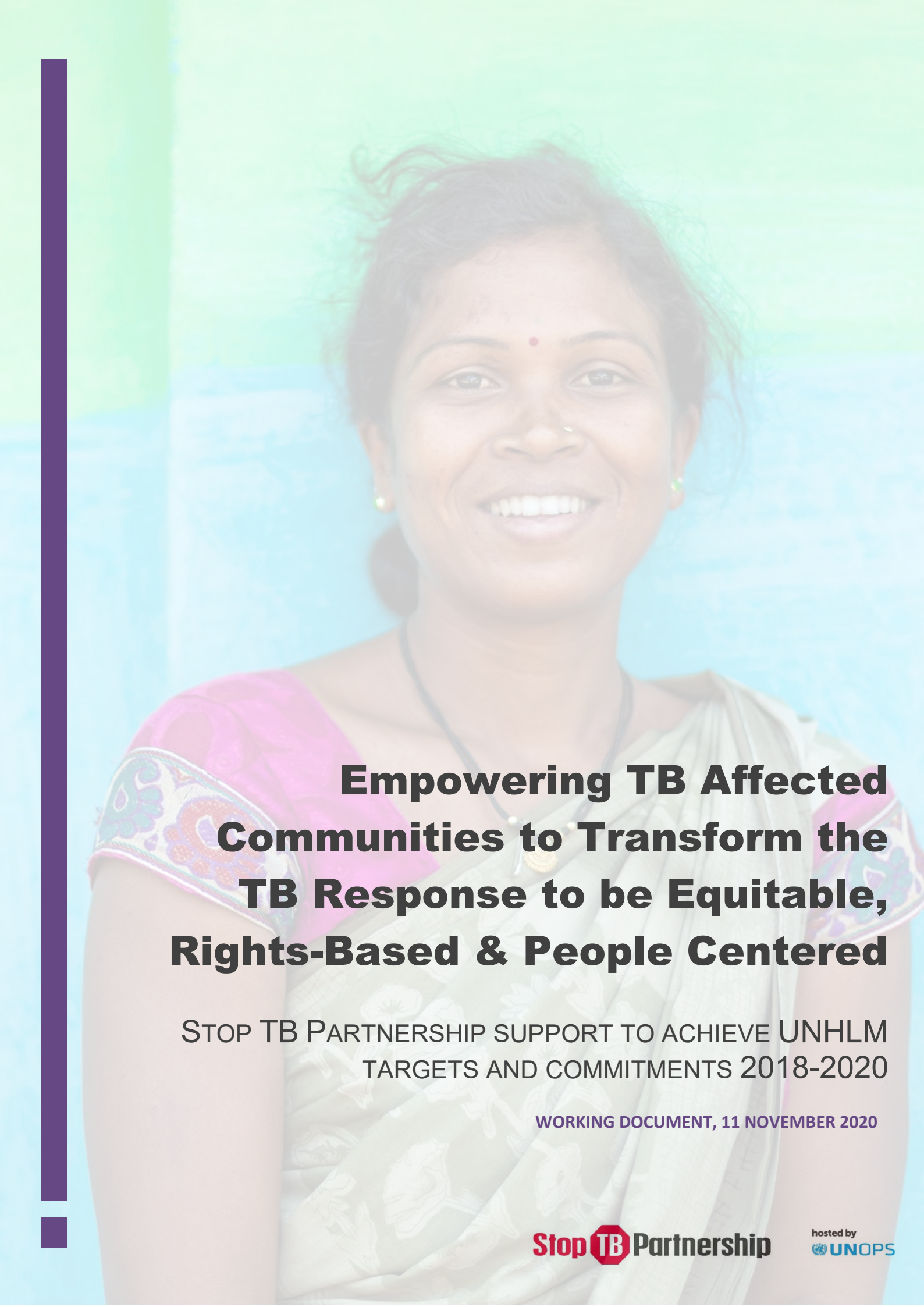


Empowering TB Affected Communities to Transform the TB Response to be Equitable, Rights-Based & People Centered

STOP TB PARTNERSHIP SUPPORT TO ACHIEVE UNHLM TARGETS AND COMMITMENTS 2018-2020

WORKING DOCUMENT, 11 NOVEMBER 2020

Stop TB Partnership

hosted by UNOPS

Contents

Introduction

Tuberculosis (TB), as a disease that disproportionately impacts the poor and vulnerable, inherently requires a response that is not limited to health centers, doctors and medicine, but addresses broader social determinants and fosters enabling environments, and prioritizes people, key populations (KPs) and the promotion and protection of human rights. Traditionally this focus on people, human rights and gender has been an outlier and afterthought. However, in recent years there has been significant progress at shifting the paradigm and making human rights, and the meaningful engagement of TB key populations and TB survivors, a central theme.

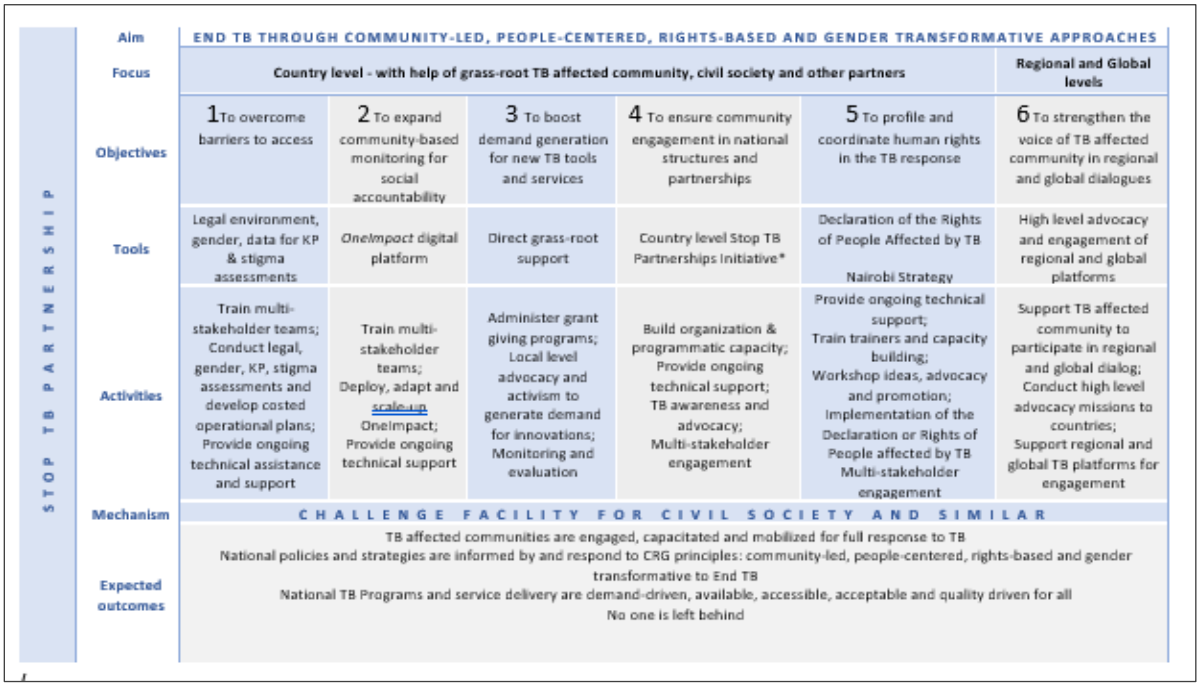
In 2015, the Stop TB Partnership (STP), through The Global Plan to End TB[1], posited that promotion and protection of human rights and gender equality were key components required to achieve the 90-(90)-90 targets and end TB. Chapter 3 of the revised Global Plan to End TB 2018–2022[2], *Reaching Key Populations*, sets the three specific actions of: (i) facilitate the involvement of TB survivors and key populations in all levels of policymaking and programmatic design in order to ensure that TB services are people-centered and meet the expressed needs of affected communities, and invest in networks and organizations of TB survivors to build the required capacity to effectively engage in TB governance; (ii) using community, rights and gender (CRG) assessment tools, to assess which populations are vulnerable to TB along with the barriers that prevent access to care, and carry out targeted outreach accordingly; and (iii) fulfil the UN High Level Meeting (UNHLM) on TB commitments to remove any laws, policies and programs that discriminate against people with TB. As a result, one may conclude that the STP has contributed to putting the rights of individuals and communities affected by TB on the national, regional and international development agenda.

In September 2018, at the UNHLM on TB, Heads of State and other world leaders endorsed the vision and recommendations developed by TB affected communities and civil society and other stakeholders in the Key Asks[3], reiterated during the UNHLM Interactive Civil Society Hearing on TB[4].

Between 2018-2020, STP, with support from The United States Agency for International Development (USAID) and the Global Fund to Fight AIDS, Tuberculosis and Malaria (TGF), has significantly scaled up efforts to support countries to achieve their CRG targets and commitments under the UN Political Declaration. This leadership has resulted in significant progress in TB and CRG concepts, barriers and solutions as well as the prioritization and implementation of CRG approaches at all levels.

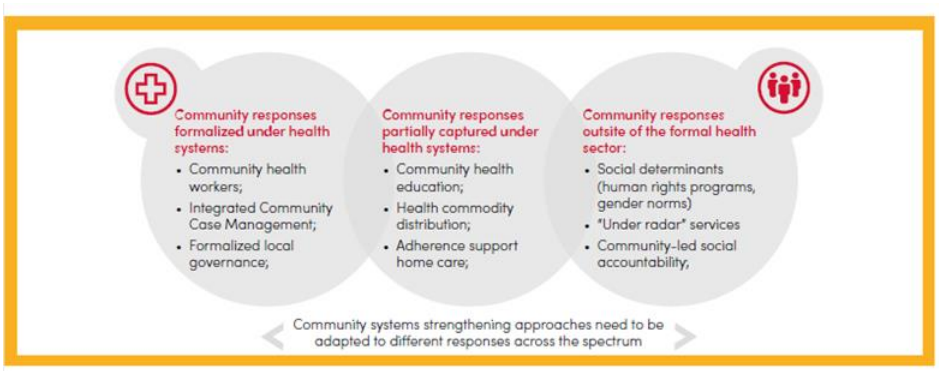
This paper documents the key areas of progress and achievements between 2018-2020 in TB CRG including: assessing and overcoming CRG barriers to access; operationalizing and implementing rights-based and gender responsive TB interventions; measuring TB stigma and discrimination; enhancing meaningful engagement of TB affected communities and key populations in monitoring, implementation and governance of programs; monitoring human rights barriers to access; advocacy for accountability; and, supporting TB affected communities and civil society to engage in TB and COVID-19 responses as part of the STP CRG framework.

