


HIV and tuberculosis: ensuring universal access and protection of human rights



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The UNAIDS Reference Group on HIV and Human Rights (the Reference Group) is an independent, advisory body, established in 2002 to advise the Joint United Nations Programme on HIV/AIDS (UNAIDS) on all matters relating to HIV and human rights. The Reference Group is composed of individuals from many different perspectives with a common commitment to, and expertise in, the area of HIV and human rights. The views of the Reference Group are independent of UNAIDS and do not necessarily reflect the views of the Secretariat or the Cosponsoring Organizations of UNAIDS.

Defining the issue

1. Like HIV/AIDS, tuberculosis (TB) transmission, prevention, treatment, care and support have long raised, and continue to raise, a wide range of human rights concerns. Persons who lack an adequate standard of living, including individuals in detention, are more vulnerable to TB infection and the spread of the disease. Underinvestment and structural gaps in health systems lead to delayed diagnosis that can increase TB transmission and lead to increased morbidity and mortality, as well as lead to the development of drug resistance and the spread of drug resistant TB. Legal and social barriers to accessing care prevent adequate and equitable treatment for socially marginalized groups including the poor,¹ migrants, indigenous peoples, people living with HIV, people who inject drugs, women, children and prisoners. Compulsory treatment measures, including forced quarantine and isolation, deprive patients of their liberty, privacy and may worsen their health status. Stigma and discrimination impinge on the lives of those affected by the disease.
2. The close connection between HIV and TB epidemics magnify and complicate the human rights issues involved. HIV and TB are so closely connected that they are often referred to as co-epidemics. The epidemics drive and reinforce one another: HIV activates dormant TB in persons, who then develop active disease and have the potential to spread the TB bacillus to others. People living with HIV progress from TB infection to disease and death more frequently and rapidly than those who are not HIV infected. TB accounts for an estimated 23% of AIDS deaths worldwide.² The risk for TB is 20 to 37 times greater in people living with HIV and in some countries in sub-Saharan Africa up to 80% of patients with TB have HIV.²
3. Even when on anti-retroviral treatment people living with HIV are six times more likely to die of TB than those without HIV.² HIV greatly increases the complexity of diagnosis and treatment, especially in children. People living with HIV are at greater risk for developing multi-drug resistant TB (MDR-TB). Infection with both HIV and TB also increases the risk of stigma and discrimination, which further exacerbates risk of death. A global standard of care exists for the prevention, diagnosis and treatment of HIV related TB,³ but universal access to this minimum basic package of interventions is still far from being achieved.²
4. A human rights approach to HIV – based on human rights standards and principles such non-discrimination in access to education, right to information, protection from arbitrary or mandatory interventions, and participation in planning, programming, monitoring and evaluation by those affected – has been promoted since virtually the beginning of the epidemic. A rights-based approach to HIV-related TB, on the other hand, has largely been neglected. Consideration of HIV/TB-related human rights issues is critical to the protection of the human rights of people living with HIV.

This document seeks to set out the major human rights concerns associated with HIV/TB, paying particular attention to how the specific transmission dynamics of TB result in distinct, but often overlapping, human rights concerns as HIV infection.

Human rights issues associated with TB transmission and prevention

5. **Right to an adequate standard of living:** International human rights law establishes certain basic economic, social and cultural rights, the absence of which sparks transmission of infection and breakdown to disease. The Universal Declaration of Human Rights (UDHR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) describe a right to an adequate standard of living that includes food, clothing and housing, and the improvement of living conditions.⁴ Such housing must protect inhabitants from “cold, damp, heat, rain, wind or other threats to health, structural hazards, and disease vectors.”⁵ The ICESCR further recognizes the right of everyone to the highest attainable standard of health, and notes that environmental hygiene and the prevention, treatment, and control of epidemic diseases are a key step in the realization of this right.⁶

When these rights are not met, and individuals live and work under crowded, unsanitary and inadequate conditions, the spread of TB is fuelled. Malnutrition, poverty and crowding have been long associated with increased TB rates and increased risk of TB transmission. Recent studies have also found that minority race/ethnicity, immigration, and low income are all strong risk factors for the disease.⁷

