

*Engage & Empower:
Supporting People on TB
treatment to identify and
overcome barriers to accessing
TB services*

INVESTMENT PACKAGE
COMMUNITY, RIGHTS & GENDER

WORKING DOCUMENT

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About

Interventions are required to find and treat all people with TB, particularly those who currently face barriers to accessing TB services or completing TB treatment, and to support an enabling environment for overcoming the various legal, social and economic barriers that people affected by TB encounter. The UN High Level Meeting on Tuberculosis (TB) Political Declaration¹, the End TB Strategy², the Global Plan to End TB³, and the Global Fund Strategy emphasise the need to overcome barriers to accessing services and empowering TB survivors and TB affected communities by 2022, and this document provides guidance on how this can be done.

Currently, TB survivors, people on TB treatment and civil society have a limited capacity to address issues related to human rights and using legal remedies to overcome barriers to access is fairly limited. However, building this capacity is essential for ensuring that people get access to the TB services, care and support they need, that governments are held accountable for the TB commitments they have made, and for mobilising TB communities on the ground.

Community, Rights and Gender (CRG) Assessments conducted in close to 20 countries demonstrate that there are barriers faced by TB patients and people affected by TB that must be addressed in order to strengthen National TB Programmes (NTP). Similarly, many NTP reviews and monitoring missions conducted in 2019 and 2020 further confirm that these barriers are a key challenge for finding missing people affected by TB and avoiding loss to follow up. In order for progress to be made in this area, TB survivors and people on TB treatment must be sensitized to the type of TB prevention, diagnosis, treatment, care and support services they are entitled to as well as introduced to methods to remedying when their entitlements are not met. People on TB treatment and TB survivors must be empowered through information and participation.

The Nairobi Strategy on TB and Human Rights⁴, under sub-objective 1 – stream one ‘support networks of affected communities of people with TB, TB survivors and civil society’ provides insight in to how this can be done:

1. Develop and support existing networks of people affected by TB
2. Design and conduct legal trainings for affected communities and civil society
3. Empower people with TB, TB survivors and civil society to make use of judicial and quasi-judicial mechanisms to safeguard their rights
4. Develop, publish and disseminate materials for TB affected community action.

¹ Political Declaration of the high-level meeting of the General Assembly of the fight against tuberculosis [Available from: https://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/73/3]

² The End TB Strategy, World Health Organization [Available from: https://www.who.int/tb/strategy/End_TB_Strategy.pdf]

³ Global Plan to End TB, Stop TB Partnership. [Available from: http://www.stoptb.org/assets/documents/global/plan/GPR_2018-2022_Digital.pdf]

⁴ Nairobi Strategy on TB & Human Rights [Available from: http://www.stoptb.org/assets/documents/communities/Nairobi_Strategy_WEB.PDF]

Several barriers and human rights issues that people who need to access TB services, people on TB treatment, TB survivors and civil society face have been identified in country level assessments:

- **Stigma and discrimination** – self stigma, family and community stigma including the breakdown of personal relationships, stigma from and toward health service providers, stigma and discrimination in workplaces including loss of jobs, and other forms of discrimination that are in conflict with existing laws and policies and can be mitigated by interventions. Empowering people on TB treatment to understand and claim their rights and exercise their agency contributes to finding people affected by TB and reducing loss to follow up.
- **Punitive or exclusive laws and policies** – laws and policies that serve to exclude or prevent different populations from accessing the TB services they need or that enforce actions in violation of rights – require attention in order to ensure universal access. Examples that have been sited include access to services for people who use drugs, undocumented migrants or people in prisons.
- **Social inequality** – as a disease of inequality, policies and laws should facilitate access for all. Social protections and social security and support services are critical for people affected by TB.
- **Legal literacy** – there is a need to build education on the law and human rights amongst people affected by TB, TB survivors and peer supporters in order to recognize rights, recognize and report violations, and coordinate responses to legal barriers to services.
- **TB key and vulnerable populations** – people living with HIV (PLHIV), migrants, prisoners, people who use drugs, and people who work in enclosed settings all require interventions tailored to their lived experience.
- **Access** – to high quality drugs (including Isoniazid Preventive Therapy (IPT)), diagnostics (including Drug-Susceptibility Testing (DST)), and audiometry testing accompanying the ‘old’ regimen are essential in realizing the right to health, ensuring people with TB are diagnosed and not only start but complete treatment.

