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How to use this Activist Guide

“TB is now in a shameful leading position among infectious killers. How can we, as human beings accept that a disease that is curable in six months kills more people than HIV/AIDS? What kind of minds and hearts do we have?”— Dr Lucica Ditiu, Executive Director of the Stop TB Partnership[2]

This document serves as a framework for activists in Southern and East Africa working on HIV, TB and human rights issues in the region. The guide is divided into the five key topics, which were identified as ones needing urgent attention in the region. These topics, while often presented as stand alone issues, require rights-based response articulation by civil society, to ensure that all people living with TB or those most vulnerable to developing TB are afforded their human rights.

For each topic, this guide will provide background to the issue and case studies from partner countries in the region, to provide best practice examples of how civil society has been able to undertake advocacy efforts to promote rights-based responses regarding the topic. A framework for a way forward for TB activists in the region regarding each topic will be outlined, including policy advocacy where there are no rights-based approaches in country’s national TB strategies and documentation of case studies to gather evidence of violations of human rights.

This is a living document, which aims to provide a starting point for activist to identify the key advocacy priorities relating to TB and human rights in their own countries and is not intended to be prescriptive.

abbreviations

ACHPR	African Commission for Human and People’s Rights
AIDS	Acquired Immuno-deficiency syndrome
ARASA	AIDS and Rights Alliance for Southern Africa
ART	Antiretroviral therapy
ARV	Antiretroviral
CBO	Community Based Organisation
CHW	community health workers
CPT	Co-trimoxazole Preventive Therapy
CSO	Civil Society Organisation
CTBC	Community-Based TB Care
DO	Directly Observed Treatment
DR-TB	Drug-Resistant Tuberculosis
DST	Drug Susceptibility testing
DS-TB	Drug-Sensitive Tuberculosis
EP-TB	Extra-Pulmonary Tuberculosis
FBO	Faith-Based Organisation
FDC	Fixed-Dose Combination
GFATM	Global Fund to Fights AIDS, Tuberculosis and Malaria
HCW	Health Care Worker
HIV	Human Immunodeficiency Virus
IC	Infection Control
ICF	Intensified case finding
INH	Isoniazid
IPT	Isoniazid Preventative Therapy
IUALTD	International Union Against Tuberculosis and Lung Disease
KELIN	Kenya Ethical and Legal Issues Network
M&E	Monitoring and Evaluation
MDR	Multi Drug-Resistant
MoH	Ministry of Health
NAC	National AIDS Council
NGO	Non-Governmental Organisation
PEPFAR:	President’s Emergency Plan for AIDS Relief
PHC	Primary Health Care
PLHIV	People Living with HIV
P-TB	Pulmonary Tuberculosis
RHT	Routine HIV Testing
SACU	Southern African Customs Union
SSA	Sub-Saharan Africa
TB	Tuberculosis
UDHR	Universal Declaration of Human Rights
WHO	World Health Organisation
XDR-TB	Extensively Drug-Resistant Tuberculosis

glossary

Community-based care
Activities conducted outside of formal health facilities (hospitals, health centres and clinics) using com-munity-based structures (such as schools, places of worship and congregate settings, homes). Care is often provided by trained lay and community health workers in the homes of people living with TB.

Human Rights
Human rights are rights inherent to all human beings, whatever our nationality, place of residence, sex, national or ethnic origin, colour, religion, language, or any other status. We are all equally entitled to our human rights without discrimination. These rights are all interrelated, interdependent and indivisible.

Universal human rights are often expressed and guaranteed by law, in the forms of treaties, customary international law, general principles and other sources of international law. International human rights law lays down obligations of Governments to act in certain ways or to refrain from certain acts, in order to promote and protect human rights and fundamental freedoms of individuals or groups

Isolation
A state of separation between persons or groups to prevent the spread of disease. Isolation measures can be undertaken in hospitals or homes, as well as in alternative facilities. The WHO recommends that this is done only as a last resort and that the rights of people living with TB are respected. Once the diagnosis is made and treatment begun, isolation is usually neither necessary nor appropriate for people who are unwilling to undergo treatment. Isolation has a very limited role to play in patients in whom treatment has failed.

executive summary

A right-based approach to Tuberculosis (TB) in Southern and East Africa

Human rights are interlinked with who develops TB. The factors that increase vulnerability to contracting [TB] or reduce access to diagnostic, prevention and treatment services, are associated with people's ability to realise their human rights.

Rights-based responses are key to decreasing disease burdens, including TB and HIV. The benefits of using human rights-based approaches cannot be understated and should shape the health response. Incorporating rights-based responses within health programming leads to increased and strengthened participation of rights-holders, they improve transparency and accountability; they reduce discrimination and vulnerabilities, by focusing on the most marginalised and excluded in society. Rights-based responses strengthen capacity and encourage agency in the rights-holders; thus promoting the realisation of their human rights; while pushing for progressive policy and practices in order to push for community-owed, sustainable results.

Language influences stigma, beliefs and behaviours. Within this Guide, we explore the way we talk about TB. This includes the way language used in TB programmes and research and the impact this has on how people living with TB view their disease, their treatment and their power to take responsibility of their own health response.

Negative terms such as 'TB defaulter', 'TB suspect' and 'TB control' have the potential of deterring people from feeling comfortable with getting screened, tested or treated for TB. Terms such as 'TB suspect' are stigmatising and harmful, transferring the 'suspicion' of the disease to the person with TB and suggesting the person is guilty of a crime or offence. Words used in technical settings by researchers and health providers have immense power to shape TB care and how people speak and think about TB.

The World Health Organisation's Stop TB Partnership launched a guide of suggested language to be used in TB communication, which suggests replacing the controversial and insensitive words and language, which are often used, with more compassionate language.

Criminalisation of TB status: involuntary treatment, isolation and detention
Current responses to TB often fail to respect the human rights of people by

The factors that increase vulnerability to contracting [TB] or reduce access to diagnostic, prevention and treatment services, are associated with people's ability to realise their human rights.

criminalising a person due to their TB status. This includes enforcing involuntary treatment, hospitalisation, isolation and detention of people living with TB in prisons, home arrests and travel restrictions.

The restrictive TB legislation usually does not meet the criteria for the limitation of individual rights for public health reasons as outlined in the Siracusa Principles and the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). These restrictive laws should be replaced by community-based models.

Human Rights and unequal access to TB care and treatment

Where you live and your income determine the quality of care and level of access to TB medicines, diagnostic and preventative services. These social determinants also determine if you live in poverty-related conditions that may make you more vulnerable to developing TB.

There are many human rights issues that contribute to the unequal burden of disease and access to prevention, treatment and care, such as funding, drug development, patent laws and research and development, which need to be addressed urgently.

Gender and TB

Gender, human rights and TB are also inextricably linked, with women bearing the brunt of the burden of TB disease and also being more affected than men when they do develop TB.

For every case of new or relapse TB in men in 2014, four women developed TB. Vulnerability to TB is related to women's unequal social status and economic dependence. Efforts to address TB must take account of social and medical factors specific to women.

People most affected by TB

Some groups of people who are more vulnerable to, or affected by TB are either at increased risk of TB because of other disease such as HIV or diabetes, or due to their social and living conditions, behaviours or unsafe workplaces, or are underserved and have poor access to healthcare because of stigma, discrimination and access barriers, such as prisoners as prisoners and sex workers.

While there are number of groups who are most vulnerable to and affected by TB, this guide will focus on health care workers, miners, prisoners and migrants and outline advocacy strategies to address the TB needs of these particularly vulnerable group.

For each of these topics, this guide outlines case studies of civil society taking action to ensure that the TB-related human rights are ensured. The proposed calls to action for civil society is outlined at the end of each section, and is summarised in the inside back cover of this document.

A rights-based approach to TB in Southern and Eastern Africa

What is a rights-based approach and how can it be used?

Human rights are a set of standards of what each human being should be afforded. They are interdependent and indivisible as all are necessary to ensure a person's dignity. The right to health is dependent on and contributes to the realisation of many other human rights, such as the right to life.[3]

The right to health includes the underlying determinants of health such as safe drinking water, food, adequate nutrition, housing, non-discrimination, healthy occupational and environmental conditions and education.[4]

A human rights-based approach to health aims to support better and more sustainable health outcomes by analysing and addressing the inequalities, discriminatory practices and unjust power relations, which are often the root causes of health problems.[5] International human rights laws, declarations and guidance documents shape a human rights-based approach; to provide a holistic framework that can be applied to advocacy, programming and litigation in your country and region.

There are several common principles which can be used to guide the use of a human rights-based approach into programme and advocacy work, including the that: [6]

- All programmes, policies and activities at national level, should aim to contribute directly to the realisation of human rights. Human rights approaches should inform all stages of programming and advocacy work, including assessment, design and planning, implementation, monitoring and evaluation of TB/HIV programmes.
- Human rights principles integrate non-discrimination, equality, participation, inclusion, accountability, the rule

A human rights-based approach to health aims to support better and more sustainable health outcomes by analysing and addressing the inequalities, discriminatory practices and unjust power relations, which are often the root causes of health problems.

[3] *World Health Organisation Global Plan to Stop TB 2011-2015 Information Note: Tuberculosis and Human Rights. 2010 Available at: http://who.int/tb/dots/humanrights.pdf*
[4] *World Health Organisation Global Plan to Stop TB 2011-2015 Information Note: Tuberculosis and Human Rights. 2010 Available at: http://who.int/tb/dots/humanrights.pdf*
[5] *Office of the High Commission for Human Rights and World Health Organisation. The Right to Health, Factsheet No. 31, 2008*
[6] *FXB Center for Health and Human Rights and Open Society Foundations. Health and Human Rights Resource Guide 5th Edition. 2013*

of law, universality, inalienability, indivisibility, interdependence and interrelatedness.

- Participation and transparency is critical at all stages of work and all actors must be accountable for their participation. Human rights should guide the relationship between rights-holders and duty-bearers (actors with an obligation to fulfil these rights, such as governments).
- A human rights-based approach is intended to strengthen the capacities of rights-holders in demanding and claiming their human rights and to enable duty-bearers to meet their obligations, as defined by international human rights law.
- A human rights-based approach also draws attention to marginalised, disadvantaged and excluded groups and endows all groups with the ability to fully participate in processes and outcomes.

The benefits of using a human rights-based approach should not be underestimated. These include that it increases and strengthens the participation of rights-holders; it improves transparency and accountability; it reduces discrimination and vulnerabilities by focusing on the most marginalised and excluded in society; it builds capacity and encourages empowerment; it promotes the realisation of human rights; it has a greater positive impact on policy and practice and it promotes sustainable results and change.[7]

International and regional human rights

There are a number of human rights standards and declarations at the international and regional levels that apply to the right to health. These can be used to document violations of the rights of individuals and advocate for the termination of these violations, to 'name and shame' rights-bearers into addressing issues, to litigate against rights-bearers for violations of national human rights laws, to file complaints with national, regional and international human rights bodies and to form alliances with other activists and groups and develop networks.[8]

Under human rights law, States have the duty to respect, protect and fulfill human rights. These obligations require that States must refrain and prevent others from interfering with the enjoyment of rights and adopt appropriate measures towards the full realisation of the rights.[9]

The right to health and other human rights are legally recognised and guaranteed on paper through numerous national constitutions as well as international and regional treaties.[10] As activists, we should promote and be able to articulate these. While our aim should be to advocate for our governments to sign these treaties and protect the human rights of people living with TB on paper; at a practical level we should be in a position to monitor their implementation and where violations occur, be able to document these to articulate evidence-based advocacy to reduce or eliminate these violations.