6. **Inadequate conditions of detention and imprisonment:** As in impoverished communities generally, conditions in detention settings, commonly characterized by over-crowding, poor ventilation, inadequate sanitation and nutrition, and lack of access to health care, exacerbate the spread of TB. While international human rights law creates standards for the treatment of individuals held in detention,⁸ these standards are not always met. Lengthy pre-trial detention periods and high rates of incarceration can be linked to higher TB prevalence at a population level.⁹
7. **Poor infection control and vulnerability to infection in health care settings:** Because people living with HIV (as well as diabetics, smokers, people with alcohol dependency, and malnourished people) may have suppressed immune systems and are frequently in contact with health care settings, poor TB infection control practices increase their risk of TB infection, including the risk of infection with primary drug resistant TB. HIV-infected health care workers are at particular risk of TB infection, especially DR-TB,¹⁰ further burdening shortages of health personnel. Committing increased resources to infection control in low-resource settings is essential to decreasing the spread of communicable disease including TB.¹¹

8. **Inadequate access to effective TB preventive therapy:** Isoniazid preventive therapy (IPT) is effective at reducing the risk of tuberculosis in people living with HIV by up to 60%,¹² yet less than 1% of all people living with HIV received IPT in 2007.²

Human rights issues associated with TB diagnosis and treatment

9. **Access to effective diagnosis:** Late detection of TB can lead to unchecked transmission and poorer health outcomes. Early diagnosis and treatment of TB is especially important for people living with HIV, however, effective diagnosis in people living with HIV is particularly challenging and stigmatizing attitudes towards HIV often extend to TB in settings where co-infection is prevalent. In 2007, only 2.2% of people living with HIV were screened for TB.¹³ While there is a need to expand TB diagnosis, it is important to include provisions for patients to receive adequate information and counseling and to take measures to obtain consent and maintain confidentiality. Additionally, TB diagnostic technologies are antiquated and less effective for individuals with compromised or immature immune systems, including people living with HIV and children.¹⁴ Diagnosis in people living with HIV can be particularly challenging as they are more likely to have smear-negative TB (where the test for TB is negative despite the presence of TB disease) or extra-pulmonary TB (TB outside of the lungs), which cannot be diagnosed with a sputum test. Access to effective diagnosis may also be hindered by the catastrophic direct and indirect costs associated with seeking care, as well as by the large indirect costs of maintaining treatment or seeking MDR-TB treatment where effective programs have not yet been launched. Rights abuses are also associated with harmful or unsafe prescribing practices in the public and private sectors, in part due to poor regulation enforcement or lack of regulation, as well as to inappropriate incentives for antibiotic sales.
10. **Equal access to treatment:** All individuals have the right to enjoy the highest attainable standard of health. The ICESCR requires States to take steps individually and through international cooperation to progressively realize this right via the prevention, treatment, and control of epidemic diseases and the creation of conditions to assure medical service and attention to all.¹⁵ Additionally, the treaty's monitoring committee has noted that States must immediately eliminate discrimination of any kind in the realization of this right.¹⁶ The committee has also proclaimed that "[S]tates are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants, to preventive, curative and palliative health services."¹⁷

Despite these protections, challenges remain in ensuring the rights of all individuals to equal access to TB treatment.¹⁸ Both international and internal **migrants** often face official discrimination in accessing TB treatment. One study

examined access to diagnosis and treatment in 28 high-income countries, finding that full access in some countries was only available to those in prison, was conditioned on registration, or required private payment.¹⁹ Even while many countries report free access to care, in reality barriers still exist.²⁰ In China, for example, a country with one of the highest TB burdens in the world, lack of awareness of TB among migrant communities, slow diagnosis, low referral, and social factors including gender, age, educational attainment, and migration status are associated with delayed TB diagnosis.²¹

