THE JOURNEY CONTINUES…

Collective learnings and challenges of communities working on TB stigma, discrimination and Human Rights

The South-to-South Learning and Knowledge Exchange project, that builds the basis of this report, was conceived, and implemented by the GCTA. The GCTA is a global platform of people affected by TB that amplifies community engagement and strengthens the capacity of TB activists at all levels. We envision a world free of Tuberculosis and work towards making this a reality.

We dedicate this report in the memory of the millions of people who die of TB every year, and to those affected by TB; those who have overcome and those continuing to struggle.

We are with you and together we dream and hope for a world without TB!

Thank you,

The GCTA Team

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Abbreviations

ACT	Africa Coalition on TB
ACT! AP	Activists' Coalition on TB Asia-Pacific
AIDS	Acquired Immuno Deficiency Syndrome
AP	Asia Pacific
APCASO	The Asia Pacific Council of AIDS Service Organisations
CBO	Community-based organization
CEO	Chief Executive Officer
CLM	Community -Led Monitoring
CRG - SI	Community, Rights, and Gender – Strategic Initiatives
CTO	Community Treatment Observatory
DOT	Directly Observed Treatment
EECA	Eastern Europe and Central Asia
GCTA	Global Coalition of TB Advocates
GFATM	The Global Fund to Fight AIDS, Tuberculosis, and Malaria
HIV	Human Immune Deficiency Virus
KELIN	The Kenya Legal & Ethical Issues Network on HIV and AIDS
LAC	Latin America and Caribbean
MDR-TB	Multi Drug Resistant Tuberculosis
NGO	Non-Governmental Organizations
NTP	National Tuberculosis Program
TB	Tuberculosis
TBEC	TB Europe Coalition
UNHLM	United Nations High Level Meeting on TB
WHO	World Health Organization

A. Executive Summary

The past few years have seen growing momentum for addressing stigma and discrimination faced by people affected by tuberculosis (TB). TB community organizations have made important progress in upholding the rights of people affected by TB. Communities and other civil society organizations have begun to receive funding that has allowed them to implement activities to address TB stigma and discrimination in many different ways. The GCTA and other TB organizations have shared the multitudes of experiences and stories of TB survivors. Their stories overwhelming show that stigma and discrimination are huge barriers throughout the cascade of TB care. GCTA and partners from the TB communities have successfully fostered advocacy to address stigma, discrimination, and build a human rights-based TB response across the world. Our high-level advocacy achieved a huge success when addressing stigma and discrimination and removing human rights barriers in TB became one of the top ten recommendations of the UN Secretary General's report in 2020.

At this juncture, GCTA found it important to bring together regional TB networks to take stock of the past five years. It was important to set aside dedicated time to facilitate exchanges focusing on progress, challenges, and remaining needs and priorities to enable south-to-south learning and cross-regional experience sharing in relation to TB stigma, discrimination, and human rights. Our TB communities have made progress on different TB rights issues, with different strategies, and to differing degrees of success. This documenting of sharing lessons from many different organizations and looking for best practices by Global South organizations and activists was an exercise in consolidating community strength. Our joint knowledge is an important yet often overlooked piece of

the puzzle of developing a community-responsive, actionable advocacy interventions into the global TB discourse. This report is a contribution towards filling that gap.

GCTA alongside regional partners Socios en Salud and Fundación Fernando Iturbide Guatemala, in Latin America and the Caribbean (LAC); TBEC in Eastern Europe in Central Asia (EECA), Africa Coalition on TB (ACT) in Africa; ACT AP! and APCASO in Asia-Pacific; and national partner Touched by TB in India shared learnings at a series of one national, four regional, and two global consultations. The information and learnings from these consultations have been analysed in for this report and were the basis for this report's recommendations. The main of goal of this process, conducted with support from Global Fund CRG-SI, is to inform the TB communities globally in their advocacy with donors, governments, and policy makers on the national, regional, and global levels. Our aim is to inform all stakeholders, including from communities, donor organizations, governments and their respective departments of which interventions have brought positive change. At the same time, we want to draw the attention of donors and government stakeholders to remaining barriers and needs we need to now focus on, to propel us towards our common goal of ending TB.

Summary of Main Findings

Each consultation centred around a set of four questions.

1) What are the main human rights issues for people affected by TB in your country?
2) What progress have you made and how did you effect this change?
3) What barriers have you encountered in your work and what do you need to overcome them?
4) What TB and human rights work would you like to do, but currently cannot, and why?

Discussions were held live with concurrent use of the online meeting software's chat function. Below is a summary of the main findings of the discussions. For additional information, kindly see the main findings section of the full report.

Main Human Rights Issues

Stigma and discrimination remain pervasive issues including in healthcare settings, communities, and the workplace. One reason continues to be limited knowledge and TB literacy with regards to treatment and transmission of TB. Access to information and gathering evidence of discrimination are challenging.

Many right violations happen within the treatment cascade. They are related to the functioning of the respective healthcare system and structural challenges that have negative effects on the **availability of safe, short oral treatment regimens** as well as availability of **quality diagnostics** that yield quick results. One of the main barriers to access to treatment are registration challenges on national level. Further violations result from the still largely medicalized approach versus the recommended community-centred, human rights-based approach to TB. Violations of access to TB care are particularly challenging for children and migrants.

Governmental environment and national legislation are another area of continued concern. Many countries restrict civil society activities and the formation and/or registration of civil society organizations, thereby violating the TB community's freedoms of assembly and association. Government attitudes towards civil society are a significant

barrier to the necessary meaningful engagement of the TB community and restrict their right to participation and self-determination.

Progress on TB and Human Rights

Engagement with legal professionals is a meaningful strategy for TB organizations. Legal approaches that participants promote include provision of legal aid, pursuit of legal cases, as well as TB-specific legislation.

More monitoring and documentation tools are now available, meaning that building an evidence base of human rights violations is getting easier. TB organizations also point to progress with increased TB literacy and self-advocacy among people with TB. Progress is recorded in particular when specific settings and follow up procedures to trainings are possible.

A few organizations have identified successful ways to engage with the government, including through promotion of government hiring of peer educators and acting as expert resources by designing and implementing successful pilot programs that gain the support of the government.

Coalition-building is a large factor for TB advocacy success, in particular when coalitions include strong cross-sector alliance, e.g., between legal organizations, HIV/AIDS, and TB organizations.

National and regional collaboration are essential for working on TB rights and the networks of TB Champions in different regions of the world are important facilitators of community engagement.

Main Challenges and Needs

Funding for TB organizations and TB rights advocacy is at the centre of several challenges. While funding for TB rights advocacy is now available, funding priorities are donor-driven and do not always meet community priorities. Funding streams as well as the budget line items that can be funded remain somewhat limited.

The **limited timeframes of grants** can make it challenging to deliver specific advocacy outcomes, especially when communities and donor agencies hold different expectations of what constitutes advocacy and how advocacy should be conducted. Advocacy in changing political environments is extremely challenging and often necessitates flexibility that may be outside of grant requirements.

Meaningful engagement between communities, government, and national policy makers is another essential area that needs further exploration. From the community perspective, meaningful engagement has to be understood as participation in decision-making rather than being consulted only.

