

ACTIVATING A HUMAN RIGHTS-BASED TUBERCULOSIS RESPONSE

A Technical Brief for Policymakers and Program Implementers



Activating a Human Rights-Based Tuberculosis Response: A Technical Brief for
Policymakers and Program Implementers

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This group photo was taken during *A Human Rights-Based Response to TB: A Legal Workshop* conducted jointly by the Global Coalition of TB Activists, the Stop TB Partnership, and the Northwestern Pritzker School of Law Center for International Human Rights in Hyderabad, India, November 2019 as a side-event during the 50th Union World Conference on Lung Health.

The concept of a human rights-based response to tuberculosis (TB) is relatively new. The century-old, medicalized approach to TB did not consider the rights of the individual in planning the response.

Of late, there has been recognition and a push towards a people-centered, rights-based TB response. We are all beginning to recognize the need to help communities affected by TB understand their rights and to build their capacity around this. Important documents have been developed on what human rights are in the context of TB and for capacity building of communities by TBpeople, ACT! Asia Pacific, and other groups.

But, this Technical Brief is the first to provide guidance directly to policymakers and national TB programs to promote their understanding of human rights in the context of TB and to improve the interventions and programs accordingly.

This Brief is envisaged as a living document. We welcome the opportunity to modify and improve it as the global TB response changes and develops.

The Global Coalition of TB Activists (GCTA) remains committed to leading the efforts to ensure communities affected by TB are central to all national plans and to ensure the voices and lived experiences of people affected by TB shape the global response.

We are extremely grateful to our members from South Africa and India who shared their experiences through interviews for this Brief. And we would also like to thank Prof. Brian Citro and his team for working with us to develop and write this document.

With this Brief, we hope that policymakers, national TB program implementers, and communities affected by TB can come together to plan and implement interventions that uphold the dignity and human rights of all people affected by TB.

Blessina Kumar
CEO of the Global Coalition of
TB Activists



I am writing this in early June 2020, working from home, during the most incredible, unreal, and heartbreaking times of my life. Mounting COVID-19 deaths, global lockdowns, the fear of a second wave of COVID, millions of people without jobs who are terrified for the future, police killing innocent people, racism, human rights abuses, protests, riots ... With this, I fear that all the progress we have made in promoting and protecting the rights of people affected by tuberculosis (TB)—reducing stigma, improving access, promoting equity—all seem to be rolled back by many years. Against this backdrop, I want to bring this point to your attention: the TB response must be people-centered, rights-based, and gender sensitive. And we want everyone to understand that enhancing the evidence base for TB and human rights and sensitizing TB stakeholders is critical if we are to achieve the United Nations High-Level Meeting on TB commitments, including ending stigma and removing discriminatory laws.

Human rights are a priority for us in the Stop TB Partnership. What I am told from the community delegation of our Board, and from the country-level work partners, is that it is human rights issues, like stigma and discrimination, inadequate psychosocial support, or services that are not or cannot be accessed by TB key populations, that are the number one priority for people affected by TB. So, in Stop TB we really want to do what we say and, as a result, human rights features in our *Global Plan to End TB 2018-2022*. We developed community, rights, and gender investment packages, conducted 12 country assessments on human rights barriers to universal TB access, piloted community-led monitoring through a special app, Onelmpact, in 10 countries. We have also championed initiatives including the *Nairobi Strategy on TB and Human Rights*, the *Declaration of the Rights of People Affected by TB*, the Right to Breath training module, the TB Stigma Assessment, and rights-based guidance on TB legislation. And we host an ongoing TB and human rights discussion group. But we did not do this work alone. All of these initiatives have been undertaken, supported, or led by TB affected communities and networks of people affected by TB.

At Stop TB, we have worked closely with our colleagues at the Global Coalition of TB Activists (GCTA) for many years. Most recently, we joined with GCTA and the Northwestern Pritzker School of Law to conduct a training of lawyers on this very topic. It therefore comes naturally to partner with the GCTA, with Blessina Kumar, and Brian Citro, and all our friends in the TB community, for GCTA's *Activating a Human Rights-Based TB Response* initiative.

It is important that GCTA takes forward this important initiative to continue building the momentum and move human rights from an outlying theme to a foundation pillar of all TB policies and interventions. Without the promotion and protection of human rights, without overcoming barriers to access, and without empowering TB survivors and people affected by TB, we will never end this epidemic. I call on us all to commit to advance human rights to end TB.

Lucica Ditiu
Executive Director of the Stop
TB Partnership



Executive Summary

A human rights-based TB response supports and enhances public health measures and good clinical practice. The approach is founded on the dignity and autonomy of people affected by TB and the critical role they must play in all aspects of the disease response. A rights-based approach places special focus on TB key and vulnerable populations, it demands a gender-sensitive response, and it leverages existing law at international, regional, and national levels to strengthen the response. This includes the rights to health, nondiscrimination, privacy & confidentiality, information, liberty, and others. Respect for these human rights promotes the health and well-being of individuals and, in doing so, protects the public's health.

