TUBERCULOSIS AND HUMAN RIGHTS
INFORMATION NOTE

Introduction

The Global Fund's new funding model is designed to enable strategic investment for maximum impact. However, strategic and impactful responses to Tuberculosis (TB) require a supportive legal and policy environment. Thus, in accordance with the Global Fund's Strategy 2012-2016, the Global Fund aims to protect and promote human rights by:

   i.   integrating human rights considerations throughout the grant cycle;

   ii. increasing investments in programs that address human rights-related barriers to access; and

   iii. ensuring that the Global Fund does not support programs that infringe human rights.

The Global Fund's Gender Equality Strategy and the Sexual Orientation and Gender Identities (SOGI) Strategy also encourage investment in programs that reduce barriers to access to health services for women and girls, as well as for sexual minorities.

Global Fund applicants are encouraged to incorporate programming that will reduce human rights barriers to service uptake. A recent Global Fund (2010) analysis of programs in Rounds 8, 9 and 10 concluded that applicants may increase their chances of success at technical review if they include a focus on addressing stigma and/or rights promotion in their funding requests. In the new funding model, human rights will be considered throughout the grant cycle.

WHO Stop TB Strategy and Human Rights

An important objective of the WHO Stop TB Strategy is to protect and promote human rights in TB prevention and care. Addressing HIV related TB (TB/HIV), multidrug resistant (MDR)-TB and the needs of poor and vulnerable populations; and empowering communities and people with TB have been identified as core components in the Stop TB Partnership's *Global Plan to Stop TB (2011-2015).*

These components emphasize patients' rights and responsibilities and the obligations of programs, policy-makers and donors to foster community participation in TB care, prevention and health promotion. The Patients' Charter for TB Care elaborates on basic human rights that apply to TB, and is referenced in the strategy.

Why are human rights important in TB responses?

TB is a disease of poverty and inequality that particularly affects key vulnerable populations[1] with little or no access to basic services. A human rights-based approach to TB prevention, treatment and care includes addressing the legal, structural and social barriers to quality TB prevention, diagnosis, treatment and care services. In some places, travelers may be barred from entering a country because of latent tuberculosis infections or TB history, and undocumented migrants may be deported before completion of the TB treatment. Studies have shown that PLHIV, sex workers, transgender people and other marginalized groups are sometimes denied equal access to DOTS Centers (Government clinics) by healthcare workers.

Drug-resistant TB, including multi-drug resistant and extensively drug resistant TB, is associated with poor prescribing, irregular drug supply, inadequate access to quality care, mandatory treatment or confinement and inability to complete treatment. Human rights approaches emphasize appropriate treatments that meet patients' needs to prevent the development of drug resistance, patients' right to be free from discrimination (including in health care settings) and to be free from forced or coerced treatment. When drug-resistant TB does develop, community-based treatment options that respect patients' rights have excellent treatment completion rates, are cost-effective, and protect public health, should be considered.

In order to achieve optimal conditions for the uptake of prevention, testing, treatment and care services, it is necessary to reduce such human rights barriers through programs that enable access to services. People are more likely to use health services if they are confident that they will not face discrimination; that their use of services will not expose them to other risks, such as detention due to criminalized status; that their confidentiality will be maintained; that they will have access to information; and that they will not be coerced into accepting services without consent.

Human rights are a set of legal rights that grow out of the basic equality and human dignity shared by all human beings. These rights can be found in international human rights treaties that set out the obligations that governments have to their citizens and to the international community. At the individual level, citizens are also required to respect the rights of others. In accordance with states' obligations under these human rights standards, applicants to the Global Fund are encouraged to identify priority areas where measurable progress can be made to eliminate barriers to service access and ensure meaningful participation of people living with and affected by the three diseases.

Assessing human rights in the TB response

Before drafting the concept note, applicants should identify human rights programs that will promote uptake and success of other TB interventions. To ensure that these interventions are pragmatic and are appropriate to the needs of affected communities, applicants are encouraged to use the country dialogue process to:

1. *Know the epidemic* – Applicants are advised to conduct an analysis of the human rights situation as it affects the TB situation, the impact on specific vulnerable populations, and overall response to the epidemic This analysis should build on existing available data and reports and utilize both quantitative and qualitative data collection methods. It may also be advisable to consult with domestic and regional experts on key vulnerable groups, and on human rights, including national human rights commissions, domestic human rights organizations and scholars, regional human rights mechanisms, and experts at the World

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[1] MARPs on TB or Key TB vulnerable and at risk groups include but are not exclusively limited to: women; prisoners; children; people working in settings that facilitate TB transmission: migrants (including undocumented migrants) and other mobile populations; refugees and internally displaced people; indigenous peoples; people living with HIV; homeless people; people with disabilities including mental health; and people who use drugs or engage in other substance abuse.