Another area of concern is the **lack of communication strategies and availability of communication materials.** Communication plans are needed to accompany dissemination of National Strategic Plans, but also in effective communication and training of TB rights literacy. Training materials need to be available for broad circulation among all stakeholders.

A large strategic barrier for addressing TB stigma, discrimination, and human rights is the fact that **human rights education** happens too late. People affected by TB often do not

get into contact with any kind of human rights education, let alone TB-specific rights education, until after they have experienced rights violations. This takes away their ability to react to violations as they occur. TB activists express a strong need for a rethinking of how TB rights education is integrated into broader human rights education efforts and for developing strategies for spaces that allow for more contact points with communities at risk of TB.

Despite the progress that legal approaches have brought, they are also fraught with challenges. Reporting a rights violation does not equal action nor recourse for the violation. **Legal approaches take time and are resource-intensive**, putting them out of reach for many who would need them. More resources are needed for e.g., training community paralegals and pursuing long-term legal strategies.

When it comes to working with government and policymakers, a major challenge to human rights work is the **sensitivity of human rights language**. When working with or within government institutions, TB organizations must be extraordinarily nimble with language. They also must stay alert of the political context in which their advocacy is meant to happen, again necessitating a large amount of flexibility when it comes to implementation timelines and planned versus eventually possible activities.

All consultations expressed some need for updated treatment recommendations and guidelines, both on the international level, but in particular, on the national level. Making new treatment and diagnostics available, incorporating community, rights, and gender (CRG) strategies into National Strategic Plans all take time, but are essential for realizing a human rights-based response to TB.

Recommendations

Based on the information gathered at the four regional consultations, one national consultations, and two global consultations, GCTA and partner organizations have developed the following recommendations.

To Multilateral Funders, Bilateral Funders, and Philanthropic Donor Organizations

With the understanding that donor organizations are operating under multiple constraints and that COVID-19 has impacted us all, GCTA recommends that donor organizations consider the following in their grant making:

1. Develop funding mechanisms that have the ability to provide **multiple-year human rights and advocacy grants** for civil society and community-based organizations. Human rights advocacy is a long-term endeavor that requires continual commitment and sustained financial investments beyond one-year funding cycles.
2. Provide community-based organizations with **core funding rather than project-based or person-count funding**. TB community organizations needs to have the ability to pay their staff sufficient salaries that allow them to concentrate on delivering quality work. Core funding including staff salaries, benefits incl. health care, office rent and peripherals are indispensable for TB rights work.
3. Provide **funding for networks and individual organizations** at the same time. A network is only as strong as its ability to work with strong member organizations. Coalition-building is an important part of human rights advocacy.

4. Provide additional **funding for community-building, e.g., TB Safe Spaces** that allow TB rights organizations to build a strong connection with their community, enable regular touchpoints and interaction for organizing and knowledge-building.
5. Increase **cross-sector funding to enable long-term** collaborations between different sectors, types of organizations, and networks, including for collaboration between TB and HIV/AIDS, but also other community organizations working on human rights.
6. More detailed **earmarking of community funding** in national or regional government grants.
7. **Include communities in priority-setting** for TB services and human rights funding strategies. TB communities and their organizations have detailed knowledge of areas that lack funding and that need to be prioritized.

To National Governments, Parliamentarians, and Policymakers

With the understanding that we will only reach our goal of a TB-free world if we collaborate effectively and build on each other's strengths, GCTA recommends that national governments and policy makers:

1. Develop **a clear definition and attached action plan for meaningful engagement** of the TB community and their organizations. This is of particular urgency in unsupportive political environments with limited community engagement.
2. Develop in partnership with the TB community a **National CRG strategy and action plan with attached monitoring tools** and funding for effective monitoring of the action plan.
3. Ensure that **staff working on TB in all regions of the country have effective training on TB rights as well as the latest treatment and diagnostic guidelines**. This should include parliamentarians, policymakers, and National TB Program staff.
4. Make **human rights training mandatory for health-related policymakers and healthcare workers.**

To the TB Community and TB Community Organizations

With the understanding that we all operate with daily constraints on our time and resource, and knowing that we are all working towards the same goal of a world in which human rights of people affected by TB are universally protected, GCTA recommends that:

1. We continue to **build and support strong TB community networks** on the national, regional, cross-regional, and global levels.
2. TB organizations through their networks **coordinate on advocacy and activities** including sharing of annual plans, consultation in strategic planning, and coordination of timelines to the extent possible.
3. TB organizations **Identify key officials and policymakers** to work with on the national level.
4. Advocate with donor organizations and national entities for **more sustainable funding for TB community organizations**.

B. Introduction: South to South Learning and Knowledge Exchange

Progression of TB and Human Rights

Unlike the well-documented activism of the HIV/AIDS communities that continues to influence the global AIDS movement, people affected by TB and their human rights have not been central to the global TB response. That has changed significantly over the past few years. For the GCTA, their tuberculosis (TB), stigma, and human rights journey began in 2016. At that time, GCTA conducted a series of workshops with communities affected by TB in Latin America, North America, in francophone and anglophone Africa, Eastern Europe and Central Asia, and the Asia-Pacific. These workshops focused on the cascade of TB care, including basic TB literacy such as understanding symptoms and the process of moving from testing to diagnosis through successfully completing treatment. During each training, attendees were asked to identify barriers within this process. Overwhelmingly, they identified stigma and discrimination as a main hinderances to accessing care, as well as lack of information and lack of counselling. Other barriers, including for example access to medicines, were listed but given a lower priority. GCTA began documenting experiences of how and when communities affected by TB encountered stigma and discrimination. In 2018, GCTA published the first resulting booklet

titled "Women and Stigma – Conversations of Resilience in the War against TB,"[1] followed by one publication focused on children,[2] and one publication focused on men.[3]

Around the same time, other professionals, organizations working on TB, and TB activists around the world also began integrating human rights analysis into their TB work. Several notable efforts emerged, with only a selection mentioned here:

- The Nairobi Strategy on Tuberculosis and Human Rights,[4] a multi-year, multi-disciplinary initiative;
- The policy brief "Activating a Human Rights-based Tuberculosis Response. A Technical Brief for Policymakers and Program Implementers"[5] by GCTA, the Stop TB Partnership, and the Northwestern Pritzker School of Law International Human Rights Center; based on requests by community and lawyers at the first lawyers and communities' joint workshop in 2019; soon available in 10 languages;
- and a re-conceptualization of the Patients' Charter for Tuberculosis Care[6] as the community and human rights centering "Declaration of the Rights of People Affected by Tuberculosis."[7]

This continuously growing body of work was in part catalysed by the eventual focus that international organizations gave to the human rights dimensions of TB, for example the Stop TB Partnership with their "Global Plan to End TB: The Paradigm Shift 2016-2020" strategy that for the first time centred a human rights-based and gender-sensitive global TB response.[8]

a. Stigma, Discrimination, and Human Rights in the Context of TB

Knowing that donor priorities would in large part govern what work they would be able to implement, community organizations working on TB focused a large amount of advocacy towards the first UNHLM in 2018. The resulting Political Declaration of the UN High-Level Meeting[9] mentions a number of activists' main demands around building community-centred programs that adhere to human rights standards; increasing access to prevention, diagnostics and treatment that is affordable for all without discrimination;