Human rights are at the core of the World Health Organization (WHO) *End TB Strategy*, the United Nations (UN) *Political Declaration on the Fight against TB*, and the Stop TB Partnership *Global Plan to End TB 2018-2022*. The third principle of the *End TB Strategy* calls for the "[p]rotection and promotion of human rights, ethics and equity." The UN *Political Declaration* commits countries to a "comprehensive response ... that addresses the social and economic determinants of the epidemic and that protects and fulfils the human rights and dignity of all people." And the *Global Plan to End TB 2018-2022* declares that, to end TB, national governments must "[t]ransform the TB response to be equitable, rights-based and people-centred, with proactive efforts to reach key populations."

Right to Health

The right to health encompasses a wide range of entitlements and freedoms to promote the highest attainable standard of physical and mental health for all. Access to good quality health facilities, goods, and services—on a nondiscriminatory basis—is a core component of the right to health and an obligation of every government. This means that people affected by TB have a right to good quality vaccines, drugs, and diagnostics to prevent, diagnose, and treat latent TB infection, TB disease, and drug-resistant TB. It also means that people affected by TB have a right to access health facilities where they can obtain good quality, people-centered care from trained health care workers, including at the community level when appropriate.

The right to health is firmly established in law around the world. The Universal Declaration of Human Rights and six international treaties establish the right to health. Four regional treaties recognize the right to health. And the right to health is enshrined in 136 national constitutions, such as the constitutions of Brazil, Colombia, South Africa, and Thailand.

Fulfilling the right to health for people affected by TB will lead to better individual and public health outcomes. Making sure the best vaccines, diagnostics, and treatments are available and accessible for people affected by TB means national TB programs must stay up-to-date with global recommendations and ensure they are financially and technically capable of procuring and incorporating new technologies into their programs and interventions. National TB programs must also make economic and

psychosocial services available and accessible to people affected by TB who need them during treatment, including nutritional support, cash assistance, and counselling. Ensuring TB services and facilities are of good quality and are available and accessible to people affected by TB also means governments and national TB programs must identify and remove all barriers to services and facilities and provide people-centered TB care.

Studies show that even when treatment is provided free of charge by national TB programs, physical and financial burdens reduce access to treatment. These include the cost of drugs and tests obtained from private providers, the distance and cost of transportation to clinics, and income loss from interruptions or loss of employment. Evidence also demonstrates that directly observed therapy (DOT) is associated with financial barriers to treatment, as well as stigma and discrimination against people with TB. Other research shows that DOT, itself, can be a barrier to treatment adherence.

Research also reveals that system-level barriers impede access to treatment for both drug-sensitive and drug-resistant TB treatments. These include shortages of first-line TB drugs, monopolistic pricing of new drugs under patent, and operational challenges, such as the need for advanced technical capacity and infrastructure for new technologies. Abundant evidence also demonstrates that accessing the best available diagnostics and treatments is especially difficult for TB key and vulnerable populations, such as prisoners and mobile and migrant populations.

Right to Be Free from Discrimination

The right to be free from discrimination prohibits both direct and indirect discrimination against people affected by TB based on their actual or perceived health status in both the public and private spheres. This includes health care settings, employment, education, housing, family, immigration, and access to social security and public entitlements. The right to nondiscrimination also prohibits discrimination against TB key and vulnerable populations, such as mobile and migrant populations, people living with HIV, people who use drugs, prisoners, and women, who are often stigmatized or denied care because of their social or legal status.

The right to be free from discrimination is widespread in law around the world. The *Universal Declaration of Human Rights* and seven international treaties prohibit discrimination. Six regional treaties establish the right to be free from discrimination. And 147 national constitutions protect against discrimination, such as the constitutions of Afghanistan, India, Kenya, and Peru.

Discrimination is closely related to and often the result of TB-related stigma. Stigmatizing language perpetuates and fuels discrimination of people affected by TB and of key populations who are most vulnerable to TB. Research demonstrates that discrimination against people affected by TB is widespread, touching upon all aspects of life, including health care, employment, education, housing, and the family. And evidence shows that stigma and discrimination against people affected by TB have grave consequences, with especially damaging, and qualitatively different, impacts for women. Stigma and discrimination lead to delayed diagnosis and treatment

initiation; challenges in treatment adherence; increased expenses associated with testing and treatment; loss of income and employment; difficulties finding and maintaining housing; interruption of education; disruptions to personal relationships and difficulties in forming families; and diminished social status and quality of life, including poor mental health.

Right to Privacy & Confidentiality

The right to privacy & confidentiality comprises the right to keep personal health information private. This means that people affected by TB have the right to privacy in all matters related to their health, including whether they have TB infection or disease. Revealing, sharing, or transferring personal health information—electronically or otherwise—is only permissible when done with the informed consent of the individual and for the purposes of their care or to protect public health. Personal health information collected, stored, transferred, or processed during public health measures, such as public health surveillance and case notification systems, may be shared or transferred without the person’s informed consent only if it is done in an anonymous manner without the person’s name or any other personally identifiable information. To ensure that digital data containing personal health information of people affected by TB is kept confidential and secure in accordance with the right to privacy & confidentiality, public health programs, research institutions, and health care providers must proactively implement robust safeguards within all electronic information systems.

