society, and the national TB Caucus (a network of parliamentarians). The work included proposing motions in Parliament and engaging with the Ministry of Health through annual advocacy meetings where concerns were raised about the high costs and side effects of former treatment regimens.

The sector also advocates for 'free and accessible' diagnostics, treatment, nutrition and related services and support (avoiding catastrophic costs), with urgent prioritisation of all key and vulnerable populations.

The need for collaboration across sectors has been urgent. In response, affected communities and civil society have demonstrated how engagement in TB-affected regional strategies can bring change. A functional model can be found in Europe – the region with the highest rate of MDR-TB in the world, largely due to harmful excessive hospitalisation practices. This includes not only prolonged hospital stays, but also, and probably more importantly, unjustified admissions to hospitals to fill the beds. Affected communities and civil society have collaborated with ministries of health and finance, national TB programmes, and others, to introduce a people-centred model of care, with a focus on DR-TB. The model builds on a regional blueprint[45] and is central to the *Tuberculosis Regional Eastern Europe and Central Asia Project (TB-REP)*, which is funded by the Global Fund, with the Centre for Health Policy and Studies, Moldova, as the Principal Recipient.[46] The work focuses on 11 countries in EECA. Its activities have included developing a standardised package of community-based, people-centred TB services and costing methodology; conducting a regional study on community, rights and gender barriers to services;[47] piloting video-observed treatment; and conducting community-led monitoring (e.g., in Ukraine, see Communities case study 14 and health systems strengthening support. The results are evident in countries which have: started the transition to new treatment regimens, including for DR/MDR-TB, in line with WHO guidelines; adopted key policies on people-centred TB service delivery, financing, and human resources; developed roadmaps to incorporate those people-centred policies into sustainable, national TB strategies. The results can also be seen within health services, such as the average length of hospital stay for someone with MDR-TB falling from 157 to 94.9 days from 2015 to 2019.

Integrated TB and HIV services

Affected communities and civil society welcomed the *Political Declaration's* commitments to integrating action on TB and HIV.[48] Yet, TB remains the biggest killer of people living with HIV – with 208,000 lives lost in 2019, and people living with HIV 18 times more likely to develop active TB disease than people without HIV[49].

The number of people living with HIV who received TPT rose to 5.3 million in 2018 and 2019, representing substantial progress towards the *Political Declaration* target of 6 million by 2022. Upon reflection, this target lacked ambition and we must now work towards TPT universal access among PLHIV.

Target check: TB preventive treatment

- 6.3 million people were provided TPT in 2018 and 2019, compared to a target of 30 million for 2018–2022
- 5.3 million people living with HIV were provided with TPT in 2018 and 2019, compared to a target of 6 million for 2018–2022
- 179,000 people over 5 years old and household contacts of people affected by TB were provided with TPT in 2018 and 2019, compared to a target of 20 million in 2018–2022.

Progress towards targets

The period 2018–20 has reflected important developments in this area, including increased investments in introducing and scaling up new short-course, rifapentine-based TPT regimens, and market shaping advocacy to ensure affordable access to these under the Unitaid-supported *Increasing Market and Public health outcomes through scaling up Affordable Access models of short Course preventive therapy for TB* (IMPAACT4TB) project.[50] This four-year project prioritises short-course TB preventive therapy (3HP) for people living with HIV, children under five, and subsequently all those in close contact with people diagnosed with TB disease in 12 high-burden countries.[51] Developments also included the publication of WHO's updated 2020 *Consolidated Guidelines: Tuberculosis Preventive Treatment.*[52]

While this remains an admirable gain in access to TPT for people living with HIV, progress regarding contacts is particularly concerning as this target still falls short of the overall target of 30 million TPT by 2022 – which means a shortfall of 23.7 million who still need to be provided with TPT.

In addition to PLHIV, there is a need to have an increased focus on TPT for contacts of people affected by TB and on primary prevention in high risk occupations.

Systemic barriers and challenges

There remains a missed opportunity to systematically link HIV and TB responses at all levels, including a concerted effort to further scale up TPT beyond people living with and affected by HIV. Affected communities and civil society stakeholders – including the Global Network of People Living with HIV (GNP+) and its constituents[53] – report that many countries with high TB and HIV still operate largely separate HIV and TB responses, with negative consequences for the quality of care for service users and efficiency for programmes. Poor practice is still reported on the ground, for example service users having to attend different facilities for TB and HIV treatment.[54] Other reported challenges include:

- Low TPT completion rates due to requirement to take Isoniazid Preventive Therapy (IPT) for 6–9 months; with numerous reported stock-outs of the essential vitamin B6.
- Lack of effective community education on the life-saving benefits of TPT; with limited adherence support
- High cost of newer TPT drugs; although generic market entry will reduce the price of rifapentine-based TPT regimens
- Limited or no access to psychosocial and other related services to support people to cope with the 'double stigma' of TB and HIV, which has mostly been observed among young people.

For TB contacts, the recent Step Up for TB Report noted limitations on real progress, including:

- Many country policies for TPT eligibility among TB contacts do not extend to include all contacts
- Many country guidelines on latent TB infection (LTBI) testing are unclear.

With the exception of the TB and mining project in Southern Africa, there have been no systematic efforts for primary prevention of TB in high risk occupations by reducing silica dust exposure in mining, construction and other dusty workplaces, as committed in the UNHLM declaration. *Step Up for TB Report* noted that 62% of the countries surveyed do not include miners and people with silicosis as groups for active screening of TB and provision of TPT. Lessons from the TB and mining project in Southern Africa, including on reduction in dust exposure and TB prevention, must now be scaled up and applied in additional occupational settings to ensure safe workplaces for all.

Community actions and responses

Affected communities/civil society showcase the benefits of community-based and led interventions that put TB/HIV linkages into practice. Examples include the work conducted under IMPAACT4TB in Malawi (See Communities case study 7).[55] Further examples include the engagement of communities/civil society in a joint national programme in South Africa (see Communities case study 8); provision of a one-stop-shop, where TB screening is provided to all people living with HIV who attend HIV care and treatment centres in Tanzania.[56] engagement of affected communities and civil society in a National TB/HIV Working Group that coordinates joint planning on the two diseases in Cambodia;[57] monitoring conducted by people living with and affected by TB and HIV of a pilot programme to scale-up TPT in HIV treatment clinics (in Ghana);[58] and forging of strategic links between TB and HIV programmes among key stakeholders at the district level in Vietnam.[59]

The TB communities/civil society who were consulted about the development of a new *Global AIDS Strategy* call for attention to five key areas:[60] 1. 100% coverage of TPT for all eligible people living with HIV to realise the TB and HIV UN HIgh-Level Meeting targets and commitments; 2. Regular, accessible TB screening and testing for all people living with HIV; 3. Measuring and reducing stigma and discrimination, as well as the identification and elimination of structural barriers to access to TB/HIV prevention, diagnosis, treatment, care and support services; 4. Scale-up of access to TB/HIV new tools, including TB lipoarabinomannan (LAM) and, in the future, a TB vaccine, together with a participatory TB/HIV research agenda to assist this; 5. Bold global and country level targets, financing, data and monitoring and evaluation plans for accountability. Affected communities and civil society eagerly await the inclusion and implementation of these priorities and look forward to partnering with UNAIDS to ensure this is realised.

Communities case study 7: Advocating for improved and scaled-up TB prevention – Malawi

In Malawi, the Coalition of Women Living with HIV and AIDS The Coalition of Women Living with HIV and AIDS (COWLHA) and Facilitators of Community Transformation (FACT) have collaborated with the IMPAACT4TB consortium to increase the engagement of people living with HIV, TB civil society networks and Members of Parliament in scaling up TPT across the country. In communities, interventions have included mobilising women living with HIV on their critical role in monitoring 3HP, in particular among child contacts. At the national level, COWLA and FACT led advocacy for stronger collaboration between the HIV and TB programmes and for TPT to be included in the country's differentiated service delivery models. The partners produced a TB/TPT financing landscape memo, highlighting the need for increased funding for scale-up. Working with the National TB Programme, they pushed for the inclusion of newer regimens in updated TPT policy guidelines. They also targeted donors, securing funding to expand TPT to all 28 districts supported by the President's Emergency Fund for AIDS Relief (PEPFAR) within the Country Operational Plan for 2020, as well as in Malawi's TB grant from the Global Fund.

Communities case study 8: Engaging in a joint, national response to TB and HIV – South Africa

In 2009, the mandate of the high-level South Africa National AIDS Council (SANAC) was expanded to include TB. The Council is currently chaired by the country's Deputy President, and membership includes representatives from civil society, affected communities and the private sector. SANAC also serves as the Country Coordinating Mechanism (CCM) for proposals to, and grant agreements with, the Global Fund. There is one strategic plan for both the HIV and TB epidemics, while the respective national programmes are coordinated by one Deputy Director-General in the Department of Health.

Refer to the CALL TO ACTION for recommendations under Area of Action 1

Area for Action 2: Making the TB response rights-based, equitable and stigma-free, with communities at the centre

Know Your Response: Community, Rights and Gender (CRG)

In 2018, the *Political Declaration* called for the response to TB to be rights-based, gender equitable and people-centred.[61]

Progress towards targets

Despite the concrete efforts and successes of affected communities/civil society in promoting and protecting the rights of those most vulnerable to TB, there remains minimal investment in this area. There is inherent scepticism among some donors and stakeholders that investments in programming to address the human rights and gender barriers in TB responses will yield tangible results. The growing evidence base is stunted by a lack of funding to support capacity strengthening on data collection and documentation methodologies; lack of partnerships across skill-sets; and lack of evidence to inform demonstrable models and best practices in responding to and addressing human rights and gender violations within TB responses.

Community actions and responses

Affected communities/civil society report that since 2018, there has been significant progress in increasing understanding and the evidence-base on how their priority issues shape TB epidemics and responses.[62] This includes the development and proliferation of the comprehensive CRG tools that were created and implemented by the Stop TB Partnership in collaboration with affected communities, civil society and NTPs[63] This package of tools includes assessments and planning materials related to legal and policy environments, human rights,[64] gender,[65] and key population data,[66] now incorporated into a combined CRG assessment protocol.[67] The tools also include the TB Stigma Assessment[68] and OneImpact community-led monitoring.[69]

By October 2020 – through the work of numerous partners supported by the Stop TB Partnership and funded by USAID and the Global Fund – 17 national CRG Assessments had been completed. These were in Bangladesh, Cambodia, DR Congo, Georgia, India, Indonesia, Kazakhstan, Kenya, Kyrgyzstan, Mozambique, Nigeria, Pakistan, Philippines, South Africa, Tanzania, Tajikistan, and Ukraine (see Communities case study 9, example from DR Congo).[70] A further nine are underway in Armenia, Benin, Cameroon, Cote d'Ivoire, Moldova, Myanmar, Uganda, Vietnam, and Zimbabwe.[71]

Communities case study 9: Developing a Community, Rights and Gender Action Plan – the Democratic Republic of Congo

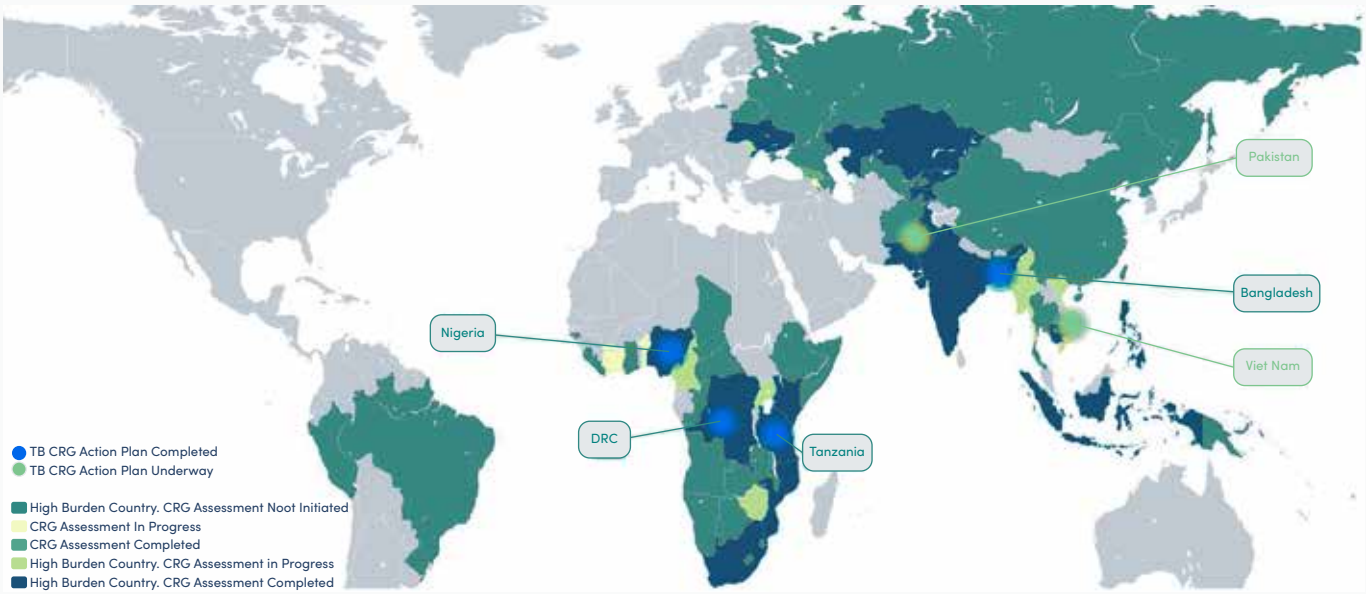
The DR Congo NTP (PNLT), together with Club des Amis Damien and the affected TB community, has developed a National Costed CRG Action Plan that responds to the findings and recommendations of the National CRG Assessment that was driven by Club des Amis Damien with strategic guidance from PNLT. The National CRG Action Plan has been integrated and included in NSP 2021-2023 and is a statement of need: the total budget calls for USD 15.6 million.