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[1] GCTA. Women and Stigma. Conversations of Resilience in the War against TB. 4 June 2018. http://gctacommunity.org/?page_id=7293&v=7d31e0da1ab9

[2] GCTA. Childhood TB and Stigma. Conversations of Resilience in the War against TB. 24 October 2018. http://gctacommunity.org/?page_id=6611&v=7d31e0da1ab9

[3] GCTA. Men and Stigma. Conversations of Resilience in the War against TB. 31 October 2019. http://gctacommunity.org/?page_id=7258&v=7d31e0da1ab9

[4] Kelin Kenya, Northwestern Pritzker School of Law Bluhm Legal Clinic, and Stop TB Partnership. Nairobi Strategy on Tuberculosis and Human Rights: a Human Rights-based Response to TB. September 2018 https://www.kelinkenya.org/wp-content/uploads/2019/03/Nairobi-Strategy-on-TB-and-Human-Rights-Brief.pdf

[5] Brian Citro. Activating a Human Rights-based Tuberculosis Response. A Technical Brief for Policymakers and Program Implementers. GCTA, Stop TB Partnership, Northwestern Pritzker School of Law Center for International Human Rights. July 2020. http://gctacommunity.org/?page_id=7493&v=7d31e0da1ab9

[6] https://www.who.int/tb/publications/2006/patients_charter.pdf

[7] https://www.tbpeople.org.uk/declaration

[8] https://www.tbonline.info/posts/2015/11/24/global-plan-end-tb-2016-2020/#

[9] https://www.who.int/publications/m/item/political-declaration-of-the-un-general-assembly-high-level-meeting-on-the-fight-against-tuberculosis

and increased financing of the TB response, to name just a few. Another sign of successful community advocacy was the 2021 report by the UN Secretary General outlining how to achieve progress towards the UNHLM targets, which as part of its *10 Priority Recommendations* lists as number six "Promote human rights and combat stigma and discrimination"; and as number seven "Ensure meaningful engagement by civil society, communities, and people affected by TB."[10]

> *"It is like a cycle. You collect the evidence; you bring up data at the highest level. You ensure that global advocacy is strong so that there is policy change, and then you bring it back to the country level for it to start rolling."*
> *– Blessina Kumar, CEO, GCTA, talking about the community's advocacy efforts at the global consultation*

Therefore, GCTA and partners in India, Indonesia, Cameroon, and Peru have been focusing on fostering alliances between the legal profession and community activists to discuss how each country can work towards stronger legal requirements for TB rights. The aim of this coalition-building is to integrate existing recommendations around TB stigma and discrimination into National Strategic Plans as well as national legislation. Similar projects are being undertaken in Guatemala and Pakistan. Communities have been very clear, that if the goal is to reduce the numbers of people who get infected with TB, and to reduce the number of TB-related deaths, stigma and discrimination need to be addressed. We will only end TB by upholding the rights of individual persons.

Motivation

The motivation for the South-to-South Learning and Knowledge Exchange project was to take stock of the diverse work that TB organizations across the world have been conducting in the context of CRG, with a specific focus on stigma and discrimination. In 2021, the World Health Organization (WHO) Global Tuberculosis Report conceded that for the first time in a decade, TB-related deaths are rising. The number of people diagnosed with TB and reported has declined significantly under the impact of the COVID-19 pandemic, for the first time in over a decade. Overall, the report shows that countries are nowhere near to reaching the global TB targets.[11] Keeping in mind preparation for the UN High Level Meeting on TB (UNHLM) in 2022, the original intention of the South-to-South project had been to collect and share best-practices around stigma reduction and anti-discrimination advocacy as experienced by TB communities across the regions. However, with the negative impact of the COVID-19 pandemic as a backdrop, the focus expanded slightly to include challenges, barriers, and needs alongside progress towards a human rights-based and people-centred TB response, thereby considering a more holistic approach to human rights and TB. A connected benefit of this approach was the ability of TB activists to communally document

[10] https://www.who.int/news/item/21-10-2020-un-secretary-general-outlines-priority-recommendations-to-accelerate-the-tb-response-and-reach-targets
[11] Global tuberculosis report 2021. Geneva: World Health Organization; 2021. License: CC BY-NC-SA 3.0 IGO

approaches that have worked well in one or more regions, and which could be appropriate for other geographic contexts as well. Ultimately, GCTA's starting point was the need for TB communities to safeguard the progress that they have made together and to collect recommendations and priorities for the challenges that continue to exist in the global TB response.

Methods

The data for this report derives from three main components. The first part of the research was comprised of desk study of existing reports on stigma, discrimination, and human rights in the context of TB, published by GCTA and other civil society organizations. The second component were six informational interviews with focal points of regional TB networks, researchers, and consultants. The third and largest source of qualitative data underlying this report was collected during online group consultations with TB activists and community organizations. Over the course of October and November, GCTA and Matahari planned and conducted the following virtual consultations to collect initial data from across the world:

- One regional consultation for Latin America and Caribbean region;
- One regional consultation for Eastern Europe and Central Asia;
- One regional consultation for Asia-Pacific;
- One regional consultation for Africa;
- One national consultation for India.

The LAC consultation had 15 participants from Brazil, Perú, Dominican Republic, Chile, Haiti, Guatemala. The EECA consultation had five participants from Ukraine, Moldova, Russia, and Kyrgyzstan. The Asia-Pacific consultation had 18 participants from Indonesia, Cambodia, Myanmar, Papua New Guinea, Thailand, Pakistan, India, and Timor-Leste. The Africa regional consultation had 18 participants from Kenya, Cameroon, Nigeria; the India consultation had 14 participants from 8 organizations as well as TB Champions.

Based on these consultations, initial findings were collated, and potential recommendations were drafted. The findings and recommendations were presented in two global consultations, both with the same agenda, to maximize participation across the different time zones. These two global consultations included speakers from the Global Fund CRG department to inform about the direction of the CRG program; GCTA on advances towards a human rights-based TB response; regional TB networks shared about regional priorities; and Brian Citro, who presented on a high-level analysis of 20 CRG country reports under Stop TB Partnership grants. The recommendations were also shared with all regional networks in writing after the global consultations for input into their refinement. This report considered verbal interventions as well as written contributions shared via the chat function of Zoom from all virtual consultations.

C. Findings

TB and Human Rights Issues

a. Stigma and Discrimination

All regional and the national consultations began by prioritizing the human rights issues of concern in relation to TB. Across the consultations it became very clear that stigma and discrimination remained pervasive. People affected by TB continue to experience stigma and discrimination in healthcare settings, in their communities, and in their workplaces. Often, participants linked stigma to lack of knowledge of everyone involved in encounters. At the same time, several comments were made with regards to continued challenges of gathering information and providing evidence of stigma and discrimination. Even though the effect of stigma and discrimination on a successful TB response has been well-established, community organizations struggle with the need to produce evidence and may not have enough data on stigmatization and TB, as brought up by participants from Moldova. In fact, one participant pointed out that stigma against people affected by TB is an issue in all post-soviet countries, and yet each country's community needs to document its own data, losing potentially valuable time that could be spent on stigma reducing activities. Participants mainly referenced the negative attitudes of healthcare workers and clinic managers as source of stigma and discrimination, combined with structural limitations of the healthcare system. While reforms of the healthcare system in e.g., Ukraine have started in 2018, including a reform of TB services, community research has found that medical workers often are not interested in providing quality services to people they perceive as problem, i.e., people

affected by TB. Interestingly, they found that there appear to be lower levels of stigmatization at the primary care level versus specialized services. Community organizations in Eastern Europe have found it easier to work with young medical workers, who overall appear more open to a change in their approach.