The first step required to address these barriers is to strengthen and ensure TB survivors, people on TB treatment and civil society have the tools and capacity to address these barriers, which will in turn strengthen their NTPs. In 2019, the Stop TB Partnership supported the regional TB advocacy network from Asia-Pacific (Activists Coalition on Tuberculosis Asia-Pacific) to develop a grass roots training module on human rights, designed to support countries in empowering and building the capacity of TB survivors, TB affected communities and civil society. The training package is called ‘The Right to Breathe: Human rights training for people affected by Tuberculosis’.

Scope

To introduce TB and human rights for those at the grassroots level, including people who are on TB treatment, TB survivors, TB affected communities, civil society and other peer supporters. The training is a step in advancing the engagement of TB affected communities and civil society in TB responses. This training should form part of broader training in TB counselling and peer support to help integrate the teachings of this training into the TB response. Also, where possible, it would be strategic to start partnerships between those who complete this training and legal service providers who can assist with addressing human rights violations or barriers that are observed and reported by TB survivors, TB affected communities and civil society.

The training should be delivered by a facilitator who understands the module and subject matter, together with a member of the TB survivor community. Additionally, relevant parts of the manual, as well as a copy of the **Declaration of the rights of people affected by TB**⁵, should be translated into local language(s). The content will cover the TB and human rights context, and provide a basic orientation on TB to ensure that a foundational level of understanding is shared by participants, including sessions focused on unpacking TB issues in the community, introducing TB and human rights, formulating community mobilization for human rights documentation, and developing advocacy skills.

The training should be delivered at the district (or possibly provincial) level in several priority locations in country. Each training should be delivered to approximately 20 people.

Objectives

To support countries in realizing the TB UNHLM commitments for a human-rights based response to TB as they make progress towards finding and treating the missing millions through:

1. Enhancing the understanding of TB affected communities of the relationship between human rights and TB
2. Building the capacity of TB affected communities to document human rights violations experienced by communities affected by tuberculosis
3. Advancing the capacity of TB affected communities to engage in advocacy that contributes to stronger national TB programmes that would overcome barriers to access and bridges gaps in their countries' response to tuberculosis
4. Partnering TB affected communities with legal service providers and partners who can advocate and seek remedies to the violation of rights experienced by people on TB treatment and TB survivors
5. Raising awareness on human rights issues facing TB affected communities and for partnerships that can facilitate remedies to these issues

⁵ Declaration of the Rights of People Affected by Tuberculosis [Available from <http://www.stoptb.org/assets/documents/communities/Declaration%20of%20the%20rights%20of%20people%20affected%20by%20TB%20-%20A5%20english%20version.pdf>]

Areas of Intervention

There are several components to this intervention:

The first component is an **exercise in community mobilization** led by local TB survivor networks and civil society organizations, in partnership with local health authorities. The aim is to identify potential peer supporters, TB survivors and people completing TB treatment to undertake the training. Each district (or province) training should be comprised of approximately 20 TB survivors, totaling approximately 100 at the country level (this number can be increased if local TB survivor networks have the capacity to coordinate a larger number). Locations for the training should be determined based on where there are significant numbers of suitable candidates representing TB survivors, people on treatment and peer supporters.

The second component is to **identify suitable trainers**, as described in the training manual and introduce them to the training manual. It is critical that the trainers have the requisite expertise and that they adequately prepare beforehand.

The third component is **arranging and delivering the training** in each of the identified locations.

The fourth component is **following up on the training** with funded advocacy efforts and communications, as well as creating systems for recording human rights violations and recording any violations that are reported. This should be coordinated by TB survivor networks, with the support of civil society organizations should it be required.

The fifth component is **identifying legal service providers** and paralegals and other stakeholders to partner with TB survivors in documenting and finding ways to resolve any recorded human rights concerns.

The sixth component is for the TB survivor network to **ensure that those who have conducted the training also receive follow up** training in peer support and counselling.

The seventh component is to **ensure ongoing engagement and coordination**, to conduct follow up trainings, debriefs and disseminating information on the human rights issues and remedies identified.