Four national costed TB CRG Action Plans have been developed in Bangladesh, DR Congo, Nigeria, and Tanzania, and seven countries are developing CRG Investment Packages. The latter can be used to strengthen national TB policies and address communities/civil society priorities within the preparation of National TB Strategic Plans and funding applications to the Global Fund.[72]

A TB Stigma Assessment has been piloted in India and Sierra Leone, with further implementation being supported in

Figure 5

TB CRG Assessments and Action Plans



Bangladesh, Ghana, Nigeria, South Africa and Ukraine. Also, responding to the need for and reliance on comprehensive, high-quality and timely data and information on the barriers faced by people affected by TB in accessing essential TB services, the OneImpact community-led monitoring digital platform and framework has been implemented in 14 countries (Azerbaijan, Belarus, Botswana, Cambodia, DR Congo, Indonesia, Kenya, Kyrgyzstan, Mozambique, Pakistan, Philippines, Tajikistan, Tanzania, and Ukraine).[73]

According to affected communities/civil society it is increasingly urgent that understanding about CRG issues is scaled up and 'translated' into updated policies and funded programmes. For example, reports by the Global Fund's Technical Review Panel (TRP), analysing applications to the latest allocation round (for 2020–2022), highlight that there are ongoing gaps in countries' interventions in this area. Examples include: the lack of differentiated strategies to reach target populations; inadequate attention to some key populations (such as internally displaced people and mobile populations); and lack of attention to leaks in the TB cascade.[74]

Action on such areas will require the ongoing strengthening of community systems alongside wider attention to resilient and sustainable systems for health. It will also require the implementation of a person-centred approach that looks beyond bio-medical factors to holistically address a person's social needs, mental health and economic status.

Promoting Human rights-affirming TB responses

Affected communities and civil society continue to advocate for a human rights-based approach to TB responses that are grounded in international, regional, and domestic law. Such laws establish the right to health, non-discrimination, privacy, confidentiality, and freedom of movement, among others. They also establish the legal obligations of governments and private actors.

In practice, the human rights barriers noted include (but are not limited to):

- Adoption of narrow definitions of 'rights' (e.g. those that do not include the right to benefit from scientific developments)[75] and limited sensitisation to these rights in the context of TB
- Legal and programmatic tendency to 'control' rather than 'support' people with TB

- Limited investment in access to justice programmes, including human rights monitoring
- Inadequately nuanced and tailored interventions relating to gender equity and key populations
- Low prioritisation given to strengthening enabling legal and policy environments that promote and protect human rights, including mental health, financial, nutritional support, and legal aid.

Community actions and responses

There has been significant progress in understanding the principles and practices required for a rights-based approach to TB during the period under review. Affected communities/civil society have scaled up human rights and TB literacy and training for policy-makers and key influencers (see *The Right to Breath,* Communities case study 10)[76] as well as the implementation of TB legal environment assessments.

A few key resources have also been developed to inform domestic application and community action. These include *Activating a Human Rights-Based Tuberculosis Response* technical brief, which includes 20 recommendations for practical actions that countries can take to activate a rights-based response to TB.[77] Another, specifically developed by affected communities, is the *Declaration on the Rights of People Affected by TB*, produced in 2019 by TBpeople with support from the Stop TB Partnership and legal experts.[78] This Declaration comprehensively covers a range of rights such as the right to: physical and mental health; life; liberty; confidentiality; information and informed consent; work; scientific progress; freedom from discrimination; and freedom from cruel, inhumane or degrading treatment.

An important donor initiative that eligible countries can tap into to support the operationalisation of TB and human rights, is *Breaking Down Barriers* – a Global Fund investment of $123 million to remove human rights barriers to HIV, TB and malaria in the 2017–2019 allocation cycle.[79] This programme has helped to catalyse increased investments in human rights, and has enabled policy-makers to identify the root causes of rights and gender barriers, determine what is needed to tackle them, and establish the costs involved in responding to these. For example, South Africa's new three-year plan to tackle gender inequality and human rights-related barriers to HIV and TB health services, launched in 2019, was shaped by the extensive baseline assessment studies conducted as part of *Breaking Down Barriers*. The country's new plan helps vulnerable and key populations to access lifesaving healthcare services while addressing the root causes of rights and gender-related barriers. This initiative has been implemented in 19 other countries.

Communities case study 10:Training affected communities and civil society on TB human rights – Asia-Pacific

Activists' Coalition on TB Asia-Pacific, together with APCASO and with support from the Stop TB Partnership's Challenge Facility for Civil Society, is implementing The Right to Breathe, a 2020–2021 initiative. The activities include a capacity building programme for people affected by TB, as well as civil society organisations, with a Right to Breathe training manual piloted in Cambodia, Indonesia and the Philippines. The project provides in-country support for the roll-out and implementation of TB and human rights advocacy plans, focusing on Nepal, Papua New Guinea and Vietnam.

Gender equality

Affected communities/civil society advocate for a gender-transformative approach to TB that addresses the social, legal, cultural and biological issues that underpin gender inequality and contribute to poor health outcomes.

The ongoing challenges in this area include: low acknowledgement of the double-burden faced by women (as people with TB and as carers); the lack of interventions specifically tailored to men, despite this population being largely impacted by TB; the paucity of disaggregated data on gender, vulnerability and access to TB services; and the use of narrow definitions of 'gender' that just address men/women, without a wider understanding of gender dynamics and different gender identities.

Community actions and responses to drive gender-responsive TB programming

However, some countries, have started scaling up gender responsive and gender-transformative approaches to TB. These activities have included: conducting gender assessments in 17 countries; utilisation of the Stop TB Gender Investment Package;[80] the development of national frameworks for gender responsive approaches in some countries, for example India (see Communities case study 11).[81]

The establishment of gender-related networks (such as TB Women) are good progress, along with the strengthening of gender-specific TB funding mechanisms. An example of the latter is the application of *A Framework of Empowerment of Women and Girls*[82] to TB REACH – supporting the grantees to look at gender-related data and evidence, formulate gender responsive interventions and promote gender equality through the empowerment of women and girls.

Communities case study 11: Developing a National Framework for a Gender Responsive Approach to TB – India

In India, stakeholders – including affected communities and civil society – have built on the findings of the India CRG assessment coordinated by REACH, to develop a National Framework for a Gender Responsive Approach to TB. This aims to catalyse dialogue at all levels and among all stakeholders in the TB response, strengthening collective understanding of TB and gender. The Framework is based on a set of principles (such as non-discrimination and working in partnership) and addresses: the interaction between TB and gender at different levels, and its impact on the TB burden and response; actions needed to move towards a gender-responsive approach; and guidance on how to implement those actions. The Framework, which is now owned by the National TB Programme, is articulated under the same headings as the National TB Strategic Plan 2017–2025 (detect, treatment, prevent and build).

Stigma and discrimination

Stigma is frequently described as a process of devaluation, whereby stigmatised people are discredited, perceived to have less value or worth, or even seen as a danger. Stigma is also a significant social determinant of health and a fundamental cause of health inequality.[83] Communities/civil society call for a response to TB that recognises how stigma and discrimination exacerbate (and even supersede) the medical, social and economic hardships of the disease. This presents as a cross-cutting barrier to accessing quality, affordable and timely care and support.

The barriers related to (internal and external) stigma include:

- High levels of TB-related stigma in health settings, workplaces and communities
- High levels of self-stigma among people affected by TB
- Lack of robust evidence about how stigma impacts on TB services
- Low understanding of community members' multiple experiences of stigma (such as for people living with both TB and HIV; those who suffer TB or DR-TB as well as being from marginalised key and vulnerable populations).

The paucity of data on how TB-related stigma presents itself has resulted in the scarcity of programmatic interventions to address TB-related stigma.

As previously stated, the *TB Stigma Assessment* tool – developed by the Stop TB Partnership and partners, including people with and affected by TB – is an important breakthrough in this area.[84] Published in 2019, the tool uses both qualitative and quantitative data collection methods to assess how, and the extent to which, stigma acts as a barrier to TB services in different settings and along the TB pathway.

It also supports the formulation of recommendations to make services available, accessible and acceptable to all. In recognition of the potential for the *TB Stigma Assessment* to strengthen national responses to TB, the Global Fund included three indicators from the tool in the core indicators of the TB modular framework for its latest round of funding.[85] These relate to TB self-stigma; stigma in healthcare settings; and stigma in community settings, and will facilitate the inclusion and monitoring of relevant interventions in national grants. Each country's progress on stigma and other aspects of the TB response can be seen on the Country TB Dashboards.[86]

Meaningful Engagement of affected communities and civil society

In 2018, communities/civil society welcomed the Political Declaration's call for responses to TB to actively engage communities/civil society.[87]

Progress towards commitments

According to the UN Secretary General's *Progress Report*, in 2019 and early 2020, 25 of 30 countries with a high TB burden conducted reviews of their National TB Programmes and National TB Strategic Plans, producing updated versions with more ambitious targets based on the *Political Declaration*. Communities/civil society were part of the process (in varying capacities) in almost all contexts.[88] The recommendations of many of those reviews called for greater and more organised engagement of communities/civil society, including through capacity building, but the level of involvement in these sorts of activities needs to be further understood.

In some contexts there has been slow progress, including around political and legal opposition to civil society contributing to the shrinking civil society space; tokenistic involvement of affected communities and civil society; lack of diversity in affected communities and civil society representation (e.g., larger, capital city-based NGOs dominating). Further, weak community systems and organisational structures (e.g., for financial management and monitoring and evaluation) hampers community systems responses. Engagement challenges include the: lack of funding for affected communities and civil society to fully participate in decision-making processes, sometimes with a presumption that involvement will be 'for free'; and lack of TB-specific representatives on decision-making structures such as CCMs and during PEPFAR Country Operational Plan and Regional Operational Plan) processes. Even where there is representation, there is often limited coordination and consultation between representatives and other groups of people affected by TB.

Communities case study 12: Coordinating community inputs into Tanzanian national processes

In Tanzania, rapid scale-up initially led to fragmentation among TB affected communities and civil society. In response, the Tanzania TB Community Network was formed to serve as an umbrella organization, with members from people with and affected by TB, community groups, civil society organizations and advocates. The Network's objectives are to: promote networking, coordination, experience sharing, learning and dialogue among members and other key stakeholders; support implementation of quality, accessible and equitable TB services in the community through health and community systems strengthening; enhance greater participation of members and other stakeholders to advocate for the development and implementation of TB policies and guidelines; and enhance dissemination of information and facilitate communication and collaborations of members and stakeholders. The Network – which has now developed its own governance structure and Advocacy Strategic Plan 20202024 – coordinates the input of communities/civil society into national processes for TB, such as the revision of the National TB Strategic Plan and meetings of the Tanzania National Coordination Mechanism (which leads on the country's funding request to the Global Fund). To support this work, the National TB and Leprosy Programme has adopted WHO's community indicators for TB and established community-based monitoring and evaluation systems to capture the contribution of affected communities and civil society to the country's TB outcomes.

Community actions and responses to build TB communities

In 2020, affected communities/civil society highlight sector-level progress – with stakeholders becoming more organised and mobilised and, as a result, increasingly able to engage effectively and have a united voice. Examples of mechanisms and platforms can be seen at all levels, including nationally, such as the range of networks and forums that have evolved in countries such as Tanzania (see Communities case study 12).[90] Regionally, examples include TB Europe Coalition in the WHO Europe Region; DRAF TB in Francophone Africa; Americas TB Coalition; ACT! AP in Asia-Pacific; MENA Network to Stop TB in Middle-East North Africa; and ACT in Anglophone Africa). Global examples include TBpeople, Global Coalition of TB Activists (GCTA), the three civil society Delegations to the Stop TB Board and WHO's *Civil Society Task Force on TB*.[89] Many affected communities and civil society sectors – such as in Moldova (see Communities case study 13) – report that they have benefited from more meaningful opportunities to engage in and influence critical processes in their countries. Examples include the revision of National TB Strategic Plans, development of national funding proposals and decision-making in Global Fund Country Coordinating Mechanisms. This often reflects a sense that the sector is gaining recognition and respect as an essential partner in the response to TB. The Global Fund country-level CCM evolution process provides a strategic opportunity for TB-affected communities to meaningfully engage in decision-making processes, and for 'top-down bottom-up' information exchange. Examples cited have included the installation of constituency-based reporting systems, which have improved information gaps between affected communities' representatives on the CCM and their constituencies.[91]

Meaningful community engagement also requires informed, capacitated and coordinated networks of people affected by TB. There are several examples that are continuing to grow in strength, including TBpeople Ukraine (Ukraine); POPTB Indonesia (Indonesia); Survivors Against TB India (India); TB Proof South Africa (South Africa); Club des Amis Damien (DR Congo), and Network of TB Champions (Kenya). However, this remains a significant gap in many countries.

Communities case study 13: Engaging communities/ civil society in national processes – Moldova

In Moldova, the National TB Strategic Plan for 2016-2020 includes a goal to 'strengthen the involvement of community and civil society organisations in TB care through a person-centred care approach'. To support this, the country operates a number of processes to ensure the meaningful engagement of communities/civil society. These include the inclusion of community/civil society representatives in the CCM (the decision-making body for the Global Fund), TB Technical Working Group and Country Council of Experts. The work of the representatives is supported by two platforms for their constituents – one for TB civil society organisations, one for affected communities.