Indigenous peoples suffer from disproportionately high TB rates compounded by low access to prevention, diagnosis, and treatment services. Inadequate housing and nutrition, overcrowding, and limited access to health services place indigenous peoples at significantly higher risk of TB infection and death than surrounding non-indigenous populations.²² The Canadian Inuit community, for example, faces tuberculosis rates 90 times higher than the non-aboriginal Canadian-born population.²³ Indigenous peoples have a right to traditional medicines and to their own health practices, as well as a right to access all social and health services without discrimination.²⁴ However, indigenous peoples often face significant geographical, cultural, and financial barriers to accessing and completing TB treatment. The Pan American Health Organization has recommended a reorientation of existing health care models to consider ethnic, linguistic, epidemiological, and social diversity, and the implementation of new care models where there are no existing health services.²⁵

People who inject drugs are another group that is both especially vulnerable to HIV and TB infection – and increased mortality if infected – and faces particular challenges in accessing treatment.²⁶ Compared to the general population, people who inject drugs were at higher risk of infection and progression to TB disease prior to the emergence of HIV, and HIV has only served to increase the TB burden among them. TB in people who inject drugs is further compounded by the fact that many of them are in prison, where overcrowding and poor infection control are rampant. People who inject drugs often lack access to health care, including antiretroviral treatment, and imprisonment, poverty, homelessness, and public and political hostility all serve to further impede access to care.²⁷ WHO, UNAIDS, and UNODC have recognized the challenges people who inject drugs face in accessing treatment and have advised equal and improved TB services for them both in and out of prison settings.²⁸

Women also suffer from serious HIV/TB-related morbidity and mortality, and face heightened barriers to obtaining treatment. Although TB notification rates have been historically higher in men than women, 50% of reported cases of extra-pulmonary TB were in women.²⁹ Research on TB and TB/HIV and their impact on women reveal that women are less likely to produce positive sputum samples and more likely to have extra-pulmonary TB and/or be co-infected with HIV. Women also experience longer delays in diagnosis, both due to under

detection of TB in women by health care providers and patient delays in seeking treatment. Women also report financial concerns that affect their health-seeking behavior, such as a reluctance to expend resources that could be used for their families on their own health care. Social challenges are particularly acute in ensuring women equal access to TB diagnosis and treatment. Women are disproportionately subject to stigma and discrimination when diagnosed with TB, undergoing divorce, desertion, or separation from their children.³⁰

Children are highly susceptible to TB. The power to resist TB infection is normally poor in the first 5 years of life. The resistance can be further reduced by malnutrition, HIV, other childhood infections, and worm infestations – all too common childhood conditions in low-income countries. An estimated 20 to 50% of children who live in households where an adult has active TB become infected. Children are especially vulnerable to infection from household contacts as they are often held close and breathed on. The risk is particularly high in low- and middle-income countries where family size is generally large, living quarters are crowded, and more than half the population is children. Diagnosis is difficult in children, and often fatally delayed – early symptoms and signs of TB in children are common and easily missed. Pulmonary TB is particularly difficult to diagnose early in children, as children’s lungs react differently than adults, and they have little or no cough (thus not being able to provide sputum for testing) and, even if produced, microscopical examination only occasionally reveals the characteristic tubercle bacilli. TB can have devastating long term effects on children who can be left deaf, blind and/or totally paralysed from TB meningitis, even after it is cured. Spread of infection to the bone can cause deformities of the spine (hunchback) or other permanent disabilities. Children with TB also lose out in the vital years of their education, which can affect their future wage-earning capacity, and may lose parents and caregivers to TB and/or HIV.³¹

Other populations face even greater obstacles: **incarcerated individuals** are unable to access medication unless it is provided to them, and TB is omnipresent in prisons.³² With mortality rates as high as 24%, TB is among the main causes of death in prisons in low- and middle-income countries generally³³ and prison health care systems in these countries are often unable to ensure appropriate TB detection and treatment.³⁴ Even where TB and MDR-TB treatment programmes are available in prisons, continuity of care upon release is often inadequate. Lack of appropriate release planning and linkages to care, treatment, and support often result in discontinuation of TB treatment upon release, with severe consequences both for the detainees and for the communities to which they return.

Certain occupations also come with markedly increased risks of TB. Examples include **health care workers** and **mineworkers**. Employers in both industries

have failed to adequately address occupational exposure risks and to ensure treatment and appropriate compensation for occupational infection.