Figure 1: Stop TB Partnership TB CRG Framework



Social justice is the driving principle behind an equitable, rights-based and people centered response to TB. We know that social determinants of health and TB, and the degree to which people access services, are linked to individual identity and factors such as socio-economic status, nutrition, access to education, legal status, access to information, language and cultural norms and gender. Therefore, it is critical that TB responses include activities that are nuanced, tailored and reach those most vulnerable. For this to be effective, TB interventions must not be limited just to the health system, but should include responses that strengthen community systems, create an enabling environment and address underlying socio-economic factors, and address legal, human rights and gender related barriers to access that currently inhibit the effectiveness of national TB responses.

Figure 2: Community Systems Strengthening[5]



2018-2020 At a Glance: Stop TB Partnership's Top Ten Achievements

1. Facilitating Stop TB Affected Community and Civil Society Delegations to undertake widespread consultation and to develop *A Deadly Divide: TB Commitments vs. TB Realities*[6], a report and advocacy strategy on progress, priorities, and recommendations against UNHLM targets and commitments.
2. Supporting 17 national civil society organisations to conduct TB CRG Assessments in 17 countries, developing 7 TB CRG Investment Packages, finalising the integrated TB CRG Assessment Protocol and development of 4 national costed TB CRG Action Plans plus 1 national TB Gender Responsive Framework.
3. Building capacity and coordination of TB affected communities and civil society through three rounds and 66 grants, funded by CRG Assessment grants and the transformed Challenge Facility for Civil Society - a multi-donor grant mechanism for TB affected communities and civil society.
4. Developing the TB Stigma Assessment, the inclusion of TB stigma indicators in the Global Fund Modular Framework, and technical assistance to 4 countries to implement the TB Stigma Assessment.
5. Developing a TB community-led monitoring conceptual and implementation framework as well as adapting the TB and TB/COVID-19 community-led monitoring framework and accountability mechanism, OneImpact, in 14 countries to facilitate the collection of real-time electronic data on human rights barriers to access for advocacy and action.
6. Building and strengthening 8 regional and global advocacy networks of civil society and people affected by TB, including launching TBWomen, a global TB network of women in their diversity, as well as a network for francophone Africa.
7. Operationalising rights-based TB responses through the *Declaration of the Rights of People Affected by TB*[7], now translated into 7 languages; supporting the development of *Right to Breathe*[8] TB Human Rights Training Module; facilitating the global TB civil society Human Rights Discussion Group; developing guidance for law makers pertaining to rights-based TB legislation; and in collaboration with the Global Coalition for TB Activists (GCTA), launching the *Activating a Human Rights Based TB Response*[9] guidance for policy makers and program managers.
8. Engaging Stop TB Affected Community and Civil Society Delegations as partners in the civil society-led TB and COVID-19 survey, report and launch; and to host the Overcoming Barriers to Access in the UNION Conference Community Connect.
9. Mobilising 30 country-level Stop TB platforms to engage national stakeholders including TB programs, civil society, affected communities, journalists, celebrities, private sector and other partners for TB accountability.
10. Delivering CRG Technical Assistance, including for CRG Assessments, CRG Action Plans and integrating TB CRG findings and recommendations in National Strategic Plans (NSPs) and TGF Funding Requests in 30 countries.

The next sections of this paper unpack each of the above achievements and efforts to advance social justice, detailing progress that has been made by countries in the process of realizing a rights-based, gender sensitive and people centered TB response per the UNHLM TB commitments.

The UNHLM TB Political Declaration

The UNHLM on TB was a critical moment for the TB response as the first time that TB moved onto the agenda of Heads of State. The resulting Political Declaration[10] is also significant as it is the guiding document for all TB actors working toward the global-level targets that will enable us to end TB by 2030. These targets include:

- Treating 40 million people, including 3.5 million children, with TB [P24];
    a. *14.1 million people with TB treated (35%)*
    b. *1.04 million Children with TB treated (30%)*
- Treating 1.5 million people, including 115,000 children, with DR TB [P24];
    a. *0.33 million people with DR-TB treated (22%)*
    b. *0.01 children with DR-TB treated (8%)*
- Preventive treatment is received by 30 million people, including 4 million children and 6 million PLHIV [P25];
    a. *6.3 million people placed on PT (21%)*
    b. *0.78 million children placed on PT (20%)*
    c. *5.3 million PLHIV on PT (88%)*
- Reaching $13billion annually for financing for the TB response [P46]; and
    a. *4.3 billion available in 2019 (110 countries reporting)*
- Increasing investments in R&D to reach $2 billion annually [P47].
    a. According to TAG, total funding in 2019 was **$900,964,590**. This is just slightly under the $906 million reported in 2018.

However, there are also many commitments focusing on TB affected communities, human rights and gender which will serve as the enablers to achieving the targets listed above. This was emphasized by the late Dean Lewis during the UNHLM TB Civil Society Hearing when he stated "we have begun talking about 'missing people with TB'. As a person who survived TB in spite of being homeless and a person using drugs, I can tell you that many of these people are not missing. They are standing right here. However, at every step we face barriers to accessing the TB care that we need. To end TB we must identify and overcome these social and legal barriers."[11] Very much in this spirit, the CRG commitments featured in the Political Declaration include[12]:

- Committing to involve affected communities and civil society in the TB response [P17];
- Committing to provide special attention to those who are most vulnerable, in accordance with the principle of social inclusion [P38], including women, indigenous peoples, health care workers, migrants, refugees, internally displaced people, prisoners, people living with HIV (PLHIV), people who use drugs, miners, homeless people, urban and rural poor [P17],
- Affirming that all people affected by TB access people-centered prevention, diagnosis, treatment, management of side effects and care, as well as psychosocial, nutritional and socioeconomic support for successful treatment [P 14];
- Committing to recognize the various sociocultural barriers to TB prevention, diagnosis and treatment services, especially for those who are most vulnerable [P18];
- Committing to promote and support an end to stigma and all forms of discrimination, including by removing discriminatory laws, policies and programs [P37];
- Committing to enacting measures to prevent TB transmission in workplaces, schools, transportation systems, incarceration systems and other congregate settings [P25];
- Committing to developing community-based health services through approaches that protect and promote equity, ethics, gender equality and human rights [P33]; and

- Committing to decisive and accountable global leadership that is multi-sectoral and inclusive of TB affected communities and civil society, and integrating these commitments into National Strategic Plans [P48-9].

The prominence of the CRG priorities in the Political Declaration reflects the involvement of TB affected communities and civil society in the development of key asks and advocacy in the lead up to the UNHLM TB, including at the Civil Society Hearing, as well as during the UNHLM TB itself. During this period, STP supported the formation and operation of the TB Affected Community & Civil Society HLM Advisory Panel[13] who helped guide the work and priorities of the HLM Coordinating Group, as well as the agenda and advocacy priorities articulated to UN Missions, the Civil Society Hearing and the UNHLM participants. The process of involvement, engagement and movement building not only secured strong CRG commitments, but provided a platform for TB affected communities like never before.

Now, 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 produced A Deadly Divide: TB Commitments vs TB Realities xii. The Communities Report documents how – two years on from the United Nations High Level Meeting on TB and 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.

In the Report Call to Action, the Delegations go on to reflect: '[This divides 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 on six key areas for action. Based on the findings, the community of people affected by TB and broader civil society engaged in the TB response – make call on UN Member States, as the signatories to the Political Declaration, to acknowledge a series of priority recommendations. The three Delegations 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.

The report and recommendations are framed by the 5 key asks that civil society took to the UNHLM back in 2018, but now, in the context of the COVID-19 pandemic, have added a 6th thematic 'ask' and then accompany the following 6 'asks' with a series of key actions that are required to realise the operationalise the priorities articulated by voices of those affected by TB:

1. Reach all people through TB prevention, diagnosis, treatment and care
2. Make the TB response rights-based, equitable and stigma-free, with communities at the centre
3. Accelerate the development of, and access to, essential new tools to end TB.
4. Invest the funds necessary to end TB
5. Commit to accountability, multi-sectorality and leadership on TB
6. Leverage Covid-19 as a strategic opportunity to end TB

The recommendations from *A Deadly Divide: TB Commitments vs. TB Realities* were presented to the Stop TB Board Meeting by members of the three delegations in November 2020 and included locking national targets, all TB high burden countries conducting the TB CRG Assessment and TB Stigma Assessment, a timeframe for countries to cease the use of outdated and harmful tools, and facilitating access to new tools, moving toward real time TB data, scaling up TB investments through Global Fund disease split, Strategic Initiatives, the Challenge Facility, and exploring opportunities for strengthening TB responses through the ACT-A and advancing accountability mechanisms at national, regional and global levels. The full report is scheduled for release in December 2020, with launches in English,

French, Spanish, Russian and Portuguese. TB affected communities and civil society will be supported in their advocacy championing the recommendations and call to action through an advocacy toolkit.

A Deadly Divide: TB Commitments vs. TB Realities is intended to complement the United Nations Secretary General's (UNSG) *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[14] prepared by the World Health Organization (WHO). The UNSG Report demonstrates progress in realizing an equitable, rights-based and people centered TB response. Notably, this includes:

- **Recommendation 6.** Promote human rights and combat stigma and discrimination
- **Recommendation 7.** Ensure meaningful participation of civil society, local communities and people affected by TB

But it also includes a shift in approach from TB stakeholders, whereby an effective TB response must be one that is based on broader principles of human rights and social justice. This includes the adoption of terminology like 'people affected by TB' rather than 'patient' as a sign that TB responses must be tailored to more than a patient, but rather their identity, their social economic and legal status, their gender, their relationships and obligations, and their individual complexity that makes them something that the label of 'patient' can never adequately represent or respond to.

Engaging & Empowering TB Affected Communities and Civil Society

Global health and social movements have long been defined by the 'nothing for us, without us' rallying cry. However, the bio-medical focus of the TB response has meant significant work is still to be done to advance the meaningful engagement of TB affected communities and civil society and to realize the intent of the guiding 'catch cry'. In particular, there has been an urgent need to ensure that the involvement of TB affected communities and civil society extends beyond service delivery to effectively playing a role informing the TB response, filling gaps, monitoring, and advocating for a rights-based TB response.

STP has taken significant steps to support countries to realize the commitments of meaningful community engagement – per Political Declaration Commitments [P14, P17-18, P34, P37-38] – in particular through the USAID and TGF supported Challenge Facility for Civil Society (Challenge Facility) grant mechanism. Challenge Facility is one of the few, if not the only, grant mechanisms that provides grants to TB affected communities, TB survivor networks and civil society at national, regional and global level enabling them to fulfill their critical functions in strengthening the TB response (as articulated under the UNHLM TB commitments).

The Challenge Facility, as well as CRG grants, support work which focuses on UNHLM TB accountability, identifying and mitigating legal, human rights and social barriers to access, TB affected community & TB survivor mobilization, reducing TB stigma, engagement of TB key populations, conducting TB CRG assessments, community-led monitoring, demand generation and human rights advocacy and sensitization. Between 2018 – 2020 STP has provided 54 grants through 3 Rounds of Challenge Facility across the African, Asia and the Pacific, Eastern Europe and Latin American and Caribbean regions.