Scaling up Community Systems Strengthening

Community-based services — In 2018, the *Political Declaration* called for responses to TB to recognise and support community-based interventions.[92] Despite this commitment, two years on, stakeholders report a number of ongoing issues in this area. These include: National TB Programmes' lack of formal acknowledgement of community-based responses; lack of investment in community systems strengthening, with organisations having poor access to training and capacity building; low levels of TB literacy in communities; and unsupportive sociopolitical environments (such as laws that restrict the functions of civil society organisations). Community-based responses also face significant financial challenges, with their resource needs often not fully recognised, heavy reliance on external donors, and a lack of 'civil society friendly' social contracting systems to facilitate domestic resourcing (which, in some countries, is prohibited by law).

The value proposition of investing in community-based services

Since 2018, the sector has continued to demonstrate the concrete value-added of community-*based,* and often community-*led,* responses. Examples include: finding 'missing' people with TB; reducing levels of loss-to-follow-up among people with TB; supporting adherence to TB treatment; promoting people-centred approaches to TB; providing psycho-social support, especially for people with DR/MDR-TB; and reducing stigma and discrimination.

Community action(s) and response(s)

There are numerous examples – from countries such as Peru (see Communities case study 14) – of where community-based responses have achieved results that would have been highly challenging or even impossible for other sectors.

According to the *Progress Report*, in 59 countries that reported data for 2019, community referrals accounted for an average of 20% of newly reported people with TB.[93] In 42 countries, the treatment success rate among people provided with community-based treatment support averaged 83%.

Communities case study 14: Conducting community-based TB screening and testing – Peru

In Peru, about half of the people with TB – 20.5% of which go unreported – are concentrated in Northern Lima, where people live in informal settlements. Here, *Socios en Salud,* a civil society organisation, has implemented TB Móvil, an outreach initiative to increase case finding. The work takes place in three districts in collaboration with the Ministry of Health and Lima Norte Health Directorate. It involves mass screening at high-density locations (such as markets and health facilities), using mobile X-ray vans to identify presumptive individuals and with sputum samples taken to an Xpert testing site. This is combined with contact tracing by community health workers using creative methods (such as murals and social media). Doctors are also present to perform clinical evaluations for anyone with an abnormal x-ray. People with bacteriologically confirmed or clinically diagnosed TB are accompanied to health facilities by community health workers to start treatment; the contacts of people with TB are given preventive treatment. TB *Móvil* is the first intervention in Peru to conduct community-based x-ray TB screening and home-based latent TB infection screening. Previously funded by TB REACH, it now receives support from the Government.

Community-based monitoring — Alongside community-based interventions, the period from 2018 to 2020 has seen major progress in community-led monitoring. This is a process whereby service users or local communities regularly gather to analyse and use information, in order to improve access to and quality and impact of services, and to hold service providers and decision-makers to account.

The *Progress Report* also cites how, in a range of countries – such Azerbaijan, Belarus, Cambodia, DR Congo, Indonesia, Kyrgyzstan, Mozambique, Tajikistan, Ukraine and United Republic of Tanzania – national networks of affected communities and civil society have begun monitoring the availability, accessibility, acceptability and quality of TB care and support services. Some countries have formed national TB Community Advisory Boards to inform research policies or advise research projects, and/or have created national networks of advocates to monitor commitments, policies and services.

This work has been supported by the development of key resources, such as *Community-Led Monitoring: A Technical Guide for HIV, Tuberculosis and Malaria Programming*[94] and *Investment Package: Community-Based Monitoring of the TB Response.*[95] It has also benefited from the development of innovative tools. An example is *OneImpact,*[96] produced by the Stop TB Partnership and affected communities and civil society partners. This provides a digital platform that, through mobile phone Apps, enables people and communities affected by TB to gain knowledge on the disease, connect with services and peers, and conduct monitoring and reporting of problems and barriers. *OneImpact* – which has been rolled out in countries such as Ukraine (see Communities case study 15)[97] – provides real-time data, through which services can be improved and stakeholders can be held to account.

Communities case study 15: Using OneImpact to conduct community-led monitoring – Ukraine

TBpeople Ukraine is one of the largest organisations of people affected by TB in Ukraine. It had long received reports of high dropouts from TB care, including due to human rights violations and poor gender-sensitivity. As part of its response, it piloted OneImpact. Every case raised is reviewed by a call-centre specialist, with the community member then redirected to a local TB civil society organisation (for services and care) or a professional specialist (such a psychologist or lawyer), or provided with immediate support (such as a food package or medical costs reimbursement). Since 2019, TBpeopleUkraine has complemented this work by building strong partnerships with TB treatment centres and civil society organisations in every region. In 2020, with support from the Stop TB Partnership and the PAS Centre, Moldova (within the TB REP 2.0 project), it is scaling-up OneImpact to all 24 regions in Ukraine, and transferring the tool to the Public Health Center of the Ministry of Health as a means to monitor the quality of services provided by communities/civil society through public funds.

Refer to the CALL TO ACTION for recommendations under Area of Action 2

Area for Action 3: Accelerating the development of, and access to, essential new tools to end TB

TB research and development

In 2018, the *Political Declaration* included commitments related to advancing TB research, development and innovation.[98]

Progress towards targets(s)

Affected communities/civil society recognise that, since 2018, the pace of work in this area has increased. Examples of progress include those relating to: identification of a vaccine candidate (M72/ASOIE, which in a phase IIb trial offered 50% protection against active TB disease and a good safety profile in healthy adults with latent TB infection);[99] introduction of the first-ever Essential Diagnostics List by WHO,[100] which has paved the way for countries to update and scale up their own diagnostics plans, including rapid molecular tests; urine-based TB LAM tests for people living with HIV; development of shorter and safer drug regimens, such as all-oral regimens for people with DR-TB and short course regimens for TPT, and the recently announced results from Study 31 which show a reduction in treatment period for drug-susceptible TB (DS-TB) from 6 to 4 months[101]. The TB 'pipeline' is more promising than in past years and, guided by WHO's *Global Strategy on TB Research and Innovation*[102], there is the *potential* to transform the response to TB.

Systemic barriers and challenges

While scientific advancements related to responses to TB are welcomed, the deadly divide of actual access – even to the older TB diagnostics and treatments – remain. In some contexts, communities in need are not able to enjoy the fruits of science, and even the minimum requirement for all high-burden TB countries have access to efficacious and affordable DS-TB drugs is not met.

Research and development (R&D) for TB is still limited in terms of scale and pace – in stark cotrast to the large-scale, accelerated action and investment in COVID-19. Monumental challenges remain in the context of TB R&D, including:

- Competition from other diseases
- Lack of profitability in TB diagnostics, drugs and vaccines
- Outdated and complex legal and regulatory systems; anticipated intellectual property related barriers to affordable access
- Lack of public/private mix models of funding
- Clinician preferences and lack of willingness to change practices
- Low focus on contextually-adaptable, people-friendly and point-of-care TB tools
- Limited engagement of communities/civil society in driving a 'people-driven' R&D agenda
- Lack of scale up of successful innovations
- Challenges with ownership of and access to research and development data (i.e. opensource science)
- Procurement and supply chain models to secure affordable access to both *existing* and *emerging* drugs, technologies and innovations.

These challenges also include a lack of advances in key tools, such as: a TB vaccine that is effective before and after exposure across a range of age groups and geographical settings; a rapid point-of-care test for TB infection and TB drug resistance; and shorter and safer regimens for treating TB infection and TB disease, especially DR-TB. There is also need for greater transparency among philanthropic efforts and collaborative government interventions, such as the BRICS TB Research Network, to advance a solid TB research-to-access agenda.[103]

Community action(s) and response(s)

Affected communities/civil society are demonstrating their readiness to roll out research developments and innovations, fulfilling people's 'right to benefit from scientific development'.[104] Examples range from the use of GeneXpert rapid molecular testing (such as in Vietnam, see Communities case study 1) to the application of digital technologies. Examples of the latter include the provision of electronic dose monitoring boxes (for example in Ukraine)[105] and the use of video-supported treatment (for example in Belarus, Georgia, Kazakhstan, Moldova, Tajikistan and Turkmenistan).[106]

Affected communities and civil society have also shown their willingness to actively engage in TB research and development initiatives. Examples can be seen at all levels, from country-level (such as Community Advisory Boards in India as part of STREAM Phase III clinical trial study sites for the first all-oral DR-TB treatment regimen) to global-level (such as the Global TB Community Advisory Board[107] – a group of community activists from Asia, Europe, Africa, and the Americas, that aims to increase community involvement in TB research, such as through liaising with pharmaceutical companies and informing the design of studies.

Funding for TB research and development

The financing of TB research and development also remains a major challenge. There is a need for innovative financing models, which will ensure de-linkage of the costs of R&D from the price and volumes of sales of final products; and which will promote collaboration, data sharing (open source science) and open licensing of intellectual property (especially for research originating from public funding).

Target check: Research and development

- Funding of $900 million provided for TB research in 2019, compared to a target of $2 billion annually 2018-2022

Tuberculosis Research Funding Trends, a report by the Treatment Action Group and Stop TB Partnership, [108] cites how global TB research funding totalled just over $900 million (USD $900,964,590) in fiscal year 2019. While this marked the second year funding exceeded $900 million, the figure remains below 50% of the $2 billion annual target set in the *Political Declaration*. The *Funding Trends* report highlights how public funders comprised more than two-thirds of total TB research and development spending, while the private sector's investment totalled $75 million (a number that has remained flat since 2015). Only three countries – the United Kingdom, the Philippines and New Zealand – met their 'fair share' targets by spending at least 0.1% of their overall research and development budgets on TB. The United States remained the single largest funder of TB research, spending nearly $400 million in 2019 (the second largest donor country, the United Kingdom, spent $56 million).

Affected communities and civil society acknowledge the particularly important role of the Global Drug Facility.[109] By May 2019, it had delivered more than $2 billion in TB medicines and diagnostics to 142 countries, including over 31 million treatment courses. The Facility remains the largest global provider of quality-assured TB medicines, diagnostics and laboratory supplies to the public sector. It also provides technical assistance and supports the uptake of innovative tools in countries.

The Treatment Action Group has highlighted how investments in TB research can provide returns in combating both TB and COVID-19, with sustained and expanded financing needed to safeguard TB research against disruptions.[110]

TB drug pricing and sustainable access to TB commodities

Affected communities/civil society expressed concern that – alongside other challenges, such as those related to procurement, patents and the use of outdated drugs – drug pricing is a further critical issue that limits the availability and accessibility of critical TB medications. This is mainly due to the exorbitant prices of innovative TB commodities, mainly due to challenges such as these being under patent; archaic procurement laws and weak pharmaceutical supply chain management systems, as well as a lack of proper forecasting within national TB programmes.

TB Drugs Under The Microscope,[111] a 2020 report by *Médecins Sans Frontières*, documents how Rifapentine-based regimens such as 3HP and 1HP have reduced TPT toxicity and improved rates of treatment completion. These have been complemented by a 70% price reduction for the drug for 100 eligible countries.[112] These reductions were derived, in part, through concerted advocacy by affected communities and civil society. The report also notes that the WHO standard shorter all-oral bedaquiline-containing regimen for DR-TB now falls below the affordable target price ceiling of $500 that the organisation called for. However, the lowest price for longer MDR-TB regimens (to treat fluoroquinolone-susceptible TB and requiring 6–18 months of bedaquiline), remain too high, at $800-1,500 per person. The lowest prices for fluoroquinolone-resistant TB requiring bedaquiline and delamanid for 20 months, are still priced at $7,500 and reach $10,500 per person when imipenem-cilastatin is added. Action is needed to secure

fully accessible price reductions for each of these three drugs. A global campaign led by affected communities/civil society is calling for the price reduction of bedaquiline to "A $ a day for bedaquiline, which is owned by Johnson & Johnson. They argue that the drug was developed through public investments; and is therefore 'a public good 'that should not be so exorbitantly priced that TB programmes are unable to scale it up.[112]

Médecins Sans Frontières also noted that intellectual property barriers contribute heavily to the exorbitant prices set by pharmaceutical companies. To address this, patent oppositions (amongst others) continue to be a critical tool for access to affordable TB medicines, given efforts from pharmaceutical corporations to conduct 'evergreening' (i.e., seeking applications for different forms or minor changes of the same medicine to extend the monopoly period). These intellectual property-related barriers are increasingly being challenged by affected communities/civil society, and within TB, there has been some success.

- In 2019, groups in India and Thailand filed oppositions calling for the rejection of Sanofi's evergreening patents of rifapentine and isoniazid fixed-dose combination, resulting in the corporation withdrawing patent filings in India, Indonesia, and the European Patent Office, and committing to abandoning patent applications in six others.
- In 2020, groups successfully advocated to Sanofi to withdraw and surrender its patents, on these drugs in countries where they were granted.[114]
- The *TIME for $5* campaign is calling for the Cepheid to drop the price of its diagnostic tests to USD $5 dollars.[115]

There is a warning that, while the global TB community finally has promising tools and policies in place to save the lives of millions of people, there is the risk of 'snatching defeat from the jaws of victory' if WHO recommended treatment regimens are not scaled up and barriers to access are not addressed.[116] These concerns extend to the Global Fund plans to transition its support out of the high burden and high incidence countries.

The above access challenges would been far more devastating were it not for collaborative efforts to improve access to TB drugs and diagnostics through mechanisms such as the Global Drug Facility (GDF).[117] Since its inception in 2001, the GDF has delivered more than $355 million TB products (including US$ 280 million worth of medicines and US$ 75 million worth of diagnostics) to 142 countries – a 46% increase compared to 2019.[118] So far, the GDF has supplied over 31 million TB treatment courses globally. In 2020, the GDF saved close to $36.4 million (a 20% price reduction for the 2020 WHO-recommended TB regimens), by negotiating price reductions and providing technical assistance to countries to improve their procurement services. The pooled procurement of TB drugs and diagnostics through the GDF must be prioritised to promote uninterrupted access and reduce further market fragmentation.