> *"Stigma is a common human rights issue as well, but TB services itself make up the bulk of reports." – Pauline, Asia Pacific regional consultation.*

> *"I represent key populations in Kisumu, Kenya. Gay, bisexual, transgender and men who have sex with me cannot access services freely, due to discrimination against them. The community is still not accepted in the country. Stigma is high in healthcare facilities and in the public sector." – Tobias Ouma, Africa regional consultation.*

b. Healthcare, Treatment, Diagnostics

A second theme of concern evolved around the nexus of national healthcare systems, TB treatment and TB diagnostics. In several instances, participants expressed serious concern about the continued unavailability or severely limited availability of safe, short oral regiments rather than the injectable regimens which have long been recognized for their serious side effects. Injectable regimes have been

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documented over and over to be the cause of side effects such as blindness, deafness. No person should have to accept such side effects when better treatment is available. Similarly challenging in some regions is the availability of quality diagnostics that allow results to be communicated back to people affected by TB quickly. One reason for the continued shortcoming on availability, mentioned by a participant from Kyrgyzstan but reflected as applicable for other countries as well, are challenges with registration of treatments and diagnostics on a national level. Challenges to registration are both internal, as well as external.

As expressed in the regional consultations, the biggest challenge in Kyrgyzstan is access to services, especially to innovative approaches and to diagnostics in TB. There is currently no general access to six-month treatments, only 20-month treatments are available. While the US Food and Drug Administration approved Pretomanid in 2019, the WHO has not yet included it in its treatment recommendations, meaning that many countries are not yet following suit with drug approval. In some instances, however, limited access can be possible as part of operational research. Similarly, while Kyrgyzstan allows the use of Bedaquiline and Delamanid under its Global Fund grant, the drugs have not yet been registered by the national administration. It is not clear how much longer the approval process may take. Barriers are observed mostly as bureaucratic obstacles

within the department responsible for registration. For example, registration for Pretomanid for children in Kyrgyzstan would require clinical trials first. The procurement challenges in Ukraine are similar to those in Kyrgyzstan. The National TB Program still cannot procure Pretomanid, despite their work with the manufacturer, who applied for registration over a year ago. Government structures were also understood to be the main challenge to a quicker approval process.

> *"QuantiFERON is not available. It needs to be written into standards & guidances. We are still using the tuberculin test, [we are] not yet using TSpot & other diagnostics. They need to be integrated into the healthcare system. Only approximately 50% of people in need get access to short regimens."* - *Bakyt Myrzaliev, Eastern Europe and Central Asia regional consultation.*

Another reason for challenges with registration is the lack of updated guidelines. Participants from Perú described that while Perú has made some progress with MDR-TB, it remains the country with the highest MDR-TB rates in the continent. And while in 2014, with much effort from local TB organizations and community groups, the Law for TB Control and Prevention (Law 302) was enacted to set out rights of and

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responsibilities towards TB communities, there remain obstacles and challenges. The last guidelines had been issued in 2013 and have previously been criticized for not sufficiently providing for TB services addressed at indigenous populations as well as migrants.[12] So while newer legislation exists, treatment guidelines have not been updated to reflect the law's requirements. As a result, people affected by MDR-TB in Perú have no access to all-oral regimens for MDR-TB during a time when COVID-19 continues to negatively impact the TB response. As described by participants from Brazil, the TB epidemic in Brazil exists at the convergence of poor political leadership, slow adoption of guidelines, scarce resources for TB services, poverty, culturally inappropriate communications on TB for migrant groups, and social stigma towards people in extreme poverty, people deprived of liberty, homeless people, and PLHIV. Participants pointed out how the emergence of new technologies could have been a real boon to people with TB in Brazil, but adoption of new guidelines on these new technologies have been extremely slow. In addition, the TB response in Brazil has been gradually defunded over the years, causing a 'great dismantling' of tuberculosis services in all regions in Brazil.

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[12] Gianella-Malca C, Ugarte Gil C, Caro G, Aylas R, Castro C, Lema C, in Vulnerable Populations TB. The case of an indigenous Community in the Peruvian Amazon. Health and Human Rights J. 2016;18.

TB is also exacerbated by a fragmented health system, with different sectors being responsible for health – for example in Perú, the Ministry of Labour is designated to provide for those who have formal employment, whereas the Prisons Ministry and the National Penitentiary Institute, who are responsible for TB services in prison, are overseen by the Ministry of Justice, which has a limited budget to diagnose and treat TB. This situation is compounded by numerous structural challenges that prevent an optimal response to TB. While civil society organizations such as Socios en Salud can provide additional support in some of these areas, structural challenges around human rights and discrimination, and financial resources cannot be solved, nor should they be fully mitigated, by civil society.

For some populations, availability of treatment is even more dire than for others. In particular, participants pointed to serious concerns with regards to TB treatment availability for children, as well as access to diagnostics and treatment for migrants and indigenous populations. In many cases, these are situations where an individual might not have the resources to access health centres on their own. In Guatemala, 8,900 migrants from Honduras and El Salvador arrive in or pass through the country every year, without any health services or measures being provided for them. Together with the challenges of cultural competence barriers as well as language barriers, migrants affected by TB are not well cared for, even when they may be able to access health services. Participants highlighted the importance of investing in culturally appropriate communications and messaging about human rights, targeted at the health personnel of all the different countries involved.[13]

Participants from Guatemala and Haiti also spoke of the immense challenge of providing TB care for incarcerated people. Treating TB in carceral settings means treating TB in an extremely challenging environment i.e., an overcrowded prison, often compounded by prolonged pre-trial detention. When those incarcerated also come from poorer segments of the populations, participants feel strongly that TB treatment needs to be viewed holistically. Persons with tuberculosis in prisons often have comorbidities and thus require not just the TB drugs, but proper nutrition and medications for coinfections.[14]

c. COVID-19

For Perú, participants mentioned that notified cases had fallen significantly, with 32,000 cases recorded annually before COVID-19, but only 24,000 TB cases recorded in 2020.[15] Similar reductions in case finding were recounted by participants from other countries, e.g., the Dominican Republic, where COVID-19 has resulted in limitations to the TB program being able to respond effectively. As a result of COVID-19 there has been a decrease of TB notifications from 4,800 cases a year to only 2,600 cases notified.[16] In addition, COVID-19 has negatively impacted contact tracing for TB, which has fallen by the wayside with health staff predominantly focusing on COVID-19 contact tracing. The COVID-19 pandemic has meant that staff normally working on TB are working on COVID-