During this time, STP has augmented Challenge Facility to be a multi-donor platform for TB affected community and civil society organizations to transform the TB response so that it is rights-based, gender-transformative, people-centered and accountable. Strengthening community and civil society actors is an ethical and programmatic imperative in this pursuit. Challenge Facility Round 9 is currently supporting 31 organizations, from 13 countries and six regions. While this is the largest ever round of Challenge Facility, with a total disbursement of USD 2.5 million, only a fraction (5%) of demand (USD47 million) was met.[15] Close working relationships with the USAID TB Local Organizational Network (LON)

and TGF CRG and Finding the Missing People with TB strategic initiatives have been developed to help strengthen, align, and scale up national CRG priorities and the ongoing work to further increase funding. Broadening the eligibility of Challenge Facility as a multi-donor platform for all high burden TB, TB/HIV and MDR-TB countries remains a priority for STP and for TB affected communities alike.

A significant outcome of Challenge Facility has been the professionalization of TB affected community networks and civil society organizations at the global, regional and country level. STP has directly supported this formalization and strengthening of: three global networks; regional networks in the Americas, Anglophone Africa, Francophone Africa, Eastern Europe and Central Asia, Asia-Pacific and most recently in the region of Middle East and North Africa (MENA); and numerous national networks of TB survivors. Examples of this include the global network of TB Survivors, TBpeople, who have been supported to legally register, produce the *Declaration of the Rights of People Affected by TB*, and develop a global Strategic Plan. In addition, the Global Coalition of TB Activists (GCTA) have been supported, together with the North Western University School of Law, to train lawyers in TB and human rights and to launch the *Activating a Human Rights Based Tuberculosis Response*[16]. Thirdly TBWomen, representing women in all their diversity, has been formed in response to a need to accelerate the realization of a gender transformative TB response has been supported to develop their Strategic Plan 2021-2025.

At the regional level, STP has supported the formation and organization of the first francophone network, Dynamique de la Réponse d'Afrique contre la Tuberculose (DRAF TB). With the registration of this network, and securing a Challenge Facility grant under Round 9, the global TB advocacy space is more inclusive and representative of francophone speakers. Second, Activists' Coalition on TB Asia-Pacific (ACT! AP) have worked to fill the gap of sensitizing people affected by TB and building TB rights literacy among TB survivors to enable them to be active participants in national TB interventions and TB accountability. The TB *Right to Breathe*[17] tool was launched in January 2020 and is currently preparing for roll out across Asia with the support of the Challenge Facility.

At the country level, the emergence of formalized TB survivor networks has been a significant achievement that has been supported under the Challenge Facility. TBpeople Ukraine, with a membership base of over 800 people, has pioneered community-led monitoring and is a sub-recipient under the TGF TB country grant. TB Proof South Africa is leading national efforts on stigma reduction

with Challenge Facility support. Club des Amis Damien in DRC led the CRG assessment, development of the national costed CRG Plan and piloting of OneImpact in Kinshasa. Network of TB Champions Kenya successfully asserted community priorities during the national dialogue and funding request development, and POP TB Indonesia is now registered, finalizing their strategic plan and partnering with the National TB Program (NTP) on the CRG agenda.

Civil society partners have also strengthened and subsequently increased their role in shaping national TB agendas. This includes 17 organizations, who together with their respective NTP, have completed CRG Assessments shaping NSPs and TGF funding requests. A further 14 organizations have implemented community-led monitoring initiatives, documenting human rights barriers to access. Examples include REACH in India, KHANA in Cambodia, EANNASO in Tanzania, KELIN in Kenya and Stop TB Tajikistan. Significantly, the examples of national TB survivor networks and capacity of civil society is no longer an outlier or exception, but an ever increasing norm of national TB responses – a trend that can be traced to the catalytic benefit of the Challenge Facility model and investments which enable grantees to test CRG innovation, align with national priorities, build strategic partnerships, access technical assistance, generate evidence, communicate results and scale up activities.
Many national civil society platforms have now been further strengthened to facilitate multisectoral dialogue on TB, including with journalists, academics, private sector and celebrities, and with a particular focus on accountability. Thirty country-level platforms have been supported in different ways, and through various grant mechanisms including Challenge Facility, and they have demonstrated diverse potential for effectiveness as well as flexibility, and clearly show the value of investing to create capacitated civil society platforms. Examples of their work include: STP Cote D'Ivoire and STP Zimbabwe mobilized groups of TB survivors to create awareness on the impact of COVID-19 on TB in 100 health centers and congregated settings. Similarly, STP Tajikistan met with religious leaders, advocating among affected communities. STP DRC together with the TB Advisor to the President, NTP, and TB Ambassadors raised awareness on TB & COVID-19 in 3 Kinshasa Health Centers and 10 awareness and screening campaigns have been implemented. STP Mozambique launched a TB bus campaign in 10 provinces, and STP Ghana mobilized TB survivors to screen for TB and COVID-19 among people in the district of Chorkor. STP Kazakhstan started a campaign "It's time to end TB" in the cities of Almaty, Taraz, and Kostanay. STP Ukraine played a fundamental role in coordinating the national dialogue for a sustainable TB response which took place between state agencies and civil society organizations on 29th October 2020. One final example that is a clear stand out is that of STP Indonesia where their partnership and lobbying has been instrumental in the development of the Presidential Decree on TB.

This development in organizational capacity and meaningful engagement has been augmented by capacity building support. In many instances, STP has provided a space to people affected by TB to

engage, inform and shape global, regional and national agendas and to collectively participate in dialogues and access forums that were previously accessible to only a select few. The significant level of support to ensure participation in UNION Conferences, International AIDS Society Conferences, United Nations General Assembly events, TB Program Reviews, and STP Board meetings has contributed to a shift in the role of people affected by TB. No longer are people affected by TB seen as merely telling a story of having TB. Now, TB affected communities are informed and empowered experts who, based on their lived experience and capacity development, are providing guidance and recommendations, challenging status quo approaches, innovating for change and re-setting agendas to put people first. This change cannot be understated. It is not simply the 'right thing to do' for social justice but, as the *Declaration of the Rights of People Affected by TB* indicates, it is a programmatic and ethical imperative to ending TB.

Formalizing TB Affected Community Governance

The principles of meaningful community engagement, the human right to participation as well as multisectoral monitoring and accountability are all at the heart of the UNHLM on TB commitments [P17, P33, P48-49]. A key component of this is strong systems of TB affected community governance. STP has always led the way in terms of community representation and governance through a well-established model of TB affected community and NGO constituencies. To formalize and professionalize this model further, three Delegations (Affected Community[18]; Developing Country NGO[19]; Developed Country NGO[20]) to the STP Board have now been instituted. With 33 members from 25 countries, these are representative groups of the most influential and active TB advocates and actors at country and regional levels. Significantly, the delegations have been established, have had their governance manuals endorsed, and will now appoint coordinators / communications focal points to ensure the delegations roles can be significant. Already, the delegations have demonstrated their capacity as a co-developer of the *Impact of COVID-19 on the TB Response: A community perspective*[21] survey, report and launch as well as in leading consultations among the TB community for the new global AIDS Strategy, and, leading the Barriers to Access track at the UNION Conference Community Connect.

This is a model for community governance at the global level and should be adapted to country level context as well. Without coordinated, capacitated and engaged networks of affected communities that

are supported by investment, and a commitment to always create space for voices of experience from TB survivors or TB affected communities, multi sectoral accountability and even TB program governance will not progress. Complementing this global level governance, STP has worked to further strengthen two global networks and has supported a third to emerge: GCTA[22] is a global network of global TB advocates and community; TBpeople[23] is a global network of TB survivors and people affected by TB; TBWomen is a new network of women in all their diversity, responding to a need for gender responsive TB interventions and commitments. At the regional level, through Challenge Facility, STP has continued to work to strengthen networks in the Americas, Francophone Africa, Anglophone Africa, Eastern Europe Central Asia, and Asia-Pacific.

At the national level there has been significant efforts at strengthening the capacity and engagement of TB affected community as well. This is reflected in several indicators exploring human rights and inclusivity in the new *TB Governance for Accountability* Report.[24] The first iteration of this report covers a range of governance issues, but includes CRG policy – including gender responsiveness and the inclusion of key and vulnerable populations in NSPs across 24 countries. This new tool is going to be a critical component of operationalizing the Multisectoral Accountability Framework at the national level, while providing tangible measurement and monitoring that can be utilized by civil society for advocacy.

Promoting & Protecting Human Rights

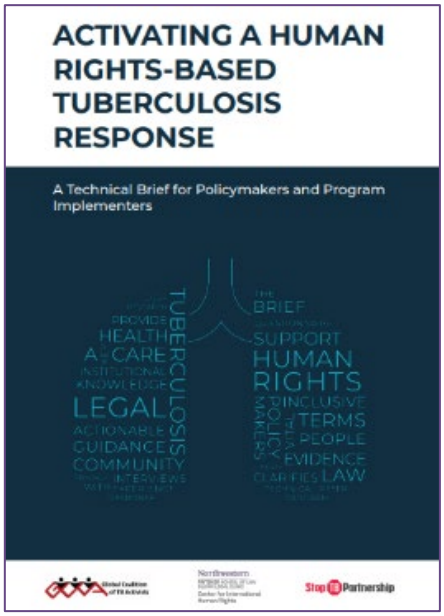
The promotion and protection of human rights and gender equality, as well as the advancement of social justice, contributes to effective TB responses, being both a pillar of public health as well as a moral and ethical imperative. This is particularly pertinent when we consider that TB disproportionally affects people who are already marginalized by poverty, legal status and/or other social exclusions. Efforts to help countries to achieve CRG related HLM commitments have included: operationalizing 'TB rights'; developing guidance on TB laws; enhancing rights-literacy among TB stakeholders; strengthening TB key population data and evidence; conducting assessments to identify and overcome human rights-related barriers to TB universal access; piloting community-led monitoring initiatives; developing costed CRG & Stigma Action Plans; and empowering communities to be meaningfully involved in all aspects of the TB response.

For countries to realize their commitments in the UNHLM TB Political Declaration [P14, P17-18, P25, P33, P37], a rights-based response must be understood and operationalized. STP has supported several initiatives to assist countries in this process. The foundations for this work can be found in the *Nairobi Strategy on TB and Human Rights*[25], a product led by TB affected communities and civil society under the leadership of the Kenya Legal & Ethical Issues Network on HIV and AIDS (KELIN) and the University of Chicago Law School. The strategy outlines several pillars upon which to build a rights-based TB response. Following the development of the strategy, the *Tuberculosis, Human Rights and the Law Case Compendium*[26] was developed consolidating the important role that lawyers and social scientists could and should play in shaping the global TB response. In many ways, these initiatives provided the basis for the extensive human rights content of the Political Declaration.