The right to privacy & confidentiality is established in law around the world. The *Universal Declaration of Human Rights* and four international treaties establish the right to privacy. Six regional treaties recognize the right to privacy. And 175 national constitutions protect the right to privacy, such as the constitutions of Brazil, Ethiopia, Nigeria, and Pakistan.

Protecting the right to privacy & confidentiality of people affected by TB, including during public health surveillance, active case finding, screening, contact tracing, and case notification, combats stigma and discrimination and encourages health-seeking behavior, thereby protecting public health. By contrast, the failure to recognize and protect privacy & confidentiality discourages people affected by TB from seeking testing and starting treatment, as they may fear stigma and discrimination and the social and economic consequences that follow. This, in turn, endangers public health by promoting the spread of disease. Evidence from around the world confirms that people affected by TB have serious concerns about their privacy & confidentiality and that there are negative consequences from the failure to protect privacy & confidentiality in health care, employment, and education settings. Despite this, a review of the national guidelines for the control, management, and treatment of TB in six countries that accounted for approximately 50% of all new TB cases in 2017 shows that only one country, South Africa, recognizes privacy or confidentiality of people affected by TB in health care settings.

Right to Information

The right to information comprises the right to seek, receive and communicate information. This means that people have the right to information about TB that is readily available, easily accessible, and understandable. All information about TB must be gender- and culturally-sensitive, imparted in a non-technical manner, in a language understood by the person receiving it, by trained counselors, including people who have themselves survived TB. This includes information about TB infection and disease, including prevention, symptoms, disease transmission, infection control, the duration of infectiousness, drug-resistance, and that TB is a curable disease. The right to information also includes information about TB prevention, testing, and treatment services—i.e., “treatment literacy.”

The right to information is established in law around the world. The *Universal Declaration of Human Rights* and five international treaties recognize the right to information. Six regional treaties establish the right to information. And 94 national constitutions enshrine the right to information, such as the constitutions of Malawi, the Philippines, South Sudan, and Venezuela.

Fulfilling the right to information for people affected by TB promotes health-seeking behavior and protects public health. Studies from around the world show that a lack of information on TB infection and disease, including about symptoms and how the disease spreads, puts people at higher risk for TB disease; erects barriers to services; contributes to delays in seeking care; causes people to self-medicate and hide their illness; and reduces treatment adherence. Evidence also demonstrates that a lack of knowledge about TB treatments negatively affects treatment access, adherence, and completion. A systematic review of trials and observational studies found that education and counseling for people with TB were associated with higher rates of treatment adherence, treatment completion, and cure. And several studies have found that peer counseling, sometimes combined with other interventions, improves TB treatment adherence and outcomes, including among adolescents and people who use drugs.

Right to Liberty

The right to liberty protects people affected by TB from arbitrary or discriminatory detention, including for involuntary isolation or treatment. Involuntary detention, hospitalization, or isolation of a person with TB is a deprivation of liberty in all cases. In accordance with the right to liberty, involuntary isolation is only permissible as a measure of last resort, in narrowly defined circumstances, for the shortest duration possible, and only to protect the public’s health—never as a means of convenience or punishment. Forced treatment of people with TB during involuntary isolation or hospitalization, or under any other circumstances, is never ethically justified and, in all cases, is a violation of human rights.

The right to liberty is established in law around the world. The *Universal Declaration of Human Rights* and five international treaties recognize the right to liberty. Six regional

treaties establish the right to liberty. And 150 national constitutions enshrine the right to liberty, such as the constitutions of Argentina, Mali, Papua New Guinea, and Uganda.

Protecting the right to liberty of people affected by TB promotes improved individual and public health outcomes by encouraging health-seeking behavior and reducing stigma. Despite this, there is a lack of national laws and policies that explicitly protect the right to liberty in the context of TB and that establish clear rules and guidelines for the rare circumstances when involuntary isolation is permissible. Moreover, involuntary isolation has grave social, economic, and physical and mental health consequences for people affected by TB and their communities. The UN Special Rapporteur on the Right to Health has explained that “[c]onfinement as a response to tuberculosis increases stigmatization of people with the disease, driving those most at risk underground and away from health care.” People isolated because of TB may be unable to earn income or they may lose their employment entirely, leading to negative financial consequences for themselves and their families. Confinement of people with TB may also exacerbate existing social inequalities and disadvantages. Evidence shows that people detained due to TB are more likely than other people with TB to come from socially disadvantaged groups, including the homeless, mobile and migrant populations, people living with HIV, people who use drugs, people with mental illness, and racial or ethnic minorities. Research also demonstrates that people confined due to TB are likely to experience stigma and social exclusion from their communities, friends, and families. And research shows that prolonged isolation for drug-resistant TB treatment induces feelings of fear, anger, self-blame, depression, and suicide.