[7]Ibid.
[8]Ibid.
[9]World Health Organisation Global Plan to Stop TB 2011-2015 Information Note: Tuberculosis and Human Rights. 2010 Available at: http://who.int/tb/dots/humanrights.pdf
[10]World Health Organisation Global Plan to Stop TB 2011-2015 Information Note: Tuberculosis and Human Rights. 2010 Available at: http://who.int/tb/dots/humanrights.pdf

TB and Human Rights

Human rights are interlinked with who develops TB. "Tuberculosis is a disease of poverty and inequality...Many of the factors that increase vulnerability to contracting [TB] or reduce access to diagnostic, prevention and treatment services are associated with people's ability to realise their human rights," according to the Global Fund to Fight AIDS, TB and Malaria (GFATM).[11] TB has often been portrayed as a disease driven by biomedical determinants, but in order to end TB, the social determinants of TB must be addressed and this requires placing people affected by TB ant the center of the TB response.

A lack of respect for human rights fuels the spread of TB.[12] TB and human rights are linked in who is most affected by TB. Key affected populations and inadequately serviced populations who are at increased vulnerability of developing TB include people living in poverty, minorities, women, children, migrants, people living with HIV, prison populations, health care workers and homeless persons, whose human rights to dignity, safety, housing and adequate food and resources has already been violated.

These groups are more likely to be exposed to living conditions that increase the risk of developing TB and they are less likely to have information, power and resources to ensure access to health care and human rights.[13]

The risk of developing TB is increased for those with a lack of access to education, face poor nutrition, inadequate housing and sanitation, poor health services and facilities, lack of employment and social security, food insecurity and malnutrition, and financial and geographic barriers to health care access, as well as political exclusion due to economic, political and social realities. These are known as the structural or social determinants of health.[14]

Some groups of people may be more vulnerable to developing TB due to their occupation, such as health care workers and miners. Often these groups are not protected by legislation or provided with compensation when they do develop TB.

Key structural determinants of TB epidemiology include global socio-economic inequalities, high levels of population mobility,

A lack of respect for human rights fuels the spread of TB. Human rights are interlinked with who develops TB

[11]Global Fund to Fights AIDS, Tuberculosis and Malaria [Global Fund], Global Fund Information Note: TB and Human Rights. 2011.
[12]Inter-Parliamentary Union (IPU), UNAIDS, UN Development Programme (UNDP). Taking Action Against HIV: A Handbook for Parliamentarians. 2007. Although the cited passage was written about HIV, the analysis of human rights violations can also be applied to TB.
[13]FXB Center for Health and Human Rights and Open Society Foundations. Health and Human Rights Resource Guide 5th Edition. 2013
[14]Stop TB Partnership, Human Rights Task Force Tuberculosis and Human Rights, Working Document on TB and Human Rights. 2011.

We will never end TB without addressing the social determinants of TB. This is where ensuring human rights is essential

and rapid urbanisation and population growth. In turn, the population distribution of where people living with TB are found reflects the distribution of these social determinants.

People living in poverty who already have many of their human rights violated face a double burden of being more vulnerable of developing TB, as higher levels of TB are found in places where there are weak and inequitable social policies.[15]

People who do develop TB are also at risk of having additional human rights violated through the impact of the disease and the consequential loss of other rights.[16] For example, TB can contribute further to existing poverty by preventing people living with TB from working and due to the high costs of accessing and then adhering to treatment and care.

People living with TB can also be subjected to discriminatory policies and laws that outline harmful measures such as involuntary treatment, detention, isolation and incarceration. TB-associated stigma and discrimination, combined with stigma and discrimination based on gender, poverty or HIV status, which can negatively affect people's employment, housing and access to social services, furthering the burden of developing TB.[17]

[15]*FXB Center for Health and Human Rights and Open Society Foundations. Health and Human Rights Resource Guide 5th Edition. 2013*
[16]*Inter-Parliamentary Union (IPU), UNAIDS, UN Development Programme (UNDP). Taking Action Against HIV: A Handbook for Parliamentarians. 2007.*
[17]*FXB Center for Health and Human Rights and Open Society Foundations. Health and Human Rights Resource Guide 5th Edition. 2013*

key points

Why are human rights important in the TB response?[18]

The integration of human rights-based approaches into TB programmes, policies and interventions can help achieve universal access to TB prevention, care and treatment through:

Contributing to TB prevention: Economic, social and cultural rights are strongly interlinked. For example vulnerability to TB infection and disease increases with a lack of access to: education, appropriate nutrition, quality housing and sanitation, health services and facilities, employment and social security. TB also increases vulnerability to poverty. A human rights-based approach addresses the socio-economic determinants of health that impact TB by ensuring that the rights to food, education, housing and social security of vulnerable and marginalised groups are promoted and protected.

Facilitating access to care: Effective diagnosis is often hindered by costs, lack of social security or health services and other barriers associated with seeking care, such as stigma and discrimination, or lack of information and specific public policies. Accessing care can lead to catastrophic expenditures, which may contribute to impoverishment for the individual and his or her entire family. These barriers can be removed if human rights implications of TB policy, legislation and programming are addressed within an integrated and multi-sectoral response to TB.

Empowering people living with TB and their loved ones: People living with TB play an integral role in TB treatment literacy, social support, advocacy, communication and social mobilisation. TB cannot be adequately addressed without meaningfully involving representatives of the most affected communities in the planning and implementation of polices and programmes that impact on them.

A human rights-based approach to TB places affected persons and communities at the centre, as equal partners, driving health policy, providing them with the tools to participate and claim specific rights to TB requires particular attention to ensuring that the specific needs and rights of vulnerable groups are recognised and adequately addressed. Stigma and discrimination against people with TB and those vulnerable to TB can prevent those most in need from accessing TB prevention, treatment and care services.

[18]*World Health Organisation Global Plan to Stop TB 2011-2015 Information Note: Tuberculosis and Human Rights. 2010 Available at: http://who.int/tb/dots/humanrights.pdf*

Improving quality of services: Poor quality of care hampers global TB prevention and care efforts. Inadequate training and supervision of health workers, inconsistent drug supplies, inadequate diagnostic tests and limited resources inhibit early detection and proper treatment, resulting in increased transmission and poor health outcomes. By tailoring services to meet the needs of patients and communities, a human rights based approach will improve service delivery, ensure that resource use matches community priorities and provide evidence that can be used to mobilise additional resources.

Addressing co-morbidities, including HIV: Early diagnosis of TB among people living with HIV is challenging, but vital. Prevention, diagnosis and treatment of TB should be integrated or coordinated to meet the needs of people living with HIV, Hepatitis C, diabetes, those on opiate substitution therapy and other common co-morbidities. Integrating and coordinating services facilitate adherence and ensures patients are not forced to choose between the therapies they need.

Preventing drug resistant TB and promoting rights-respecting treatment: 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 emphasise appropriate treatments that meet people living with TB's needs to prevent the development of drug-resistance and the person's 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 people's rights, have been documented to have excellent treatment completion rates, are cost effective and protect public health should be used. Community-based palliative care for some people with drug-resistant TB is also needed, including access to both effective opiate pain relief and social support. Treatment for drug-resistant TB should be non- restrictive and avoid long in-patient hospitalisation and detention of people living with TB and should be people-centered.

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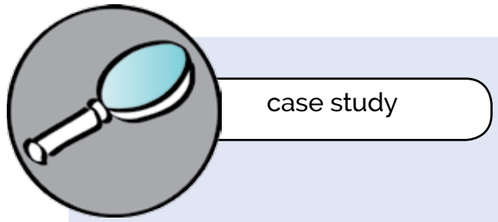


case study

Advocating for the Constitutional Rights of people living with TB in Kenya[19]

A woman (known as "Mrs X") at Kenyatta National Hospital in Nairobi was diagnosed with extensively drug-resistant tuberculosis (XDR-TB). She is one of more than 600 people confirmed to be living with drug-resistant TB in Kenya, less than half of which receive the necessary treatment.

Mrs. X was left for four months without receiving proper treatment. She was finally prescribed three expensive medicines, but was forced to pay for two of these herself. The third medicine, Viomycin, is not registered for use in Kenya and was therefore inaccessible to Mrs. X and other people living with TB.

According to the Kenyan Constitution Article 43 (1), every citizen has the right to the highest attainable standard of health and the country adopted the WHO's international standards of TB care and patients' charter for tuberculosis care, which state that governments must ensure that TB treatment is provided free of charge.

Activists at the Kenya Legal and Ethical Issues Network (KELIN), a national network, which responds to human rights concerns relating to health and HIV, took on Mrs. X's case and worked with 15 other civil society organisations. Together they delivered an advisory note to government ministers and Kenya's Attorney General outlining the facts of the case and urging immediate action.

Following the civil society action, the Kenyan government agreed to provide Mr. X with the two available TB drugs at no cost, but it stressed that it is unable to guarantee the supply of these drugs beyond a few weeks. Mrs. X needed at least several months of treatment to overcome XDR-TB. She also needs the third medicine, Viomycin, but that remains unavailable in Kenya.

Although government efforts to provide some of the necessary drugs are a positive development, ongoing concrete actions are needed to improve policies and programs to detect and treat drug-resistant TB and realise the human rights commitments for people living with TB in Kenya's constitution.

[19] *Howe, E. Timely treatment for drug-resistant TB in Kenya. Open Society Foundations Voices. 2012. Available at: https://www.opensocietyfoundations.org/voices/timely-treatment-for-drug-resistant-tb-in-kenya*

TB and language: Every word counts

The way we talk about TB and the language used in TB programmes and research impact on the human rights of people living with TB. Language influences stigma, beliefs and behaviours. [20]

Negative terms such as 'TB defaulter', 'TB suspect' and 'TB control' have the potential of deterring people from feeling comfortable with getting screened, tested or treated for TB. Terms such as 'TB suspect' are stigmatising and harmful, transferring the 'suspicion' of the disease to the person with TB and suggesting the person is guilty of a crime or offence. Words used in technical settings by researchers and health providers have immense power to shape TB care and how people speak and think about TB.

This kind of negative language, which is pervasive in the current TB response, identifies a person living with TB solely as a disease and places the blame on the person living with TB. "From a patient perspective, it is our opinion that these terms are at best inappropriate, coercive and disempowering, and at worst they could be perceived as judgmental and criminalising, tending to place the blame of the disease or responsibility for adverse treatment outcomes on one side —that of the patients," wrote a group of activists and researchers in a journal article.[21]

Showing compassion and understanding of the challenges people living with TB face starts with the language and words we use to speak to and about people living with TB. Following continued advocacy and input from activists, researchers and TB programmes, the World Health Organisation's Stop TB Partnership launched a guide of suggested language to be used in TB communication, which suggests replacing the controversial and insensitive words and language which are often used, with more compassionate language.[22]

The way we talk about TB and the language used in TB programmes and research impact on the human rights of people living with TB. Language influences stigma, beliefs and behaviours.

[20] *Stop TB Partnership and UNOPS. United to End TB. Every Word Counts: Suggested Language and Usage for Tuberculosis Communication 1st Edition. 2015*
[21] *Zachariah, R et all. Language in tuberculosis services: can we change to patient-centred terminology and stop the paradigm of blaming the patients? Int. J. Tuberc. Lung Dis.2012; 16 (6): 714-7*
[22] *Stop TB Partnership and UNOPS. United to End TB. Every Word Counts: Suggested Language and Usage for Tuberculosis Communication 1st Edition. 2015*

key points

Every work counts: key terminology[23]

case

Although this term is used widely in public health to refer to an instance of disease, it should be used with sensitivity in health care settings to avoid dehumanising people with TB. A person is not a case but a fellow human being. People seeking or receiving care may find it demeaning if they overhear a health worker describing them as 'cases'.

compliance / non-compliance ➔ adherence

The terms compliance and non-compliance are used to describe the degree to which every required dose of medicine is taken over the course a TB treatment. These terms unfairly assign blame to the person receiving treatment when many external factors outside a person's control (health system factors, economic reasons) may be the cause.

defaulter ➔ person lost to follow-up

It is generally poor quality of health services and lack of a person-centred approach that leads to treatment interruption or failure to begin treatment, and it is incorrect to shift the blame and place it on people with TB by labelling them defaulters. The term person lost to follow-up or treatment non- completion should be used as an alternative.