11. **Structural gaps in health care and drug resistant TB:** In addition to the threat of drug sensitive TB to people living with HIV, the increasing prevalence of drug resistant forms of TB in recent years has potentially devastating public health consequences. Multi-drug resistant TB (MDR-TB) is resistant to two of the four first-line anti-TB drugs,³⁵ while extensively drug resistant TB (XDR-TB) increases the number of drugs to which patients are resistant to include fluoroquinolones and any of the second-line anti-TB injectable drugs.³⁶ An estimated 500,000 people fell ill with MDR-TB worldwide in 2006³⁷ and XDR-TB has been identified in all regions of the world.³⁸

The emergence of MDR- and XDR-TB is closely connected to the failure to ensure appropriate access to care to poor and marginalized populations. High treatment interruption rates during patients' initial courses of drugs and resulting low cure rates – which lead to the development of drug resistance – may derive from inappropriate initial drugs, dosage, or duration of treatment regimens; poor case management; lack of or delayed drug susceptibility testing; insufficient support (cost, transportation, education); programmatic issues such as irregular drug supplies and undertrained personnel; and patient malabsorption or poor adherence.³⁹ As MDR-TB arises from the mismanagement of TB, XDR-TB emerges through mismanagement of MDR-TB treatment.⁴⁰ Also, delays in diagnosis and treatment and treatment interruptions can result in the primary transmission of drug resistant TB.

Structural gaps and low treatment adherence leading to the development of drug-resistant TB affect some developing countries at a significantly greater rate than their developed country counterparts: Approximately half of adults in South Africa with active TB are cured annually, considerably lower than rates achieved elsewhere.⁴¹

12. **Access to HIV treatment:** As has been recently demonstrated, widespread availability of antiretroviral treatment (ART) for HIV has the potential to significantly decrease new cases of TB, predominantly in the HIV-infected population.⁴² Thus, access to ART plays a key role in global efforts to reduce TB — and particularly drug-resistant TB — morbidity and mortality. Like TB treatment, ART is subject to significant barriers to access, particularly among vulnerable populations, and committing increased resources to ART provision in low-resource settings will be essential to efforts to improve outcomes related to both diseases. Essential to achieving greater access to HIV treatment will be the expansion of HIV testing programs generally, and especially in TB clinics, while ensuring that such programs respect rights and ensure confidentiality, counseling, and informed consent.⁴³

13. **Compulsory treatment-related measures:** The UDHR establishes the right to liberty of person,⁴⁴ and provides that “[n]o one shall be subjected to arbitrary arrest, detention or exile”⁴⁵ or to arbitrary interference with privacy, family, home, or correspondence.⁴⁶ The ICCPR echoes these provisions.⁴⁷ But, under some circumstances human rights may be limited, and recently a debate has been waged in the public health community over whether compulsory measures may legitimately be used in cases of drug-resistant TB in accordance with the Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights.⁴⁸ Compulsory measures including involuntary treatment, compulsory medical examination, compulsory quarantine, and isolation of infected persons have been proposed as justified under international human rights law in cases of drug-resistant TB.⁴⁹

Yet such limitations, while plausible in theory, may be unnecessary and could be dangerous and thus should be considered very carefully by the government in question and by international community.⁵⁰ In the past, isolation provisions instituted by government authorities have been criticized for failure to comply with human rights law provisions.⁵¹ Current isolation of patients infected with drug-resistant TB in South Africa is has been the subject of similar criticism, and provides an example of how, in practice, the requirements set by Siracusa for limitations on the patients’ rights to liberty, privacy, and family life may not be met.⁵² Experts working in the field have noted that detention is not central to combating MDR-TB, instead citing needed improvements in infection control, increases in decentralized treatment mechanisms, increased treatment literacy, a patient-centered approach and community supports, coupled with an increase in development of new drugs and diagnostics.⁵³ Resource constraints in particular have led to arbitrary and discriminatory detention, particularly in Southern Africa, often resulting in higher rates of detention for migrant and impoverished DR-TB patients.