Objectives

The objective of this Technical Brief is to provide clear and actionable guidance to tuberculosis (TB) policymakers and program implementers on how to activate a human rights-based TB response. To this end, this Brief presents a set of action-guiding recommendations. It then outlines the contours of a human rights-based TB response. Finally, it highlights five vital human rights, explaining their content and legal foundations, and presenting extensive evidence for the critical role they must play in the disease response.

Methodology

This Technical Brief was developed and written based on extensive desk research, key informant interviews conducted with people affected by TB and TB health care providers, and prior field work in Azerbaijan, India, Nigeria, and Tajikistan. The questionnaires used to conduct the key informant interviews are available in the Appendix. The institutional knowledge and experience of the organizational authors also contributed greatly to the development of the content and recommendations in the Brief. These include the Global Coalition of TB Activists, the Stop TB Partnership, the Northwestern Pritzker School of Law Center for International Human Rights, and the Northwestern University Access to Health Project.

Note on Language

This Technical Brief uses the inclusive term “people affected by TB” to refer to any person with TB disease or who previously had TB disease, as well as their caregivers and immediate family members, and members of TB key and vulnerable populations, such as children, health care workers, indigenous peoples, people living with HIV, people who use drugs, prisoners, miners, mobile and migrant populations, the rural and urban poor, and women.

20 Recommendations to Activate a Human Rights-Based TB Response

These 20 recommendations for TB policymakers and program implementers provide concrete guidance to activate a human rights-based TB response. The recommendations are based on extensive desk research, field work, key informant interviews, and the institutional knowledge and experience of the organizational authors. In particular, the evidence presented in the *Five Vital Human Rights in the Fight against TB* section of this Brief provides direct support for these recommendations.

Right to Health

To realize the right to health and ensure the availability and accessibility of good quality TB services to all who need them, policymakers and program implementers should:

1. **Create a TB Technologies Task Force** to stay up-to-date on global recommendations, coordinate financial and technical resources to procure and quickly integrate into the national TB program the best available vaccines, diagnostics, and drugs for latent TB infection, drug-sensitive TB disease, and all forms of drug-resistant TB;
2. **Eliminate intellectual property and patent barriers** to ensure the affordability of new TB technologies, including vaccines, drugs, and diagnostics, in line with the UN *Political Declaration on the Fight against TB* through the use of “flexibilities” in the World Trade Organization’s (WTO) *Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS Agreement)*, as reaffirmed in the *WTO Doha Declaration*, such as:
 - a. Compulsory licensing and government use for production of generic technologies;
 - b. Parallel importation of generic or more affordable branded technologies;
 - c. Pre- and post-grant patent challenges, including by third parties and on the basis of public health and accessibility concerns; and
 - d. Heightened criteria for patent eligibility, including demonstration of enhanced therapeutic effect for derivatives of known substances;
3. **Review and develop a national strategy to identify and eliminate all physical, financial, systemic, gender-related, and other barriers** to TB health facilities, TB vaccines, TB diagnosis, and TB treatments, paying special attention to country-specific TB key and vulnerable populations, such as children, health care workers, indigenous peoples, mobile and migrant populations, people living with HIV, people who use drugs, prisoners, the rural and urban poor, and women; and

4. **Engage and empower communities of people affected by TB to undertake community-led monitoring** on the availability, accessibility, and quality of TB services.

Right to Be Free from Discrimination

To protect people affected by TB against discrimination, policymakers and program implementers should:

5. **Explicitly prohibit, in law and policy, all forms of discrimination** against people affected by TB, in the public and private sectors, including, but not limited to, the health care, employment, education, housing, family, and detention settings;
6. **Review, revise, and replace all stigmatizing language** in all TB-related laws, policies, regulations, national strategies, guidances, and other documents with non-stigmatizing, compassionate language that respects the dignity and autonomy of people affected by TB, based on the Stop TB Partnership's *United to End TB—Every Word Counts: Suggested Language and Usage for Tuberculosis Communications*;
7. **Mandate and provide recurring training for all TB health care providers on people-centered care** to eliminate stigmatizing or discriminatory treatment in health care facilities, including in prisons and detention centers; and
8. **Undertake a national TB stigma assessment** to establish a baseline measurement of stigma experienced by people affected by TB and to develop targeted interventions to reduce and eventually eliminate TB-related stigma and discrimination.

Right to Privacy & Confidentiality

To recognize and protect the right to privacy & confidentiality of people affected by TB, policymakers and program implementers should:

9. **Recognize and protect the right to privacy & confidentiality** for people affected by TB in all TB-related laws, policies, regulations, national strategies, guidances, and other documents, for all matters related to their health, including whether they have TB infection or disease, during the provision of health care and during all public health measures, such as surveillance, screening, active case finding, and contact tracing activities;
10. **Require all TB health care providers and program implementers to obtain explicit informed consent** prior to collecting, sharing, or transferring any personal health information—electronically or otherwise—of people

affected by TB, including in prisons and detention centers;

- a. Personal health information collected, stored, transferred, or processed during public health measures, such as public health surveillance, screening, active case finding, contact tracing, and case notification, may be shared or transferred among authorized officials without a person's informed consent only if it is done in an anonymous manner without the person's name or any other personally identifiable information and in accordance with the safeguards for digital privacy and security outlined in Recommendation 11;