TB control ➔TB prevention and care

The term 'control' may create the perception that TB experts are in full control of all aspects of prevention, treatment and care of people with TB. It is useful to examine the term 'control' critically so as to avoid neglecting the resources of communities and people with TB.

TB suspect ➔ person to be evaluated for TB

TB suspect is sometimes used to define a person who presents with symptoms or signs suggestive of TB. This is a terms usually used for criminals and is insensitive to people living with TB.

[23] *Ibid*

Way forward for activists and civil society

There are a number of activities and interventions that can be undertaken in each country in the region to ensure that the human rights of people living with TB are guaranteed.

1. Conduct law and policy review and reform:

- Review and advocate for the reform of laws and policies that hamper effective TB responses (i.e. access to TB prevention services for key vulnerable groups) or those, which encourage rather than discourage involuntary detention for patients. Policies should promote access to community based care models, patient economic and social support for people living with TB.
- Provide support to legal service providers, Ombudsmen offices, and National Human Rights Institutions to engage in community outreach, campaigns, and advocacy with government for changes in law and policy.

2. Monitor and evaluate proposed interventions using human rights principles:

- The use of participatory research approaches that involve people affected by TB and communities in monitoring and evaluating interventions
- Establish evaluation indicators based on human rights criteria for example measuring levels of service access and involvement for marginalised groups
- Develop redress mechanisms for use when human rights are violated
- Share best practices and ensure lessons learned are transferred across programmes

3. Advocate for the provision of legal services for people affected by TB and vulnerable groups:

- Provide advice and support – including strategic litigation where appropriate – on legal issues, such as discrimination and problems in accessing care, privacy, confidentiality and informed consent issues.
- Provide support for people living with TB made redundant and/or facing deportation in relation to the completion of TB treatment.

4. Advocate for and implement programmes to reduce stigma and discrimination:

- Advocate for and/or provide training of health workers on non-discrimination, informed consent, confidentiality and duty to treat all people living with TB fairly
- Provide Human Rights and TB treatment literacy such as ‘know your rights’ campaigns

Criminalisation of TB status: involuntary treatment, isolation and detention

Global guidance on involuntary treatment, isolation and detention

Current responses to TB often fail to respect the human rights of people by criminalising a person due to their TB status. This includes enforcing involuntary treatment, hospitalisation, isolation and detention of people living with TB in prisons, home arrests and travel restrictions.

Governments limit the rights of people living with TB in the name of TB prevention and care, especially due to the concerns over the spread of drug-resistant TB, citing TB as an example of when it may be justified to limit patients’ rights to protect the health and safety of the public.[25] These public health measures aimed at ‘containing’ the disease, spread the disease further, due to the coercive measures used - often violating the rights of people who would otherwise take ownership of their health response and participate as ‘partners’ in their own treatment.

However, according to international human rights law, outlined in the International Covenant on Civil and Political Rights (ICCPR)[26] and the International Covenant on Economic, Social and Cultural Rights (ICESCR),[27] a person’s individual human rights (such as the freedom of movement) may only be restricted in limited circumstances when:

- these restrictions are strictly necessary to achieve a legitimate objective (such as preventing the spread of TB)
- the restrictions are in accordance with the law
- the restrictions are consistent with other human rights

The extent to which individual rights may be restricted for public health reasons is outlined in the Siracusa Principles, which is a non-binding document adopted by the United Nations Economic and Social Council in 1984.[28] These principles state that restrictions on human rights must be:

- provided for and carried out in accordance with the law
- directed toward a legitimate objective of general interest
- strictly necessary in a democratic society to achieve the objective

[25] Howe E, “Is TB a Human Rights Issue?”, Open Society Foundations, Voices, Oct. 4, 2010. www.soros.org/voices/tb-human-rights-issue.
[26] International Covenant on Civil and Political Rights, arts. 4, 12.
[27] International Covenant on Economic, Social and Cultural Rights, art. 5.
[28] UN Economic and Social Council, Siracusa principles on the limitation and derogation provisions in the International Covenant on Civil and Political Rights, E/ CN.4/1985/4 (1985). www1.umn.edu/humanrts/instree/siracusaprinciples.html.

- the least intrusive and restrictive available to reach the objective
- based on scientific evidence and neither arbitrary nor discriminatory in application
- of limited duration, respectful of human dignity, and subject to review

If in your country, the government is limiting the rights of people living with TB for public health measures, the Siracusa Principles are an excellent yardstick by which to test if the restrictions of human rights are in line with these principles. In practice, the Siracusa Principles do not provide governments with adequate guidance for developing measures that protect public health while respecting human rights as public health authorities are able to exploit ambiguous provisions in the law and can result in excessive restrictions of individual rights that go beyond what is necessary.[29] For example, it has in some cases been argued that involuntary detention may legitimately be used in a limited number of cases when a person with drug-resistant strains of TB refuses treatment. In practice, however, some countries have implemented broad sweeping rights-limiting policies that affect people living with TB.[30]

key points

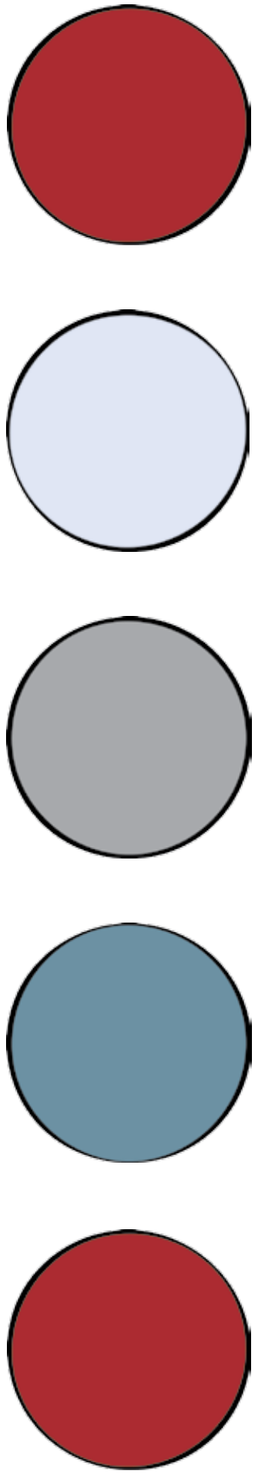
The legitimacy of limiting people with TB's human rights in the name of public health

Incarceration and other coercive TB measures unjustifiably interfere with patients' human rights and dignity because:

- They neglect more effective, rights-respecting alternative models of treatment and care, such as the provision of community-based treatment, adherence support and in-patient or out-patient treatment options. These ambulatory and community-based models of care have shown to have successful health outcomes, especially in resource-constrained settings.[31]
- There is strong evidence that rights-limiting measures increase vulnerability to TB by subjecting individuals to conditions that favor TB infection, transmission, illness and death.[32]
- They are generally considered by human rights experts to be "unnecessary from a scientific standpoint and dangerous from a programmatic perspective".[33]

Criminalisation of TB status, involuntary treatment, involuntary isolation and involuntary detention are the four main areas where governments implement laws, policies and practices which undermine the health and other human rights of people affected by TB, as discussed below.

[29] *Todrys KE et al. Failing Siracusa: governments' obligations to find the least restrictive options for tuberculosis control. Public Health Action 3, no. 1 (2013): 7-10. Available at: http://dx.doi.org/10.5588/pha.12.0094.*
[30] *Amon J et al. Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al. Health and Hu man Rights. 2009 Available at: www.hhrjournal.org/blog/perspectives/limitations-tb/*



Criminalisation of TB

In some countries, people living with TB are criminalised if they refuse to take treatment or if they do not complete their treatment. The restrictive TB legislation usually does not meet the criteria for the limitation of individual rights for public health reasons as outlined in the Siracusa Principles and the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR), due to the reasons outlined below:

- TB legislation is often focused on punishing patients who "default" from treatment rather than access to quality and affordable medicines. In some countries, people with TB can be imprisoned for months without proper treatment, information, legal representation, or an opportunity to defend their actions.
- Many individuals with TB do not complete treatment due to various reasons. These include a lack of understanding of or education about how the disease works and treatment methods; anticipation of negative side-effects from the treatment, lack of food and most often, inconsistent access to drugs.
- Criminalisation discourages individuals with TB symptoms from seeking diagnosis and treatment for fear of imprisonment and can thereby delay diagnosis of TB (including drug-resistant TB) and increase the risk of transmission as people are more likely to use HIV and TB services if they are confident that they will not face discrimination, their confidentiality will be respected, they will have access to appropriate information and counseling, and they will not be forces into accepting services.[34]
- Criminalisation and imprisonment of people living with TB increases discrimination and stigmatisation and intensifies the wrong done to people who are already ill.[35] his also burdens the prison system as TB is spread easily within these confined settings among other inmates. This in effect creates "TB factories".
- People with TB who are criminalised are often placed in prisons with criminal offenders, often in crowded and unventilated living environments and without proper nutrition. While imprisoned, they can easily infect other prisoners or be reinfected. There are little to no mechanisms in place to ensure that other prisoners do not contract TB from the infected individuals, re-infect individuals once they are well, or spread the disease back to their homes and communities when they are released. These measures go against public health principles, which are used to justify the criminalisation of people living with TB in the first place. [36]

[31] *Todrys KE et al. Failing Siracusa: governments' obligations to find the least restrictive options for tuberculosis control. Public Health Action 3, no. 1 (2013): 7-10. Available at: http://dx.doi.org/10.5588/pha.12.0094.*
[32] *Amon J et al. Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al. Health and Hu man Rights. 2009 Available at: www.hhrjournal.org/blog/perspectives/limitations-tb/*
[33] *Todrys KE et al. Failing Siracusa: governments' obligations to find the least restrictive options for tuberculosis control. Public Health Action 3, no. 1 (2013): 7-10. Available at: http://dx.doi.org/10.5588/pha.12.0094.*
[34] *Francis LP and Francis JG. Criminalizing Health-Related Behaviors Dangerous to Others? Disease Transmission, Transmission-Facilitation, and the Importance of Trust, Criminal Law and Philosophy 6: 47–63. 2012*
[35] *KELIN. Press Release: Should we treat TB Patients like Criminals? Aug. 17, 2011. http://kelinkenya.org/tag/imprisonment-of-tb-patients/*
[36] *Ibid.*

Involuntary Treatment

The World Health Organisation (WHO) clearly affirms that it is unethical to force a person with TB to undergo medical treatment that they have objected to. “TB treatment should be provided on a voluntary basis, with the patient’s informed consent and cooperation...[E]ngaging the patient in decisions about treatment shows respect, promotes autonomy, and improves the likelihood of adherence,” states the WHO’s TB and ethics guidance.[37]

Involuntary treatment is also unlikely to result in the public health purpose, as non-adherence is “often the direct result of failure to engage the patient fully in the treatment process.”[38]

Involuntary Isolation

Involuntary isolation should never be implemented as a form of punishment. People living with TB who decline treatment and who pose a risk to others, should be made aware in advance that their continued refusal for treatment may result in compulsory isolation.[39]