"GDF price reduction on bedaquiline-based shorter regimen now cheaper than injectable-containing shorter regimens (km): $540 vs $562" **GDF, November 2020**

Refer to the CALL TO ACTION for recommendations under Area of Action 3

Area for Action 4: Investing the funds necessary to end TB

Target check: Funding

- Funding of $6.5 billion for universal access to TB prevention, diagnosis, treatment and care provided in 2020, compared to a target of $13 billion annually by 2022

In 2018, the *Political Declaration* called for Member States to mobilise the necessary funds to end TB.[119]

Progress to target(s)

Today, communities/civil society are concerned that funding for TB – which is predominantly derived from domestic sources[120] – remains severely off-track. Global levels are currently only half of the $13 billion target for 2022 (*see Figure 6*).[121] Such statistics are, in turn, reflected in national budgets, with many affected communities/civil society stakeholders reporting gaps in their country's budget for health more widely, or TB specifically.[122] Unlike other diseases – including COVID-19 – TB has traditionally received very little donor support. To realise a holistic, people-centred TB response, and achieve 100% of the targets set in the *Political* Declaration, there is an urgent need for donors, private sector and multi-lateral partners to invest in the comprehensive implementation of responsive and equitable TB programmes, thereby closing the TB funding gap.

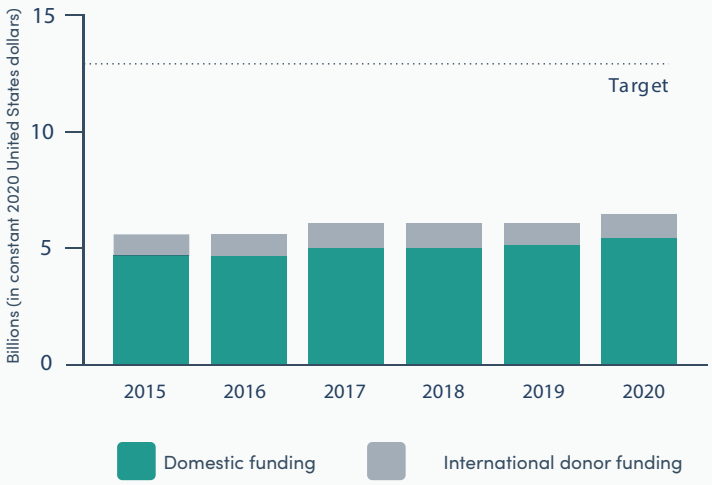
Barriers and challenges to TB investments

The challenges experienced in this area include:

- A limited range of major international donors involved in TB
- TB being de-prioritised in domestic funding in favour of other diseases or issues, despite the proliferation of TB investment cases
- Lack of 'political will' to scale up domestic level contributions
- Lack of communities/civil society engagement in domestic TB budgeting and resource allocation processes.

Figure 6

Funding for TB prevention, diagnosis, treatment and care in low- and middle-income countries, 2015–2020



Source: Report of the Secretary General Progress towards the achievement of global tuberculosis targets and implementation of the political declaration of the high-level meeting of the General Assembly on the fight against tuberculosis, 2020

Community actions and responses

Affected communities and civil society also acknowledge that there are some positive developments in the financing of TB. Examples include: an increased allocation by the Government of the United States (the largest bilateral donor to TB); and a successful replenishment of the Global Fund (the largest single source of international funding for TB, responsible for about 70%),[123] with increased TB funding envelopes for many countries and more catalytic funding in the form of matching funds and strategic initiatives. Increases have also been seen in some domestic allocations to TB and/or health more widely, often as a result of advocacy by communities/civil society and partners, such as in Nigeria (see Communities case study 16).[124]

Progress has also been made in understanding the financial impact of ineffective responses to TB. For example, modelling research in the Philippines showed that as many as 1,958 people and 233 people were likely to have died as a result of loss-to-follow-up for drug sensitive TB and MDR-TB (respectively); while 588 people were likely to have died as a result of TB medicine stock-outs. In economic terms, this translates into a cost to the country of $8,000 per person with drug sensitive TB and $17,000 per person with drug resistant TB.[125] Meanwhile, the total costs of drug stock-outs for the country total as much as $21 million (comprised of $1.5 million for additional service delivery and $19.5 million for out-of-pockets costs for service users).

Since 2017, TB has been recognised as a major global health issue in both the Ministers of Health Declaration and Heads of State Communique. This has been driven by the G20 TB Coordination Group, led by the Global TB Caucus Secretariat and affected communities and civil society. It will now be important to turn the words from these Declarations into actions.

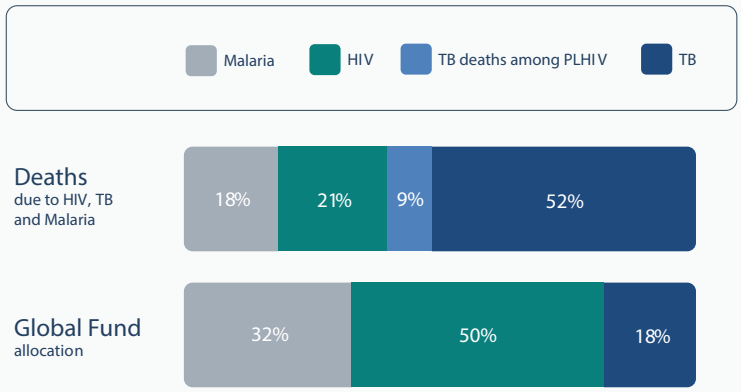
Affected communities and civil society are launching campaigns to mobilise key institutions and mechanisms to increase their investment in TB. For example, in October 2020, the Africa Coalition on Tuberculosis launched a campaign calling on the Global Fund to increase its allocation to TB to 33% - based on the rationale that TB has disproportionate unmet needs, low availability of funding, high mortality rates and need for rapid action to meet targets by the end of 2022.[126]

Communities case study 16: Advocating for increased domestic and Global Fund resources – Nigeria

In Nigeria, advocacy by communities/civil society and the TB Caucus network of parliamentarians contributed to the development of a road map for transforming the TB response and contextualising the Political Declaration targets for different tiers of Government (federal, state and local). This led to the country making a financial commitment of $12 million (a 20% increase) to the Global Fund in 2019 and, also within the Replenishment, committing to increase domestic resources for health and disease programmes.

Figure 7

TB33% Campaign to fully fund the Global Fund to increase the TB allocation



Funding for affected communities/civil society

Affected communities/civil society express particular concern about the resourcing of TB interventions that are community-based and/or community-led. Such interventions often remain unrecognised in national strategies and, in turn, unallocated for in national budgets.[127]

Many communities/civil society organisations remain dependent on international donors to channel increased financial and/or technical support to their work. Examples include the *Finding the Missing People* as well as *Community, Rights and Gender Strategic Initiatives* by the Global Fund (see Communities case study 17)[128] and the *Challenge Facility for Civil Society* by the Stop TB Partnership.[129] A significant success has been the transformation of the *Challenge Facility* into a multi-million dollar, multi donor platform providing 54 grants between 2018 and 2020. For affected communities and civil society, this mechanism it is one of a kind. The current round is valued at USD$2.5 million, but this addressed just 5% of the total demand ($47 million). The announcement to triple the *Challenge Facility* budget in 2021 is strongly applauded, although there is very real potential to further scale up TB financing of communities through this mechanism (see Communities case study 18). The support of USAID and the Global Fund raises hopes that other donors can join the Stop TB Challenge Facility mechanism to ensure TB-affected communities can access the funding they need and deserve. In addition to notable efforts under Strategic Initiatives mentioned above, there is also significant opportunity for the Global Fund to continue to increase its investments in TB-affected communities. This should include community systems strengthening initiatives for national networks of people affected by TB, and for this to be a pillar of building resilient and sustainable systems for health. Further, it should include an enhanced focus on TB-affected communities in the Human Rights Strategic Initiative and the CCM Evolutions project. As part of this, Global Fund must stay true to its mandate of the three diseases, and not be stretched into new endeavours that force further trade-offs around already scarce resources.

A further contribution is the TB Local Organizations Network (LON) project, managed by USAID as part of its Global Accelerator to End TB.[130] This provides cooperative agreements with local communities/civil society organisations in the donor's TB priority countries to implement locally-generated solutions to improve TB diagnosis, treatment, and prevention. It has a focus on country empowerment and accountability in order to accelerate the transition to local ownership and sustainability.

Communities/civil society also highlight the need for increased resourcing of their TB interventions from domestic sources, including in contexts where donors are transitioning out of countries. They cite examples where the switch from donor to domestic funding has resulted in major gaps in programming for TB key and vulnerable populations.[131] To avoid such risks, stakeholders emphasise the need for social contracting systems that are civil society-friendly, have a supportive regulatory system and are accompanied by action around the social and legal barriers faced by communities/civil society. Experiences in Eastern Europe and Central Asia (see Communities case study 19) [132] provide useful lessons-learned in this area.

Communities case study 17: The Global Fund's Community, Rights and Gender Strategic Initiative

Catalytic investment to strengthen the meaningful engagement of communities/civil society in Global Fund-related processes across HIV, TB and malaria. It has three components:

1. Short-term technical assistance program
Of the assignments delivered, 37.1% (59 assignments) were focused on HIV/TB and 6.2% (10) on TB. For example, support was given for TB affected communities and civil society to build their capacity to advocacy for the inclusion of their needs in funding requests in Mauritania, Nigeria and South Africa's mining sector.

2. Long-term capacity strengthening of key and vulnerable population networks and organisations
TB grantees represent a robust portfolio, including two international networks and three regional networks, adding up to strong geographic coverage in most regions: Africa Coalition on TB; Asociación de Personas Afectadas por Tuberculosis; Global Coalition of TB Activists; TB Europe Coalition; and TBpeople.

3. Six regional communication and coordination platforms
TB grantees represent a robust portfolio, including two iFor example, the Platforms made a concerted effort to expand their reach to TB implementing communities, including sharing of relevant information resources and engagement in events dedicated to these disease components.

Communities case study 18: Investing to build stronger community systems in the Philippines

ACHIEVE is the recipient of the Local Organizational Network (LON) Grant in the Philippines. The grant represents a significant and unprecedented opportunity for TB-affected communities in the Philippines to meaningfully engage and strengthen the national TB response. The grant includes elements of capacity building, community-led monitoring and advocacy for action. ACHIEVE has worked closely with TB key and vulnerable populations, including migrants and PLHIV, for close to 20 years. However, ACHIEVE first embarked on TB-specific work with a grant under the Challenge Facility for Civil Society. ACHIEVE went on to lead the national TB CRG Assessment and to engage in the work of the regional TB network ACT! AP. ACHIEVE is one example that shows the importance of and return from investment in TB civil society and affected communities.

Communities case study 19: Developing mechanisms for social contracting in Eastern Europe and Central Asia

In Eastern Europe and Central Asia, middle-income countries are undergoing transition from donor to domestic funding for TB, due to the withdrawal of the Global Fund. At the same time, countries face challenging TB epidemics, with the need to find 'missing' cases, address high levels of MDR-TB and introduce new drugs, diagnostics and models of care. Here, as part of the TB-REP 2.0 project, the TB Europe Coalition has provided technical support to communities/civil society in 11 countries to promote social contracting as a means to secure resources through state funding. The aim is to avoid gaps in services for key and vulnerable populations and build a multisectoral response. The work includes National Dialogues that bring communities/civil society together with decision-makers - such as from the Ministry of Health and National TB Programme - to identify priorities and develop functional contracting mechanisms. Examples of results include that: in Kazakhstan, social contracting to communities/civil society increased from $57,533.8 in 2018 to $65,040.32 in 2019; and, in Ukraine, a law on social services was adopted in 2019 that, for the first time, allows the government to purchase services from communities/civil society.

Target check: Universal Health Coverage

- 49% of people with TB and their households face catastrophic costs, compared to a target of zero by 2020

Universal Health Coverage

The *Political Declaration* contextualised TB targets within the achievement of Universal Health Coverage (UHC), including the removal of catastrophic costs for individuals and households.[133]

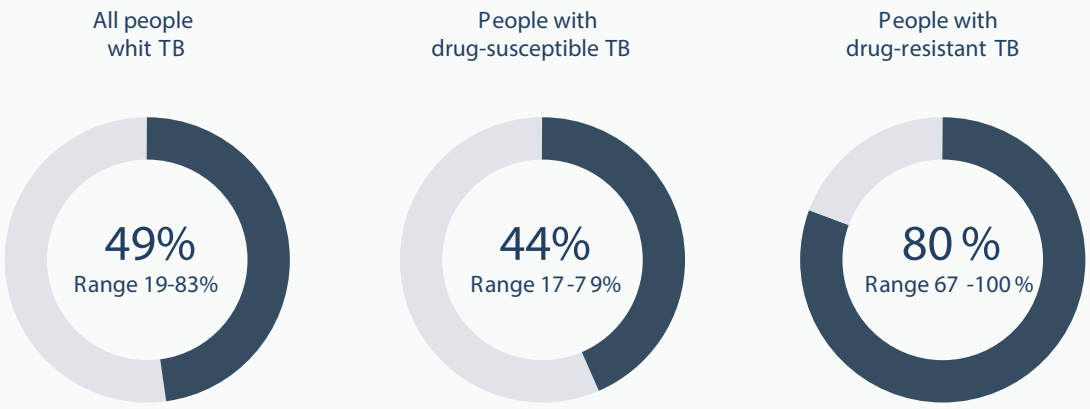
Affected communities/civil society report that progress on UHC has been slow in some countries, with challenges in relation to the integration of TB into negotiated UHC packages. Examples of the latter include where UHC mechanisms, such as health insurance and social protection schemes, may: lack attention to the social determinants of TB (such as poverty and homelessness); foster competition with other diseases and health areas; not include TB key and vulnerable populations and the poorest in society; be based on weak community systems; not incorporate joint TB/HIV interventions; and lack fully comprehensive policies that cover all aspects of TB programmes (such as DR-TB). Furthermore, even where Universal Health Coverage schemes have been introduced, some community members continue to face significant out-of-pocket costs related to their TB care (*see Figure 7*). This is particularly the case for those with DR-TB.