The *Declaration of the Rights of People Affected by TB*[27] is one of the most significant contributions in supporting the realization of the various UNHLM commitments on TB and Human Rights. In 2019, STP partnered with TBpeople and legal experts to develop a comprehensive overview of how established human rights norms, principles and treaties are relevant to be claimed and applied to the TB response. The *Declaration of the Rights of People Affected by TB* is a tool for National TB Programs, people affected by TB and TB survivors that Justice Edwin Cameron, formally of the Constitutional Court of South Africa, described as *"assertive, expressive, dignified…(and) unparalleled in a world grappling with TB".* [28]

The scope of the *Declaration* includes the right to: the highest attainable standard of health; life; liberty; privacy; confidentiality; information and informed consent; work; food; scientific progress; freedom from discrimination; freedom from cruel, inhumane or degrading treatment, among other established human rights and it has been incorporated into several TB CRG Investment Packages[29] for inclusion in TGF country proposals.

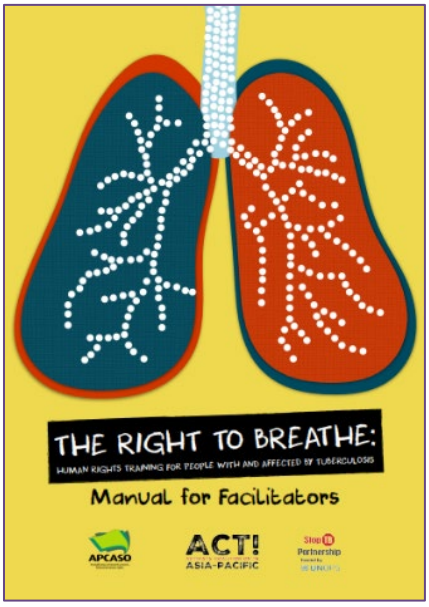
To maximize the reach of the *Declaration of the Rights of People Affected by TB* STP support four further initiatives to assist countries in achieving their HLM commitments, including the Global Coalition of TB Activists (GCTA) and North Western University Law School *Activating A Human Rights-Based TB Response*[30] which articulates guidance to policy makes and Program Managers providing 20 recommendations on how to operationalize a rights-based TB response at the national level. Launched by WHO Director-General Dr Tedros Ghebreyesus, this product ensures a continued global level focus on TB and human rights. Again, as with the *Declaration of the Rights of People Affected by TB*, and also with the 2019 KOCHON Prize being for TB and human rights and awarded to KELIN[31], this represents high level engagement in TB and human rights – elevating this discussion from the periphery to a central theme. GCTA are currently being supported through the Challenge Facility mechanism to implement recommendations from the brief in India, Indonesia, Cameroon and Peru.



STP efforts to professionalize TB and human rights through enhanced tools and evidence base were further emphasised through the development of guidance on TB legislation, through the Human Rights Initiative with Georgetown University, and also through work with Northwestern University School of Law. STP, together with the O'Neill Institute from Georgetown University, has worked to advance the understanding of human rights and key populations. This includes the report on *Migration, TB and the Law*[32] which sets forth relevant legal and policy frameworks and includes case studies which highlight the situational analysis to make the case for law and policy reform and improvements.[33] It also includes the report on *Coercion, Criminalization and TB*.[34] For this report, the laws in 20 of the 30 TB high-burden countries were surveyed, and their relevant laws were coded in order to assess their consistency with human rights. The report reveals that the vast majority of countries have laws related to the TB response that violate even the most basic human rights laws and norms. This work maps and assesses legal frameworks in priority countries, laying the foundations for being able to measure what a human rights-based TB legal environment comprises. This work builds directly into the UNHLM commitments on prioritizing key populations and also overcoming legal barriers to access.

Working with Northwestern University School of Law, the Global TB Caucus and other partners, STP also advanced guidance regarding rights-based TB legislation. While the development of a 'TB Law' is not a recommended product from the perspective of TB and rights, this TB legislation guidance[35] offers guidance and human rights safeguards for law makers in instances where parliament is committed. It has been utilized in Panama[36] and was the basis for technical assistance on state-based legislation in Pakistan. This guidance is critical for ensuring further legal and policy barriers are not instituted through legislative efforts, and that lessons learned regarding unintended consequences from TB legislation are understood by law makers, complementing work that has been done to identify and unpack human rights barriers experienced by people affected by TB.

Over the course of these efforts to enhance the evidence base on TB and human rights, one clear priority was building the capacity and literacy on rights at a grass roots level. While the *Declaration of the Rights of People Affected by TB* created the framework for operationalizing TB and rights, many people affected by TB at a grass roots level needed to develop strong foundations in human rights, and understanding their rights in order to be able to utilize the other TB rights tools. The *Right to Breathe*[37] training is one part of the process of bridging this gap. A CRG investment package has been developed to support the roll out of this tool.



The objectives of this training are threefold:
1.To enhance the understanding of TB-affected communities of the relationship between human rights and tuberculosis;
2.To build the capacity of TB-affected communities to document human rights violations experienced by communities affected by tuberculosis; and
3.To build the capacity of TB-affected communities to engage in advocacy that contributes to stronger National TB Programs that would overcome barriers to access and bridges gaps in their countries' response to tuberculosis.

STP has delivered country-level human rights support between 2018-2020. This has included the provision of human rights sensitization workshops in Indonesia and Ukraine, and also contributing to projects focusing on key populations. One example of this is the provision of technical assistance to Botswana for the Botswana Miners Right to Health Project led by Botswana Labour Migrants Association (BoLAMA), Center for Economic and Social Rights and Northwestern Pritzker School of Law Center for International Human Rights. The project assessed the right to health of the miners in Botswana, and was launched with a keynote address from United Nations Special Rapporteur on the Right to Health, and distinguished remarks from the Judiciary and the CEO of the Botswana Chamber of Mines.[38]

The global TB community has begun to acknowledge the significant achievements in terms of TB and human rights. In 2019 the KOCHON Prize theme was TB and human rights and was awarded to our long-time partner KELIN. Similarly, the Stop TB Community Award has also been awarded for CRG initiatives, including to Stop TB Tajikistan and Civil Society Movement Against Tuberculosis Sierra Leone for community-led monitoring, and to TBpeople for their work mobilizing a global network of TB survivors and developing the *Declaration of the Rights of People Affected by TB*. In 2020, there will be

three winners of this award – one at national level, one at regional level and one at global level. The National Network of TB Champions Kenya were awarded for their work advancing community priorities during Global Fund processes. At regional level, Americas TB Coalition was awarded for shining a light on TB and COVID-19 in the Americas region. And at the global level the award was given to a coalition of ten civil society and affected community organisations, who came together from both high TB burden and donor contexts to build evidence for advocacy concerning the impact of COVID-19 on TB affected communities.

Identifying & Overcoming Legal, Human Rights & Gender Barriers to Services

The need for TB CRG Assessments is premised on the understanding that TB is a disease of poverty that is exacerbated when human rights are neglected, and gender inequalities are allowed to persist[39]. International commitments and internal needs require countries and regions to work towards rights-based and gender transformative TB programming. However, in most countries there is a lack of strategic information, or substantive evidence about the current legal, rights and gender-related TB context, particularly from the perspective of TB key and vulnerable populations. This lack of evidence obscures the extent to which rights and gender are central to an effective TB response. Lack of evidence further undermines the capacity of many TB programs to develop appropriate responses.

CRG Assessments are, therefore, designed to be community-led and country-owned processes that, through an inclusive and multi-sectoral process, generate strategic information that informs the development of national action plans. Action plans, in turn, are expected to result in activities that drive the TB response towards being rights-based and gender transformative, ensuring nobody is left behind. Ultimately, the CRG Assessments and resulting action plans are expected to lead to an enabling environment that further facilitates availability, accessibility, acceptability and quality of TB services and support services for people affected by TB, and improved steps towards attaining the Global Plan to End TB's 90-(90)-90 goals.

In what is seen by many as a long overdue development, the UNHLM Political Declaration brought human rights in TB to the front and center of the TB response [P14, P17-18, P25, P33, P37]. STP has prioritized efforts to build evidence, awareness and action in response to these prominent human rights-based commitments. Developing and implementing TB CRG Assessment tools to prioritize, assess and monitor human rights in the context of TB at the country level has been central to this end. This work has seen the development of the TB Community, Rights and Gender Assessment Tool[40] (which includes a TB legal environment assessment, gender assessment and key population data for action framework), the TB Stigma Assessment Tool[41] and the Community-Led Monitoring Conceptual

and Implementation Framework and Digital Tool (OneImpact)[42]. Collectively these tools have been implemented to identify and overcome human rights, legal, and social (including stigma and gender related) barriers to universal TB access across more than 20 countries in the regions of Asia-Pacific, Africa and Eastern Europe, supporting the process of removing legal, human rights and gender related barriers and to support countries to achieve their End TB and UNHLM on TB targets and commitments.

TB CRG Assessment

The STP CRG Assessment tool has been rolled-out at country level by civil society and TB affected communities, in partnership with National TB Programs and other national stakeholders. The aims of the tool are, firstly, to support countries to assess key and vulnerable populations, the legal and policy environment as well as gender related barriers of the TB response, and secondly, to recommend actions to help remedy the identified barriers. *The Communities, Rights and Gender Integrated Protocol* has also been developed to help strengthen and streamline the implementation of assessments.

The assessment process involves a participatory analysis of TB key and vulnerable populations and their data gaps, relevant legislation, policy documents and guidelines, and is based on a wide range of secondary data sources. In addition, the process involves interviews and focus groups to understand the various legal, policy and social barriers to universal TB access experienced by people affected by TB and the various viewpoints relating to the underlying issues involved.

The CRG Assessment process also provides a unique opportunity to strengthen relationships between country stakeholders, particularly between civil society and the NTP as equal partners. This process demonstrated the value add of civil society, the capacity of civil society, and established and cemented strong partnerships with national TB programs to advance CRG in the TB response. This outcome is a significant achievement, but it was not the only significant outcome. The Assessment further responded to the needs of the TB affected communities through:

- Taking a participatory, multi-sectoral approach that is inclusive of TB affected communities and key and vulnerable populations as equal partners in all aspects of the assessment thereby fulfilling the right to participation of the affected communities.
- Taking a participatory research approach, that includes research, TB CRG concepts and TB science capacity building with TB affected communities and key and vulnerable populations. This localized knowledge is key to generating demand and capacity for equitable service delivery.

The knowledge and trust gained by maintaining an ongoing relationship with community partners in the action planning process afforded National TB Programs the opportunity to tailor interventions to the needs of a vulnerable community and thereby increase the sustainability of efforts that influence positive outcomes of people with TB. Over the course of implementation, this process contributes to realizing the UNHLM Political Declaration [P17-18, P37-38, P48].