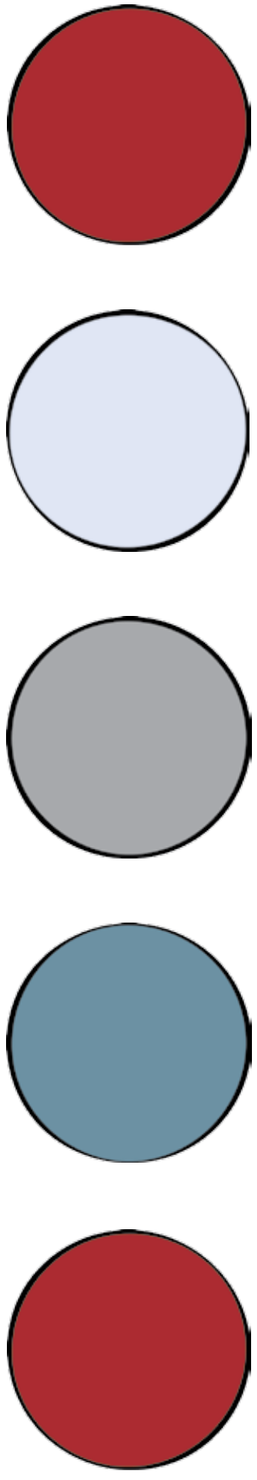
The World Health Organisation stresses that involuntary isolation of people living with TB is to be viewed as a last resort measure, and limited to any of three “exceptional circumstances” when an individual is:

1. “known to be contagious, refuses treatment, and all reasonable measures to ensure adherence have been attempted and proven unsuccessful”
2. “known to be contagious, has agreed to ambulatory treatment, but lacks the capacity to institute infection control in the home”
3. “highly likely to be contagious (based on symptoms and evidence of epidemiological risk factors) but refuses to undergo assessment of his/her infectious status”.[40]

It is stressed that involuntary isolation should be limited to exceptional circumstances for rare individual cases that meet the above criteria. If a judgment is made that involuntary isolation is the only reasonable means of safeguarding the public, it is essential to ensure that the manner in which isolation or detention is implemented complies with applicable ethical and human rights principles, as set forth in the Siracusa Principles.[41]

Involuntary isolation should never be implemented as a form of punishment. The World Health Organisation stresses that involuntary isolation of people living with TB is to be viewed as a last resort measure

[37] *WHO, Guidance on ethics of tuberculosis prevention, care and control (2010). Available at: http://www.who.int/tb/features_archive/ethics/en/.*
[38] *Ibid*
[39] *FXB Center for Health and Human Rights and Open Society Foundations. Health and Human Rights Resource Guide 5th Edition. 2013*
[40] *WHO, Guidance on ethics of tuberculosis prevention, care and control (2010). Available at: http://www.who.int/tb/features_archive/ethics/en/.*
[41] *Boggio A et al. Limitations on human rights: Are they justifiable to reduce the burden of TB in the era of MDR- and XDR-TB. Health and Human Rights 10, no. 2 (2008). www.hhrjournal.org/index.php/hhr/article/view/85/169.*



However compulsory involuntary isolation often violates these guidelines in the following ways:

- Involuntary isolation cannot be considered an effective last resort, as less-restrictive measures exist, such as community-based treatment models which have proven effective to ensure patients complete treatment, while also preventing the spread of TB, when compared to more traditional hospital-based care.[42]
- Involuntary isolation measures are often ineffective in containing TB it does not prevent the spread of disease because of the delay between diagnosis and admission to a facility, widespread infection may have already occurred.
- Many TB patients are isolated in sub-standard conditions that violate their basic constitutional rights. While involuntary isolation should only limit the right to the freedom of movement, it often limits many other rights, such as the right to dignity if the health facility conditions are substandard, right to work if they lose their job while involuntary confined, right to raise a family if they are forcibly separated from young children and have no alternative caregiver, and right to housing if they lose their homes as a result of confinement.
- Investing limited anti-TB resources in building expensive isolation facilities could rather be used to provide reasonable social support to isolated people living with TB and their families, in practice this may not take place.
- The WHO notes that people with TB may go to great lengths to escape stigma and isolation, “lengths that may prolong both their own suffering and the length of time they remain infectious.”[43]

Contagious people living with TB who refuse treatment and/or infection control measures can be isolated to prevent the spread of disease. Within isolation, if patients provide an informed refusal of treatment, their decision should be respected.

Involuntary Detention

The three exceptional circumstances and the five Siracusa criteria described above to determine whether involuntary isolation is ever justified also apply to involuntary detention.[44]

Involuntary detention, has not been proven to be an effective TB treatment and prevention mechanism, because:

- Involuntary detention can deter sick individuals from seeking diagnosis.
- it does not prevent the spread of disease because of the delay between diagnosis and admission to a facility, widespread infection may have already occurred.

[42] *Howe E. Is TB a Human Rights Issue? Open Society Foundations, Voices, 2010. www.soros.org/voices/tb-human-rights-issue.*
[43] *Stop TB Partnership. TB and Human Rights Task Force. www.stoptb.org/global/hrtf/.*
[44] *WHO, Guidance on ethics of tuberculosis prevention, care and control (2010). Available at: http://www.who.int/tb/features_archive/ethics/en/.*

- Poor hygiene and living standards at confinement facilities themselves can further spread infection to healthcare workers and visitors, which in turn can spread the infection to families and communities.
- 2007 WHO Guidance on human rights and involuntary detention states that governments should make prevention and access to accurate diagnosis and high-quality treatment high priorities, rather than on involuntary detention.[45]
- Given evidence of the effectiveness and scalability of community-based delivery models in resource-constrained settings, involuntary detention could rarely be considered the least restrictive means available - particularly if less restrictive means have not been applied.

Involuntary detention has not been proven to be an effective TB treatment and prevention mechanism

Community-based TB treatment

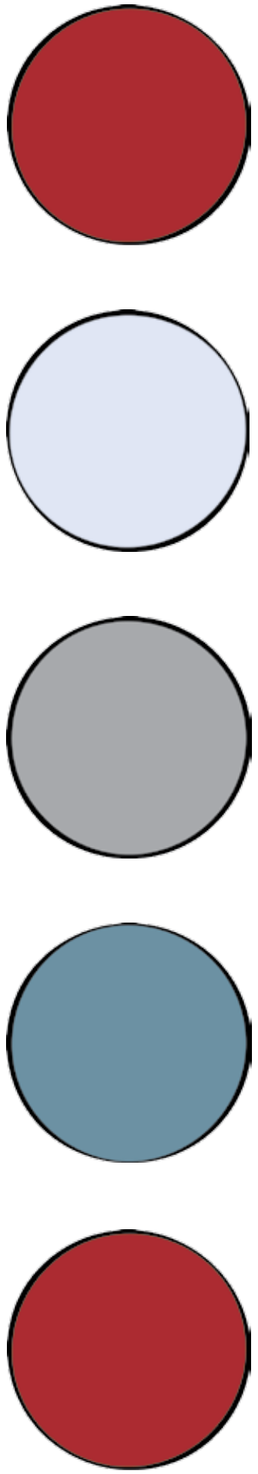
The alternative to involuntary isolation and/or detention is community-based TB treatment, especially as an alternative for drug-resistant TB treatment.

The World Health Organisation recommends that people with drug-resistant TB should be treated using mainly ambulatory (outpatient) care rather than models of care based principally on hospitalisation.[46]

A systematic review indicated that there is no significant difference in treatment outcomes between inpatient and outpatient models of care.[47]

Outpatient models of care can either be clinic-based (people living with TB travel to the clinic daily for directly observed therapy (DOT)) or community-based (a health care worker travels to the house daily for DOT, or meets the person living with TB at a mutually agreed point). This is also known as a home-based model of care. The community-based model is also referred to as a home-based model of care. This encourages community-based responses to TB and reduces stigma and discrimination, as there is participation in the treatment of the person with TB disease.

Under the clinic-based model, people living with drug-resistant TB receive the full course of treatment at an outpatient health care facility, irrespective of the sputum smear/culture status. This model of care requires staff at the clinic to be properly trained, especially on the early detection and proper management of adverse drug reactions, and in the management of social support services.



This model of care requires the person living with TB to travel from home and receive the medicines under DOT at the clinic. Rapid access to DOT should be ensured to allow a quick departure from the facility. This practice will not only reduce the exposure to potential sources of TB and other infections but also enable patients to reduce the costs associated with reduced time at the workplace or household. Long daily travel times can be a reason for defaulting treatment. [48]

Under the community or home-based model, people living with drug-resistant TB receive full course of treatment under direct observation, irrespective of their sputum smear/culture status, at a venue in the community, such as a patients' or relatives' household or the workplace. The venue is agreed between the patient and the DOT provider. The backbone of community based MDR-TB care is often a community MDR-TB supporter, who may come from the same neighborhood where the person living with TB lives. Community-based MDR-TB providers need to be properly trained and supervised by qualified health care workers.[49]

The preference of people living with TB (and family) on where they would like to receive treatment should be taken into consideration. Each of these models have been implemented in Southern and East Africa with successful treatment outcomes, such as in South Africa, Lesotho and more recently Uganda.

[45]WHO. Guidance on human rights and involuntary detention for xdr-tb control. 2007. www.who.int/tb/features_archive/involuntary_treatment/en/index. html.
[46]WHO. Guidelines for the programmatic management of drug-resistant tuberculosis, 2011 Update. Geneva: 2011
[47]Bassili A et al. A systematic review of the effectiveness of hospital- and ambulatory-based management of multidrug-resistant tuberculosis. American Journal of Tropical Medicine and Hygiene 2013; 89(2):271–280.

[48]WHO. Companion handbook to the WHO guidelines for the programmatic management of drug-resistant tuberculosis. 2014. Available at: http://www.ncbi.nlm.nih.gov/books/NBK247420/pdf/Bookshelf_NBK247420.pdf
[49]Ibid.

case study

Botswana's Draconian Public Health Act

In 2012, the Government of Botswana introduced the Public Health Bill (no 23 of 2012) without public consultation, which contained many draconian measures to be taken to limit the rights of people living with communicable diseases such as TB in the name of public health or the public good.

However, many of these limitations of rights went beyond what is necessary to prevent the spread of communicable diseases and go against the criteria which need to be met in order to limit individual human rights as set out in the Siracusa Principles.

For example, Section 57 (1) allows a medical practitioner, health officer or authorized officer to detain a person in a healthy facility if that person has a communicable disease and they believe detention is necessary to prevent the spread of the disease. Such person can Such person can, in terms of section 57(2) be detained until the medical practitioner, health officer or authorised officer is satisfied that the person is no longer infected or that the discharge of the person will not endanger public health. A person who escapes such detention commits an offence [section 57(3)].[50]

Section 57 violates the right to freedom of movement guaranteed in section 14 of the Botswana Constitution and Artcile 12 (10) of the African Charter on Human and People's Rights (ACHPR) and the right to be free from cruel, inhuman and degrading treatment.[51]

The Botswana Network on Ethics, Law and HIV/AIDS (BONELA) worked with UNAIDS, WHO, Southern Africa Litigation Center (SALC), AIDS Alliance and ARASA to challenge the Bill through press releases and submissions which heeded calls to make amendments to the Bill. BONELA and partners also worked tirelessly to make the public aware of the unnecessarily restrictive nature of the Bill.

Some of the most restrictive provisions such as notifying cases of TB to the police services were removed from the Bill. Despite the actions of BONELA and partners, the Bill, which still contained many human rights violations for people with HIV in particular was signed into legislation in September 2013.