Affected communities/civil society do cite some areas of progress on UHC in some countries. These include examples where TB services are incorporated into national health insurance schemes. Where such strategies are comprehensive – and have benefited from the engagement of communities/civil society – they present a vital opportunity for holistic approaches to health, within which TB is an essential component. A key challenge noted by some key and vulnerable populations, such as healthcare workers, is where TB is being legally recognised as a compensable occupational disease. As a result, when these affected communities acquire occupational TB, they are unable to access health insurance.

Refer to the CALL TO ACTION for recommendations under Area of Action 4

Figure 8

Levels of catastrophic cost faced by people with TB



Source: Report of the Secretary General Progress towards the achievement of global tuberculosis targets and implementation of the political declaration of the high-level meeting of the General Assembly on the fight against tuberculosis, 2020

Area for Action 5: Committing to accountability, multisectorality and leadership on TB

Accountability across the TB Response

The *Political Declaration* committed to accountability for the response to TB and to meeting the global targets.[134]

Progress towards commitments

Affected communities/civil society report a modest level of progress in this area, including through work related to WHO's *Multisectoral Accountability Framework for TB (MAF-TB)*. Published in May 2019,[135]the Framework aims to guide stakeholder activities to strengthen accountability; accelerate progress to end TB by 2030 and meet the commitments in the *Political Declaration*.

In March 2020, WHO issued a *Baseline Assessment Checklist* for countries to assess their progress towards developing and implementing a MAF-TB at the national level.[136] The checklist is divided into four sections (commitments, actions, monitoring and reporting, and review) and incorporates the meaningful engagement of affected communities/civil society.

However, stakeholders argue that greater attention to accountability at all levels – (global, regional, national, district, etc.) – remains fundamental to fulfilling the commitments within the *Political Declaration*[137] and closing the 'deadly divide' between its commitments and reality. Further, that work is required so that accountability frameworks are practical, independent, and owned across sectors, whilst being adapted to national contexts. They highlight that these frameworks need to meaningfully engage communities/civil society – with clear responsibilities, including for monitoring progress and reporting on the commitments in the *Political Declaration*. Without such accountability, the Declaration risks being a theoretical aspiration, rather than something that is operationalised and saves lives.

Community actions and responses

Affected communities and civil society report that, in some cases, the MAF-TB has been used to catalyse and inform similar Frameworks at others levels – a process that has sometimes involved the engagement of affected communities and civil society. Experiences in countries such as Uganda (see Communities case study 20),[138] and regions such as Eastern Europe and Central Asia (see Communities case study 21[139]) show that progress can be achieved.

Communities case study 20: Strengthening national TB accountability in Uganda

The Uganda TB Caucus – a network of parliamentarians launched in 2018 – has been active in putting TB on the political agenda in the country and, more recently, maintaining the response to TB during COVID-19. The work has included collaborating with WHO on a MAF-TB to set out and achieve Uganda's targets for the *Political Declaration*. This was complemented by work by affected communities and civil society, collaborating with the National TB and Leprosy Programme. Together they developed a *Communiqué* about the MAF-TB that was sent to all Government Ministries, the President's office and members of the TB Caucus. This generated positive responses from several Ministries, including those for Gender and Social Development, Housing and Local Government. It led to involvement of these stakeholders in the development of the National TB Strategic Plan and a TB/HIV joint concept note for the Global Fund. With the arrival of COVID-19, there has been full engagement in strategies to both respond to the pandemic and continue action on TB. For example, the Caucus and affected communities and civil society were instrumental in advocacy for the Government to increase its overall health budget for 2020–2021.

Communities case study 21: Strengthening regional TB accountability in Eastern Europe and Central Asia

In Eastern Europe and Central Asia, the challenges to multisectoral accountability for TB include low levels of political will and the lack of periodic high-level reviews by inter-ministerial commissions of national TB responses that engage with key stakeholders. Here, the TB Europe Coalition – Challenge Facility Grantee and WHO TB Civil Society Task Force representative – contributed to the development of a MAF-TB checklist, and has provided technical support to roll it out in countries as part of a wider strategy to advocate for strong, national multisectoral mechanisms and monitor progress on the *Political Declaration*. This work has included supporting National Dialogues in countries such as Belarus and Azerbaijan, and agenda items include the establishment of multisectoral accountability mechanisms and implementation of the MAF-TB checklist. In 2021, TB Europe Coalition will produce operational guidelines focusing on the engagement of communities/civil society in multisectoral accountability processes and in conducting in-country baseline assessments. The work is supported by an information campaign to promote the MAF-TB and leverage high-level political leadership on TB.

Among communities/civil society, much of the work in this area has been led by the *TB Community Platform on Accountability,* a body established in 2019 to bring together stakeholders interested in accountability, including people with or affected by TB, civil society, Global TB Caucus, WHO, Stop TB Partnership, governments, and academics.[140] The *TB Community Platform on Accountability* aims to understand, analyse and share learning on how to implement accountability for the *Political Declaration*. It has identified a number of ongoing challenges, including the lack of:

- sustained political will.
- meaningful engagement of communities/civil society.
- agreed guidance on countries 'national share' of the *Political Declaration* targets.
- involvement of actors beyond TB, including those for UHC.
- clear roles and responsibilities among stakeholders.
- resources assigned to accountability work.[141]

The Platform advocates for better accountability at all levels, including for the UN to conduct regular, comprehensive reviews of global progress on the *Declaration*, and calling on regions and countries to do the same at their levels.

Of note, community-led monitoring (as described earlier) is playing an increasingly important role in accountability with affected communities and civil society able to report on the degree to which national commitments are being translated into tangible progress on the ground.

Communities case study 22: Strengthening national TB accountability in Indonesia

In Indonesia, the National TB Strategic Plan for 2016–2020 largely focused on bio-medical aspects of the disease. In contrast, the development of the Strategic Plan for 2020–2024 involved communities/civil society; all 34 Provincial Health Provinces; different Ministries; religious organisations; health practitioners and academics; with the National TB Programme open to discussion, including about how to reach the country's targets for the Political Declaration. This approach led to a Plan that includes attention to human rights, gender, community-based monitoring, multisectoral partnership, TB/HIV collaboration and support for key and vulnerable populations. Its strategies – which form the basis of the country's proposal to the Global Fund – also serve as the building blocks for a *Presidential Decree on TB Elimination*. This aims to strengthen active case finding, ensure effective treatment services and intensify prevention, and includes high-level monitoring and review with the involvement of communities/civil society.

Reinforced leadership and promotion of multisectorality

The *Political Declaration* called for strong leadership and a multisectoral response to TB.[142]
This is especially important considering the broader determinants of TB, including undernourishment, HIV infection, alcohol abuse disorders, smoking and diabetes.[143]

Progress towards the target(s)

Affected communities/civil society report, that in some contexts, there has been little progress in the development of a fully functional multisectoral mechanism for TB, including one that meaningfully involves people with and affected by TB. In others, there have been some positive examples of multisectoral mechanisms that involve a diverse range of stakeholders, from governments to people with TB, parliamentarians and celebrities. Best practices in countries such as in India, Pakistan, Nigeria and Indonesia (see Communities case study 22)[144] illustrate that such mechanisms have benefitted from the highest level of national leadership, in the form of the President, Prime Minister or First Lady.

According to the UN Secretary General's *Progress Report*, in 2020, 86 countries reported that a national multisectoral accountability mechanism is in place under high-level leadership, and that 62 of those mechanisms included representatives of affected communities/civil society).[145]
The *Global TB Report 2020* cites how, in the 2020 round of TB data collection, WHO requested countries provide information on three key elements of multisectoral accountability in the national response to TB: National TB Strategic Plans; annual TB reports; and multisectoral and multi-stakeholder review mechanisms under high-level leadership.[146] The resulting data indicates that the levels of communities/civil society engagement varied significantly. For example, for engagement in the development of National TB Strategic Plans, the lowest levels (39%) were seen in countries in the Europe and Western Pacific regions and the highest (85%) in Africa. For multisectoral review mechanisms, the overall levels of engagement were less, with the lowest in the Americas (13%) and highest in Africa (51%).

However, it is noted that where there is engagement of TB-affected communities/civil society, this engagement remains 'tokenistic' and does not reflect meaningful engagement of 'equal partners in the TB response'. Affected communities were not engaged as 'community experts'.

Multisectoral mechanisms have been enhanced by the strengthening of infrastructure within individual sectors. These include the networks and alliances that have been built among affected communities and civil society (see Area for Action 2). They also include Stop TB Partnership's voluntary alliances between organisations from the public, civil society and private sectors that collaborate with National TB Programmes - which have been established in 30 countries.[147]

In addition, TB Caucuses – networks of parliamentarians have been developed in 54 countries (such as Cote D'Ivoire and Paraguay - see Communities case study 23.[148] The Global TB Caucus now has 2,500 members who share a commitment to: working across geographical and political divides in a non-partisan and inclusive fashion; engaging with civil society and all other stakeholders involved in the response to TB; confronting stigma and social isolation associated with TB.[149]

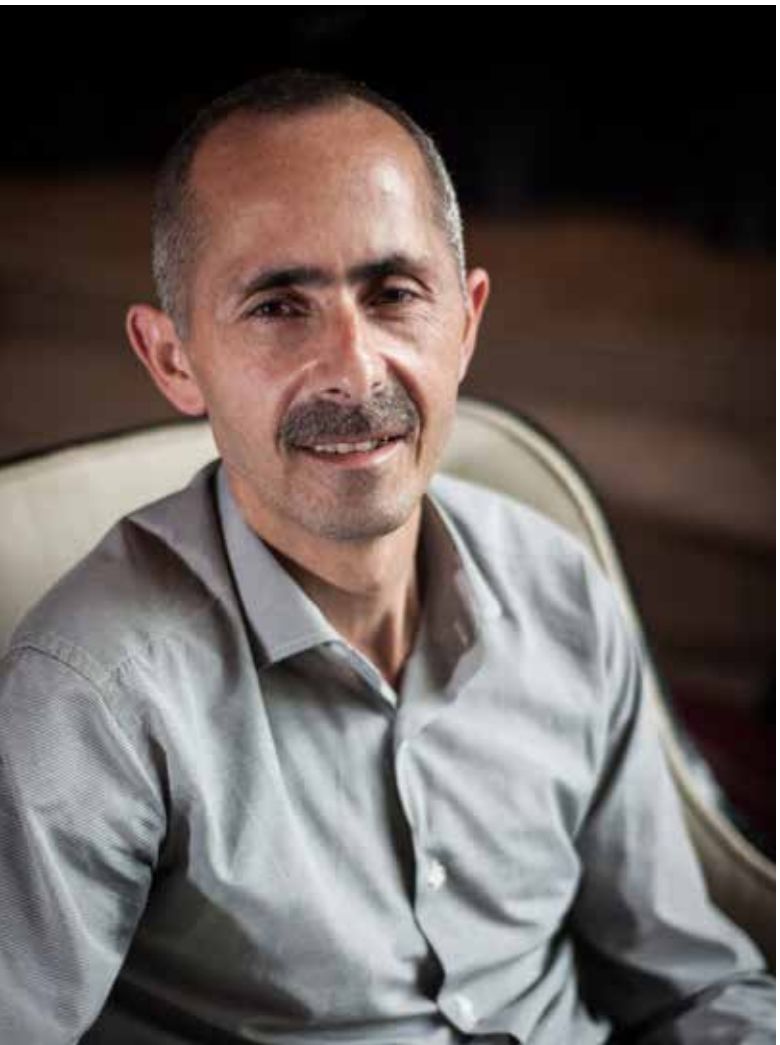
All sectors – from First Ladies to journalists, musicians and celebrities – have a vital role to play in increasing the visibility of TB – a global emergency that requires a vast and multisectoral global response. We have seen a concerted effort that began in the leadup to the UNHLM meeting in New York and continues today, with the engagement of TB Champions, including: First Lady of Nigeria; Bebecool, Uganda; Zaskia Sungkar, Indonesia; Richard Mofe-Damijo, Nigeria; Scherezade Shroff, India; BFlow, Zambia; Noziya Karomatullo and Shabnam Surayyo, Tajikistan (see Communities case study 24); Florent Ibenge, DR Congo; Gilberto Mendes, Mozambique; Claire Forlani, United Kingdom; Tamaryn Green and Gerry Eldson, South Africa; and Sania Saeed, Pakistan. Mascots have also been associated with TB, including Hello Kitty. These individuals (and icons) have made steps towards making TB more of a mainstream discourse. Their efforts should be applauded and scaled up.

Communities case study 23: Developing a national TB Caucuses Cote D'Ivoire and Paraguay

In Cote D'Ivoire, following the UN High Level Meeting on TB in 2018, members of the TB Caucus – alongside government agencies, development partners and communities/civil society – participated in a 'joint restitution meeting' on how to achieve the targets of the *Political Declaration*; strengthen multisectoral accountability for the response to TB; shape the next National TB Strategic Plan, and monitor all stages of the process. In October 2019, the country launched an initiative to engage key actors and coordinate efforts to end TB. The general objective is to establish a national TB control partnership and implement high level advocacy with the meaningful engagement of communities/civil society, celebrities, journalists and the media, to increase social and political commitment to end TB. To support this, legislator members of the TB Caucus underwent capacity building on a human rights-based approach to TB, the role of community-based responses and the country's international obligations for TB and HIV.