To date, TB CRG Assessments have been conducted in 17 countries: Bangladesh[43], Cambodia[44], DR Congo[45], Georgia[46], India[47], Indonesia[48], Kazakhstan[49], Kenya[50], Kyrgyzstan[51], Mozambique[52], Nigeria[53], Pakistan[54], Philippines[55], South Africa[56], Tanzania[57], Tajikistan and Ukraine[58]. We anticipate that, with the support of STP, a further 9 countries – Armenia, Benin, Cameroon, Cote d'Ivoire, Moldova, Myanmar, Uganda, Vietnam, and Zimbabwe – will complete TB CRG Assessments in the coming months.

It is vital to acknowledgement STP country partners in this process, for their leadership and commitment: EANNASO Tanzania; KELIN Kenya; TB/HIV Care South Africa; ADPP Mozambique; Communication for Development Center Nigeria; PAS Center Moldova; Alliance for Public Health Ukraine; ACHIEVE Philippines; Yayasan Spiritia Indonesia; KHANA Cambodia; SCDI Vietnam; REACH

India; BRAC Bangladesh; Alliance Myanmar; New Vector Georgia; Gender & Development Tajikistan; Kazakh Union of People Living with HIV Kazakhstan; TB Coalition Kyrgyzstan; DRAF TB Cameroon; Alliance Cote d'Ivoire; Club des Amis Damien DR Congo; and APLHIV Pakistan. It is also important to note that these Assessments were predominantly conducted with support of USAID and TGF, but Assessments in three francophone Africa countries have advanced with the support of Expertise France.

In all 17 countries, the evidence base concerning TB CRG, specifically on human rights, legal and gender related barriers pertaining to the availability, accessibility, acceptability and quality of TB services was significantly enhanced. And, through this, has directly shaped National Strategic Plans, and TGF Funding Requests. The findings from across the Assessments, included:

Country	*Notable Observations*
Bangladesh	Clear need for enhanced community participation. The legal and social barriers were particularly evident for those most vulnerable including migrants, refugees, urban poor and garment workers. Some of the observed barriers included access in terms of the times and locations where services were available, real or perceived stigma and discrimination in the context of workplaces and across genders, limited outreach to these same community groups and language barriers.
Cambodia	Information on the user experience and user perception of barriers is limited and there is a need for community led monitoring to help understand this more. There is also a need for enhanced data relating to gender, access and including KPs to determine how best to ensure programs are gender responsive, including interventions for screening and prevention. Also, the need for enhanced integration so people impacted by one health condition, e.g. HIV, can also access TB services at the same location. Thirdly, a need for local level prioritization to facilitate access to social protections for those most vulnerable (poor)
DRC	Extreme poverty is a central theme of TB and CRG in DR Congo. Legal, policy, gender, and health system barriers as well as social determinants and risk factors are also increasing peoples' vulnerability to TB. This also prevents peoples' ability to access effective TB prevention, diagnosis, treatment care and support, especially those considered key and vulnerable. Specific barriers and social determinants increasing vulnerability and limiting access to TB care and support services include; poor housing conditions, limited access to health insurance, low levels of nutrition, stigma and discrimination, frequent drug stock outs and with nearly 60% of people living in rural settlements geographic barriers prevent people from accessing services.
Georgia	Barriers identified included the need to strengthen gender-responsive treatment support, scale up mental health, counseling, and social protection support, as well as legal protections regarding TB and discrimination in the workplace.
India	There is a clear need to broaden the response to TB at the community level with the help of non-medical and intersectoral approaches and generate local solutions to improve the qualitative experience of vulnerable communities through the care cascade. Gender barriers faced by men, women, and by sexual minorities and for key populations. Limitations in knowledge in legal and rights, development of a curriculum to address this, includes issues of privacy, confidentiality, information, discrimination, and access and was relevant to both public and private providers.
Indonesia	There are some legal foundations that could be strengthened or further adapted to the TB context, including TB and discrimination in workplace settings. The need to understand the nuanced gender in the context of TB – and sensitizing decision makers on this issue – was apparent. Diagnostics and treatment literacy as a barrier and scaling-up funding of TB civil society and affected communities from both donor and domestic sources was identified. More nuanced strategy to reach and engage TB KPs was an overarching theme of the Assessment.
Kazakhstan	Delays in diagnosis for KPs including PLHIV was identified as a barrier, as was the lack of qualified psychological and mental health assistance. Catastrophic consequences of TB especially for women, including self-stigma identified as a significant barrier, and this was linked with lack of financial independence, agency and childcare provisions and privacy.
Kenya	Several barriers identified and the lack of funding for grass roots TB affected community was seen as particularly important. The lack of an isolation policy and the inadequate protection provided by existing laws and policies to protect the rights of people on treatment was identified as key. While TB drugs are free, related treatment e.g. chest Xray has a cost and this is a barrier for those who are most vulnerable.
Kyrgyzstan	Barriers to TB services included lack of information, restriction for key populations – including criminalization of people who use drugs, legislative barriers regarding the right to work for people with TB, and gender related barriers, including violations of reproductive rights of pregnant women with TB,

	gender based violence and catastrophic consequences of TB including stigma that are linked to financial independence, agency and childcare provisions.
Mozambique	Ppoor knowledge about TB and the misconceptions in the ways in which is it commonly understood and represented, limited geographic coverage of the health sector, widespread poverty and marginalization of vulnerable groups, high prevalence of stigma and discrimination. Entrenched gender-related power imbalances and disparities are, together, common barriers to TB service access. In addition, there are several legal environment-linked barriers to TB diagnosis and treatment. These include limited translation and implementation socialization of laws and policy into strategies and interventions. Moreover, there is limited community participation, human rights promotion and protection, and removal of barriers related to gender-dynamics.
Nigeria	Several human rights barriers were identified including issues of confidentiality, misinformation, language barriers, poor relationships with some health service providers. On gender, there were good examples of gender responsive interventions that require scale up, and a need to further sensitize regarding gender, TB and economic and social relationships.
Pakistan	The decentralized nature of the TB response provides an additional layer of complexity. Age, sex and KP disaggregated data have limited availability at national level. There are limited formal systems to educate people with TB on their rights. There is limited tailoring of gender in health responses. Additional barriers identified including stigma, discrimination, privacy and literacy. It was noted that there is no accountability mechanism if policy makers or service providers violate the rights of people with TB.
Philippines	Findings included barriers due to stigma, discrimination, accessing social support, and levels of community mobilization. However, there is also a national TB legislative framework that could be leveraged to enhance support for these. Other barriers identified include limited performance targets, M&E and financing for community engagement and community governance and the issue of accessing income during treatment.
South Africa	Identified challenges for people with TB included the loss of income due to illness, limitations on available TB KP data, the degree of community health worker knowledge of TB and the TB community. For key populations, the power dynamic to address health in the workplace including farm workers, and the criminalization of people who use drugs. On gender, it was noted that men frame TB risk outside the home while women frame it in relation to the home and it is cultural attitudes that impact the health seeking behavior of men in relation to TB diagnosis, treatment and care.
Tajikistan	Barriers included the right to and access of social support, the experience of key population relationships with health service providers and the occurrence of stigma and discrimination featured. Migrants as a key population were seen as facing particular barriers in accessing the prevention, diagnosis, treatment, care and support services they need.
Tanzania	Stigma and discrimination was a dominant theme. The manifestations of stigma included disorientation, lack of acceptance, negative perception in community and health facilities. For key and vulnerable groups criminalization was seen as a particular barrier for people who use drugs, lack of personal protective equipment for health care workers, and language barriers for migrants and ethnic minorities. For many, financial constraints including transportation costs were seen as particular impediments to access care.

In order to understand and critically analyze these issues further, and to develop strategic interventions in response to barriers identified, a right to health lens can be utilized, focusing on availability, accessibility, acceptability and quality:

TB services dimensions	***Human Rights related barriers***
Availability -- *resources available for delivering an intervention in relation to the size of the target population in need*	- Existing laws and policies pertaining to TB provide inadequate protection of the rights of people with TB; - Where there is specific TB legislation, issues of social, legal and economic protections are often omitted or not enforced; - Various laws and policies exclude or discourage key vulnerable populations from accessing TB services: laws criminalizing people who use drugs or undocumented migrants, requirements for an ID document and fixed address etc.; - Lack of isolation policy - health facilities operate without guidelines for isolation standards and there is limited or no options to appeal or review decision or implementation of such policies; - Lack of legal aid access to justice, accountability and complaint-handling mechanisms for people with TB and key vulnerable populations to report problems and violations; - Related systems of social protection (legal aid, financial, mental health, nutrition among others) are limited or challenging to access; - Lack of comprehensive data on key vulnerable populations at national level, manual data collection and analysis at facility level; - Case finding and management strategies for key vulnerable populations are not systematic, effective contact tracing and linkage to care is inadequate due to lack of training, capacity and resources; - Local clinic capacity not always matches the size of the served population and complex cases; - Stock-outs of anti-TB drugs, TB preventative therapy and diagnostics, delays in service provision, N-95 respirators are not regularly supplied and available; - Limited targeted interventions and programs for key vulnerable populations; harm reduction approach for people who use drugs not integrated in TB management system; - Lack of compensation system for healthcare workers for occupationally acquired TB and lack of workplace protections against discrimination for people with TB; - Lack of rapid diagnostics (ex. Xpert) and/or limited use of DST; - Cultural expectations, norms and practices contribute to the barriers experienced by women seeking to access TB services. This can include finance, relationship status, stigma, transportation among others.
Accessibility -- *physical access and financial affordability (including right to seek and receive information in an accessible format) for all in need*	- Limited TB information for people with TB, including diagnostics, treatment, care, prevention, limited rights and gender literacy among people with TB and TB service providers, messages are not reaching TB affected community, low TB literacy – including culturally and linguistically appropriate materials, and facilities accessible for people with disabilities; - Limited geographic access to TB services for testing and treatment, long distances and geographic barriers to clinics for key vulnerable populations, and security concerns for some of these populations; - Daily travel for TB services is impractical, inconvenient and unaffordable or many people with TB; - While TB drugs are free in public health facilities, many people with TB pay out of pocket for related treatment (fees for consultation, CXR, lab tests, transport among others) for themselves and family members, high cost for consultation in private clinics; - Key populations were not aware of the formal mechanisms which are required to ensure the inclusion of the communities in planning for national TB response; - Imposing criminal penalties on drug providers re mandatory reporting can result in fewer facilities stocking drugs.; - Social protection systems may not be inclusive, comprehensive or easy to access leaving many without the income, mental health, nutrition and transport support they need to complete treatment;
Acceptability -- *capacity of the health services to be appealing and sought by the people (including culture, beliefs, religion, gender, language, age-*	- Lack of confidentiality and privacy, as most service delivery points are known with the signpost “TB clinics” or a lack of dividers in general health facilities; - Stigma and discrimination in communities (isolation, disorientation, lack of acceptance, negative perception, existing myths and misconceptions about TB) which manifests in community events, personal relationships, health facilities, in employment and other settings; - Stigma at health facilities (ex: poor attitude, PWUD, prisoners and other KPs are considered criminals and not people with TB);