[50] *Southern Africa Litigation Center. Comments on the Botswana Public Health Bill 23 of 2012. 12 February 2013. Available at: http://www.southernafricalitigationcentre.org/1/wp-content/uploads/2013/02/SALC-Commentary-on-Public-Health-Bill.pdf*

[51] *Southern Africa Litigation Center. Comments on the Botswana Public Health Bill 23 of 2012. 12 February 2013. Available at: http://www.southernafricalitigationcentre.org/1/wp-content/uploads/2013/02/SALC-Commentary-on-Public-Health-Bill.pdf*

Way forward for activists and civil society

1. Conduct law and policy review and reform

- Review and advocate for the reform of laws and policies that criminalise TB. Policies should promote access to community-based care models, patient economic and social support for people living with TB.
- Provide support to legal service providers, Ombudsmen offices, and National Human Rights Institutions to engage in community outreach, campaigns, and advocacy with government for changes in law and policy.

2. Document cases of human rights violations regarding the criminalisation of TB

- Document all individual cases where human rights are not being respected through the criminalisation of TB, including involuntary isolation and detention.
- Use these cases in advocacy strategies to draw attention to the issue through awareness-raising campaigns, collaboration with the media, alerting stakeholders such as the WHO and UNAIDS of such cases.

3. Advocate for increased accessibility, availability, acceptability and quality of community-based treatment and care of TB, especially in the case of drug-resistant TB

- Review and advocate for the reform of laws and policies that do not allow for community-based treatment and care of TB.

4. Integrating drug-resistant TB into community-based work[52]

NGOs and other civil society organisations (CSOs) could integrate drug-resistant TB into their community-based work in many ways, without trained medical staff.

- Assisting early case finding: Encouraging people who present with symptoms of TB such as chronic cough, weight loss, night sweats and fever to contact a health worker or visit a health facility.
- **Assisting contact investigation:** Engaging members of the community to assist health care workers in contact tracing.
- Providing **treatment support:** Ensuring patients being treated for drug-resistant TB are given support to take their drugs and finish their treatment.
- Education **programmes and projects:** Incorporating messages of TB. prevention and care into curricula and classroom learning, that contribute to de-stigmatise the disease, prevent discrimination and promote early case detection and adherence to treatment.

[52] *WHO. Companion handbook to the WHO guidelines for the programmatic management of drug-resistant tuberculosis. 2014. Available at: http://www.ncbi.nlm.nih.gov/books/NBK247420/pdf/Bookshelf_NBK247420.pdf*

Human Rights and unequal access to TB care and treatment

Unequal burden of disease and access to TB care and treatment

Human rights and access to TB care in treatment are inextricably linked. Where you live and your income determine the quality of care and level of access to TB medicines, diagnostic and preventative services. These social determinants also determine if you live in poverty-related conditions that may make you more vulnerable to developing TB.

At an individual level, economic, social and legal factors often delay and impede contact with health care systems. Common barriers include a lack of money to facilitate transportation to health facilities, lack of information about treatment options, fear of being stigmatised by family and community and a lack of social support in the event of sickness. For many, maintaining employment may take precedence over maintaining health. People without access to a social safety net must often have to choose between following treatment to get well or working to support their families.

The Southern African region faces the highest TB burden in the world due to poor access to TB prevention, care and treatment. In 2014, the African region accounted for almost a third (28%) of the world's TB cases and has the most severe burden relative to the population at 281 cases for every 100 000 people. This is more than double the global average of 133 cases per 100 000.[53]

The African region also accounts for a staggering 74 % of the 9.6 million people worldwide who were also HIV-positive.[54] Only a third of the 1.2 million people living with HIV estimated to have developed TB in 2014 had been placed on antiretroviral therapy. The number of people living with HIV who were treated with isoniazid preventive therapy reached 933 000 in 2014, an increase of about 60% compared with 2013. However, over half of these people (59%) were in South Africa,[55] which in all likelihood means that IPT was not provided sufficiently in other countries in Southern and East Africa.

In terms of the TB response in the region, none of the Global Stop TB 2015 targets for TB incidence, prevalence and mortality were met for the African region.[56] Effective TB diagnostics and therapies have been available for

[53]*The African region is not disaggregated per sub-region, but we do know that the majority of TB cases are found in the Southern African region. WHO. Global Tuberculosis Report. 2015.*
[54]*Ibid*
[55]*Ibid*
[56]*Ibid*

An alarming 37% of funds needed for TB control in African region is unfunded, according to the World Health Organisation.

decades, yet many individuals in the region continue to receive substandard care or none at all, due to poverty or other marginalised status, poor access to health services, a broken health system and a human resource crisis as seen in many countries in Southern and Eastern Africa.[57] In addition, an alarming 37% of funds needed for TB control in African region is unfunded, according to the World Health Organisation.[58]

Poor access to health care services creates gaps in accessing TB diagnosis and treatment. This contributes to increased incidence of active TB cases, reduces positive clinical outcomes and increases the proliferation of drug resistance.

There are many human rights issues that contribute to the unequal burden of disease and access to prevention, treatment and care, such as funding, drug development, patent laws and research and development.
Access to new medicines and diagnostics

The current treatment regimen for drug-sensitive TB is effective in over 90% of cases. However, the treatment process is long and arduous – particularly so for children, as there are NO PAEDIATRIC formulations available and children are given smaller doses of adult treatments. This is alarming in and of itself.

"This leads to a situation where, attempting to arrive at a suitable dose of a TB drug for a young child, the clinic staff may take a kitchen knife to halve an adult tablet and then perhaps, will have to halve it again. This must lead to inaccuracies and the possibility of under dosing affecting efficacy and over-dosing that could precipitate toxicity. In the early twenty first century this is no longer an acceptable situation", says Professor Peter Donald of the University of Stellenbosch and Tygerberg Children's Hospital in South Africa.[59]

Treatment for adults and children takes at least six months and many people report unpleasant side effects in the initial phases of taking the treatment. Accompanied by a lack of food security in some cases, people on TB treatment miss doses, and do not manage to complete their course of medication as a consequence. This can result in the return of symptoms and drug-resistance.

Treatment of multi-drug resistant TB (MDR-TB) is costlier and more challenging. The drugs are less effective, more toxic, and treatment regimens are longer. At best, MDR-TB can be cured in just 70% of patients.

[57]*FXB Center for Health and Human Rights and Open Society Foundations. Health and Human Rights Resource Guide 5th Edition. 2013*
[58]*Ibid*
[59]*Starke, J. Tuberculosis in Children. Semin Respir Crit Care Med, 2004;25(3). Available at: www.medscape.com/viewarticle/484123*

Current TB medications were introduced between the 1950s and 1980s, in the early years of the global HIV epidemic, and before the link between TB and HIV was widely recognised. Since that time, there have been great advances in treatment for HIV with the advent of anti-retroviral therapy (ART). Advances in treatment for TB have not kept pace.

There is an urgent need for new TB drugs that can dramatically shorten the duration of treatment, target drug-resistant TB, simplify treatment by reducing the pill burden and dosing frequency and be co-administered with ARVs, especially for the Southern and East Africa region, which accounts for a large proportion of the global TB burden.

Due to a lack of market incentive, TB continues to receive little attention from companies that develop improved medicines. To address this neglect, *The Human Rights Guidelines for Pharmaceutical Companies in relation to Access to Medicines*[60] were created to provide guidelines for pharmaceutical companies on issues including transparency, quality, clinical trials, neglected disease, patents, pricings, ethics, marketing and partnerships. The right to the highest attainable standard of health requires that existing medicines are accessible as well as that much-needed new medicines are developed as soon as possible.

The development of new TB medicines such as bedaquiline, delamanid and pretonamid prove that new TB drugs can be developed. However, the process is slow, difficult and costly. There is also an urgent need for a safe and efficacious vaccine and for better diagnostics.

The introduction of the MTB/RIF Xpert molecular test, which detects the DNA in TB bacteria and can give results in less than two hours, represents a major milestone for global TB diagnosis and care. However, what is really needed is a true point of care TB test, similar in its operational simplicity to the HIV antibody test. It needs to be suitable for use in situations where there is no electricity supply, and where there may be considerable temperature extremes. It also needs to be available at a much lower cost.

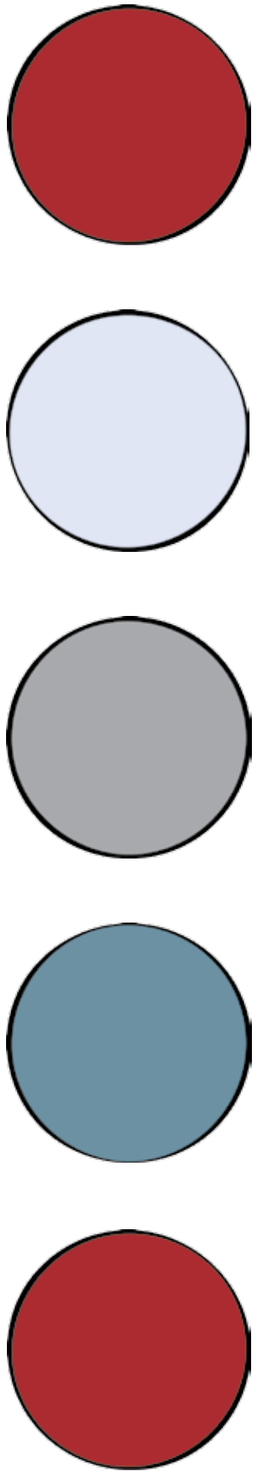
Research and development for TB medicines and vaccines

The most recent estimate of the annual funding gap for global research and development related to TB is at US$ 1.3 billion.[61] TB is concentrated among the poorest people in the poorest countries of the world, so there is little market incentive to address the illness.

New TB medicines bedaquiline, delamanid, linezolid, and pretomanid (PA-824) are currently being tested whether they can reduce the treatment time to six to eight months. The new TB medicines are nearly all patented, expensive and manufactured outside Africa.

[60] *United Nations General Assembly 63rd session. Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms. 11 August 2008. Available at: http://www.who.int/medicines/areas/human_rights/A63_263.pdf*

[61] *WHO Global TB Report 2015 Fact Sheet. 2015. Available at: http://www.who.int/tb/Global_TB_Facts.pdf*



Treatment Action Group's (TAG) 2014 *Report on Tuberculosis Research Funding Trends*,[62] which measures investments in TB research and development against the Stop TB Partnership's *2011–2015 Global Plan to Stop TB*,[63] has consistently reported funding gaps and in 2014 and increasing instability. In the private sector, pharmaceutical companies are running for the exits, disbanding TB research programmes as part of an industry-wide pivot away from anti-infectives research for communicable diseases toward efforts to develop new biologics, including vaccines, and drugs for chronic illnesses. These factors impede on people's right to access to healthcare and medicines to prevent and treat TB.

Patent restrictions

Patent restrictions are one of the key element which push the price of life-saving TB medications to unattainable levels for many countries in Southern and East Africa.

Compulsory licensing is a flexibility built into the World Trade Organisation's agreement on intellectual property, the Trade-Related Aspects of Intellectual Property Rights (TRIPS), which is when government allows the production of a patented product without consent of the patent owner. Countries are free to determine the grounds for granting compulsory licenses, which might include lack of registration or in some cases and decrease exorbitant prices for medications, diagnostics and vaccines.

However, in recent years, developing countries have faced pressure when negotiating Free-Trade Agreements (FTA) to implement more restrictive patent laws under TRIPS-Plus, including provisions that limit the use of compulsory licenses and restrict generic competition[64] and prevent countries in the region from accessing medicines at lower prices, rendering them unavailable to many individuals which impedes on their human rights.