11. *Design and implement policies, protocols, and practices for digital privacy and security* within electronic information systems used by TB health care providers, public health programs, and research institutions, including, but not limited to:

- a. Encrypted and password protected electronic platforms installed on all computers and devices used in the system;
- b. Clear protocols for who may enter, access, process, transmit and dispose of data within the system;
- c. Anonymized data with a coded, unique identifier system that strip data of all personal identifiers, whenever possible given the nature of the activity for which the data has been collected and is being used;
- d. Secure in-house servers or use of cloud storage services that guarantee the security, accessibility and longevity of data storage;
- e. Secure data transmission methods through the use of private networks or, when using public networks, by use of data encryption, such as Hypertext Transfer Protocol Secure (https), and Virtual Private Networks (VPNs);
- f. Crypto-shredding practices that render data unreadable by deliberately overwriting or deleting data encryption keys when disposing of data;
- g. Employing information technology (IT) professionals to monitor electronic systems, address and repair problems and breaches, and ensure security and privacy measures are upgraded and up-to-date as technology and practices evolve;

12. *Review and supplant all physical infrastructure that intrudes upon privacy & confidentiality* of people affected by TB, such as signs that say "tuberculosis" or "TB", in all TB health and program facilities, including directly observed therapy (DOT) centers and clinics in prisons and detention centers; and

13. *Recognize and protect the right to privacy & confidentiality in employment, education, and housing settings* for people affected by TB for all matters related to their health, including whether they have TB infection or disease, unless the information is strictly required, based on laboratory evidence, for their own safety or the safety of others in their workplace, school, or housing complex.

Right to Information

To protect people affected by TB against discrimination, policymakers and program implementers should:

14. ***Design, mandate, and provide training for all TB health care providers on the provision of gender- and culturally-sensitive information*** to people affected by TB about TB infection and disease, and treatment literacy, including in prisons and detention centers;
15. ***Establish, recruit, and activate a workforce of professional psychosocial counselors*** and ensure counselors are present and available in all TB health facilities, including DOT centers and clinics in prisons and detention centers; and
16. ***Establish, recruit, and activate a workforce of peer-to-peer counselors*** comprised of TB survivors to support people undergoing TB treatment and ensure the peer-to-peer counselors are present and available in all TB health facilities, including DOT centers and clinics in prisons and detention centers.

Right to Liberty

17. ***Develop and implement a human rights-based, people-centered policy for isolation and involuntary isolation or hospitalization*** of people with TB through national law and policy, in accordance with the WHO Ethics Guidance for Implementation of the End TB Strategy;
18. ***Create an independent national body comprised of physicians, legal, ethics, and human rights experts, and TB survivors*** to hear and decide all requests by health care providers to involuntarily isolate or involuntarily hospitalize people with TB, and allow the person with TB to participate with legal representation in the adjudication;
19. ***Explicitly prohibit the involuntary isolation or involuntary hospitalization of people with TB in prisons*** or other detention centers, instead requiring all isolation and hospitalization to occur in a medically appropriate setting; and
20. ***Establish in national law and policy the right of people affected by TB to appeal in a court of law*** all decisions related to involuntary isolation or involuntary hospitalization.

Introduction to a Human Rights-Based TB Response

A human rights-based TB response supports and enhances public health measures and good clinical practice. The approach is founded on the dignity and autonomy of people affected by TB and the critical role they must play in all aspects of the disease response. A rights-based approach places special focus on TB key and vulnerable populations, it demands a gender-sensitive response, and it leverages existing law at international, regional, and national levels to strengthen the response. This includes the rights to health, nondiscrimination, privacy & confidentiality, information, liberty, and others. Respect for these human rights promotes the health and well-being of individuals and, in doing so, protects the public's health.



Respect for human rights protects public health.

Prof. Brian Citro, Northwestern Pritzker School of Law (USA)

Human rights are at the core of the World Health Organization (WHO) *End TB Strategy*, the United Nations (UN) *Political Declaration on the Fight against TB*, and the Stop TB Partnership *Global Plan to End TB 2018-2022*. The second and third Principles of the End TB Strategy call for a “[s]trong coalition with civil society organizations and communities” and the “[p]rotection and promotion of human rights, ethics and equity,” respectively. In the UN *Political Declaration*, the Heads of UN Member States commit to a “comprehensive response ... that addresses the social and economic determinants of the epidemic and that protects and fulfils the human rights and dignity of all people.” Finally, the *Global Plan to End TB 2018-2022* declares that, to end TB, national governments must actively engage TB survivors, affected communities, and civil society to “[t]ransform the TB response to be equitable, rights-based and people-centred, with proactive efforts to reach key populations.”



The importance of human rights is about the patient's identity—you don't stop being a person just because you have TB. You belong to a family. You still have to work. You have rights.