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[13] Luis Sánchez, Guatemala

[14] Rolandy Edouard, Haiti

[15] Leonid Lecca, Socios En Salud

[16] William Duke, Dean of Medicine, Dominican Republic

19, and that the multiplicity of roles was compromising gains made in TB overall, and not just contact tracing alone.[17]

d. Medicalized Approach vs. Community-centred

Participants from Chile and India brought to our attention that the country continues to espouse a medicalised approach to TB, i.e., an TB response that focuses on clinical actions, administering treatment, and managing TB programs, but failing to espouse a dedication to community work and structural challenges in TB. Participants from the Asia Pacific regional consultation also commented on the paternalistic view of treatment via Directly Observed Treatment (DOTs) that negatively affects the ability of people on treatment to work, participate in formal education, as well as everyday life. Implementation of a community-centred approach to treatment would reduce the burden on those seeking care, including transportation to hospitals and clinics. Pre-enrolment in hospitals would also lessen the burden on people affected by TB by reducing the amount of time they need to spend in hospital administrative procedures for each time they seek care. Comments in the India national consultation pointed out that in this context, it is important to see positive behaviour

Africa Regional Consultation

on how not to stigmatize. Our focus should not exclusively be on pointing out violations, but in addition also lift examples of what to do instead.
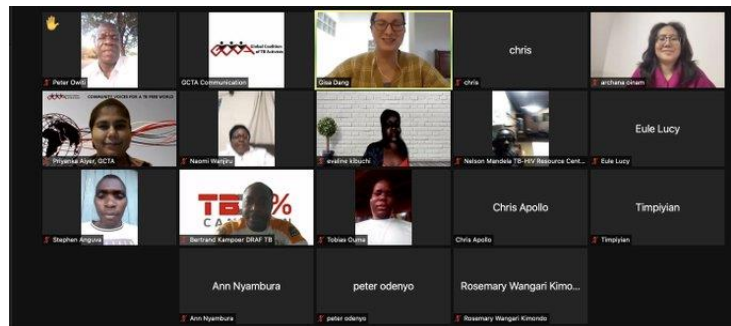
> *"The issue is access to quality healthcare. At some clinics, whether you go to pick up medication or appointment, it takes an average of eight hours to get service. Because the clinicians have gone to a meeting, or are somewhere else, and the nurse is not there. Sometimes, people have to go back home without the drugs or the diagnostics they require. This adds to out-of-pocket expenses if they have to come back. This affects the quality of care. This is a violation that is very challenging to address. You try to be as diplomatic as possible so that you don't look like you are harassing government service providers. We raise issues on the side, not [always] through official complaints." – Peter Owiti, Africa regional consultation.*

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[17] Olivia Horna-Campos, Chile

e. Government Relations

Many participants emphasised that political leadership was a crucial factor negatively affecting access to services for TB communities. One participant made the following statement:

> *"We cannot confront tuberculosis with the current government. We cannot confront tuberculosis with a government who is uncommitted to the fight against social inequalities, to the fight against structural racism, sexism, misogyny and homophobia." – LAC regional consultation.*

Other participants spoke of similar sentiments of lagging implementation of new policies, non-commitment to structural change, and in some cases outright hostility towards civil society were voiced from all regions. In some countries, operating a community organization is a challenge in itself. As has been widely documented elsewhere, governments often restrict citizens' freedoms of assembly and association, i.e., their ability to come together, to organize, and to form sustainable organizations. While a

LAC Regional Consultation

human rights infringement in itself, non-support of civil society and community organizations runs counter to the important TB strategy of meaningful engagement of communities, by inadvertently restricting a community's right to participation in policy making.
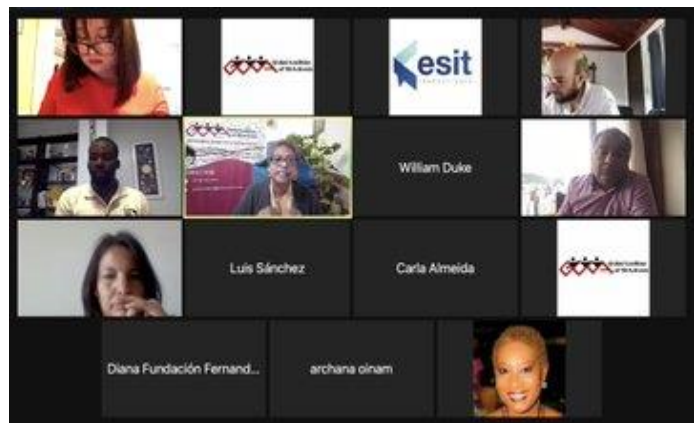
Progress

Despite the multitude of challenges, some of which are laid out above, and despite the fact that CRG approaches to TB remain relatively young, participants from all regions had positive examples of progress to share throughout the consultations.

a. Legal Approaches

Many participants commented positively on the developments around legal approaches. Especially participants from Eastern Europe and Central Asia, as well as from the African continent, have made progress towards protecting the human rights of people affected by TB by collaborating with legal professionals. Communities commented that their ability to utilize a legal road came from very targeted collaborations with lawyers, judges, or legal rights organizations. Training programs and publications specifically for the legal professions, supported by international donors and conducted in collaboration with GCTA and other civil society organizations, have made legal aid available to some communities affected by TB. Collaborations in e.g., Kenya have shown that it is critical to engage lawyers and TB advocates together to conduct

legal aid clinics. Generally, these approaches have been viewed as very positive and impactful. Activists would like to expand legal approaches, making legal aid much more widely available, e.g., through training TB Champions as paralegals to provide support at the community level.

> *"It's critical to engage lawyers and advocates to conduct legal aid clinics. Through KELIN resources, Stop TB Partnership and Amref, close to 100 lawyers have been trained and sensitized on TB and human rights. Whenever we have reports [of rights violations] from our community, we can link them up. The challenge is that resources are limited, that is the biggest gap. However, moving forward having resources for filing cases and following up on cases is important, because cases can take a long period, two years or even five years. But with more resources, we can carry them through and highlight them." - Stephen Anguva Shikoli, Africa regional consultation.*

In Ukraine, community activists have been heavily involved in crafting a TB law, which includes specific human rights protections for people affected by TB. Activists saw this as a clear victory for the TB community. They were particularly proud about the fact that the law is phrased in non-stigmatizing language. For example, the text of the law does not use the words "patient" or "case", but instead uses very tolerant terminology such as "people with TB".

b. Information and Human Rights Education

One reason participants gave for why legal approaches have become a possible mode of advocacy is the fact that they have gained abilities to documents human rights abuses. Compared to just five years ago, more monitoring and documentation tools and guidance on how to utilize these tools are available now. These include, for example, the GCTA *Rights based TB Response-Technical Brief for Policymakers and Program Implementers*, APCASO's *Right to Breathe*, the Stop TB Partnership's *One Impact* tool, Community Treatment Observatories (CTO) as well as the Stigma Index. With these tools, those organizations that have had the opportunity and ability to use them say they have been able to gather data more coherently, more easily, as well as use these tools to conduct community workshops.