Health Organization (WHO), Stop TB Partnership, or UN Office of the High Commissioner for Human Rights (UNHCHR) and other related partners.

For instance, in a country where TB prevalence is high among a specific population such as people who use drugs, applicants may opt to examine the country's policies and laws to assess whether these create an enabling environment for interventions among people who use drugs, or whether reforms would help to ensure these other interventions are successful. Countries are encouraged to analyze the status of human rights of those affected by TB and MDR/XDR-TB, and to develop indicators to measure the political commitment of funds devoted to TB Control as a percentage of of GDP or of health budgets.

2. *Consult with representatives of key vulnerable groups* – Patients and communities play an integral role in TB treatment literacy, social support, monitoring, advocacy, communication, and social mobilization. TB cannot be adequately addressed without meaningfully involving those most affected in the planning and implementation of policies and programs that impact them. Systems of representation that are 'owned' by the patient community are the most effective and sustainable mechanisms of involvement. A human rights-based approach to TB places affected persons and communities at the centre, as equal partners, driving health policy, and providing them with the tools to participate and claim specific rights.

   In assessing potential human rights barriers to effective interventions, and designing programs to address them, applicants are encouraged to draw on the knowledge and experience of those vulnerable to and affected by TB. Countries are encouraged to create a human rights advisory committees including key representatives and affected communities. Representatives of these communities should be on the Country Coordinating Mechanism (CCM) and involved in the development and oversight of concept notes and grants. However, if they are not currently part of the CCM or other formal consultation mechanisms, they should still be involved in the development and oversight of concept notes and grants through the country dialogue process. Such consultation also creates local ownership and channels for communication that ensure human rights programs are fully implemented.

   Country applicants should also consider the need to develop mechanisms for cross-border and transnational continuation of care and should address the needs of mobile and displaced populations, whether domestic or cross-border.

3. *Link human rights programs to other interventions* – Based on these consultations, applicants should identify human rights interventions that are closely aligned with health interventions for which the applicant also requests support. For instance, if an applicant aims to increase the number of people who test for TB, but learns through consultations with networks of vulnerable groups that many people fear that their medical information will not be kept confidential, the applicant may focus on working with health providers to create and implement a policy that ensures medical confidentiality, in order to encourage groups in vulnerable situations to come forward, be tested and receive care free of charge.

4. *Explore potential inter-sectoral partnerships* – Some human rights initiatives may be developed solely within health ministries. However, most require establishing relationships with partners in another sectors, including legislators, civil society organizations, Justice Department, economic and labor ministries, etc. Assessing the potential for productive partnerships with other sectors should be part of the consultation process. To a limited extent, Global Fund TB investments may be directed at the inter-sectoral level, to address drawbacks in state functions that adversely affect multiple sectors including health, and that consequently interfere with effective delivery of disease control programs.

5. *Create a plan for technical assistance*: Applicants should build technical assistance needs into funding request. Technical assistance on human rights can be provided by domestic and regional networks of vulnerable populations, domestic and regional human rights organizations, and through the assistance of UN agencies and the Stop TB Partnership.

Designing human rights interventions

Once interventions have been identified, applicants should develop plans that can be embedded within and/or linked with national TB strategic plans, and consider the following four activity areas:

1. *Laws and policies*: If existing laws or policies create barriers to effective TB responses (i.e., lack of access to TB prevention services for key vulnerable groups), then the first step may be to review and reform those laws or policies. Some activities in this area include consultations on law reform, legal research, drafting proposed laws and policies, and policy advocacy, among others. Policies should promote access to community-based care, patient economic and social support for TB and MDR-XDR TB patients and their families.

   However, in many countries, laws and policies are supportive of the TB response, but are not fully implemented. In others, law reform is not feasible or a priority. In those contexts, human rights interventions should also consider the following three areas:

2. *Training and capacity-building*: This can include training in rights-friendly laws and how they should be implemented, and/or training in informed consent and confidentiality, for police, court officials, health workers, civil society, and others. It can include the Patients' Charter and know-your-rights campaigns for patients and TB treatment literacy campaigns. Note that training on legal rights is more effective when combined with sound laws, fair enforcement of those laws, and independent monitoring. All four elements together can ensure tangible progress on human rights.

3. *Legal support and advocacy for high-risk groups and patients with MDR-TB*: This can include support for legal aid services for people with TB, MDR-TB and vulnerable populations to litigate on such issues as discrimination, problems in accessing care, privacy, confidentiality, and informed consent. Activities may also include legal support for TB patients facing deportation because of active TB disease; legal aid services or advocacy for undocumented migrants or other vulnerable groups; support for community mobilization; promotion of the patients' charter; and other redress and advocacy activities.