Dr. Thiloshini Govender, King Dinuzulu Hospital (South Africa)

In 2019, people affected by TB mobilized and launched the global *Declaration of the Rights of People Affected by TB* [1]. Led by TBpeople, sponsored by the Stop TB Partnership, and recognized by Director-General of the WHO and the Executive Director of the Global Fund to Fight AIDS, TB and Malaria (The Global Fund), the Declaration presents and contextualizes a comprehensive set of

human rights critical to the fight against TB. In doing so, it represents the first such declaration of rights by people affected by disease and it lays the foundation for the content of a rights-based TB response.



Rights are a power that already exist. They're there for me to claim. We're not asking for a special right or something new. We just want to take advantage of what's already there in the constitution and elsewhere.

Prabha Mahesh, ALERT India and Touched By TB (India)

In addition to these strategies, several tools now exist to better understand and promote the role of human rights, gender, and community in the TB response. The Stop TB Partnership's Integrated Community, Rights, and Gender Assessment (CRG Assessment) combines a legal environment assessment, gender assessment, and data framework for action on key and vulnerable populations into one, integrated tool [2]. National TB programs and civil society organizations have jointly conducted CRG Assessments in 12 countries, with assessments ongoing in three more countries. National TB programs and partners have leveraged the results of the CRG Assessments to develop costed action plans and investment packages and to launch a national framework for a gender-responsive approach to TB. The Stop TB Partnership has also developed and piloted the OneImpact digital platform to support community-led monitoring initiatives in 10 countries, to monitor the availability, accessibility, and quality of TB services at the country level [3].



In order to take care of the people who get sick with TB, we must protect their rights.

Dr. Jennifer Furin, Harvard Medical School (USA)

The Stop TB Partnership, in collaboration with the WHO, the United States Agency for International Development (USAID), the Global Fund, and civil society organizations from around the world, has also developed the TB Stigma Assessment [4]. The TB Stigma Assessment uses qualitative and quantitative methods to assess the extent and ways in which TB-related stigma acts as a barrier to services and to support the development of targeted interventions to reduce and eliminate stigma.

In 2016, the Global Fund launched the Breaking Down Barriers Project in 20 countries to provide intensive support to develop and implement a comprehensive human rights response as part of national HIV and TB responses [5]. In-country assessments were conducted to: identify human rights- and gender-related access barriers to HIV and TB services; highlight existing efforts to address barriers that could be strengthened and scaled-up; and reveal gaps

in human rights programming to recommend comprehensive, costed responses. Based on the outcome of the assessments and multi-stakeholder meetings, the countries led the process to develop multi-year responses to eliminate human rights- and gender-related barriers in TB and HIV.

5 Vital Human Rights in the Fight Against TB



In prison, you're in the midst of hundreds of people, but you feel you are all alone. There was no support or care when I got sick with TB. Nothing favored me. Everything was against me.

Karabo Rafube, Preacher and Prisoners' Rights Activist (South Africa)

This section introduces five human rights that are vital to the fight against TB. First, it explains their content and scope. It then shows their widespread establishment in international, regional, and national law. Finally, it highlights the evidence for why we must respect, protect, and fulfill each right in order to support and enhance the TB response, improve the health and well-being of people affected by TB, and protect public health.

Right to Health

The right to health encompasses a wide range of entitlements and freedoms to promote the highest attainable standard of physical and mental health for all. Access to good quality health facilities, goods, and services—on a nondiscriminatory basis—is a core component of the right to health and an obligation of every government. This means that people affected by TB have a right to good quality vaccines, drugs, and diagnostics to prevent, diagnose, and treat latent TB infection, TB disease, and drug-resistant TB. It also means that people affected by TB have a right to access health facilities where they can obtain good quality, people-centered care from trained health care workers, including at the community level when appropriate. The right to health also requires policymakers and program implementers to pay special attention to TB key and vulnerable populations, such as children, mobile and migrant populations, people living with HIV, the rural and urban poor, prisoners, and women, who often face greater barriers than others to good quality services.



It took more than a year of taking the wrong drugs—and I lost my hearing—before I was correctly diagnosed with XDR-TB. Overall, I had a 3 years and 8 months long, grueling experience with TB.

Phumeza Tisile, TB Proof (South Africa)

■ *Legal Recognition of the Right to Health*

The right to health is firmly established in law around the world. The *Universal Declaration of Human Rights* and six international treaties

establish the right to health, including the *International Covenant on Economic, Social and Cultural Rights* and the *Convention on the Rights of the Child*. Four regional treaties recognize the right to health, including the *African Charter on Human and Peoples' Rights* and the *American Declaration of the Rights and Duties of Man*. And the right to health is enshrined in 136 national constitutions, such as the constitutions of Brazil, Colombia, South Africa, and Thailand [6].

■ *The Evidence: Why We Must Fulfill the Right to Health*

Fulfilling the right to health for people affected by TB will lead to better individual and public health outcomes. Making sure the best vaccines, diagnostics, and treatments are available and accessible for people affected by TB means national TB programs must stay up-to-date with global recommendations and ensure they are financially and technically capable of procuring and incorporating these technologies into their programs and interventions. National TB programs must also make economic and psychosocial services available and accessible to people affected by TB who need them during treatment, including nutritional support, cash assistance, and counselling. Ensuring TB services and facilities are available, accessible, and of good quality also means national TB programs must identify and remove all kinds of barriers to services and facilities and provide people-centered TB care.