appropriate services and confidentiality)	- Gender related stigma, double or triple stigma (ex. PLHIV, PWUD, prisoners, migrants) which is exacerbated due to power and financial inequalities and can contribute to relationship breakdown and violence; - Discriminatory workplace practices: fear of loss of employment based on a positive TB diagnosis, lack of safe working conditions, the availability of treatment at work facilitates access but undermines confidentiality; - Unfavorable clinic opening times, especially for key vulnerable populations, lack of childcare facilities linked to health services; - Language or literacy barriers for minority communities in accessing information on TB and TB services including for indigenous, tribal, nomadic, migrant and refugee communities; - While participation is open to all by law, stigma associated with sexual orientation and sex work hinders meaningful participation of some vulnerable groups in programming for TB; - Inadequate peer-support, mental health counselling, and reporting mechanisms (particularly those that are community led) for when further legal, social, medical or economic barriers are encountered; - Limited structures of peer support and peer led counselling; - Limited opportunities for TB affected community meaningful engagement and participation in TB community governance – prioritization, design, implementation, monitoring and review.
***Effective coverage -- or quality**, which requires diagnostic accuracy, provider compliance with evidence-based treatment, continuity of services, effective referrals and adherence*	- People with TB and key vulnerable populations experience poor quality of diagnostics, prevention, treatment and care (ex. use injectables against WHO recommendations, limited access to DST, old diagnostics like smear microscopy); - Lack of treatment adherence and counselling support, especially for key vulnerable population; - Inadequate investment in resilient community systems among TB survivors and TB affected community; - Lack of social, nutritional and financial support for key vulnerable populations; - Delays in TB diagnostics and treatment; - Lack of community paralegals / grassroots legal advocates and legal aid services to seek concrete review, recourse and remedies to instances of injustice in the context of TB; - Lack of user inputs, monitoring and reporting of quality of services that are available and accessible.

An academic article is currently being developed by the STP Country and Community Support for Impact (CCS4I) Team to articulate the findings, recommendations, and trends from the 17 completed TB CRG Assessments.

TB Key & Vulnerable Populations

The Key Population (KP) component of the TB CRG Assessment process also responded to the needs and rights of key and vulnerable populations through incorporating a consensus building process for the prioritization of key populations in the local context. While there are many factors that increase the risk and likelihood of TB, there is also a need to understand the nuance of particular populations and to ultimately tailor and invest in interventions that will ensure that no person or community is left behind, that barriers are identified and mitigated, and access to TB services is universal. The UNHLM Political Declaration includes an extensive list of TB key and vulnerable populations. The Political Declaration notes 'women and children, indigenous peoples, health care workers, migrants, refugees, internally displaced people, people living in situations of complex emergencies, prisoners, people living with HIV, people who use drugs, miners and others exposed to silica, urban and rural poor' among others [P17]. STP has developed and incorporated the TB KP prioritization tool into the TB CRG Assessment, and this has helped to shift attention to social justice for these groups – communities who are most vulnerable, marginalized and left behind. It is important to note that in many countries this tool was utilized to also unpack barriers relating to human rights and gender, and there was clear intersectionality between key population and gender in several countries. This exercise has been significant in advancing the need to have programming that responds to the needs of those who need to access and use the services. The prioritization exercise yielded the following outcomes:

Country	**Prioritized Key & Vulnerable Populations**
Bangladesh	Garment workers, urban poor, elderly, children, rural poor, diabetics, refugees, prisoners, hospital workers
Cambodia	people living with HIV, people aged 55yrs+ people with diabetes, prisoners, people who use drugs, and people who inject drugs
DR Congo	Prisoners; People living with HIV; Refugees; People who use drugs
Georgia	People who use drugs; people with a history of imprisonment; internally displaced persons
India	Urban slums, Migrants, Tribal, Diabetes Mellitus and Miners
Indonesia	Urban poor, People living with HIV, prisoners, rural poor, children, elderly, miners, mobile populations
Kazakhstan	Prisoners, People living with HIV; Internal migrants
Kenya	People living with HIV; People who use drugs; Children at school age; Prisoners; Migrants; Refugees
Kyrgyzstan	People who use drugs; Prisoners; Internal migrants
Mozambique	Prisoners; Health workers; People who use drugs; People living with HIV; Mineworkers
Nigeria	People living with HIV; Prisoners; Sex workers; Internally displaced people; Urban poor; Rural poor; Smokers; People who use drugs; Children; Hospital workers
Pakistan	People living with HIV, Transgenders, men who have sex with men, HIVTB co-infected, People who use drugs, Prisoners, Urban Poor, and Heath workers
Philippines	Prisoners, smokers, elderly, people with diabetes, Slum Dwellers, Street Dwellers, People who use drugs
South Africa	Farm workers; Healthcare workers; People who use drugs; TB contacts
Tanzania	People living with HIV; Mineworkers; Refugees; Prisoners; People who use drugs; Slum dwellers (urban poor); People with diabetes; Children; Elderly; Health workers (including CHWs); Fisherfolks; Traditional healers
Ukraine	People living with HIV, people with silicosis, migrants/internally displaced persons/refugees, prisoners, People who use drugs, people with alcohol dependency, Smokers, Ethnic Minorities (Roma), homeless and people with mental health challenges

The country level prioritization yielded diverse populations. However, it can be noted that several populations stand out:

1. Prisoners and Detainees
2. People Who Use Drugs
3. Urban Poor and People living in Slums
4. Refugees, Migrants and Displaced People
5. People Living with HIV
6. Miners
7. Elderly

STP has developed TB Key Population briefs for TB key and vulnerable populations, including for: prisoners[59], urban populations[60], people who use drugs[61], mobile populations[62], people living with HIV[63], miners[64], health care workers[65], children[66], rural populations[67] and indigenous peoples[68].

In several countries this process has evolved into a dialogue on TB key and vulnerable populations. A particular note on Georgia where the process was led by New Vector – a key population network (people who use drugs). In Indonesia this prioritization exercise contributed to an extended list of TB key populations being incorporated into the National Strategic Plan. Lessons learned and awareness of the value of conducting assessment in five southern African countries has resulted in the scale up of mining KP CRG Assessments to all the 16 Southern African Development Community (SADC) countries. Follow up efforts on these identified key populations are now being supported through the Challenge Facility, with grants supporting the engagement of the transgender community in India, nomadic populations in Nigeria as well as indigenous populations, migrants and prisoners in the Americas, while the completed national costed TB CRG Action Plans all contain tailored interventions for the prioritized populations. Further work on undertaking size estimates of national key populations will be a strategic next step to further support efforts to engage and support universal access for TB key and vulnerable populations and ensure they are not left behind.

The assessment and action planning process provided strategic information for planning and mobilizing resources at country level. Specific follow-up TA has been provided by STP to incorporate findings and recommendations into TGF funding requests, NSPs, and program reviews in 20 countries: Bangladesh; Cambodia; Congo Brazzaville; DR Congo; Ghana; India; Indonesia; Kenya; Malawi; Mozambique; Myanmar; Nigeria; Pakistan; Philippines; South Africa; Tanzania; Uganda; Ukraine; Zambia; and Zimbabwe.

TB & Gender

Gender is relevant to all aspects of the TB response. It shapes who is at risk of infection and disease, when and how diagnosis occurs, treatment access, the likelihood of adherence and treatment completion as well as the social and monetary consequences of TB disease. Two thirds of TB cases globally are among men, indicating that there are significant gender-related barriers for increased risk and/or prevention services. Studies have shown that women, however, face disproportionate barriers in accessing TB care services, as well as higher levels of stigma and psychosocial consequences of TB disease. Women also face numerous additional challenges related to TB and maternal health.

A gender-based approach to TB acknowledges and responds to the social, legal, cultural and biological issues that underpin gender inequality and contribute to poor health outcomes. Gender-based responses to TB are further built on the acknowledgement that all TB interventions have the capacity to either reinforce or mitigate harmful gender norms. TB Programs therefore have an ethical responsibility to monitor interventions to ensure broad, positive impact.

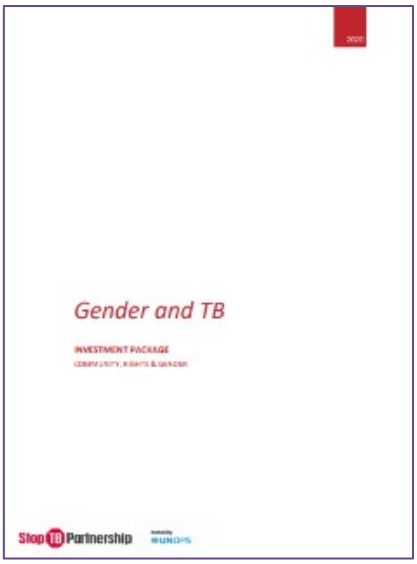
The STP supported the implementation of Community Rights and Gender (CRG) Assessments, including specific Gender Assessments in 17 countries. These qualitative assessments revealed the extent to which gender differences shape TB vulnerabilities and care access in different contexts. They have also

revealed some broad commonalities, including a lack of gender sensitization in healthcare workers, particularly in relation to transgender people. Other commonalities include poor availability and use of detailed gender-disaggregated data, the absence of gender mainstreaming in monitoring and evaluation processes, ongoing gender-bias in the health workforce, gender-blind TB policy, the commonality of TB-related stigma, and a wide array of other gender-related barriers to care access. Together the CRG Assessments highlight the urgent need for TB programs to put gender front and center of their programming.

What has become clear from the TB CRG Assessments is that there is an increased acknowledgement of having gender-related interventions as part of the TB response, but there is less understanding with regard to how to integrate gender responsive elements into ALL policies, programs, guidelines and systems.

Focus areas for strengthening gender in TB responses:

- Service provider sensitisation and capacity building
- Monitoring and evaluation of gender responsive TB programming
- Gender equity in the TB workforce
- Development of a national gender strategy and action plan
- Facility based service quality improvement
- TB education and stigma reduction
- Community-based case finding
- TB services for TB key populations



Addressing sociocultural barriers, eliminating stigma and discrimination and the meaningful engagement of women, are all central to the UNHLM political declaration. Further, there is a commitment at P33 calling for gender equality to be a guiding principle for the TB response. The key themes described above have all been unpacked and budgeted in the Stop TB Gender Investment Package [69] which has been made available to country partners.

The newly formed global network TBWomen will play an important role in ensuring community voices continue to drive discourse on TB and gender.