Investment in TB, stigma and discrimination

14. **Low overall investment in TB:** The UNAIDS Programme Coordinating Board has called for significantly increased investment in TB control programs, in particular to prevent further development and spread of drug-resistant TB.⁵⁴ The UN Secretary-General’s Special Envoy to Stop TB has decried the “woefully inadequate” current investment in TB control, surveillance and research.⁵⁵ Increased worldwide investment is necessary to the full implementation of a rights-based approach to TB transmission and treatment.
15. **Stigma and discrimination:** Stigma and discrimination (strictly prohibited by international law⁵⁶) have been associated with TB, sometimes because of a perceived link between TB infection and HIV status.⁵⁷ Fear of infection is also a major cause of TB-related stigma.⁵⁸ Such fear of infection and resulting stigma are acute in the context of drug-resistant TB.⁵⁹ Stigma and discrimination can have devastating effects on the lives of affected individuals and on households,

as well as negative public health consequences, as they may lead people not to seek testing or treatment and may negatively impact adherence to treatment. Efforts and interventions to decrease stigma surrounding both HIV and TB, including among health care workers, and to bolster anti-discrimination laws and their enforcement, are essential to a rights-based approach to TB and HIV.

Lessons learned from the HIV response

16. **Engagement of communities:** Community-based organizations have been at the forefront of HIV prevention and treatment advocacy efforts,⁶⁰ raising awareness, challenging stigma, teaching HIV prevention techniques, and offering treatment and psychosocial services to patients and support to caregivers.⁶¹ The importance of empowering communities and community-based organizations has been a crucial lesson learned about creating effective public health responses and ensuring government accountability.⁶² UNAIDS has in particular noted the importance of this strategy in reaching the most hard-to-reach, and most at-risk, populations.⁶³
17. **Emphasis on treatment literacy:** In the context of HIV, treatment education to individuals and communities has proved to be an essential complement to drug regimens and medical care. Knowing one's HIV status, obtaining access to treatment, adhering and supporting others to adhere to treatment, and understanding the benefits of HIV treatment, the importance of maintaining protective behaviors, and the negative role played by stigma, discrimination, and gender inequality are all necessary to preparing people for treatment and allowing both individuals and communities to fully understand the issues related to HIV treatment.⁶⁴ Treatment education aims to encourage more widespread voluntary counseling and testing; increase knowledge of ART, anticipate treatment-related costs; advocate for increased access to treatment; provide support to individuals on ART; continue protective behaviors; reduce HIV-related stigma and discrimination; and connect prevention, care and treatment services.⁶⁵ Individual and community treatment education is vital to the full realization of the benefits of ART treatment, to decreasing stigma, and to the success of HIV prevention and treatment programmes generally.⁶⁶
18. **Rethinking of approaches:** The HIV/AIDS epidemic has highlighted the importance of rethinking traditional responses to disease management and devising new solutions tailored to the particular public health challenge. For example, the HIV/AIDS response has found that programmes that respect human rights are ultimately the most successful in achieving impact and that, particularly in the context of stigmatized diseases and socially marginalized communities, attention must be paid to the broadest array of civil, political, economic and social rights.⁶⁷ The AIDS and Rights Alliance of Southern Africa and Human Rights Watch, as well as other human rights organizations, have emphasized the crucial importance of policy and legal frameworks to protecting individuals living with or vulnerable to HIV infection, and have

documented the consequences when these protections are violated. In particular, human rights organizations have illustrated the relationship between vulnerability and freedom of expression, association, and the right to seek, receive and impart information; the right to be free from violence and the rights of non-discrimination and equitable access to health care; the right to livelihood and property; in addition to the right to health and the determinants of health to achieve impact on HIV.⁶⁸ Rethinking past approaches to disease management, and carefully considering new proposals which address both structural barriers and human rights in the context of the specific social and epidemiological context of the disease, are essential lessons learned from the HIV/AIDS response.⁶⁹

Recommendations

19. **Engage communities:** Community engagement and peer education can serve to both change social attitudes toward disease and to improve home care and individual treatment literacy. UNAIDS and WHO should continue and expand help to governments to augment existing community education campaigns geared toward raising TB awareness, reducing stigma, increasing treatment literacy, and educating vulnerable populations about their rights. Global bodies should also support the efforts of community groups to participate in the development and contribute to the implementation of TB and TB/HIV policies that impact them. Support for community representation in TB global forums, such as the working groups of the Stop TB Partnership, the UNITAID board, the Global Fund support delegation and the WHO's Strategic and Technical Advisory Group, is important, as are efforts to involve communities in advocacy at the national level to change policies or improve their implementation, monitor government commitments and raise TB/HIV in the media.