“

Going to the clinic every day for DOT was unnecessary and time-consuming. I had to wait for water to take my meds. I even had to share a cup sometimes. And the clinic was always too full of people in the morning. It interrupted everyone's lives.

Phumeza Tisile, TB Proof (South Africa)

In 2018, three million people with TB—30% of all people who fell sick that year—were not notified [7]. These “missing millions” likely could not access good quality TB diagnosis or treatment. Thus, despite the recent diagnostic and therapeutic advances and new global recommendations, outlined here below, almost one third of people who get sick with TB lack access to basic testing and treatment.

In order to provide good quality, people-centered TB care at the level of prevention, the WHO now recommends short-course regimens for preventive therapy. These include three months of once-weekly isoniazid plus rifapentine, or three months of daily rifampicin plus isoniazid [8]. The WHO also conditionally recommends a one-month regimen of daily rifapentine plus isoniazid and a four-months regimen of daily rifampicin alone, as alternatives [8]. These regimens represent shorter, more effective treatments to daily isoniazid treatment for

latent TB infection and prevention of TB disease.

People-Centered Care

The WHO defines people-centered health services as an approach to care that “consciously adopts the perspectives of individuals, families, and communities ... [to] respond to their needs and preferences in humane and holistic ways ... [and to ensure they] have the education and support they need to make decisions and participate in their own care.”

Service Delivery and Safety, WHO, <https://www.who.int/servicedeliverysafety/areas/people-centred-care/ipchs-what/en/> (last visited May 13, 2020).

Good quality, people-centered TB care also requires universal access to new, improved diagnostic technologies to find people with TB, identify drug-resistance, initiate appropriate treatment, and prevent the spread of the disease. Sputum smear microscopy—still the dominant diagnostic method—has very low sensitivity, resulting in false negatives and missing as many as half the people who are sick with TB. It also cannot detect drug-resistance [9]. The risk of a false negative is especially high for children [10] and people living with HIV, both vulnerable populations for TB disease [11].



My diagnosis for extrapulmonary TB was quite delayed in the private sector. I expected better service from private providers, but I was proven wrong.

Dr. R. Gopa Kumar, Uniworld Foundation and Touched By TB (India)

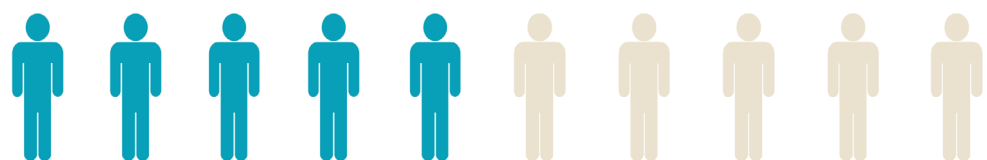
The WHO now recommends the use of rapid molecular assays—Xpert MTB/RIF and Xpert MTB/RIF Ultra (Cepheid Inc.) and Truenat MTB and MTB-RIF Dx (Molbio Diagnostics Pvt. Ltd)—as initial tests to diagnose TB and rifampicin-resistance for all people at risk of the disease, at all ages [12]. The WHO also recommends the use of rapid second-line probe assays for people with confirmed rifampicin-resistant or multidrug-resistant TB to detect additional resistance to second-line drugs [13].¹ And the WHO recommends the lateral flow urine lipoarabinomannan assay (LF-LAM)—Determine TB LAM Ag (Abbott Laboratories)—for the diagnosis of active tuberculosis in people living with HIV [14].

And, in March 2020, The Global Fund’s Expert Review Panel for Diagnostics (ERPD) approved two real-time molecular tests for the rapid detection of TB and resistance to rifampicin and isoniazid—the

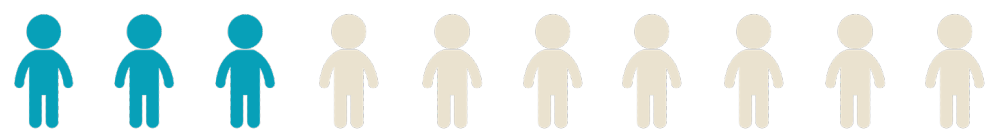
¹ Detection of resistance to several second-line drugs used in priority regimens for treatment of drug-resistant TB, including bedaquiline, linezolid, clofazimine, and delamanid, however, requires use of phenotypic culture-based methods.

Abbott RealTime MTB and MTB RIF/INH tests (Abbott Laboratories) and the BD MAX MDR-TB test (Becton, Dickinson and Company) [15]. The Global Fund’s ERPD approval operates as an interim mechanism on the way potential WHO endorsement, and it allows countries to use The Global Fund funding to procure approved diagnostics.