For example, according to a study,[65] the newest MDR-TB drug prices could fall by up to 95% if generic production of patented products could be achieved in the same way as for antiretroviral drugs. This could result in a ten-fold increase in the number of people who could be treated for MDR-TB with the current funding that is available for TB.[66]
A low (2-5%) but increasing percentage of TB patients have drug-resistant TB, for which there were until recently only old, expensive and not very effective or safe medicines, requiring treatment for up to 18 to 20 months. Only one of these MDR-TB medicines (cycloserine) is made in Southern Africa. Drug-

[62] *Available here: http://www.treatmentactiongroup.org/tbrd2014*
[63] *Available at http://www.stoptb.org/global/plan/plan2/*
[64] *Treatment Action Group's (TAG) 2014 Report on Tuberculosis Research Funding Trends. 2015. Available here: http://www.treatmentactiongroup.org/tbrd2014*
[65] *Gotham D et al. Target generic prices for novel treatments for drug-resistant tuberculosis.15th European AIDS Conference, Barcelona, abstract PS2/4, 2015.*
[66] *Alcorn, K. Newest MDR-TB drug prices could fall by up to 95% through generic production. 22 October 2015. Available at: http://www.aidsmap.com/Newest-MDR-TB-drug-prices-could-fall-by-up-to-95-through-generic-production/page/3008555/*

The newest MDR-TB drug prices could fall by up to 95% if generic production of patented products could be achieved in the same way as for antiretroviral drugs.

resistant TB comprises only 2.2% of South African cases, but it consumes 32% of the country's total TB budget due to the high cost of medicines and hospitalisation.

In the case of bedaquiline, it would be possible to reduce the price of the drug from approximately US $136 a month to between US$8 and US$16 a month – a price reduction of approximately 90 to 95%.[67] However, in order to achieve these savings, patent barriers to generic production will need to be overcome, especially in middle-income countries. The savings implied by the model assume that it will be possible to negotiate bulk purchases for very large quantities, rather than placing multiple small national orders.[68] Civil society needs to advocate for a price reduction and access to bedaquiline.

Health systems strengthening

Strengthening the facilities and systems in which people access health services is an essential component of the response to TB prevention, care and treatment. This will also address supply chain management problems, which can result in drug stockouts.

As the Global Fund notes, "Poor quality of care hampers global TB control efforts. Inadequate training and supervision of health workers, inconsistent drug supplies, inadequate diagnostic tests and limited resources inhibit early detection and appropriate treatment resulting in increased transmission and poor health outcomes. By tailoring services to meet the needs of patients and communities, a human rights focus will improve service delivery, ensure that resources used match community priorities and provide evidence that can be used to mobilise additional resources."[69]

case study

Addressing intellectual property for increased access

In April 2013, the Global TB Community Advisory Board (TB CAB), supported by civil society organisations in Southern and East Africa, sent open letters to India's Prime Minister and Minister of Health supporting India's refusal of TRIPS-Plus provisions in their FTA negotiations with the European Union, as these provisions could have devastating global effects on access to medicines, especially given India's role supplying affordable medicines throughout the developing world.

Two years later in May 2015, civil society sent a letter to the World Trade Organisation demanding that it grant least-developed countries (LDCs) an extension of the transition period with respect to pharmaceutical products and for waivers from their obligations under the TRIPS agreement. This decision would combat the health challenges that LDCs face by improving access to medicines for as long as said countries remain LDCs.[70]

In November 2015, the WTO-TRIPS Council adopted a decision granting Least Developed Countries (LDCs) an exemption from patents and test data protection for pharmaceutical products for a duration of 17 years. With this exemption, LDCs will not be obliged to implement or apply or to enforce patents as well as test data protection for pharmaceutical products until 1 January 2033.

Had the WTO-TRIPS Council granted the LDCs their desired and valid requests, it would have demonstrated to the world that the WTO will take the necessary steps to protect the poor and vulnerable. Instead, unfortunately due to strong opposition mainly from the US, the WTO-TRIPS Council reached a decision to accord LDCs' a transition period of 17 years.

[67] *Ibid.*
[68] *Alcorn, K. Newest MDR-TB drug prices could fall by up to 95% through generic production. 22 October 2015. Available at: http://www.aidsmap.com/Newest-MDR-TB-drug-prices-could-fall-by-up-to-95-through-generic-production/page/3008555/*
[69] *Global Fund, Global Fund Information Note: TB and Human Rights (2011). Available at: http://goo.gl/vyb6Z.*
[40] *http://www.tbonline.info/advocacy/#intellectual-property*

Way forward for activists and civil society

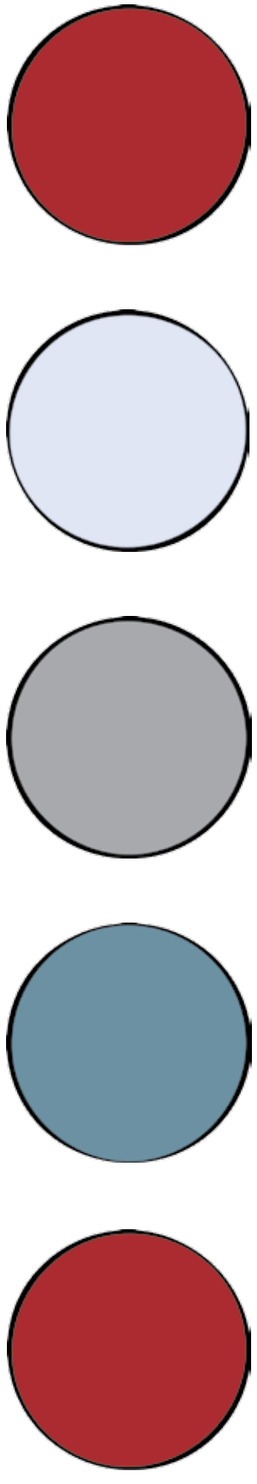
1. Monitor funding made available for TB and HIV interventions and advocate for increased funding (including global and domestic funding):

Most countries in Southern and East Africa have excellent TB and HIV guidelines, which outline ambitious targets. However, this is not matched with sufficient funding to implement these interventions. Civil society should conduct rigorous budget monitoring of funds allocated to TB treatment and care, especially at country level as well as globally.

2. Monitor and advocate for the implementation of TB prevention and care methods for people living with HIV:

- At national, provincial and district level, civil society should monitor the following:
  - HCT targets and numbers reached
  - ART targets and numbers reached
  - Numbers of people on IPT (this can be done through simply monitoring if isoniazid is available in health care facilities in the first instance)
  - The existence and implementation of infection control plans at health care facilities
- Monitor and assist with the implementation of TB case finding
- Advocate for TB/HIV integration
- Monitor availability of lay counsellors at facilities

3. Advocate for countries to use compulsory licensing to increase the production of generic TB vaccines, diagnostics and treatment



Gender and TB

Gender, human rights and TB are also inextricably linked, with women bearing the brunt of the burden of TB disease and also being more affected than men when they do develop TB.

For every case of new or relapse TB in men in 2014, four women developed TB. TB remains a leading cause of death among women, with more than 480 000 women dying of the disease in 2014 across the world, including 140 000 deaths among women who were HIV-positive.[71]

TB is most often found in women during their most economically active years. Women of reproductive age are more likely to develop active TB if they encounter TB bacteria, yet they are less likely to seek help for TB symptoms than men. This has an impact not just on their own health, but on the welfare of their family, especially their children.

Vulnerability to TB is related to women's unequal social status and economic dependence. In order for women to access health care services, they often have to overcome several other barriers. For example, women undertake multiple roles in reproduction and childcare, leaving them with less time to reach diagnostic, treatment and care services for TB.

Women often wait longer to seek diagnosis and treatment for TB, which can increase the severity of their illness, decrease the success of treatment, and raise the risk of TB being transmitted. Women may also be given less priority for health needs and often have less decision-making powers over the use of scarce household resources.

While men and women may both face TB-related stigma, women can also face lost marriage prospects, divorce, desertion and separation from their children. Gender-based inequality can also negatively affect women's ability to exercise and claim their human rights, including the rights to information, participation, freedom of movement, privacy and individual autonomy, and health.[72]

TB is also linked with poor reproductive health outcomes, such as risk of infertility, premature birth, obstetric morbidity and low birth weight. Infants born to women who have TB are six times more likely to die at birth and are twice as likely to be born prematurely or with a low birth-weight, when compared to women without TB.[73]

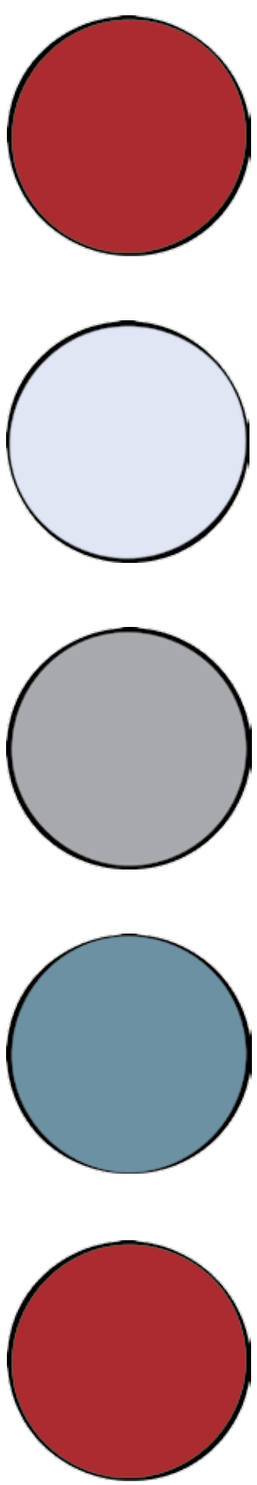
For every case of new or relapse TB in men in 2014, four women developed TB. Vulnerability to TB is related to women's unequal social status and economic dependence.

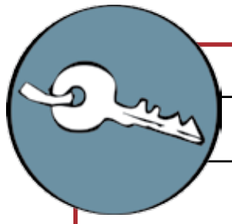
[71] *WHO, Global TB report 2015. Available at: http://apps.who.int/iris/bitstream/10665/191102/1/9789241565059_eng.pdf*
[72] *WHO, Guidelines for social mobilization: A human rights approach to TB (2001). www.who.int/hhr/information/A%20Human%20Rights%20Approach%20 to%20Tuberculosis.pdf.*

In Africa, TB rates are up to 10 times higher in pregnant women living with HIV than in pregnant women without HIV infection. TB among mothers living with HIV is associated with more than double the risk of vertical transmission of HIV to the unborn child. TB in pregnant women living with HIV increases the risk of maternal and infant mortality by almost 300%.[74]

TB disease in women can result in disordered menstruation, pregnancy complications, TB being transmitted to the infant and infertility. This is especially true for women who develop genital TB.

For women with both HIV and TB who wish to avoid an unintended pregnancy, potential drug reactions with anti-TB therapy can make the management of hormonal contraception more challenging.[75]





key points

Efforts to address TB must take account of social and medical factors specific to women, including:

Language and literacy: Women are less likely to be literate than men. They are less able to seek help or to understand printed medical information and may not have access to information about the care and treatment of TB.

Family responsibilities: Women wait up to twice as long to seek treatment as men experiencing the same symptoms. This may be because they have to stay at home looking after children, or are reluctant to use scarce family resources.

Confidentiality: Women may need a chaperone when going to an appointment or may have to explain where they are going. The stigma around TB can make them reluctant to seek help.

HIV: The majority of new HIV infections worldwide are occurring in women, increasing their vulnerability to TB.