Similarly, in Paraguay, the national TB Caucus facilitated the formation of an Inter-Ministerial Committee on TB in 2018, where civil society has a permanent seat, alongside parliamentarians. In just a short time, this model of partnership resulted in a significant increase in domestic spending on TB.

Refer to the CALL TO ACTION for recommendations under Area of Action 5



Communities case study 24: Working with celebrities in the Tajikistan's TB response

In Tajikistan, TB has been traditionally managed at the level of Ministry of Health and the National TB Program, and has had insufficient political visibility among the many competing health priorities in the country. The Stop TB Partnership Tajikistan works to improve multisectoral leadership and political commitment to engaging State Ministries, Committees, local Governments, Members of Parliament and the National TB Caucus. A particularly effective advocacy approach has been to engage publicly-prominent people, such as singers, artists, sportsmen, writers, opinion leaders, private companies and prominent public figures from all trades, who have a public voice with their followers and fans. Famous pop singers, Shabnam Surayo and Noziya Karomatullo, are now recognised as Stop TB Ambassadors in the fight against TB. Their active involvement has raised the profile of TB in the country, not only among the general public, but also politicians, helping to reduce stigma and increase commitment to accelerating the TB response.

Figure 9

Levels of communities/civil society engagement in the development of National TB Strategic Plans and high-level review mechanisms

a) National strategic plan (NSP) for TB and annual TB report

WHO Region	Number of countries and territories	NSP Exists		Representatives of civil society and affected communities were actively involved in NSP development		NSP was developed or updated since the UN high-level meeting on TB in September 2018		Annual TB report available publicly	
Africa	47	42	89%	40	85%	32	68%	39	83%
The Americas	45	32	71%	21	58%	16	36%	21	47%
Eastern Mediterranean	22	17	77%	11	50%	12	55%	16	73%
Europe	54	25	46%	21	39%	14	26%	30	56%
South-East Asia	11	11	110%	9	82%	8	73%	9	82%
Western Pacific	36	21	58%	14	39%	15	42%	19	53%
High TB burden countries	30	30	100%	29	97%	25	83%	27	90%
Total	215	148	69%	116	54%	97	45%	134	62%

b) High-level review mechanism(s)

WHO Region	Number of countries and territories	Nacional multisectoral and multi-Stakeholder accountability/ review mechanism(s) in place		Representatives of civil society and affected communities participate in the mechanism(s)		Documentation available describing or explaining the mechanism(s)		Recommendations provided via the mechanism(s) made available publicly	
Africa	47	26	55%	24	51%	22	47%	11	23%
The Americas	45	13	29%	6	13%	8	18%	2	4%
Eastern Mediterranean	22	6	27%	3	14%	5	23%	1	5%
Europe	54	19	35%	14	26%	16	30%	7	13%
South-East Asia	11	7	64%	4	36%	6	55%	3	27%
Western Pacific	36	15	42%	11	31%	12	33%	6	17%
High TB burden countries	30	16	53%	12	40%	15	50	7	23%
Total	215	86	40%	62	29%	69	32%	30	14%

Source: World Health Organization Global TB Report 2020

Area for Action 6: Leveraging COVID-19 as a strategic opportunity to end TB

When the *Political Declaration on the Fight Against Tuberculosis* was agreed in 2018, the world did not foresee that, by 2020, it would face another major global health crisis in the form of COVID-19. The disruptions caused by the pandemic could lead to an additional 6.3 million people developing TB by 2025 and an additional 1.4 million deaths.[150] The Global Fund warns that two decades of progress on HIV, TB and malaria is now at serious risk, with deaths doubling if health and social support systems are overwhelmed, programmes disrupted and resources diverted.[151]

With regards to access to TB diagnostics and medicines, the GDF noted disruptions to global supply chains as a result of COVID-19. These disruptions extended to access to rifampicin and DS-TB medicines. These include access to active pharmaceutical ingredients (API), the key ingredients in most medicines. The global reliance on China, which produces 40% of APIs, and India, which produces up to 40% of the world's generic medicines, resulted in issues due to the national lockdowns. Some factories in China closed down, resulting in 30% decrease in API production, and a 50 to 90% reduction in medicine production.[152] Also of urgent concern are delays in quality assurance activities of both APIs and medicines. The GDF also recorded increased technical assistance service requests from National TB programmes due to COVID-19. Despite these challenges, the GDF responded through several interventions, including: (i) repurposing and reinforcing staff; (ii) identifying risk and intensifying monitoring; (iii) prioritising orders to avert stock-outs, while ensuring that new regimens were introduced. Through these concerted efforts, the GDF averted 102 potential TB-product stockouts in 2020.

Challenges posed by COVID-19

Affected communities/civil society report that COVID-19 has exacerbated existing challenges in the response to TB, while also bringing new ones. These are being felt most acutely within communities – where demands for TB services were already intense, resources constrained, and stigma high. Across the world, affected community/civil society stakeholders are documenting their struggles as their countries try to fulfil their commitments to TB and the *Political Declaration*, at the same time as responding to COVID-19. A survey conducted by 10 global networks among a range of affected communities and civil society stakeholders found that:

- People with TB are experiencing significant challenges in accessing TB services due to the pandemic and associated lockdowns.
- TB frontline healthcare workers report major reductions in TB care.
- TB Policy and Programme Officers cite that TB services and programme resources have declined significantly.
- TB advocates express deep concern about the rise of stigma and marginalisation and the diversion of political and media attention.
- TB researchers face significant interruptions as personnel, equipment and funding are diverted to COVID-19.
- A need for more robust, inclusive, and accessible social protection systems that include income and livelihood support, mental health support, nutritional support and legal aid has never been more apparent.[153]

Communities case study 25: Adapting a community-based TB model to respond to COVID-19 in Sierra Leone

In Sierra Leone, the first case of COVID-19 was reported on 31st March 2020, in a country with an already weak health system. Partners in Health, the Civil Society Movement Against Tuberculosis and National TB

Programme are implementing MIND-TB in Kono, a poor rural mining district. The project uses a decentralised model, including home-based sputum collection and referral, plus community-based screening through informal providers. COVID-19 threatened this approach, with reduced human resources (e.g., TB community health workers were reassigned to COVID-19 screening); breaks in supply chains (e.g., delays to the shipment of GeneXpert diagnostic equipment); and increased barriers to TB care (e.g., heightened stigma against people with a cough). Reports indicated a 20–50% reduction in the use of key health services, with a high proportion likely to be for TB. In response, the civil society organisations and their partners identified an opportunity to build on the MIND-TB model and support action on COVID-19, while also maintaining a response to TB. This involved providing a package of support for community-based, frontline workers, including: comprehensive COVID-19 and infection prevention control training; protective gear for infection control; the secondment of infectious disease specialists to the COVID-19 treatment centre in Freetown; and the construction of additional community treatment centres. This was complemented by measures at service delivery points, such as the use of a 'cough ticket' at all points of care (to channel people identified as priority patients) and attention to patient flows (to avoid co-infections). The organisations also adapted their own working practices, for example, introducing the CommCare App (to capture real-time data at all points of TB care); and virtual consultation methods (to enable advocates to continue their work within the grant-writing period for the Global Fund allocation cycle).

The survey specifies that the impacts of COVID-19 are not felt equally across or within countries. Populations that are already marginalised and vulnerable – such as children, people living with HIV, mobile populations, indigenous people, miners, urban poor, people in prison and other closed settings, and people who use drugs – are being disproportionately impacted. Together, COVID-19 and TB pose a dual, deadly threat that feeds on social inequities and poverty.

For people in congested setting such as prisons, the impact of COVID-19 and TB are especially far reaching because of overpopulation and limited infrastructures. Civil society report that COVID-19 response plans have been slow in prison settings. As at October 2020, there were reports of increased COVID-19 testing with support from multilateral partners, but the turn-around times of test results have been slow. Inmates are often not informed about their results because prison officials fear the increased stigma and discrimination. There are also reports of reduced contact tracing and screening for TB, as health staff do not have sufficient access to PPE, and are therefore sceptical about exercising their duties due to fears of contracting COVID-19 from prisoners.

Community actions and responses

However, despite the very real threats that they face, communities/civil society have demonstrated that they are both willing and able to be central to ensuring a response to COVID-19, while maintaining a response to TB. Their actions have taken diverse forms, such as:

- Expanding community-based TB services to also address COVID-19 (for example in Sierra Leone – see Communities case study 25)[154]
- Advocating for the earlier adoption of digital tools to aid the monitoring of people with TB during lockdown (such as in Moldova)[155]
- Facilitating diagnosis, providing nutritional support and organising virtual meetings to support people to adhere to TB treatment (such as in India).[156]

Affected communities/civil society also argue that COVID-19 brings strategic opportunities that, if maximised, could enhance progress towards the Political Declaration. For example, investments in the COVID-19 pandemic – such as to increase contact tracing or diagnostic capacity – could be leveraged for TB, while heightened awareness of infectious respiratory diseases could be an entry point for a renewed focus on ending TB.

The International Federation of Red Cross and Red Crescent and partners[157] advocate for particular protection of integrated, community-based TB service delivery in the context of COVID-19, while ensuring that affected communities are not further marginalised through stigma and discrimination.

They recommend a series of specific considerations for such programming, for example: the prioritisation of people-centred outpatient and community-based care over facility-based TB treatment; capacity building of communities/civil society to deliver services; the use of digital health services; and the engagement of community actors in monitoring the challenges experienced by people accessing TB services in the context of COVID-19.

Affected communities/civil society call for COVID-19 to not serve as an excuse for countries failing to meet their TB targets (which were already off-track before 2020). However, they also demand that measures to address COVID-19 – from the increased funding of research and development[158] to the expansion of social protection schemes and strengthening of health systems incorporate TB (see Communities case study 25). Without this, there will be what has been termed a 'second tragedy' for people with TB.[159]

Affected communities/civil society call for the global TB community to 'build back better' with fully-funded TB/COVID Catch-Up Plans at country, regional, and global levels (see Communities case study 26). These should: have clear targets and monitoring frameworks; meaningfully engage communities/civil society; and address the priority needs of TB key and vulnerable people. They should also leverage all of the new tools, innovations, and systems that have been put in place for COVID-19 for the benefit of TB. Examples include Apps, cough detection sensors, novel sample collection systems, tele-healthcare, digital adherence tools, point-of-care molecular technologies, e-pharmacies, and real-time data tracking and dashboards. If such measures can be adopted for COVID-19, they must be adopted for TB. Meanwhile, there is a need to emphasise that investing in TB is a means to invest in all respiratory infections, including COVID-19 and any potential future airborne, infectious pathogens.

Communities case study 26: Unified Efforts to raise TB voices in the face of COVID-19

In response to early warnings of the devasting impact of COVID-19 on people affected by TB and TB programmes around the world, 10 diverse global networks quickly came together to take action. They launched a survey to document lived experiences of those affected by TB. Findings were collated from reports from people with TB, frontline healthcare workers, programme and policy officers, TB researchers and TB advocates.

The resulting *Impact of COVID on the TB Response: A Community Perspective* report presents lessons-learned, advocacy recommendations, and opportunities to mitigate the damage of COVID-19 in order to get countries back on track in achieving elimination targets and re-build post-COVID to better end TB.

Significantly, findings and recommendations from the report have been incorporated into the Global Fund *Information Note: Catch Up Plans to Mitigate the Impact of COVID-19 on Tuberculosis*

The Global Fund recommends that the overall goal of TB/COVID-19 Catch-Up Plans should be to "restore and accelerate the diagnosis, treatment and prevention of TB".[160] The specific objectives should be to: reverse the losses in diagnosis, treatment, and prevention of TB to pre-COVID-19 levels during 2021; accelerate TB diagnosis, treatment and prevention services to get back on-track to attain the UN HIgh-Level Meeting targets by 2022; scale up the promotion and protection of human rights programming; and, adapt TB care models to the new COVID-19 context and requirements.

The Access to COVID-19 Tools Accelerator (ACT-A), is a ground-breaking global collaboration to accelerate development, production, and equitable access to COVID-19 tests, treatments, and vaccines.[161] There is no doubt an opportunity to leverage investments in ACT-A to strengthen national TB and TB/COVID-19 responses, as the mechanism seeks to find and fund solutions and improve disease surveillance, especially in regions and countries with weak health systems. The commodities and tools developed for COVID-19 should stimulate the diversification of tools, including:

- The development of multiplexed point-of-care testing (xPOCT) diagnostic tools, which will support options such as bidirectional screening of COVID-19 and TB
- Increased access to scientific data through proliferation of open-source systems
- Challenging the elasticity of the current patent system; as witnessed by the proposal to the World Trade Organization (WTO) Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) Council by the governments of South Africa and India, for a "TRIPS Waiver", allowing countries to suspend the protection of certain kinds of intellectual property (IP) related to the prevention, containment and treatment of COVID-19.[162]

For affected communities/civil society, this is an opportunity ensure targeted advocacy on integrated TB and COVID-19 investments. It is also an opportunity to strengthen their research capacity, especially in the area of vaccines development, and fortify their engagement in clinical trials through the community advisory boards, improving trial designs, especially phase III, and for operational research support.

We issue this Call to Action to demand social justice in the response to TB. **A disease that is preventable and curable, yet takes the lives of 4,000 people every day, including 700 children.** We want to ensure that TB-affected communities and civil society have a voice. That our realities and our priorities are understood. That lives are saved.