National Costed TB CRG Action Plans

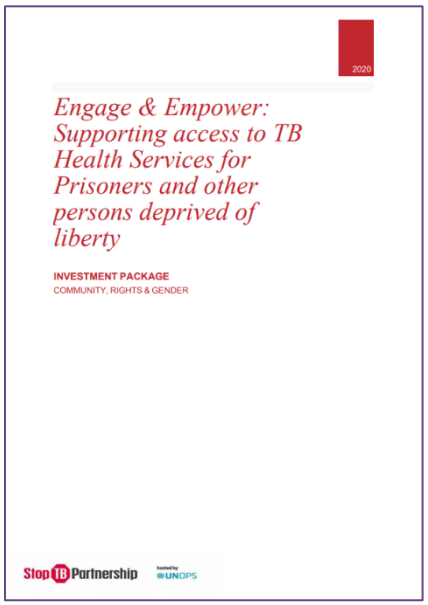
While TB CRG Assessments have been critical in shining a light on barriers and challenges experienced by people affected by TB in the areas of laws and policies, human rights, gender and key populations, there has been a need to take the findings and recommendations and to develop a series of interventions that respond to the identified issues, are costed and monitored, and that are owned by the national TB program.

Costed National TB CRG Action Plans are also significant as they are owned by the National TB Program of the respective country but are developed in close partnership with national TB affected communities and civil society. Further they are also costed and linked to monitoring and evaluation frameworks, serving to mainstream CRG in TB. For each of the four completed costed national TB CRG Action Plans in Tanzania [70], DRC [71], Bangladesh [72] and Nigeria [73] (in addition to India where a TB Gender Framework has been developed), the plans have been incorporated into, or alongside, the National Strategic Plan, and have been the basis for TB CRG funding under the TGF Funding Requests.

- **Tanzania**: The Tanzania NTP, together with EANNASO, TB affected communities and STP, have developed the first national TB Operational Plan. The Ministry of Health, Community Development, Gender, Elderly and Children is committed to the Plan's implementation. In terms of particulars, there are 5 focus areas: Addressing Stigma, Discrimination & Gender Inequality, Reform of Laws and Policies, Multisectoral Collaboration, Community Mobilization and Targeting Key and Vulnerable Populations. The total budget for the Plan is USD 1.6 million, with various parts funded by several sources including TGF and Challenge Facility.
- **DRC**: The DRC NTP (PNLT), together with Club des Amis Damien and the affected TB community have 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.
- **Bangladesh**: After the TGF Technical Review Panel requested stronger TB CRG interventions in the national TB funding request, the Bangladesh NTP requested support from STP in developing a costed TB CRG Action Plan. This plan was developed on consultation with national partners, is informed by the national CRG Assessment from BRAC, and was finalized during the TGF country grant making. The Plan budget is over USD 3 million, around USD 700,000 has already been included in the national TB grant.
- **Nigeria:** The 5-year Human Rights and Gender Action Plan for Tuberculosis Care and Prevention in Nigeria is the most recently finalised TB CRG Action Plan. The first objective of the plan is to work towards an enabling environment of laws, policies, guidelines and systems; to strengthen the legal system to support rights and gender in TB management; to reduce stigma and discrimination; to increase access for TB key populations; and is combined with an accountability mechanism for the realization of these objectives.
- **India:** has also progressed the findings and recommendations from their CRG Assessment. This has been in the form of developing a *National Framework for a Gender Responsive Approach to TB in India*[74].

STP will work with country partners who have completed TB CRG Assessments to also complete costed national TB CRG Action Plans. This will include Pakistan and Vietnam – both scheduled to be completed before the end of 2020. Noting the recommendation in *A Deadly Divide: TB Commitments Vs. TB Realities* calling for TB CRG Action Plans to be developed in all high burden TB settings, STP is ready to scale up this support.

CRG Investment Packages

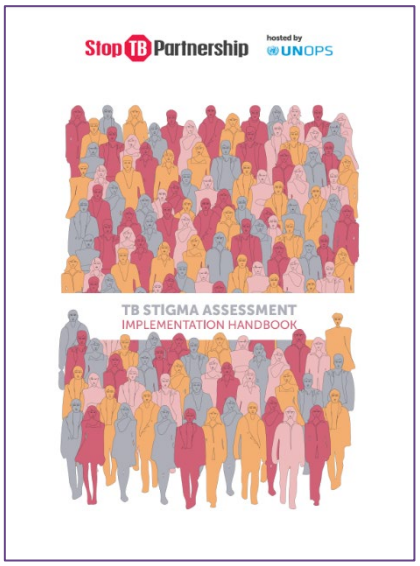


Given the significant evidence, information and lessons learned from the 17 TB CRG Assessments, STP has developed several TB CRG investment packages that can be adopted at country level and can be operationalized and incorporated into National Strategic Plans, TGF Funding Requests and other donor opportunities. The investment packages provide context to interventions, rationales, implementation guidance and indicative budgets. The focus areas for the TB CRG investment packages are: TB stigma measurement[75]; assessing legal and social barriers to TB services[76]; community-led monitoring[77]; TB affected community human rights training and sensitization[78]; TB rights sensitization for lawyers and judges[79]; TB, CRG and prisons[80]; and, gender responsive TB programming[81].

These TB CRG Investment packages have been utilized by several countries in developing national Funding Requests during the opening windows of TGF Funding Requests.

TB Stigma Assessment

A cross-cutting finding from the TB CRG Assessments conducted in 2018-2020 revealed that TB stigma is a barrier preventing people from accessing TB services. Based on this as well as calls from community and civil society to measure and respond to TB stigma, STP developed the TB Stigma Assessment. The assessment builds on the efforts and work led by KNCV on TB stigma measurement and was conceptualized and developed collaboratively with global, regional and national networks of people affected by TB with input and support from WHO, USAID and the TGF. It supports countries to measure the levels and dimensions of self, anticipated, enacted, observed and secondary stigma in different settings to understand how it is acting as a barrier to both accessing and providing TB care and support services. The output of the assessment is a costed evidence-based stigma reduction action plan. The Assessment was pilot tested in India and Sierra Leone and further implementation is being supported in Ghana, Nigeria, South Africa, Bangladesh and Ukraine.



In support of the stigma measurement process, STP developed an Implementation Handbook, Data Collection Tools and a Data Entry and Analysis Tool. Based on the tool, TGF included TB stigma indicators in the TGF Modular Framework to allow countries to establish and monitor levels of stigma against TB stigma reduction strategies.

Today there is still a dearth of information on TB stigma and its impact on the TB response. To help build a body of evidence on TB stigma and its impact, STP collaborated with Saw Swee Hock School of Public Health, National University of Singapore, National University Health System, Singapore, KHANA, Center for Population Health Research, Phnom Penh, Cambodia on a study *Characterizing and Measuring Tuberculosis Stigma in the Community: A Mixed-Methods Study in Cambodia*[82]. The research aimed to characterize, measure, and explore the determinants of TB stigma among people with TB in Cambodia. The study was conducted in 12 of Cambodia's 162 Operational Districts. Of note is that 56% of respondents (people affected by TB) experienced self-stigma and 51% experienced perceived stigma by the community, which led to the conclusion that TB stigma is prevalent. This suggests a need for the nationwide measurement of TB stigma (using the STP TB Stigma Assessment) and the incorporation of stigma-reduction strategies in the national TB response to end TB stigma by 2022.

OneImpact Community-Led Monitoring

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 has given rise to the need for community-led monitoring (CLM). The UNHLM on TB makes strong commitments for meaningful community participation and multisectoral accountability. These commitments were reiterated in the findings of CRG Assessments and in response, in collaboration with multiple partners, STP developed a framework and digital platform (OneImpact) [83] to enhance and facilitate CLM.

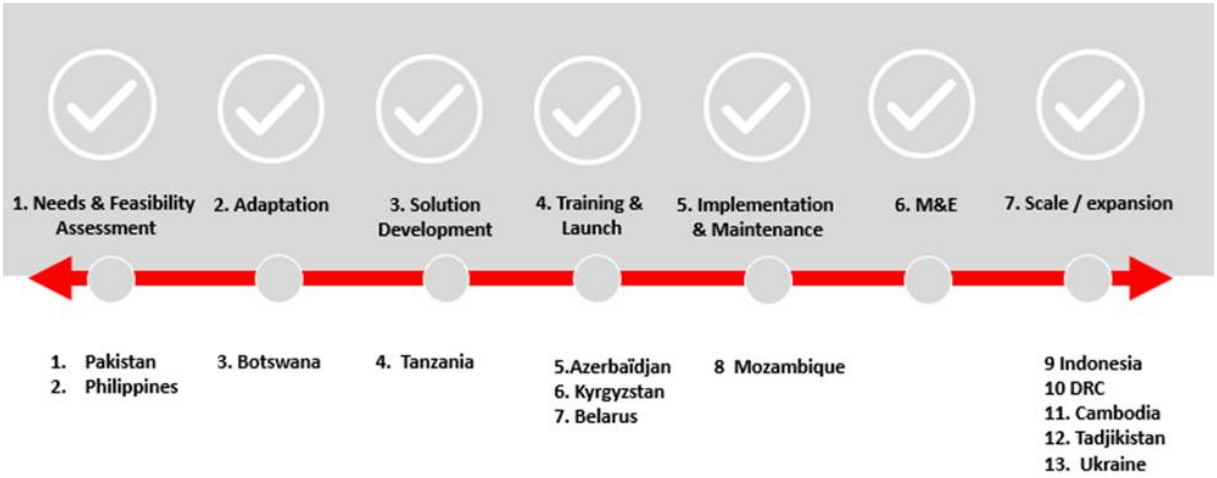
Among other elements the CLM Framework conceptualizes how CLM can protect and promote the rights of people affected by TB, and it provides implementation tools to support the execution of the intervention including: a needs and feasibility assessment; legal and landscape assessment; data privacy and security training modules; an adaptation protocol; and training guides. The CLM Framework was developed in collaboration with International Treatment Preparedness Coalition (ITPC), legal experts, and OneImpact implementers.

The CLM Framework consists of:

1. An app which aims to empower people affected by TB with information, with ways to connect in virtual spaces with other people affected by TB, and with ways to report human rights barriers to access. The app has 5 components:
    a. **Know your Rights:** A module that orients users on the rights of people affected by TB and the obligations and responsibilities of State and Non-State Actors.
    b. **Get Information:** A module on what all people affected by TB need to know about TB from TB medical experts and people affected by TB.
    c. **Get Access:** A TB service locator module that helps users access nearby TB health services, information about the services, and they can also rate the services.
    d. **Get Connected:** A module that connects users with other people with TB, peer support groups, national networks of people affected by TB, and different discussion forums.
    e. **Get Involved:** A module that allows users to report human rights barriers preventing them from accessing quality TB prevention, diagnostics, treatment, care and support services.
2. A first responder dashboard with a platform which allows first responders to monitor human rights barriers reported by people affected by TB and to prompt the coordination of a response, leveraging support from community, health, legal, and social welfare systems.
3. An accountability dashboard with a platform for leading community advocates to monitor CLM indicators and trends that will inform and identify community advocacy priorities, inform the design of programmatic interventions and facilitate the evaluation of interventions that address the barriers to access, enhancing accountability in the TB response.