Pregnancy and childbirth: While TB treatment is safe during pregnancy, maternal TB infection has been linked to complications such as premature birth, low birth weight and increased side-effects from TB treatment. TB is a leading infectious cause of death during pregnancy and delivery, especially among women living with HIV.

In Africa, TB rates are up to 10 times higher in pregnant women living with HIV than in pregnant women without HIV infection.

[73]WHO. Tuberculosis in Women Factsheet. 2013. Available at: http://www.who.int/tb/publications/tb_women_factsheet_251013.pdf
[74]WHO. Tuberculosis in Women Factsheet. 2013. Available at: http://www.who.int/tb/publications/tb_women_factsheet_251013.pdf
[75]http://www.whatworksforwomen.org/chapters/19-Preventing-Detecting-and-Treating-Critical-Co-Infections/sections/51-Tuberculosis

case study

Empowering women with knowledge to address TB

While the TB response has historically focused on addressing the medical factors which make people vulnerable to TB, very little research and consequent interventions have been developed to address the social factors that make women more vulnerable to TB and that increase their burden of the affects of TB, especially for child-bearing women.

One of the interventions which has been shown to empower women with TB with knowledge, resulting in improved health outcomes is the formation of Women's Groups (as done in rural Nepal) and/or TB groups (as done in northern Ethiopia).

In Nepal, women's groups, which work through participatory learning and action, improved maternal and newborn survival for women living with HIV and/or TB. Women in the groups met monthly, and a facilitator led them through a participatory action cycle intervention where teachers and learners engaged in dialogue, exchanging ideas and experiences.[76]

It was hoped that exchange within communities would enable a critical awareness of environmental, economic and social constraints to health improvement and communities would be motivated to act to improve their situation. This is different from traditional health education interventions that focus on transmission and learning of technical 'messages', but instead allowed for women to come to realisations about how they could best improve their health during pregnancy and childbirth and how they could prevent developing TB.[77]

The results showed that not only did the health outcomes of the women in the groups improve, participating in the groups also developed confidence, encourage women to disseminate information within communities, and increased community capacity to take action.[78]

Evidence from the implementation of TB clubs, made up mostly of women, aimed addressing the social determinant of health, by providing club members with psychosocial support and tools to address stigma and discrimination related to TB, resulted in improved understanding of TB and addressed misconceptions as to the cause and treatment of TB. It was also found that the TB club approach had a significant impact in improving women's adherence to anti-TB treatment and in building positive attitudes and practice in the community regarding TB.[79]

[76]Morrison J. Understanding how women's groups improve maternal and newborn health in Makwanpur, Nepal: a qualitative study. International Health 2 (2010) 25–35. 2010
[77]Ibid.
[78]Ibid.
[79]Demissie M. Community tuberculosis care through "TB clubs" in rural North Ethiopia. Social Science & Medicine Volume 56, Issue 10, May 2003

Way forward for activists and civil society

1. Advocate for commitment to address gender and TB

- Mobilise commitment in country policies and strategic plans to assure gender-equitable access, including women-friendly services to TB prevention, diagnosis, treatment, care and support.

2. Advocate for collaboration and integration of services.

- Advocate for TB, HIV, maternal, neonatal and child health programmes and primary care services to collaborate and integrate to maximise the entry point to TB care for women at all levels.
- Advocate for TB screening to be integrated into reproductive health services, including family planning and antenatal and postnatal services.

3. Advocate for better data collection regarding women

- Advocate for improved recording and reporting of TB data, to be disaggregated by sex and age, including for TB treatment initiation and outcomes.

4. Advocate for women-centered research and development

- Advocate for increased research for the development of new diagnostics and drugs, which take into account the specific needs of women living with HIV and pregnant and breastfeeding women.

People most affected by TB

Some groups of people who are more vulnerable to, or affected by TB are either:

- People at increased risk of TB because of other disease such as HIV or diabetes, or
- People who are vulnerable to TB because of their social and living conditions, behaviours or unsafe workplaces, such as health care workers, miners, migrants, prisoners or people living in poverty, or
- People who are underserved and have poor access to healthcare because of stigma, discrimination and access barriers, such as prisoners as prisoners and sex workers.

While there are number of groups who are most vulnerable to and affected by TB, this guide will focus on health care workers, miners, prisoners and migrants.

The average annual risk of developing TB disease is three times higher for HCWs (across all settings) compared to the general population.

Health care workers (HCWs)

A systematic review of TB incidence in low- and middle-income countries estimated the annual risk of TB infection in HCWs to range from 3.9% to 14.3% (mostly due to occupational exposure). The average annual risk of developing TB disease is three times higher for HCWs (across all settings) compared to the general population.

A delay in DR-TB diagnosis, less effective treatment for DR-TB, and longer periods of healthcare contact for people living with DR-TB, increase the potential for transmission of DR-TB strains to HCWs. Accordingly, HCWs are up to six times more likely to be hospitalised for DR-TB than the population they care for due to the nosocomial spread of TB. Furthermore, HCWs with DR-TB are diagnosed late and have poor treatment outcomes, even when HIV-uninfected.[80]

Health care workers are usually not compensated for the lack of income due to TB, even though their exposure to TB is inextricably linked to the occupational hazard of treating and caring for people who have TB, in settings with poor infection control.

Career implications of a TB diagnosis also play a role in discouraging disclosure and driving stigma. Health care work in developing countries is challenging and is usually coupled with low salaries and poor working conditions. Many HCWs who work in the public sector fear that if they complain about working conditions they could be fired or re-assigned. This prevents HCWs from disclosing their TB diagnoses and advocating for safer working conditions, thus fuelling the vicious cycles of misinformation, discrimination, and unchecked TB transmission in health facilities.[81]

Miners

The tuberculosis epidemic and elevated incidence related to the conditions that miners face in southern Africa has been well documented. The estimated TB incidence rate among gold mineworkers in South Africa is about 2500-3000 per 100,000 which exceeds by far the World Health Organisation (WHO) threshold for emergency which is 250 cases per 100 000 population.[82] The key groups affected are current and ex-miners and their families, and the communities around the mines and communities in the labour sending areas.

TB and silicosis often affects ex-mineworkers several years after leaving the mines. This poses a challenge of providing post-employment occupational health services to ex-mineworkers and their families, which needs to be addressed in the region.

The estimated TB incidence rate among gold mineworkers in South Africa is about 2500-3000 per 100,000 which exceeds by far the World Health Organisation (WHO) threshold for emergency which is 250 cases per 100 000 population.

[80] *Von Delft A. Why healthcare workers are sick of TB. International Journal of Infectious Diseases Volume 32, March 2015.*

[81] *Ibid.*

[82] *GFATM. TB in Mining Sector Regional Concept Note. January 2015*

key points

Risk factors for miners[83]

A combination of environmental and occupational risk factors explain the elevated risk of morbidity and mortality from TB among mineworkers:

Exposure to silica dust: Exposure to silica dust increases the risk of pulmonary TB, silicosis, pneumoconiosis, and other lung disease, particularly among gold mineworkers. Between 18 to 31% of gold mineworkers in South Africa and Botswana have scarring lesions characteristic of silicosis, which means that they are three times more likely to develop pulmonary TB compared to those without silicosis.[84]

Occupational conditions: Mineworkers work in crowded and poorly ventilated shafts and live in congested hostels. These conditions are highly conducive for TB infection as well as recurrent TB. A survey of a cohort of 600 mineworkers in South Africa found a rate of recurrent TB of about 8 per 100 person-years (as opposed to half of this rate or less in the general population) with 69% of the recurrent cases attributable to re-infection rather than relapse.[85]

Migration and HIV: Long absences from home leads to mineworkers and their families being highly vulnerable to HIV infection.[86] This leads to higher levels of HIV/TB co-morbidity among mineworkers.

Mobility and TB: The TB risk in the mines also impacts the surrounding communities since mineworkers with TB have a risk of transmission to the communities close to mines. Further, migration of mineworkers across regions within a country and across countries makes TB in the mining sector a complex regional problem. High rates of TB have been reported among ex-miners living in Swaziland, Lesotho, and Mozambique.

Efforts to address TB in the mining sector have accelerated in the last four years leading to the signing of the Southern African Development Community (SADC) declaration on TB in the mining sector in 2012; a framework for harmonised management of TB in 2014; and code of conduct on TB in the mining sector in January 2015. These policy documents set the context for delivering a regional TB response in the mining sector.

[83] *Ibid*
[84] *S. Basu et al., The Production of Consumption: Addressing the Impact of Mineral Mining on Tuberculosis in Southern Africa: Globalization and Health, 2009.*
[85] *S. Charalambous, et al., Contribution of Re-infection to Recurrent Tuberculosis in South Africa, a Study of Migrant and Nonmigrant Men and Their Partners (2008).*
[86] *L. Corno and D. de Walque, Mines, Migration and HIV/AIDS in Southern Africa, 2012.*

Prisoners have the right to the same level of medical care as that of the general community. Developing TB is not part of a prisoner's sentence. The level of TB in prisons is up to 100 times higher than that of the civilian population, according to the World Health Organisation.

Prisoners

Prisoners have the right to the same level of medical care as that of the general community. Developing TB is not part of a prisoner's sentence. The level of TB in prisons is up to 100 times higher than that of the civilian population, according to the World Health Organisation.[87] Cases of TB in prisons may account for up to 25% of a country's burden of TB, including high levels of drug-resistant TB.

Late diagnosis, inadequate treatment, overcrowding, poor ventilation and repeated prison transfers encourage the transmission of TB infection. HIV infection and other factors which are more common in prisons (such as malnutrition and substance abuse) encourage the development of active disease and the transmission of TB.

Prisons act as a reservoir for TB, spreading the disease into the rest of the community through staff, visitors and inadequately treated former inmates as TB does not respect prison walls. Improving TB prevention, treatment and care in prisons benefits the community at large.

Migrants

Migration as a social determinant of health increases TB-related morbidity and mortality for migrants and their communities along all migration pathways. There are risk factors for TB exposure, infection, transmission and poor outcomes throughout the migration process, including overcrowded poor living and working conditions, increased vulnerability to HIV infection, undernutrition, language barriers, lack of legal immigration status, migrant-unfriendly health services and a lack of awareness of entitlement to health services.

Migration as a social determinant of health increases TB-related morbidity and mortality for migrants and their communities along all migration pathways.

Among migrant workers with a legal status, their access to TB diagnosis and care is subject to contracts, work permits and ability to access health care services or insurance from the State or the employer. Undocumented migrants face challenges such as fear of deportation that limit their access to diagnostic and treatment services. Deportation while on treatment or poor adherence may lead to drug-resistant disease, poor outcomes and further spread of infection. Migrants in detention centres or trafficked persons often live in unhealthy conditions for extended periods of time, creating pockets of vulnerability to TB. Forced displacement of persons after conflict or a natural disaster is often associated with increased TB risk due to malnutrition, overcrowding in camps or other temporary shelters, treatment interruption from disruption of health services and risk of drug resistance.[88]

[87] *WHO. Tuberculosis in prisons. Available at: http://www.who.int/tb/challenges/prisons/story_1/en/*
[88] *International Organisation for Migration (IOM) and WHO. Tuberculosis Prevention and Care for Migrants. 2014. Available at: http://www.who.int/tb/publications/WHOIOM_TBmigration.pdf*

case study

Historic mine workers court case takes mining industry to court for silicosis and TB compensation[89]

Three legal teams are working to represent 69 miners are taking 32 mines (that make up the entire gold mining industry in South Africa) to court in the Bongani Nkala v Harmony Gold Mining Company Limited & Others case. They are applying to be allowed to bring a class action on behalf of all miners who have silicosis and tuberculosis as a result of their exposure to silica dust since 1965, and of the families of all miners who have died of silicosis and tuberculosis.