In 2020, the three civil society delegations to the Board of the Stop TB Partnership (Affected Community, Developed Country NGO, and Developing Country NGO) have led broad consultations among their constituents and other key stakeholders from over 60 countries, culminating in *A Deadly Divide: TB Commitments vs TB Realities.* This *Communities Report* documents how – two years on from the United Nations High-Level Meeting on TB and the *Political Declaration on the Fight Against Tuberculosis* – there is a major gap between the targets endorsed by heads of state and governments, and the results achieved. This is felt most acutely within communities, where it results in deaths and suffering. *A Deadly Divide* is informed by extensive inputs from TB-affected communities and civil society throughout the world. It presents evidence and experiences for six key Areas for Action. Based on the findings, we – as the community of people affected by TB and broader civil society engaged in the TB response – call on UN Member States, as the signatories to the *Political Declaration*, to acknowledge the following recommendations as our priorities. We also call for these priorities to be funded, operationalised, monitored and evaluated at the country level, with the meaningful engagement of, and broader social justice for, TB-affected communities and civil society at every step.

Call to Action

We call upon Heads of State to lead UN Member States in taking action in the following areas:

1 Reach all people through TB prevention, diagnosis, treatment and care

By setting ambitious and time-bound national targets for TB to meet the commitments in the Political Declaration, and by operationalising them through aligned National TB Strategic Plans, implementation plans, budgets and monitoring and evaluation frameworks.

Specifically, we call for:

- National targets for TB that are strong, context-specific and unchangeable, and supported by aligned plans, frameworks and resource allocations;
- Innovative and community-driven strategies to find the 3 million 'missing' people with TB;
- Targeted, funded and person-centred strategies to address the needs of TB key and vulnerable populations;
- Recognition of drug resistant TB as a public health crisis requiring universal access to rapid molecular diagnostics and all-oral drug regimens; all diagnosis and treatment to be free to service users; and global health solidarity, with a central position in the antimicrobial resistance agenda, including of the G20;
- Prioritisation of paediatric TB interventions, with the scale up of contact tracing within families, and development of, and access to, child-friendly diagnostics and treatment;
- Promote integrated TB/HIV at all levels, emphasising the scale up of family approaches to TB preventive treatment to achieve 100% TPT coverage for adults, adolescents and children, including HIV-negative household contacts of people with HIV; and have fully transitioned to short-course TPT regimens based on rifapentine and rifampicin.

2 Make the TB response rights-based, equitable and stigma-free, with communities at the centre

By every high-TB burden country, before the end of 2022, completing a TB Community, Rights and Gender Assessment and a TB Stigma Assessment, followed by the development, funding, monitoring and evaluation of a national Community, Rights and Gender Action Plan and Stigma Reduction Strategy. Using the latter as the official plan to operationalise action on community, rights and gender-related issues in the National TB Strategic Plan.

Specifically, we call for:

- Human rights principles (as set out in the Declaration of the Rights of People Affected by TB)[163] and social justice to be the non-negotiable foundations for all responses to TB at all levels;
- TB-affected communities and civil society to have a leadership role at all stages in countries' CRG Assessment and Action Plan and Stigma Reduction Strategy implementation, monitoring and review processes, as part of national commitment to TB community systems strengthening;
- CRG Assessments and Action Plans and Stigma Reduction Strategies that prioritise TB key and vulnerable populations to be a pre-requisite for a country developing a TB funding request to, and receiving a TB grant from, the Global Fund to Fight AIDS, Tuberculosis and Malaria and other donors;
- The implementation of the 20 recommendations for countries outlined in Activating A Human Rights-Based TB Response[164];
- The establishment and strengthening of a national network of people affected by TB, and its meaningful engagement in aspects of the governance of the national response to TB.

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

By ceasing, before World TB Day (24 March) 2021, the use of all outdated or harmful TB diagnostics, drugs and models of care (including injectable-based regimens and smear microscopy), for all – no matter a person's location, identity or economic status – in accordance with WHO Guidelines. Instead, scaling up access to newer, safer and quicker options, and fast-tracking the development of priority, innovative new tools, including: an accessible vaccine; a rapid, user-friendly and point-of-care test; and shorter and less side-effect-prone treatments for all forms of TB. Also, funding the operational and implementation research necessary to improve TB treatment outcomes for all.

Specifically, we call for:

- Advocacy to pharmaceutical and diagnostic companies to remove any cost barriers to the introduction of newer, safer and quicker treatment options to facilitate immediate phase out of harmful TB treatment, and newer, rapid diagnostics to phase-out microscopy.
- Ongoing support for the TB Global Drug Facility to provide affordable and quality-assured TB medicines, diagnostics and laboratory supplies, and support for the uptake of innovative tools;
- Action to ensure that the benefits of TB research and development are free at the point-of-care, with their costs de-linked from research and development expenditure;
- The meaningful engagement of TB-affected communities and civil society to be a prerequisite for all stages of TB research and development processes;
- Expediting the roll-out and rapid scale up of new TB tools as soon as they become available through closer collaboration – between product developers, technical agencies, donors, governments, TB-affected communities and civil society – and with attention to the updating of guidelines and action on regulatory barriers;
- Capacity building, including for TB-affected communities and civil society, to prepare for and roll out new TB tools;
- Countries to pay their 'fair share' of the necessary financial investment in TB research and development ($2 billion annually), by spending at least 0.1% of their research and development budgets on TB.

4 Invest the funds necessary to end TB

By collaborating to achieve 100% of the Political Declaration's targets for financial investment in the response to TB, and the scaling-up of domestic and international funding for community-based and led TB interventions.

Specifically, we call for:

- Collaboration to fully achieve the $13 billion annual investment needed to achieve the Political Declaration's target, including: donor countries collectively doubling their investment in TB, based on fair-share contributions; and implementing countries increasing their domestic investment in TB
- The Global Fund to Fight AIDS, Tuberculosis and Malaria to increase its allocation for TB from 18% to 33%, in recognition of the scale of unmet need, high mortality, and low investment
- Implementing countries to develop social contracting systems that, especially in contexts of donor transition, effectively channel domestic resources to TB-affected communities and civil society
- Donor countries to increase investment in tailored funding mechanisms for community-based and led TB interventions, as well as capacity building, evidence gathering, partnerships and advocacy. Including by continuing to scale up the: TB Local Organizations Network project (USAID); Community Rights and Gender Strategic Initiative (the Global Fund); and Challenge Facility for Civil Society (Stop TB Partnership) – with Australia, Canada, France, Germany, Norway and the United Kingdom each contributing to this mechanism in the period 2021–2023
- Parliamentarians to engage in domestic resource mobilisation to ensure that TB programmes are fully funded, including community systems strengthening and the implementation of new tools.

5 Commit to accountability, multisectorality, and leadership on TB

By addressing the current weaknesses in accountability for TB, through urgently implementing an independent National Multisectoral Accountability Framework for TB in every country (as committed to by 2019), with high-level leadership and supported by a strong, national monitoring and review system. Using the results to strengthen accountability action, including the production of annual country and global progress reports on the Political Declaration and the holding of a United Nations HIgh-Level Meeting on TB in 2023.

Specifically, we call for:

- Each country to not merely adopt but implement the TB National Multisectoral Accountability Framework – facilitating the engagement of diverse sectors (including TB-affected communities and civil society, journalists, lawyers, judges, members of parliament and celebrities) and with a review mechanism that is triggered when targets are not met;
- Based on their Framework, each country to provide an annual report to the UN General Assembly on their progress towards the *Political Declaration* and to use that report as the basis for an annual review of progress on TB in parliament;
- The establishment of an independent, international mechanism to undertake an annual process of documenting and reviewing country progress against TB targets, and suggesting actions to improve the response, including where progress is too little and too slow to meet the *Political Declaration's* commitments. This should have membership from both donor and high-burden TB countries, including representatives of the government, civil society, TB-affected communities and the private sector;
- An urgent move towards systems of real-time, national-level TB data collection that is disaggregated by key and vulnerable populations, and inclusive of community-led monitoring initiatives that target the identification of human rights barriers to TB and related services;
- The holding of a United Nations High-Level Meeting on TB (exclusively) in 2023 – in acknowledgement that TB cannot be subsumed within a broader health agenda and must remain a priority in its own right. The Meeting should be attended by Heads of State and have a Affected Communities and Civil Society Hearing in advance, with both events co-organised by WHO and the Stop TB Partnership, with the meaningful engagement of TB-affected communities and civil society. They should be directly informed by a second iteration of this Community Report, *A Deadly Divide,* to be completed in late 2022.

6 Leverage Covid-19 as a strategic opportunity to end TB

By developing, funding and implementing TB/COVID Catch-Up Plans to enable National TB Programmes to get back on track and accelerate progress towards the Political Declaration's commitments, with COVID-19 framed, not as an excuse to fail to meet TB targets, but an opportunity to 'build back better'.

Specifically, we call for:

- The development of TB/COVID Catch-Up Plans that: are based on human rights principles; meaningfully engaging communities affected by TB and civil society at all stages; scale up joint TB and COVID-19 test and trace initiatives, using the latest methods; and leverage national COVID-19 infrastructure and innovations – such as real-time data systems – for TB;
- The provision of inclusive and comprehensive social protection systems within Universal Health Coverage, that avoid catastrophic costs for TB/COVID-19 service users, and that include support for areas such as mental health, legal aid, nutrition, and loss of income/livelihood;
- Collaboration to ensure the allocation of adequate financial investment to implement TB/COVID Catch-Up Plans, including through the Access to COVID-19 Tools (ACT) Accelerator;
- Scale up of investments in the diagnostic pillar of ACT-A, including clear allocation of funds for multi-use diagnostics, covering both TB and COVID-19, ensuring equity and access;
- Ensuring current investments in the global COVID-19 response, and efforts to strengthen pandemic preparedness systems long-term, are TB-sensitive and can be leveraged as part of global efforts to end TB.

Annex 1: Methodology

TB-affected Community, Developing Country NGO and Developed County NGO Delegations

Inputs were provided and reviews conducted by members of the three civil society Delegations to the Board of the Stop TB Partnership:

TB-affected Community Delegation:

- Timur Abdullaev (Board Member), TBpeople, Uzbekistan
- Thokozile Nkhoma (Board Member), Facilitators of Community Transformation, Malawi
- Abdulai Sesay, CISMAT, Sierra Leone
- Albert Makone, Shiloah Zimbabwe
- Carol Nawina, CITAM+, Zambia
- Dilshat Haitov, TBpeople Kyrgyzstan
- Endalkachew Fekadu, Volunteer Health Services, Ethiopia
- Fabrice Kotoko, L'Association des Anciens Patients Tuberculeux du Bénin, Benin
- Kate O'Brien, We are TB, United States
- Ksenia Shchenina, TBpeople, Russian Federation
- Maurine Murenga, Lean on Me Foundation, Kenya
- Maxime Lunga, Club des Amis Damien, DRC
- Meirinda Sebayang, Jaringan Indonesia Positif, Indonesia
- Olya Klymenko, TBpeople Ukraine
- Paul Thorn, TBpeople United Kingdom
- Peter Ng'ola, Wote Youth Development Projects, Kenya
- Rhea Lobo, Bolo Didi, India

Developing Country NGO Delegation:

- Austin Obiefuna (Board Member), Afro Global Alliance, Ghana
- Stela Bivol, Center for Health Policies and Studies (PAS Center), Moldova
- Olive Mumba, EANNASO, Tanzania
- Mayowa Joel, Stop TB Nigeria
- Bertrand Kampoer, DRAF TB, Cameroon
- Márcia Leão, Stop TB Brasil
- Subrat Mohanty, REACH, India
- Amara Quesada, ACHIEVE, Philippines
- Philip Wugeru, NOPE, Kenya
- Choub Sok Chamerun, KHANA, Cambodia

Developed Country NGO Delegation:

- Aaron Oxley (Board Member), RESULTS UK, United Kingdom
- David Bryden, RESULTS Education, United States
- Deliana Garcia, Migrants Clinicians Network, United States
- Olya Golichenko, Frontline AIDS, United Kingdom
- Janika Hauser, RESULTS UK, United Kingdom
- Katy Kydd Wright, International Civil Society Support, Canada

Regional reviews

Regional Focal Points were commissioned to conduct reviews of progress and challenges in relation to the *Political Declaration on the Fight Against Tuberculosis* in their geographic area. Their work was based on a research protocol and included: conducting interviews/e-mail communication with key regional stakeholders; analysis of responses from their region to an e-survey of communities/civil society to inform the UN Secretary General's *Progress Report*; review of regional data and information sources related to communities/civil society and TB; and identification of country case studies. The reviews were conducted by:

- Africa Region: Olive Mumba
- Asia Pacific Region: Meirinda Sebayang
- Latin America and the Caribbean Region: Deliana Garcia
- Europe and Eastern Europe and Central Asia Region: Stela Bivol

Interviews or written submissions, plus responses to the survey for the UN Secretary General's *Progress Report*, were received from the following regional stakeholders:

Africa region:

Interviews/written submissions			
	Name	**Organisation**	**Country**
1.	Rosemary Mburu/Fitsum Lakew	WACIHEALTH	Pan Africa
2.	Donald Tobaiwa	Jointed Hands	Zimbabwe
3.	Endalkachew Fekadu	Voluntary Services Overseas	Ethiopia
4.	Evaline Kibuchi	Stop TB Partnership, Kenya	Kenya
5.	Ingrid Schoeman	TB Proof	South Africa
6.	Jerry John Larbi	Ghana National TB Voice Network	Ghana
7.	Lynette Mabote	Independent Consultant	South Africa
8.	Rodrick Mugishagwe	EANNASO/TTCN	Tanzania
9.	Anna Fruehauf	Partners in Health	Sierra Leone
10.	Roger Paul Kamugisha	Top Health Advocacy in the Tropics	Uganda
11.	Rhoda Igweta	EGPAF	Kenya
12.	Amal El Karouaoui, Khouloud Ben Alaya, Yassine Kalboussi, Alim El Gaddari, Zakaria Bahtout, Marwa El Harrar	MENA Network to STOP TB	Algeria, Morocco, Tunisia
Written responses to questions:			
	Name	**Organisation**	**Country**
13.	Rodrick Mugishagwe	TTCN/EANNASO	Tanzania/Anglophone Africa
14.	Yvonne Kahimbura	EANNASO	Tanzania/Anglophone Africa
15.	Thoko Phiri Nkhoma	FACT	Malawi
16.	Carol Nawina Nyirenda	CITAM+	Zambia
17.	Dorah Kiconco	UGANET	Uganda
18.	Fitsum Lakew	WACI Health	Pan Africa
19.	Rogerio Cumbane	AMIMO	Mozambique
20.	Evaline Kibuchi	Stop TB Partnership	Kenya