> *"When you go and educate communities, you need to leave them with informational material. Some people like reading. It is not just about what you give them, but what they remain with. Not just what you tell them, but what they refresh. A small material, a pamphlet." – Africa regional consultation.*

These tools appear to go hand-in-hand with the TB community's efforts to train their community in human rights, both TB-specific as well as general human rights knowledge.

One TB Champion in the Asia Pacific consultation pointed towards increased knowledge and self-advocacy among patients, self-assessed after training sessions. They have found that the following components need to be in place to make TB and human rights trainings for communities successful: (1) Teaching in small groups, (2) the use of short videos, (3) easily relatable and applicable human rights examples, and (4) frequent follow up post-workshop via phone call and SMS. This experience underscores that it is not enough to only provide access to knowledge, but to also provide that knowledge in a manner appropriate to the respective audience and provide individualized follow up support. In some areas in the Asia Pacific, TV has proven to be an important vehicle for sharing information on TB, stigma, and discrimination.

> *"We understand that in a country like Pakistan, with a huge population, with four big provinces, these trainings [on TB stigma] are definitely very effective. At the same time, working with GCTA we have started thinking strategically and are using electronic and print media to bring human rights activists, TB survivors together along with the programs in all four provinces, so that the human rights message goes in parallel with these trainings. We are using all media. We have now planned six TV talks before end of December where we are bringing TB survivors, rights activists, and celebrities together to talk about the human rights aspects of TB. "– Dopasi Foundation, AP regional consultation.*

c. Government Relations

TB communities across the consultations reported that successful collaboration with national governments and their different departments requires a lot of local knowledge and thought. Despite the significant challenges outlined above, some organizations were able to report progress based on their approaches to building government relations and advocacy. An organization in Indonesia recounted their experience working with a local government entity to increase government hiring of TB peer educators from three to 15 over the course of five years. They said that in their eyes, this was a significant development as it showed a shift in government attitude. Activists from Papua New Guinea successfully completed a pilot project on peer counselling, i.e., counselling by people affected by TB for TB survivors and caregivers, which resulted in their National TB Program requesting them to document their experience and develop a new protocol for education, counselling, and support options for people affected by TB.

In India, GCTA together with a coalition of TB community organizations and civil society representatives, worked closely with the National TB Program to develop the National Strategy to End TB Stigma and Discrimination. Activists noted that in their experience, collaborative approach and building the confidence of NTP with support has been important to developing the basis for this successful government-civil society collaboration.

India Consultation

In some countries, staying in close contact with government agencies is required for conducting any kind of publicly visible work. In Eastern Europe and Central Asia, TB organizations routinely share their plans for the year with their government counterparts. For specific events, they may also be required to seek permission, sometimes in the form of guidance, before a program or event can take place. While this can be a barrier to TB rights work, in some instances this is also one component of building mutual trust and eventually collaboration. Without this careful approach to TB rights work, community activists may jeopardize their ability to conduct human rights advocacy.

"A challenge we have in francophone Africa is language. The first step was to translate the [GCTA] books into French. We shared the documents with our partners in West and Central Africa. And what we realized is, the information, the knowledge can change the situation. Actually, human rights, stigma, everyone knows the words. But the actual content, the rights, our people in the TB community do not know. We started to realize that with the empowerment of people affected by TB in the region [they] started to organize conversations with their National TB Programs on human rights and how to include human rights in the National TB Strategic Plan. This has now become reality in some countries in the region." – Bertrand Kampoer, Africa regional consultation.

d. Coalition-building

Many participants in the consultations listed collaboration and strategic coalition-building as an important component of any progress on TB rights, stigma, and discrimination. In particular, participants commented positively on the significance of cross-sector collaborations. These include working with legal professionals as outlined above, but also working with other community organizations, including for example those of people living with HIV/AIDS, sex workers, workers' rights, former prisoners, drug users etc. Besides collaborating across sectors, collaborations both on the national level and on regional levels are seen as highly important. As quoted in the introduction, advocacy can be described as a cyclical approach where national and international levels both play an important role in creating positive change.

> *"Our program is made up of several NGOs partnering with government and our relationships with them are essential for improving TB care and presenting a united front in advocacy." - Tess Keam and Allan Kuma, AP regional consultation.*

Another form of collaboration is the network of TB Champions. Whether TB Champions are loosely cooperating or organizing more closely, the kinship and camaraderie TB Champions have seemed to be an important motivating factor; as well as their ability to act as resources for each other, for the TB community and for TB organizations.

> *"We have been able to address the human rights issues of access to information, in particular correct information about treatment. We have been able to address issues that our community brought to our platform through our network of TB Champions." - Stephen Anguva Shikoli, Africa regional consultation.*

Challenges and Needs

While undoubtedly TB communities and their organizations have made progress towards protecting the rights of people affected by TB, all of this progress is paired with both old and new challenges. During the consultations, we asked participants to share specific challenges, both those that they had overcome as well as those that remained. We also asked them to think about what work they think is necessary for them to do, but that they cannot currently do, and explain the reasons why this work appears unattainable. This set of questions was used to guide participants into a discussion of needs, both on the community as well as the organizational level, for gaining more positive impact on TB rights.

> *"When it comes to what we want to do but cannot, we want to do human rights work. But the reality is that most of the funders that are available out there are focused on immediate results without really looking at the broader architecture of what human rights for TB should be, and what should be the outcomes, and how can we sustain funding throughout, up until we reach our goals. That really presents a huge difficulty for us. Once we train TB affected communities, it just ends there. We cannot even commit the funding to that what comes afterwards. We have to look for additional sources of funds to continue the work, which is always very difficult when we work on human rights & health." – Asia Pacific regional consultation.*

a. Funding

As is so often the case for community-based organizations, funding was a concern on everyone's mind. For the community of TB activists that participated in these consultations, funding for TB community organizations remains highly donor-driven, i.e., they voiced that they often shape their programs and proposal towards what stream of funding is available, rather than having the ability to fundraise successfully based on their community's priorities. This is challenging because at the same time, only a limited set of funding streams for CRG work are currently available. Many participants commented on the fact that national funding for TB community organizations to work on human rights, or CRG, remains a rarity. Especially networks and national organizations rely on international funding sources. Globally, there is a limited number of donor organizations that give specifically to TB and human rights.

"We have the landmark case of addressing the punitive healthcare laws. One of the lessons learned is the importance of working as a team, the importance of having the community together, the importance of working together with legal minds at the country-level. And having the resources. If KELIN Kenya did not have the resources to take this to court, we would not have succeeded. So, there should always be reserves in terms of resources, for legal pursuits." – Evaline Kibuchi, Africa regional consultation.

For example, in the case of Latin America and the Caribbean, participants commented on the significant number of migrants, including children, who have difficulty accessing TB services, or any health services. They said this was an area worth funding that remains overlooked. Participants from the same region emphasized that there was a large need to fund the work of TB communities to centre the needs of TB-affected communities more holistically.

"Here in Port-au-Prince where we work, the prisons are overcrowded, that is to say, a prison that was meant for a thousand people has four thousand prisoners. And a lot of people with tuberculosis in prisons come from the slums and have secondary illnesses or comorbidities, so what's needed isn't just the TB drugs, but nutrition and access to drugs for their comorbidities. We really need help on this." - Rolandy Edouard, LAC Consultation.