STP and Dure Technologies have supported the implementation of OneImpact in 14 countries: Azerbaijan; Belarus; Botswana; Cambodia; DR Congo; Indonesia; Kenya; Kyrgyzstan; Mozambique; Pakistan; Philippines; Tajikistan; Tanzania; and Ukraine. Over 3,500 people affected by TB were oriented on their rights and engaged actively in designing the CLM intervention and tool, as well as in monitoring the availability, accessibility, acceptability and quality of TB services. For each barrier monitored, each country developed response protocols leveraging multi-sectoral response teams to overcome each barrier at a local level, strengthening linkages between community, health, legal, and social welfare systems. Each country can now identify community priorities for advocacy, based on evidence generated by the affected community through the OneImpact platform.

Figure 3: stages of implementation of the OneImpact platform



For the first time, countries have an electronic monitoring system that collects information on human rights barriers from people affected by TB, and have access to real time data. With hundreds of people actively engaged in monitoring the TB response, and with accountability mechanisms, multi-sectoral response teams and community advocacy networks in place, national TB programs are using a rights-based approach to identify and overcome, in real time, human rights barriers that are hampering national efforts to end TB.

There are clear examples where the implementation of this tool directly contributes to supporting country efforts in realizing TB HLM targets and commitments. These include examples from Mozambique, DR Congo and Ukraine:

- In the districts of Matola and Chibuto in Mozambique, **71%** of people with TB (163 people) enrolled in the OneImpact CLM intervention reported a barrier at least once between May-September 2020. Of all barriers (703) identified 25% related to the availability of TB services. Of the 85 people who reported availability barriers, 50% of the barriers were to do with household contacts not being screened. As a result, ADPP in collaboration with the local health authorities developed and conducted community-based active case findings strategies in Matola and Chibuto districts which resulted in 20 children under 5 years old being put on TB preventive therapy.
- In Kinshasa, DR Congo, **46%** of people with TB (366) enrolled in the OneImpact CLM intervention reported a barrier at least once between July and December 2019. Of all the barriers (1542) reported, 16% had to do with the availability of services. Of the 77 people who reported availability barriers 16% had to do with TB drugs not being available at the health facility. Club des Amis Damien (CAD), who led the CLM OneImpact intervention, worked with the National TB Program and designed a response protocol to report drug stock outs at facility level, which involves CAD immediately alerting the National TB Program for every reported incidence of drug unavailability.
- In Cherkasy, Ukraine, **56%** of people with TB (714) enrolled in the OneImpact CLM intervention reported a barrier at least once between April 2019-October 2019. Of all the barriers (78) reported, 39% related to TB stigma. Seventeen people reported experiencing TB stigma 17 times, among which 29% experienced TB stigma in health care setting, 25% experienced TB stigma in a family setting, 25% in a work environment, and 21 in a community setting. TBpeople Ukraine subsequently led national community advocacy efforts to raise awareness about the impact of stigma on people with TB and successfully

succeeded in ensuring the roll out of a national TB stigma assessment, which is currently underway. It will provide more information on the levels and impacts of TB stigma and support national efforts to end TB stigma by 2022.

Ensuring a higher level of accountability for the availability, accessibility, acceptability and quality of services in the TB response, and the promotion and protection of human rights more generally, will be facilitated by:

1. Empowering individuals and affected communities to increase the capacity and capability of communities to identify local priorities and monitor and advocate for improvements in the TB response
2. Enhancing capacity building and development:
    a. To strengthen community-level data on the barriers that prevent people from being diagnosed, treated and reported in the TB response
    b. To strengthen affected community advocacy and increase the community's level of accountability for the TB response
3. Increasing access to effective TB prevention, diagnosis, treatment, care and support, and reducing vulnerability:
    a. To inform the design of interventions to remove barriers in the TB response
    b. To evaluate interventions in the TB response based on the community-level data
    c. To overcome barriers that impede the TB response

More recently STP assessed the data privacy and security issues associated with the OneImpact CLM and implemented technical, legal and programmatic measures to promote and protect the human rights of people affected by TB, the foundational principles and central objective of OneImpact CLM. And, building on the lessons from OneImpact, STP together with Frontline AIDS and EANNASO have developed *Community Monitoring: A technical guide for HIV, TB and malaria programing.*[84] This technical guide will inform civil society organizations at the grassroots and other levels, communities, country coordinating mechanisms (CCMs), and consultants to design, cost and implement CLM effectively as one of the main interventions within the TGF's community systems strengthening (CSS) module, which features the OneImpact case study from DRC.

Providing CRG Technical Support

STP has worked to support National TB Programs and national affected community partners to take the findings, evidence and recommendations from the TB CRG assessments, human rights, stigma and discrimination initiatives and community-led monitoring, and integrate them into National Strategic Plans – in alignment with the UNHLM Political Declaration [P48].

Over the past 24 months, STP, with support of USAID and the TGF under the Strategic Initiative on Finding the Missing People, has provided technical assistance to 30 countries to support the integration of CRG in NSPs, including through CRG Assessments, the development and finalization of national costed TB CRG Action Plans (described above) as well as other support. This has resulted in advancing rights-based, gender responsive and people centered TB responses in: Bangladesh; Benin; Cambodia; Cote d'Ivoire; DR Congo; Cameroon; Congo Brazzaville; Georgia; Ghana; India; Indonesia; Kazakhstan; Kenya; Kyrgyzstan; Malawi; Mozambique; Myanmar; Niger; Nigeria; Pakistan; Philippines; Sierra Leone; South Africa; Tajikistan; Tanzania; Uganda; Ukraine; Vietnam; Zambia; Zimbabwe; as well as at the regional level for TGF TB in the Mining Sector (TIMS) regional proposal.

This technical assistance has been critical in ensuring that CRG learnings were operationalized, integrated and funded, as well as for supporting countries on the path to achieving the UNHLM on TB targets and commitments.

The Impact of COVID-19 on the TB Response: A Community Perspective

The COVID-19 pandemic has significantly impacted the progress of all TB UNHLM targets and commitments. Existing inequalities have been exacerbated, and for many who are marginalized, vulnerable or experience infringements on their rights, the pandemic has made their experiences in accessing TB services and completing treatment even more challenging. STP modelling has revealed conservative estimates of an additional 1.4 million deaths and 6.3 million additional people with TB between 2020 and 2025[85]. This is obviously a devasting outcome. But there has also been a critical need to further understand the additional implications for CRG commitments deriving from the pandemic, the lock down, issues of job loss and food insecurity and increased marginalization and stigmatization.

In response to early warnings that COVID-19 was having a devastating impact on people affected by TB and TB programs around the world, the STP civil society delegations joined forces with 8 global networks (ACTION, GCTA, TBpeople, RESULTS, Global TB Caucus, McGill International TB Center, TBPPM, WeAreTB) to take action. This collective launched a civil society-led survey, aimed at enriching our understanding of experiences in various regions and key stakeholder groups, with the following objectives:

- To identify critical gaps and needs in TB services resulting from the pandemic and raise awareness among national governments, program implementers, policymakers, parliamentarians and the wider global health community;
- To raise the voices of TB-affected communities and civil society to ensure their ideas and concerns were incorporated into national, regional, and global responses;
- To support greater alignment of TB and COVID-19 priorities and services at country level;

- To work collaboratively to ensure coordinated advocacy efforts and concrete political actions to address identified gaps in funding, resources, and services;
- To strengthen engagement of and relationships across TB-affected communities and civil-society networks engaged in the fight to end TB.

The insight and feedback received was extensive, insightful and was compiled in a formal report, entitled *The Impact of COVID-19 on the TB Response: A Community Perspective*[86] with a clear call to action. A high-level virtual launch of the report findings and call to action featured Peter Sands, Madhu Pai, Nick Herbert, Lucica Ditiu, Tereza Kasaeva, Joanne Carter along with TB survivors and civil society. The report provided global findings, but also had country specific focus sections for Kenya, India and the United States to showcase the information gained from close to 1000 respondents from 89 countries.

The call to action from *The Impact of COVID-19 on the TB Response: A Community Perspective* included the following:

1. Development and implementation of a 'Catch-Up' plan to build back better, that features the priorities of and investments in TB affected communities to recover lost ground and then accelerates to ensure national targets and UNHLM on TB commitments are met;
2. Enhancing social security systems to be inclusive and comprehensive now and in the recovery from the pandemic;
3. Simultaneous screening (and diagnostics) for TB and COVID-19 in high burden TB settings;
4. Real time TB data, including for TB key populations, that mirrors real time COVID-19 data systems;
5. Leveraging COVID-19 R&D investments to incorporate TB and COVID-19 R&D;

In addition, STP has taken immediate steps to adapt the OneImpact community monitoring platform to assess barriers for TB and COVID-19 to ensure that the continuance of real time data can inform TB responses.

As TB 'Get Back on Track' plans are developed globally and at the national level, this real time experience of people affected by TB will continue to be critical in design, implementation, monitoring and accountability. The strong community and civil society networks enhanced and strengthened through the Challenge Facility, will also be critical in insuring that CRG priorities continue to increase in prominence, are adapted to the context of TB/COVID-19 and remain on the agendas of national TB and health programs and that all UNHLM targets and commitments are met.

Conclusion

Significant progress has been made in transforming the TB response to being equitable, rights-based and people centered, and in making progress against CRG inspired UNHLM on TB targets and commitments, particularly those commitments contained in Ps 14, 17, 18, 25, 33, 37, 38, 48 and 49. STP, through the Country and Community Support for Impact Team, has directly contributed to this progress including through CRG Assessments and action plans, community-led monitoring, measuring and mitigating stigma and discrimination, operationalizing human rights and gender in the context of TB, and significantly, through the meaningful engagement and governance of TB affected communities and civil society. With that being said, there is still much work to do before 2022. We acknowledge the recommendations from *A Deadly Divide: TB Commitments vs. TB Realities* and stand ready to scale up the utility of the Challenge Facility, increasing the number of priority countries, while continuing to strengthen and support initiatives from TB affected communities and civil society that build evidence and partnerships, raise political will and financing, and monitor for advocacy and accountability. We look forward to continuing our partnerships with USAID and Global Fund to Fight AIDS, Tuberculosis and Malaria to further empower and strengthen the TB affected community to reach an equitable, rights based and people-centered response to TB. This work serves to bridge individual context and primary health care, by focusing on enabling environments and structural reforms. These are much needed to ensure the promotion and protection of the rights of people affected by TB, strong public health outcomes, and the realisation of social justice for every member of society, ensuing no one if left behind.

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Empowering TB Affected Communities to Transform the TB Response to be Equitable, Rights-Based & People Centered

Stop TB Partnership Support to Achieve UNHLM Targets and Commitments 2018-2020

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