4. *Human rights monitoring*: Applicants are encouraged to include monitoring to ensure that laws and policies are fully and fairly implemented. This can include monitoring and reporting by ombudsmen, TB survivors, patient associations, and national human rights commissions on issues facing TB patients and key vulnerable groups, reporting on complaints received and how they were handled by health care facilities, compensation in case of error attributable to TB program, as well as human rights investigations by community-based organizations, patient support groups, networks of vulnerable groups, or others.

When preparing a TB funding request, countries should also explore where development synergies may already exist that aim to promote gender equality to ensure girls and women have equal access to TB care, to strengthen rule of law, accountability, and human rights standards. For example, in a country that already has programs in existence that train judges in human rights standards, it would be advisable to add TB-related components and the participation of affected communities to such a training program rather than to create a new program.

Human rights interventions that directly relate to TB service or partnership interventions should be included in funding request that focus on TB. If a human rights program will affect two or more diseases (such as interventions and activities aimed at improving prison conditions or access to health services for migrants and refugees), it should be included in funding requests for health, and community systems strengthening.

Strengthening the evidence base

The Global Fund recognizes that a strong evidence base will ensure sound programming. The Global Fund also recognizes that data can be scarce for some populations and issues – for example in relation to migrants, miners, refugees, prisoners, and people who use drugs. In cases where evidence is poor applicants can request support to do operational research to strengthen the evidence base on key populations and human rights-based programs as part of their concept note at local, regional or national level. Ideally these activities should be planned for the first phase of grant implementation so that data generated can inform the later stages of investment. Applicants should seek input from marginalized or criminalized populations when designing data collection interventions in order to ensure that members of these populations are not put at risk by the collection of data.

TB and Human Rights Task Force

The Stop TB Partnership has established a TB and Human Rights Task Force, which has developed a draft policy framework for a rights-based approach to Stop TB so as to advance health, development and effective TB prevention, diagnosis and treatment. The framework includes the following five elements, which have also informed the development of overall Global Fund Human Rights tools:

- Empower individual and communities
- Address the socio-economic and other determinants of TB
- Expand access to quality TB prevention, care and support
- Create an enabling legal and policy environment
- Develop and implement accountability mechanisms

The Task Force is composed of major stakeholder constituencies from affected communities and risk groups, UN agencies, human rights and civil society organizations, health and human rights experts and development partners.

The WHO Stop TB Department and UNAIDS jointly provided Secretariat support for this Task Force. Open Society Institute and Human Rights Watch are part of the core planning team for the Task Force.

More information is available at: http://www.stoptb.org/global/hrtf

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Key References

Human rights standards

- International Covenant on Economic, Social and Cultural Rights,
  http://www2.ohchr.org/english/law/cescr.htm

- The Right to the Highest Attainable Standard of Health, General Comment No. 14,
  http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En

Guidance on TB and Human Rights

- Briefing Note on Tuberculosis and Human Rights, Stop TB Human Rights Taskforce (2011)
  http://www.stoptb.org/assets/documents/global/hrtf/Briefing%20note%20on%20TB%20and%20Human%20Rights.pdf

- *Patients' Charter for Tuberculosis Care* (2006):
  http://www.who.int/tb/publications/2006/patients_charter.pdf

- UNAIDS Reference Group on HIV and Human Rights, *HIV and Tuberculosis: Ensuring universal access and protection of human rights* (2010)
  http://data.unaids.org/pub/ExternalDocument/2010/20100324_unaidsrghrtsissuepapertbhrts_en.pdf

TB Strategy and Guidelines

- WHO Stop TB Strategy: http://www.who.int/tb/strategy/en/index.html

- Global Plan to Stop TB, 2011-2015:

  http://www.stoptb.org/assets/documents/global/plan/TB_GlobalPlanToStopTB2011-2015.pdf

- *Addressing Poverty in TB Control* (2005):
  http://www.who.int/tb/challenges/poverty/en/index.html

- WHO *TB Care and Control in Refugee and Displaced Populations: An interagency field manual* (2007): http://www.who.int/tb/challenges/refugees/en/index.html

- *Guidelines for Social Mobilization: A human rights approach to TB* (2001):
  http://www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf

- *Policy guidelines for Collaborative TB and HIV Services for Injecting and Other Drug Users* (2008), http://www.who.int/hiv/pub/idu/tb_hiv/en/index.html

- WHO guidance on human rights and involuntary detention for XDR-TB control
  http://www.who.int/tb/features_archive/involuntary_treatment/en/index.html

- UNDP, UNAIDS and the Global Fund on HIV/AIDS, Tuberculosis and Malaria (2010) *Analysis of Key Human Rights Programmes in Global Fund-support HIV Programmes:* http://content.undp.org/go/cms-service/download/publication/?version=live&id=3107370