The Process

It is a 12-month process, guided by the human rights principles of universality, indivisibility and interdependence, equality, non-discrimination, accountability, and participation. The process is guided by the NTP, led by human rights experts and driven by the TB-affected community. It also requires multi-stakeholder involvement, including the legal community, to ensure that there is broad buy-in to address the human rights issues and violations that are documented and to explore the potential remedies.

Steps	Details
Month 1	
1. TB survivors, peer supporters and people undertaking TB treatment identified for training programme	<ul style="list-style-type: none"> • TB survivor network, together with local health officials, identify TB survivors, peer supporters and people undertaking TB treatment to complete the training programme. • Strategic districts with high TB burden and with high TB survivor engagement potential are identified as locations for training to be undertaken
2. TB survivor network, civil society and the NTP identify trainers to be briefed	<ul style="list-style-type: none"> • Trainers to be introduced to the training module • Trainers plan approach, timeline and role-out of the module • Arrangements to translate activities from the Module and the Declaration of the Rights of People Affected by TB into local language(s) are made.
Month 2-4	
3. Trainers and TB affected community partners schedule training	<ul style="list-style-type: none"> • Complete required logistics to ensure training can be undertaken • Rollout training in each of the selected districts • Formalise follow up advocacy and document human rights violation plans and processes • Conduct ongoing de-briefs and evaluation of the delivery of training and follow up activities
Month 5-12	
4. Identify legal partners and other stakeholders to engage in documentation of human rights violations	<ul style="list-style-type: none"> • Identify legal service providers and paralegals who can provide professional support in documenting and accessing potential remedies for any human rights violations identified. • Bring together legal partners and other stakeholders to build relevant partnerships for exploring remedies to various human rights violations that are documented.
5. Implement the plan to document human rights violations and initiate advocacy and communications plan	<ul style="list-style-type: none"> • Coordinated by a TB survivor organisation, document human rights violations, and implement communications efforts to raise the profile of human rights issues in the TB response. • Regular communication and coordination work to be undertaken by TB affected community organization. • Document and disseminate human rights violations that are identified in the course of the work as well as the remedies, or potential remedies available for community members.

Steps	Details
6. Conduct a follow up workshop & debrief	<ul style="list-style-type: none"> • Bring together leading TB survivors and peer supporters who actively engaged in documenting human rights violations and exploring potential remedies to conduct a debrief and to plan for next steps. • This workshop may be most appropriate at the national level to maximise cross learnings.
7. Peer Support & Counselling Capacity	<ul style="list-style-type: none"> • Ensure that those who have completed the human rights training continue to develop as peer counsellors.

Expected Results

The process will build the capacity and coordination of TB affected communities, engage non-traditional actors from the legal community, build data and information on human rights barriers and violations experienced by people affected by TB and identify potential remedies to address the documented violations.

This activity will be undertaken concurrently in several districts and coordinated at the country level by national TB survivor networks. Building this capacity and engagement will help to ensure that more people affected by TB are found and treated, that less people are lost to follow up, that structural barriers to access are identified and where possible remedied, and subsequently that the NTP will be supported in advancing a component of the Nairobi Strategy on TB and Human Rights as well as meeting the targets it has committed to under the political declaration of the UNHLM on TB aiming to:

- Empower TB survivors with knowledge and ownership of human rights barriers and violations
- Enhance the capacity and coordination of TB survivors in the TB response nationally and at district level
- Document real barriers and violations faced by people affected by TB which may result in loss to follow up and may impede initiatives to find and treat all missing cases to meet the national HLM targets.
- Form new partnerships between TB survivors and legal experts
- Document and disseminate barriers and violations, together with real or potential remedies