20. **Decrease barriers for vulnerable populations:** Despite the equal right of all individuals to enjoy the highest attainable standard of health without discrimination, particular challenges still exist for migrants, indigenous peoples, people who inject drugs, women, children, and incarcerated individuals in accessing TB diagnosis and treatment. Aiding governments in eliminating all legal barriers hindering access by these populations to treatment, as well as providing support for the development of programmes specifically aimed at increasing treatment among these populations, is necessary for the achievement of non-discriminatory access to care. Programmes aimed at increasing TB treatment and decreasing TB prevalence in these populations could include TB education specifically geared toward and conducted in relevant communities (using culturally and linguistically appropriate methods); health system strengthening in serving vulnerable populations; creation of new care models for areas where health services do not exist or are inadequate (especially expanding outreach and mobile services); improvement of diagnostic capacity for TB in children; and improved conditions and health care systems in prisons. Occupational health protections are required that minimize

the transmission of TB in working environments; and functional treatment and compensation systems are necessary.

21. **Close structural gaps in health care:** To effectively address HIV/TB access to care for poor and marginalized populations is essential, particularly in countries where drug-resistant TB is most prevalent. WHO and UNAIDS should work to support governments, donors and other key stakeholders, in ensuring supplies of appropriate medicines, increasing capacity and numbers of trained personnel with the ability to diagnose and prescribe initial medicines, providing technical support and ensuring adequate financial support for case management and patient support in adhering to treatment, and expanding the ability to provide adequate TB diagnostic services, such as timely drug susceptibility testing. Additionally, WHO and UNAIDS should promote measures to guarantee socio-economic support to patients on treatment – particularly those whose treatment would prevent them from pursuing normal daily activities – as a means of enhancing rates of adherence to treatment.
22. **Improve infection control and access to TB screening and prevention for people living with HIV:** Poor TB infection control practice in health care settings exposes people living with HIV and others to greater likelihood of TB infection. Supporting governments in developing infection control protocols and planning for increased resources to institute better infection control in low-resource settings is a key component of decreasing TB transmission to risk groups. Access to TB screening and IPT for people living with HIV needs to be scaled up rapidly in line with the Global Plan to Stop TB.
23. **Avoid compulsory treatment-related measures:** Successful community-based MDR-TB and XDR-TB treatment in Lesotho, Peru, Russia and elsewhere indicate that the bar for limiting a patient's human rights in the context of TB treatment must be set very high. WHO and UNAIDS need to affirmatively work with governments to ensure that they do not resort to compulsory treatment-related measures except in exceptional cases, where patients resist treatment after all feasible programmatic solutions have been exhausted, and where proper checks, balances, and safeguards are ensured. Rights-respecting treatment approaches recommended by WHO must be promoted in countries worldwide as the most effective course of action in TB and drug-resistant TB treatment.
24. **Eliminate inadequate conditions of detention and lengthy pre-trial detention:** WHO and UNAIDS should support governments in developing policies, allocating adequate funding, and taking all necessary steps to ameliorate conditions of detention, so as to minimize overcrowding, improve ventilation and sanitation, and meet international standards. Furthermore, WHO and UNAIDS should proactively work with governments to ensure that rights violations including lengthy pre-trial detention do not leave individuals jailed, and subject to significant health risks, for long periods prior to a determination

of guilt. Instituting appropriate release planning and linkages to community-based care are also key to maintaining the health of former prisoners and to ensuring that TB is appropriately treated so drug resistance does not develop and to prevent TB transmission to the community upon release.

25. **Increase overall investment in TB:** Global investment in HIV and TB control and treatment worldwide is currently inadequate. Advocating for increased funding for rights-based approaches to HIV and TB, and reprioritizing HIV/TB as a major issue for donors, international agencies, and governments worldwide, is a crucial role that UNAIDS and the WHO may play in combating this global epidemic.

ENDNOTES

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