Another challenge at the intersection of funding and human rights are the timeframes within which TB community organizations are forced to operate. Grants to community organizations often follow limited timeframes but expect tangible advocacy results within that timeframe. Participants felt that the expectations placed on them for advocacy outcomes were often unrealistic to be achieved within the confines of short-term grants, e.g., one-year grants. Another point of contention was the sometimes-differing opinions between donors and TB community organizations on what constitutes advocacy and

how advocacy should be conducted. This is in particular challenging for organizations operating in non-supportive political systems, or in political systems without a lot of administrative stability. For example, in Eastern Europe, participants commented on the fact that much of their advocacy works with individuals within specific ministries, e.g., the Ministry of Health or Ministry of Social Security. Much of the advocacy work that they do with these individuals is based on relationship building. As soon as the political environment changes or a minister change, personnel within ministries can also change, forcing them to begin anew. Much of this type of advocacy cannot happen publicly and is therefore not visible for donors.

> *"There is always an expectation that when civil society are being funded that it immediately translates into results. And with the political economy that we have, that is not the case for human rights. We cannot expect that we build the capacity of TB affected populations of what their human rights are, that suddenly there will be a spike in human rights violation reporting. Or that these kinds of learnings on human rights immediately translate into legal changes. Not to say that legal changes can take years, if not decades, to pass." – Jeffry Acaba, AP regional consultation.*

b. Documentation and Advocacy

While many participants felt that there has been significant progress towards documentation and advocacy for the protection of TB rights, they pointed to significant remaining challenges. Understanding what constitutes a human rights violation and the reporting it are only the first two steps. A reported violation does not equal action nor recourse. Legal strategies hold much promise but take a significant amount of time to conclude and are resource intensive. TB activists, however, see increased resources for this strategy as highly important. Resources for training and maintaining community paralegals was one idea mentioned in this context.

Participants also saw a lot of promise in the increased availability of tools for documenting and understanding human rights violations in the context of TB, that have been developed over the last few years. At the same time, a challenge with many of these tools is that they require specialized training for community organizations to implement these tools. That funding and knowledge is not yet widely available.

> *"The community-led monitoring aspect is a really good opening for us how we quantify and operationalize stigma and discrimination, that is understandable at least in the context of service delivery. But this kind of work should not just stop in monitoring and reporting what individual violations are. At the end of the day, it has to be contextualized to address human rights and dignity of people with Tuberculosis." – Jeffry Acaba, AP regional consultation.*

As mentioned above, advocacy occasionally requires working quietly within government institutions rather than being vocal publicly. Advocacy also needs to have the ability to be responsive to changing or evolving situations. In some countries, using human rights language is not possible. Instead, organizations chose language that reflects values but eschews normative human rights terminology. Participants from India, for example, overall prefer the term of dignity over human rights terminology.

> *"As of now, very few have actually used our CLM platform to report human rights violations, stigma, or discrimination. Some have emphasized the notion that even when these violations are reported, government won't act on them. Hence, people feel that reporting these issues are futile. The Philippines lacks a clear protocol on how to cascade data from the ground up and steps on how to address these issues using a whole-of-system/society approach. We believe a policy or guidance on how various partners and agencies can integrate and work together would definitely move this forward." - Reiner Tamayo, AP regional consultation.*

Another challenge for advocacy especially in the realm of access to services, is the need to work on multiple levels of governance and with multiple agencies at the same time. In the example of the need for updated treatment guidelines, advocacy is necessary on the WHO level, as well as with member states to influence the WHO. Advocacy also needs to happen with National TB Programs, regional entities including regulatory and financial bodies, as well as fund seeking mechanisms. In countries with a limited number of TB rights-focused organizations, this is an incredibly large undertaking, especially because many organizations bridge both advocacy and service provision.

> *"When it comes to human rights, based on our experience, we need to work alongside the National TB Program, for example to do gender assessment and key population assessment. These two documents are part of CRG and very important. They have been used by the National TB Program. The way that we work, we build from those assessments and provide our inputs into the National Strategic Plan for 2021-2030." - Choub Sok Chamreun, AP regional consultation.*

c. Meaningful Engagement, Government and Policymakers

Closely entwined with challenges around funding and advocacy are challenges with establishing working relationships with government and policymakers. Meaningful engagement is not a new concept. It has been promoted widely by multilateral donor agencies and international organizations. The approach is also a stalwart in the global HIV/AIDS response. Regardless, participants pointed out that meaningful engagement is not always given the same priority by National TB Programs, national governments, and

policymakers. Some even said that they felt the need to elaborate on the definition of meaningful engagement with national governmental partners, in order to have a joint understanding of what was expected. For participants, meaningful engagement meant not only being consulted for their input or being invited to a meeting. Instead, they said without participation in the actual decision-making, engagement would not be meaningful. One example of how meaningful engagement can quickly fail is tied to funding of communities. When National TB Programs or other government departments or agencies invite communities to attend meetings that require travel or other resources, without also providing the financial means for participation (e.g., travel, accommodation etc.) many community representatives have no ability to join the meeting they have been invited to.

> *"It is actually discrimination of communities to be told we cannot be supported to participate in policy processes." – Evaline Kibuchi, Africa regional consultation.*

Meaningful engagement also requires a supportive legal and political environment for civil society organizations. In many countries, that is not a given.

> *"No doubt we need to work together, but it is a tricky one. In some countries there is a challenge when the civil societies and TB affected community's agenda, and the National TB Program's agenda don't match. There is a little bit of friction, we need to work towards overcoming that, work towards making ourselves a group or entity that the National TB Program respects and cannot ignore, because we need each other. While a collaborative relationship is very important, we also need to be able to raise our voices. For example, when countries are still using harmful injectables when safe oral regimens are available." – Blessina Kumar, India national consultation.*

d. Knowledge, Communications, and Materials

Despite everything that has been done, the need for TB community organizations to provide basic TB literacy trainings, keep the community informed of new developments, and provide TB human rights education remains just as high as ever. One major concern that participants in the Africa regional consultation expressed was the fact that TB rights education happens too late. It usually happens after human rights violations have already taken place. There is an urgent need for strategies that bring human rights and TB knowledge to people before they are affected by TB, so that they have the ability to respond when something happens to them, rather than recognizing it after much time has passed.

> *"I feel we have the wrong approach. We wait for the human rights violation to happen and then we react. We are not working to prevent it from happening. That will only happen when we sensitize the community at large about human rights violations, even before they become patients. Then they already know about their human rights. Let's be proactive in addressing human rights violations." – Evaline Kibuchi, Africa regional consultation.*

Regardless, TB and human rights training approaches remain of high value. One challenge that participants pointed out is the very limited funding available for communication materials and professional communication strategies. For example, participants in the African regional consultation commented on the fact that the mere issuance of a new National Strategic Plan for TB is not sufficient. Instead, the issuance of the National Strategic Plan needs to be accompanied by a dissemination strategy that takes into account both dispersing knowledge about the content of the plan, as well as provision of different materials and modes of dissemination. One participant mentioned that often, they find themselves in the position where they have no materials to leave with participants of a workshop after the training concludes. They cannot leave any materials behind because they have no budget for printing and design.