Resources Needed

(A) Item	(B) Details	(C) Unit	(D) Number of Units	(E) Unit Costs (US\$)	(F) Amount (US\$) (D) x (E)
(1) TB Survivor Network National Coordinator	Full-time compensation	Months	X	Xx	Xx
(2) TB Survivor Network National Project Officer	Part-time compensation				
(3) Trainers	Part-time compensation	Days	X	Xx	Xx
(4) Human rights training	Venue in each district (e.g., local community hall or NGO office) hire per day (trainees are local)	Days	X	Xx	Xx
	Lunch and refreshments	Person-days	X x X	Xx	Xx
	Public transportation	Person-days	X x X	Xx	Xx
(5) National Workshop for cross learnings, debrief and next steps	Venue in capital	Person-days	X	Xx	Xx
	Lunch and refreshments	Person-days	X	Xx	Xx
	Hotel / DSA	Person-days	X	Xx	Xx
	Travel from districts to capital	X	X	Xx	Xx
(6) Communication & Documentation	Design and publication	Consultancy	X	Xx	Xx
	Translation	Consultancy	X	Xx	Xx
(7) Multi-stakeholder meetings with legal partners	Venue (e.g., local community hall or NGO office) hire per day (participants return home at the end of Day 1, no hotel needed)	Days	X x X	Xx	Xx
	Lunch and refreshments	Person-days	X x X x X	Xx	Xx
	Public transportation	Person-days	X x X x X	Xx	Xx
				TOTAL	XXXX

Global Fund Support

The Global Fund to Fight AIDS, Tuberculosis and Malaria (TGF) is the most important source of external funding for TB and it is increasingly supporting Community, Rights and Gender (CRG) work related to TB prevention and care. The Stop TB Partnership strongly encourages countries to include CRG priorities in their applications (Funding Requests) to TGF. It is highly recommended that, prior to applying to TGF, countries properly reflect these priorities in the National TB Strategic Plans (NSPs).

Currently, TGF is receiving applications for the new allocation cycle 2020-2022, where the majority of grants will be implemented between 2021 and 2023. The application modalities and materials are available on <https://www.theglobalfund.org/en/funding-model/applying/materials/>

Under the TB component there is a special Module where most CRG interventions should be included (table below).

Model interventions for TGF TB Module 'Removing human rights and gender related barriers to TB services'

<i>Intervention</i>	<i>Scope and description of intervention package</i>
Stigma and discrimination reduction	Activities to reduce stigma towards people with TB: <ul style="list-style-type: none"> • Situational analysis and assessments, for example, Stop TB-CRG assessment, and TB Stigma Assessment • Media and edutainment activities on TB and stigma such as integration of non-stigmatizing language into TB communication materials, radio shows • Engagement with religious and community leaders and celebrities • Peer mobilization and support developed for and by people with TB and affected communities aimed at promoting wellbeing and human rights
Human rights, medical ethics and legal literacy	For communities affected by diseases, key populations and CSOs: <ul style="list-style-type: none"> • Peer outreach on human rights and legal literacy in the context of TB • Development of communication materials on TB patient rights • "Know-your rights" programs For (community) health care workers: <ul style="list-style-type: none"> • Medical ethics and human rights specialized TB training
Legal aid and services	Activities related to legal aid and services, including but not limited to: <ul style="list-style-type: none"> • Establishment of peer para-legal activities, for example, street lawyers, Hotlines • Legal aid, legal support through pro bono lawyers, human rights organizations to increase access to justice • Engagement with community and religious leaders for dispute resolution based on human rights and gender equity
Reform of laws and policies	It includes activities related to legal reforms including, but not limited to: <ul style="list-style-type: none"> • Engagement with parliamentarians, Ministry of Justice, Interior, Corrections, religious and community leaders, among others, for advocacy and sensitization • Training of parliamentarians on human rights and the role of protective legal frameworks in the TB response • Legal audit, legal environment assessment • Community mobilization and community-led advocacy and monitoring support • Monitoring of laws and policies, including compliance
Community mobilization and advocacy	Activities related to community mobilization and advocacy: <ul style="list-style-type: none"> • Community-led outreach campaigns to address harmful gender norms and stereotypes and other human rights-related barriers • Community-based monitoring of service delivery quality, including stigma, discrimination, confidentiality and privacy and informed consent • Patient group mobilization and building capacity/supporting community-led advocacy efforts

Examples of CRG-related indicators in TGF's Modular Framework are given below:

CRG-related indicators in the list of Core Indicators for TB components

<i>Type of indicator</i>	<i>Indicator</i>	<i>Disaggregation categories</i>
Outcome	Percentage of people diagnosed with TB who experienced self-stigma that inhibited them from seeking and accessing TB services	Gender (female, male)
Outcome	Percentage of people diagnosed with TB who report stigma in health care settings that inhibited them from seeking and accessing TB services	Gender (female, male)
Outcome	Percentage of people diagnosed with TB who report stigma in community settings that inhibited them from seeking and accessing TB services	Gender (female, male)
Coverage	Number of TB cases (all forms) notified among prisoners	
Coverage	Number of TB cases (all forms) notified among key affected populations/ high risk groups (other than prisoners)	Target / Risk population group (Migrants/ refugees/ IDPs, Other population group)
Coverage	Number of notified TB cases (all forms) contributed by non-national TB program providers – private/non-governmental facilities	
Coverage	Number of notified TB cases (all forms) contributed by non-national TB program providers – public sector	
Coverage	Number of notified TB cases (all forms) contributed by non-national TB program providers – community referrals	

The Global Fund offers a variety of resources to help applicants prepare their funding requests. Materials for the 2020-2022 period are available on this page:

<https://www.theglobalfund.org/en/funding-model/applying/resources/>

Key CRG-related information materials the applicants may find useful when preparing the Funding Requests are listed below.

Information Notes

Tuberculosis Information Note: download in [English](#) | [Español](#) | [Français](#)

Building Resilient and Sustainable Systems for Health through Global Fund Investments Information Note: download in [English](#) | [Español](#) | [Français](#)

Frequently Asked Questions

2020-2022 Funding Cycle Frequently Asked Questions: download in [English](#) | [Español](#) | [Français](#)

Technical Briefs

Assessment and Best Practices of Joint TB and HIV Applications: download in [English](#)

Community Systems Strengthening Technical Brief: download in [English](#) | [Español](#) | [Français](#)

Gender Equity Technical Brief: download in [English](#) | [Español](#) | [Français](#) | [Русский](#)

Human Rights and Gender Programming in Challenging Operating Environments Guidance Brief: download in [English](#) | [Español](#) | [Français](#)

Programming at Scale with Sex Workers, Men who have Sex with Men, Transgender People, People who Inject Drugs, and People in Prison and Other Closed Settings: download in [English](#) | [Español](#) | [Français](#)

Tuberculosis, Gender and Human Rights Technical Brief: download in [English](#) | [Español](#) | [Français](#) | [Português](#) | [Русский](#)

Case Study - How We Engage: Stories of Effective Community Engagement on AIDS, Tuberculosis and Malaria: download in [English](#) | [Español](#) | [Français](#)

Community, Rights & Gender Technical Assistance

<https://www.theglobalfund.org/en/funding-model/throughout-the-cycle/community-rights-gender-technical-assistance-program/>

The CRG Technical Assistance Program is a Global Fund Board-approved strategic initiative. The initiative aims to ensure that all people who are affected by the three diseases can play a meaningful role in TGF processes and ensures that grants reflect their needs. This programme provides support to civil society and community organizations to meaningfully engage in the Global Fund model, including during:

- Country dialogue
- Funding request development
- Grant-making
- Grant implementation

Under this programme, national civil society and community organizations can apply for technical assistance in a range of areas, such as:

- Situational analysis and planning
- Participation in country dialogue
- Program design
- Oversight and monitoring of grant implementation
- Engagement in sustainability and transition strategy development

Some examples of technical assistance requests include:

- Support to design, plan and implement a consultation process to identify key population priorities for HIV funding request development
- Designing and budgeting for community systems strengthening programmes as part of the grant-making process
- Facilitating a funding request review among youth organizations to identify gaps and propose appropriate interventions for inclusion
- Proactive, peer-led community engagement support to civil society and community in sustainability and transition planning

Technical assistance is provided by nongovernmental organizations – including key population networks, universities and civil society organizations – that were selected through an open tender process for their demonstrated skills and capacities on CRG competencies.

CRG Technical Assistance Program Providers List: download in [English](#)

The program currently does not support:

- Strengthening Country Coordinating Mechanisms
- Long-term capacity building of civil society organizations
- Funding request writing

Organizations can request CRG technical assistance at any time throughout the funding cycle. The following resources are available to learn more about CRG technical assistance:

CRG Technical Assistance Program Frequently Asked Questions

download in [عربي](#) | [English](#) | [Español](#) | [Français](#) | [Português](#) | [Русский](#)

CRG Technical Assistance Program Request Form

download in [عربي](#) | [English](#) | [Español](#) | [Français](#) | [Português](#) | [Русский](#)

Annex

- The Right to Breathe: Human rights training for people affected by Tuberculosis
Available from: [insert link](#)