Africa region (cont.):

Survey responses:		
Name	**Organisation**	**Country**
21. Tom Muyunga-Mukasa	Advocacy Network Africa	Kenya
22. Austin Arinze Obiefuna	Africa Coalition on TB	Ghana
23. Hervé Nashememzwe	Association des Volontaires pour Lutter contre TB	Burundi
24. Philip Waweru Mbugua	National Organization of Peer Educators	Kenya
25. Rodrick Mugishagwe	Tanzania TB Community Network	Tanzania
26. Oscar B Mwaibabile	Health Promotion Tanzania	Tanzania
27. Kitso Phiri	Botswana Labour Migrants Association	Botswana
28. Venance Muzuka	Service Health and Development for People Living Positively with HIV/AIDS Kahama	Tanzania
29. Olive Mumba	EANNASO	Tanzania
30. Ingrid Schoeman	TB Proof	South Africa
31. Thokozile Phiri	Facilitators of Community Transformation	Malawi
32. Sansan Kambou Edourd	DRAF TB	Cote D'Ivoire
33. Coulibaly Gaoussou	ONG Stop Tuberculose Bouaké	Cote D'Ivoire
34. Maxime Lunga Nsumbu	Club des Amis Damien	Democratic Republic of Congo
35. Ida Savadogo	RAME	Burkina Faso
36. Sékouna Kalivogui	AJADIG/AGUISOC-TB/PNOSCVIH-TB	Guinea
37. Bertrand Kampoer	DRAF TB	Cameroon
38. Adama Niang	Réseau Aslut	Senegal

Asia Pacific region:

Interviews/written submissions			
	Name	Organisation	Country
1.	Dr Ramya Ananthakrishnan	REACH	India
2.	Dr Karam Shah	Stop TB Partnership Pakistan	Pakistan
3.	Thea Hutanamon, Lukman Hakim	Stop TB Partnership Indonesia	Indonesia
4.	Mara Quesada	ACHIEVE	Philippines
5.	Shiva Shrestha	Results International	Australia
6.	RD Marte	APCASO	Regional/Thailand
7.	Iman Abdurrakhma, Budi Hermawan, Ani Hernasari	POP-TB	Indonesia
8.	Md Akramul Islam, PhD	BRAC	Bangladesh
9.	Luan Nguyen Quang Vo, Andrew Codlin, Rachel Forse	Friends for International TB Relief	Vietnam
10.	Elvi Siahaan	Menara Agung Foundation/ACT-AP	Indonesia
11.	Achut Sitaula	Trisuli Plus Hope Center	Nepal
12.	Niluka Perera	GFAN Asia-Pacific	Sri Lanka
Survey responses:			
	Name	**Organisation**	**Country**
13.	Louie Teng	TBpeople Philippines	Philippines
14.	Thet Naing Maung	Myanmar Medical Association	Myanmar
15.	Daniel Marguari	Spiritia Foundation	Indonesia
16.	Jeffry Acaba	Activists Coalition on TB – Asia Pacific	Thailand
17.	Rajesh Kumar Singh	INFIMAS	India
18.	Choub Sok Chamreun	KHANA	Cambodia
19.	Thea Hutanamon	Stop TB Partnership	Indonesia
20.	Sharon Cox	London School of Hygiene and Tropical Medicine	Philippines
21.	Surya Prakash Rai	Innovators in Health	India
22.	Ramya Anathakrishnan and Anupama Srinivasan	REACH	India
23.	Subrat Mohanty	UNION	India
24.	Wesli Nallarathnam	Genesis Educational Trust Chidambaram Cuddalore Tamil Nadu India	India
25.	Asghar Satti	Association of People Living with HIV/AIDS Pakistan	Pakistan
26.	Rhea Gail Lobo	Bolo Didi/Touched by TB/TB People	India

Latin America and the Caribbean region:

Interviews/written submissions			
	Name	**Organisation**	**Country**
1.	Márcia Leão	Stop TB Brazil	Brazil
2.	Eva Limachi	Fundacion Habitat Verde	Bolivia
3.	Francisco Olivares	Red de Comunicadores en VIH and TB Corresponsalves Claves	Chile
4.	Sandra Patricia Escandon Moncaleano	Americas TB Coalition	Colombia
5.	Zulma Unzain	Alvida	Paraguay
6.	Luis Bustamante	Americas TB Coalition	Guatemala
7.	Jaime Argueta	Asociacion Nacional de personas positivas vida nueva	El Salvador
8.	Anonymous	-	Peru
9.	Robyn Waite	Results Canada	Canada
10.	Giorgio Franyuti	Medical IMPACT	Mexico
Survey responses:			
	Name	**Organisation**	**Country**
11.	Julio Cesar Aguilera	Fundación Hábitat Verde	Bolivia
12.	Silvia Esquivel Leon	Servicio de Medicinas Pro Vida	Peru
13.	Leonid Lecca	Socios En Salud	Peru

Europe and Eastern Europe and Central Asia region:

Interviews/written submissions			
	Name	**Organisation**	**Country**
1.	Safar Naimov	Stop TB Partnership Tajikistan	Tajikistan
2.	Abdusamad Latifov	Stop TB Partnership Tajikistan	Tajikistan
3.	Olya Klimenko	TBpeople Ukraine	Ukraine
4.	Yuliia Kalancha	TB Europe Coalition	EECA Regional
5.	Alesya Matusevyych	Global TB Caucus EECA	EECA Regional
6.	Elchin Mukhtarli	Saglamliga Khidmat	Azerbaijn
7.	Liliana Caraulan	PAS Center	EECA Regional, Moldova
8.	Cristina Celan	PAS Center	EECA Regional, Moldova
9.	Stefan Radut	ASPTMR	Romania
10.	Lasha Goguadze	IFRC	Georgia
Survey responses:			
	Name	**Organisation**	**Country**
11.	Zahedul Islam	Alliance for Public Health	Ukraine
12.	Oxana Rucsineanu	SMIT TB Patients Association	Moldova
13.	Stela Bivol	Center for Health Policies and Studies	Moldova
14.	Yuliia Kalancha	TB Europe Coalition	Regional network in WHO/Euro region
15.	Natalia Kryshtafovich	Let's Defeat TB Together	Belarus
16.	Marifat, Abdusamad, Katoen, Mysara and Safar	Stop TB Partnership	Tajikistan
17.	Bakhyt Myrzaliev	KNCV	Kyrgyzstan
18.	Anonymous	-	Uzbekistan

Global review

To complement the work of the Regional Focal Points, a review was commissioned to look at progress and challenges in relation to the *Political Declaration on the Fight Against Tuberculosis* at the global level. This work included: conducting interviews with key global stakeholders (to provide inputs on specific technical or institutional perspectives); analysis of global data on TB; analysis of global responses to an e-survey of communities/civil society to inform the UN Secretary General's Progress Report; review of global information sources related to communities/civil society and TB; and identification of global case studies. The review was conducted by Sarah Middleton-Lee.

Interviews or written submissions, plus responses to the survey for the UN Secretary General's *Progress Report*, were received from the following global stakeholders:

Interviews/written submissions		
	Name	**Organisation**
1.	Lasha Goguadze	International Federation of Red Cross and Red Crescent
2.	Mike Frick	Treatment Action Group
3.	Eliud Wandwalo and Daisy Lekharu	TB Department, The Global Fund to Fight AIDS, Tuberculosis and Malaria
4.	Hyeyoung Lim, Ed Ngoksin, Alexandrina Iovita and Gavin Reid	Community, Rights and Gender Department, The Global Fund to Fight AIDS, Tuberculosis and Malaria
5.	Sharonann Lynch	Médecins Sans Frontières
6.	Anjali Kaur	The Bill and Melinda Gates Foundation
7.	Beatrijs Stikkers	KNCV Tuberculosis Foundation
8.	Madhukar Pai	McGill International TB Centre
9.	Cheri Vincent	USAID
10.	Pierre Blais	Canada International Development Agency
11.	Sarah Kirk, Cintia Dantas, Tushar Nair and colleagues	Global TB Caucus
12.	Tushar Nair, Aaron Oxley and colleagues	The Tuberculosis Community Platform on Accountability
13.	Blessi Kumar and colleagues	Global Coalition of TB Activists
14.	David Lewinsohn, Ann Ginsberg, Jennifer Wooley and colleagues	New Tools Working Group, Stop TB Partnership
15.	Georgina Caswell, Rico Gustav and colleagues	Global Network of People Living with HIV
16.	Grania Brigden, Paul Jensen, Meaghan Derynck and colleagues	International Union Against Tuberculosis and Lung Disease
17.	Mustapha Guidado, Basil Uguge, Bethrand Odume, Beatrijs Stikkers and Emily van der Ginten	KNCV Tuberculosis Foundation
18.	Peter Wiessner	Action Against AIDS (Germany)
19.	Trevor Stratton	Canadian Aboriginal AIDS Network
20.	Perry Gottesfeld	Occupational Knowledge International
21.	Marilyn Fingerhut	International Commission on Occupational Health
22.	Lucica Ditiu, Suvanand Sahu, Wayne Van Gemert, Viorel Soltan, Jacob Creswell, Jacqueline Huh, Greg Paton, Gisela Schmidt-Martin, Ricarda Steele and colleagues	Stop TB Partnership
23.	Katherine Floyd and colleagues	World Health Organization

Survey responses:		
Name	**Organisation**	**Country**
24. Brian Citro	Northwestern Pritzker School of Law	USA
25. David Bryden	RESULTS	USA
26. Catherine Connor	Elizabeth Glaser Pediatric AIDS Foundation	USA
27. Kate O'Brien	Stop TB Community Delegation	USA
28. Laila Løchting	LHL International	Norway
29. Sébastien Morin	Medicines Patent Pool	Switzerland
30. Elizabeth Lovinger	Treatment Action Group	USA
31. -	Stop TB Developed NGO Delegation	IMF advanced economies

Annex 2: Policies Checklist

Step Up for TB 2020 provides the following checklist of key policies that must be adopted and fully implemented by every country to meet the commitments of the *Political Declaration on the Fight Against TB*.

Diagnosing TB:

- Rapid molecular TB tests as the initial test for all people who need diagnosis, with specimen referral in place as needed.
- Urine-based TB LAM tests for all people living with HIV with signs and symptoms of TB, especially those with advanced HIV or who are critically ill, regardless of CD4 count in both inpatient and outpatient settings.
- Comprehensive universal drug susceptibility testing, including: rifampicin and isoniazid resistance for all people starting on treatment; at least fluoroquinolone resistance testing for all people with rifampicin-resistant TB; and drug susceptibility testing methods available in country for rifampicin, isoniazid, fluoroquinolones, bedaquiline, delamanid, linezolid and/or clofazimine, when these drugs are used for routine treatment.

Treating TB:

- People-centred TB policies, including decentralised treatment initiation and follow-up at primary healthcare facilities, self-administered therapy as opposed to directly observed therapy where possible, and comprehensive treatment support and adherence counselling.
- Injectable-free, all-oral regimens for all children with drug-resistant TB and child-friendly formulations for all.
- Injectable-free, all-oral regimens for all eligible people with drug-resistant TB.
- Extension beyond 6 months and combination of drug-resistant TB treatments bedaquiline and delamanid allowed.

Preventing TB:

- Shorter TB preventive treatment regimens prioritised for eligible people with latent TB infection, with adequate support to ensure treatment completion.
- Systematic screening for active TB disease and testing for latent TB infection among household contacts, and provision of TB preventive treatment to those without active TB disease, regardless of age.
- ART initiation regardless of CD4 count and universal provision of TB preventive treatment for all people living with HIV.
- Inclusive eligibility for TB preventive treatment of vulnerable and at-risk groups.

Procuring medicines for TB:

- Streamlined regulatory systems and approaches that encourage access to medicines, including mutual recognition between regulatory authorities, domestic registration, collaborative registration procedures and accelerated approval mechanisms.
- Full alignment between the national Essential Medicines List and the more recent of either the WHO Essential Medicines List or WHO guidelines, when Essential Medicines List inclusion is a prerequisite for medicines importation, with a plan for regular updates.
- Requirement for WHO-prequalified status or approval from an internationally recognised stringent regulatory authority for all TB medicines, whether they are procured from international or domestic manufacturers.
- Transparent national tenders, including publication of selection criteria, winning bidder and final price information.
- Ability to use international pooled procurement for health products allowed by law, including when domestic funding is used.

Annex 3: References

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[12] *Progress Towards The Achievement Of Global Tuberculosis Targets And Implementation Of The Political Declaration Of The High-Level Meeting Of The General Assembly On The Fight Against Tuberculosis: Report of the Secretary-General*, United Nations General Assembly, 16 September 2020.

[13] *Progress Towards The Achievement Of Global Tuberculosis Targets And Implementation Of The Political Declaration Of The High-Level Meeting Of The General Assembly On The Fight Against Tuberculosis: Report of the Secretary-General*, United Nations General Assembly, 16 September 2020.

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