A class action is when the outcome of a court case brought by a smaller group of individuals applies to an entire population or group (known as a class). The main applicants are asking the court to certify two proposed classes, made up of all current and former gold mineworkers with silicosis and/or TB and the dependents of those who have died as a result of silicosis and/or pulmonary TB. These two classes represent more than 25 000 individuals, but the numbers who stand to benefit from the lawsuit is conservatively estimated to be between 100 000 and 200 000.

The mineworkers say the mines are to blame because they failed over the years to take steps to protect mineworkers against excessive levels of dust and the risks of silicosis and tuberculosis. Despite the death and serious injury of thousands of mineworkers over decades, the mining industry has provided little compensation to ill current or former mineworkers.

Two prominent activist groups in the region, the Treatment Action Campaign (TAC) and Sonke Gender Justice were granted permission to join the litigation as Amicus Curiae ("friends of the court") to provide evidence of the socio-economic and gendered impact of silicosis and TB to mine-sending communities.

Throughout this trial, activists continue to organise marches and pickets and gather outside the courthouse to support the miners in their struggle and will continue to do so as the case continues. The case is on-going.

[89] *Sonke Gender Justice and Treatment Action Campaign. Bongani Nkala v Harmony Gold Mining Company Limited & Others Factsheet. 2015. Available at: http://www.genderjustice.org.za/publication/bongani-nkala-v-harmony-gold-mining-company-limited-others/*

case study

TB in Zambian Prisons[90]

Prisoners in Zambia are affected by malnutrition, overcrowding, grossly inadequate medical care, and the risk of rape or torture, according to the Prisons Care and Counselling Association (PRISCCA), AIDS and Rights Alliance for Southern Africa (ARASA), and Human Rights Watch: three human rights organisation working together to address human rights violations of prisoners in Zambia.

The conditions in TB isolation cells are life-threatening, yet inmates who have completed TB treatment choose to continue sleeping in the cells with prisoners with active TB because they are less crowded than general population cells.

Medical care in the prison was non-existent when this advocacy started in 2009. The scenario was bleak: with the Zambia Prisons Service employing only 14 healthcare workers to serve 15 300 inmates, and only 15 of the country's 86 prisons had clinics or sick bays. Inmates were frequently turned away when accessing health facilities outside the prison based on the sole judgment of non-medical officers and most often challenges such as the lack of transportation and/or security fears on the part of prison officers, led to many injustices.

The groups called on the Zambian government and its partners to make immediate improvements in prison conditions and medical care, and the criminal justice system to respect the rights of prisoners and to protect public health. The groups released a report, which outlined their demands and used the media to draw attention to the issue.

Through the national advocacy efforts by partners, led by PRISSCA who have been working with government stakeholders, various reforms have been seen since the release of the report. The advocacy, both policy and community advocacy has led to prisoners being treated better and being able to access HIV and TB medicines. The issue of 'congestion' has been addressed by the Correctional Services in collaboration with the Ministry of Finance. These two departments have increased the prisons' budget in order to build more prisons. The advocacy is ongoing and pressure continues to be placed in the government of Zambia to continue these reforms.

[90] *Human Rights Watch, PRISCCA and ARASA. 2010. Unjust-and-unhealthy: hiv-tb-and-abuse-zambian-prisons. Available at: https://www.hrw.org/report/2010/04/27/unjust-and-unhealthy/hiv-tb-and-abuse-zambian-prisons*

Way forward for activists and civil society

1. Advocate for meaningful participatory planning and engagement of key populations in addressing TB in these groups

- Involve members of the community and those who work in the community when planning TB interventions
- Actively participate in the development of strategic plans, legislation and policies and country dialogue to ensure key affected populations' needs are addressed
- Involve peer community members in TB care delivery
- Eliminate discriminatory legal and administrative barriers
- Empower key population communities through social mobilisation and health communications

2. Advocate for health services that are tailored to the needs of Key Populations

- Advocate for additional services, including outreach and screening that are tailored to the needs of Key Populations.
- Advocate for innovative models of care delivery that are sensitive to the socio-cultural needs of Key Population groups.
- Highlight issues related specifically to Key Populations and share best practices
- Participate in epidemiological assessments to identify Key Populations, estimate size and burden
- Advocate for the sensitisation of health personnel and build cultural competency reflective of Key Population groups' TB needs.

3. Advocate for measures to address TB in migrants to be taken at country-level

- Advocate for the establishment of cross-border referral systems with contact tracing and information sharing to ensure continuity of care for migrants and harmonise treatment protocols across borders along migration corridors.
- Ensure policy coherence between health and non- health sectors, such as immigration and labour, to support migrant TB interventions within and across countries.
- Adopt policies and/or regulations which improve migrants' access to services, financial and social protection, regardless of status.
- Promote inclusion of TB in bilateral or regional agreements on migration with appropriate accountability; pursue innovative public-private partnerships.
- Pursue research, including on social determinants, new tools and intervention approaches, taking into account migrants' needs.

4. Advocate for the TB needs of HCW and miners to be addressed

- Improve infection control in health facilities, prisons and mine shafts and hostels.
- Ensure that employers take responsibility to ensure protective equipment (e.g. N95 masks) and the implementation of guidelines and standards for TB infection control in health facilities and mine shafts and hostels
- Education for all health care workers about the epidemiology, diagnosis, transmission and preventive measures
- Advocate for increased participation of health care workers in the development of institutional strategies to prevent TB transmission
- Advocate for progressive occupational compensation for HCW and miners

5. Advocate for the TB needs of prisoners to be addressed

- Advocate for improved infection control measures in prisons
- Advocate for regular TB screening upon admission to prisons, routinely during incarceration and at exit from the prison system.
- Advocate for, and monitor, the provision of prompt diagnosis, treatment and care of TB in all inmates.

Additional resources

Human rights documents

1. 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%20 Human%2 Rights.pdf
2. Declaration of Human Rights (1948) http://www.un.org/en/doc ments/udhr/
3. International Covenant on Economic, Social and Cultural Rights (1966) http://www2.ohchr.org/english/law/cescr.htm
4. International Covenant of Civil and Political Rights (1966). http:/ www2.ohchr.org/english/law/ccpr.htm
5. Committee on Economic, Social and Cultural Rights, General Comment No. 14 http://www.unhchr.ch/tbs/doc.nsf/(symbol) E.C.12.2000.4.En
6. Committee on Economic, Social and Cultural Rights, General comment No. 20 on non discrimination in economic, social and cultural rights, http://www2.ohchr.org/english/bodies/cescr comments.htm
7. Convention on the Rights of the Child (1989) http://www2.ohchr.org english/law/crc.htm
8. Convention on the Elimination of All Forms of Discrimination Against Women (1979) http://www.un.org/womenwatch/daw/cedaw/
9. International Convention on the Elimination of All Forms of Racial Discrimination (1963) http://www2.ohchr.org/english/law/cerd.htm
10. Convention on the Rights of Migrant Workers (1990) http://www2 ohchr.org/english/law/cmw.htm
11. Declaration of Alma Ata (1978) http://www.who.int/hpr/NPH/docs declaration _almaata.pdf
12. Siracusa principles: http://www1.umn.edu/humanrts/instree siracusaprinciples.html
13. Special Rapporteur on the Right to Health (2002): http://www2.ohchr org/english/issues/health/right/

TB-related documents

14. WHO Stop TB Strategy: http://www.who.int/tb/strategy/en/index html
15. Updated Global Plan to Stop TB, 2011-2015: http://www.stoptb.org/assets/documents/global/plan/TB GlobalPlanToStopTB2011-2015.pdf
16. Global Plan to Stop TB, 2006-2015: http://www.who.int/tb/features archive/global_plan_to_stop_tb/en/index.html
17. UNAIDS Strategy (including TB/HIV): http://www.unaids.org/en media/unaids/contentassets/documents/unaidspublication/2010/ C203 4_UNAIDS_Strategy_en.pdf
18. Patients' Charter for TB Care: http://www.who.int/tb publications/2006/patients_charter.pdf
19. Social determinants and TB: http://whqlibdoc.who.int publications/2010/9789241563970_eng.pdf
20. Poverty and TB: http://www.who.int/tb/challenges/poverty/en/index.html
21. TB in Prisons: http://www.who.int/tb/challenges/prisons/en/index html
22. TB care and control in refugees and displaced populations: http:/ www.who.int/tb/challenges/refugees/en/index.html
23. Women and TB: http://www.who.int/tb/womenandtb.pdf
24. Union statement on TB among undocumented migrants: http://www.theunion.org/images/stories/download/guide Undocumented-migrants-
25. Statement_2008.pdf
26. Guidelines for social mobilization. A human rights approach to TB: http://www.who.int/hhr/information/A%20Human%20Rights%2 Approach%20to%20Tuberculosis.pdf
27. Community involvement in TB: http://www.who.int/tb/people_and communities/involvement/resources/en/index.html
28. Active engagement of civil society organizations
29. http://whqlibdoc.who.int/hq/2010/WHO_HTM_TB_2010.15_eng.pdf
30. Policy guidelines for collaborative TB and HIV services for injecting and other drug users http://www.who.int/hiv/pub/idu/tb_hiv/en index.html
31. WHO guidance on human rights and involuntary detention for xdr-tb control http://www.who.int/tb/features_archive/involuntary treatment/en/index.html
32. Principles for the Greater Involvement of People with TB (GIPT) http://www.worldcarecouncil.org/content/greater-involvement people-tb-gipt
33. Guidance on ethics of tuberculosis prevention, care and control http://whqlibdoc.who.int/publications/2010/9789241500531_eng.pdf Health and Human Rights documents
34. WHO Health and Human Rights/Department of Ethics, Equity, Trade and Human Rights: www.who.int/hhr/
35. HIV and human Rights: http://data.unaids.org/Publications IRC-pub07/jc1252-internguidelines_en.pdf http://www.unaids.org en/PolicyAndPractice/HumanRights/20070601_reference_group_
36. TB/HIV and human Rights: http://data.unaids.org/pub ExternalDocument/2010/20100324_unaidsrghrtsissuepapertbhrts en. pdf

Summary of way forward for activists and civil society

This is a summary of the Calls to Action for each section of this Guide. More details can be found within the Call to Action of each section.

TB and Human Rights:

- Conduct law and policy review and reform to ensure that human rights principles are upheld
- Monitor and evaluate proposed interventions using human rights principles
- Advocate for the provision of legal services for people affected by TB and vulnerable groups
- Advocate for and implement programmes to reduce stigma and discrimination

Criminalisation of TB:

- Document cases of human rights violations regarding the criminalisation of TB
- Advocate for increased accessibility, availability, acceptability and quality of community-based treatment and care of TB, especially in the case of drug-resistant TB.
- Advocate for the integration of drug-resistant TB into community-based work
- Access to TB prevention, treatment and care:
- Monitor funding made available for TB and HIV interventions and advocate for increased funding (including global and domestic funding)
- Monitor and advocate for the implementation of TB prevention and care methods for people living with HIV
- Advocate for countries to use compulsory licensing to increase the production of generic TB vaccines, diagnostics and treatment

TB and Gender:

- Advocate for commitment to address gender and TB
- Advocate for collaboration and integration of services
- Advocate for better data collection regarding women
- Advocate for women-centered research and development

People most affected by TB:

- Advocate for meaningful participatory planning and engagement of key populations in addressing TB in these groups
- Advocate for health services that are tailored to the needs of Key Populations
- Advocate for measures to address TB in migrants to be taken at country-level
- Advocate for the TB needs of HCW and miners to be addressed
- Advocate for the TB needs of prisoners to be addressed