> *"Another thing is information, education, and communication materials. These are the biggest lacking things in our country, because even currently, the TB program healthcare workers do not have access to the full national strategic plan." - Stephen Anguva Shikoli, Africa regional consultation.*

In the course of the discussion around the need for both continuing approaches that provide access to knowledge and materials in ways that are effective as well as rethinking the system by which TB rights education can be provided earlier in a person's experience with stigma and discrimination, participants brought up the idea of TB safe spaces. These spaces are part community centre that provide activities and regular opportunities for exchange among people affected by TB and the broader community. They can also provide a space of refuge for people who are shunned by their community and in search of kinship, as described above for the TB Champions. At the same time, these spaces can significantly increase the amount of interactions community organizations, TB Champions, peer educators etc. have with people affected by or at risk of TB.

> *"We need TB safe spaces." - Nelson Mandela TB-HIV Resource Centre Nyalenda, Africa regional consultation.*

D. Conclusions and Next Steps

For some seasoned activists in the TB and human rights space the experiences, challenges, progress, and general needs outlined in this report may not offer many new ideas. That does not, however, make them any less relevant. What is new is the progress that has been achieved across the world with regards to TB rights and reduction of stigma and discrimination. Participants were quite clear about where their main challenges lie and what they would need to continue towards a world in which the human rights of people with TB are respected, protected, and fulfilled. Based on these findings, TB organizations should be confident to demand that the social management of TB, i.e., strategies to reduce stigma, discrimination, and human rights violations, becomes a non-negotiable facet of TB care, with actionable principles and standards attached to any aspirational plans, thereby giving human rights equal footing with the clinical and public health aspects of TB management.

Even though COVID-19 is proving extremely harmful to the overall progression of the global TB response, participants did not dwell on COVID-19 as a major hurdle. It was but one additional challenge that they were ready to tackle.

"In terms of the biggest challenges, it is resources. Many of our colleagues are running support groups, these groups need resources to be run. When you sit and discuss for two hours, you need refreshments. When you put someone there on an empty stomach, you can't get them to engage much. But with some refreshments, you can run the conversation much better. And for networking, we have some counties that are remote. We need to support them [financially] to come for a session, with transportation for example" – TB Champion, Africa regional consultation.

So where do we go from here? Part of what needs to happen next are open dialogues between TB organizations and donor organizations on how TB community priorities and donor priorities can be further aligned. A strong partnership between donor agencies and TB activists already exists. Now, we need to work towards making the field of TB and human rights more sustainable to achieve the long-term outcomes we all envision. Communities and governments also need to continue to flesh out the ways in which they engage with each other. Considering the below

Global Consultations – 1 & 2

recommendations, stakeholders in the TB response should look inward to realign their processes with human rights priorities and identify specific action plans to address the number of challenges outlined in this report. In those countries that have already included a strategy to end stigma associated with TB into their National TP Plans, like India, the next focus should be on operationalizing and integrating the strategy into actionable and measurable advocacy, communication, and community engagement plans at the central, state, and local levels. Strategic plans are only as strong as their accountability measures.
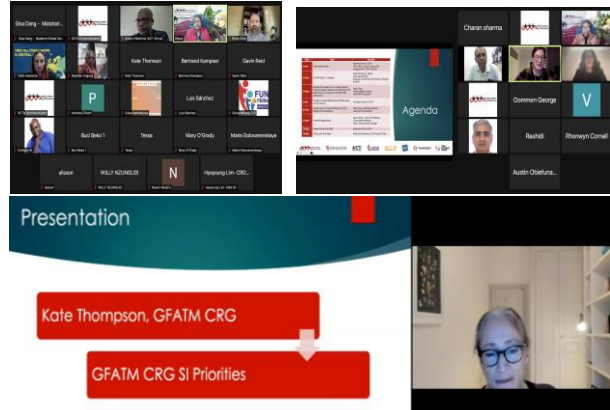
"Social management of TB needs to receive the same level of importance [as clinical management] and become non-negotiable. Once this is accepted, no donor can leave it unaddressed." – Oommen George, India national consultation.

Global Dissemination of Findings

E. Recommendations

Based on the information gathered at the four regional consultations, one national consultations, and two global consultations, GCTA and partner organizations have developed the following recommendations.

To Multilateral Funders, Bilateral Funders, and Philanthropic Donor Organizations:

With the understanding that donor organizations are operating under multiple constraints and that COVID-19 has impacted us all, GCTA recommends that donor organizations consider the following in their grant making:

1. Develop funding mechanisms that have the ability to provide **multiple-year human rights and advocacy grants** for civil society and community-based organizations. Human rights advocacy is a long-term endeavor that requires continual commitment and sustained financial investments beyond one-year funding cycles.
2. Provide community-based organizations with **core funding rather than project-based or person-count funding**. TB community organizations needs to have the ability to pay their staff sufficient salaries that allow them to concentrate on delivering quality work. Core funding including staff salaries, benefits incl. health care, office rent and peripherals are indispensable for TB rights work.
3. Provide **funding for networks and individual organizations** at the same time. A network is only as strong as its ability to work with strong member organizations. Coalition-building is an important part of human rights advocacy.
4. Provide additional **funding for community-building, e.g., TB Safe Spaces** that allow TB rights organizations to build a strong connection with their community,

enable regular touchpoints and interaction for organizing and knowledge-building.

5. Increase **cross-sector funding to enable long-term** collaborations between different sectors, types of organizations, and networks, including for collaboration between TB and HIV/AIDS, but also other community organizations working on human rights.

6. More detailed **earmarking of community funding** in national or regional government grants.

7. **Include communities in priority-setting** for TB services and human rights funding strategies. TB communities and their organizations have detailed knowledge of areas that lack funding and that need to be prioritized.

To National Governments, Parliamentarians, and Policymakers

With the understanding that we will only reach our goal of a TB-free world if we collaborate effectively and build on each other's strengths, GCTA recommends that national governments and policy makers:

1. Develop **a clear definition and attached action plan for meaningful engagement** of the TB community and their organizations. This is of particular urgency in unsupportive political environments with limited community engagement.

2. Develop in partnership with the TB community a **National CRG strategy and action plan with attached monitoring tools** and funding for effective monitoring of the action plan.

3. Ensure that **staff working on TB in all regions of the country have effective training on human rights** in the context of TB. This should include parliamentarians, policymakers, and National TB Program staff.

4. Make **human rights training mandatory for health-related policymakers and healthcare workers.**

To the TB Community and TB Community Organizations

With the understanding that we all operate with daily constraints on our time and resource, and knowing that we are all working towards the same goal of a world in which human rights of people affected by TB are universally protected, GCTA recommends that:

1. We continue to **build and support strong TB community networks** on the national, regional, cross-regional, and global levels.

2. TB organizations through their networks **coordinate on advocacy and activities** including sharing of annual plans, consultation in strategic planning, and coordination of timelines to the extent possible.

3. TB organizations **Identify key officials and policymakers** to work with on the national level.

4. Advocate with donor organizations and national entities for **more sustainable funding for TB community organizations**.