Unfortunately, very few advances have been made in more than 50 years to the six months-long treatment of drug-sensitive TB [16]. However, in 2019, the WHO released new guidelines for the treatment of multidrug-resistant TB that, for the first time ever, recommend “all-oral,” shorter regimens using new and repurposed medications. Providing good quality, people-centered TB care requires that national TB programs procure and integrate these new medicines for all people who need them. Among other things, the WHO now recommends a shorter—9 to 12 months—all oral regimen with the new drug bedaquiline as a superior replacement for injectable drugs; an older, repurposed antibiotic, linezolid; and a fluoroquinolone (levofloxacin or moxifloxacin) [17]. The WHO also recommends the use of another new medicine, delamanid, for treatment of multidrug-resistant TB [17]. Also, in 2019, the United States Food and Drug Administration (FDA) approved a new three-drug, six months regimen to treat highly-resistant or treatment intolerant forms of TB with bedaquiline, linezolid, and the new drug pretomanid [18].



Less than 50% of people living with HIV receive TB preventive therapy.



Less than 30% of children under 5 who are household contacts of people diagnosed with TB receive TB preventive therapy.

(WHO Global TB Report, 2019)

However, despite these recent advances and global recommendations, new TB drugs and regimens remain largely unavailable and inaccessible to people who need them. Significant gaps exist in reaching the groups recommended by the WHO for preventive therapy. In 2018, for example, less than 50% of people living with HIV received preventive TB treatment and less than 30% of children under 5 who were household contacts of people with TB received preventive therapy [7]. And these data reflect use of isoniazid preventive therapy, as data are not yet

available for the new therapies. Globally, only 22% of people with new or relapse TB were diagnosed using a rapid diagnostic in 2018, and only 15 of the 48 WHO TB high-burden countries used a rapid diagnostic as the initial test for more than half the people diagnosed with TB in their country [7].

Serious barriers also exist to the new TB drugs bedaquiline and delamanid. Along with challenges to technical program capacity, both drugs are on patent and priced too highly by their manufacturers for many national TB programs, despite the fact that bedaquiline was developed with the use of public funds [19][20]. Also, they are not even registered for use in many countries, though some countries are eligible for waivers [19][21][22][23][24]. This is especially concerning for bedaquiline, which is strongly recommended as a Group A drug for treatment of multidrug-resistant TB to replace painful injectables that cause hearing loss. In fact, as of September 2019, only 4 of the 30 countries that accounted for more than 95% of all people with rifampicin-resistant or multidrug-resistant TB had replaced injectables with bedaquiline in their treatment regimens [25]. And while 500,000 people fell ill with rifampicin-resistant TB in 2018 (78% with multidrug-resistant TB) [7], as of March 2020, 150,000 courses of bedaquiline had been procured from the Global Drug Facility via a donation program, but only 24,620 have been used [26]. In other words, only 16% of bedaquiline procured through the Global Drug Facility has been provided to the people with drug-resistant TB who need it.

Ensuring people affected by TB can access health facilities for good quality, people-centered treatment not only entails procuring and equitably distributing enough of the best available drugs and diagnostics. It also requires identifying and removing a wide range of barriers people face accessing clinics, diagnosis, and treatments. Importantly, studies show that, even when tests and medications are provided free of charge in public clinics, financial and physical burdens reduce access to TB services. These include the cost of tests and drugs obtained from both public and private providers, the distance and cost of transportation to clinics, and income loss from interruptions or loss of employment [27][28][29][30][31][32][33].

Many studies also demonstrate that directly observed therapy (DOT) is associated with financial barriers to treatment and stigma and discrimination against people with TB [34][35][36][37][38]. Further evidence shows that DOT, itself, can be a barrier to treatment adherence [36][39].

Other research reveals that system-level barriers also impede access to treatment for both drug-sensitive and drug-resistant TB treatments. Alarming shortages of first-line TB drugs, such as isoniazid and rifampicin, have occurred around the world, including in high-

income countries like Australia and the United States of America [40][41][42][43][44]. New technologies recommended for diagnosis and treatment of drug-resistant TB are often unavailable and inaccessible due to a host of factors. These include high costs from monopolistic pricing of drugs under patent [19][23][24]; operational challenges, such as the need for advanced technical capacity and infrastructure for new technologies [45][46][47][48]; the failure of pharmaceutical companies to invest sufficiently in more expensive, resource-intensive later stage clinical trials to complete safety and efficacy testing [49][50]; the failure of pharmaceutical companies to register new drugs in countries that need them [21][24]; and a lack of prompt guidance or recommendations on the use of new technologies from global authorities, including the WHO [51].

Abundant evidence also demonstrates that accessing the best available diagnostics and treatments is especially difficult for TB key and vulnerable populations. For example, studies indicate that prisoners often do not receive screening for TB upon entry, they are often not tested or provided good quality treatment for TB when they need it, and they do not receive continuity of care upon their release or transfer to a new facility [52][53][54][55][56][57][58]. This is due, among other things, to a lack of financial support and training for health staff, deficient medical infrastructure, shortages of TB drugs, and a lack of screening and diagnostic tools [59]. Evidence also shows that mobile and migrant populations very often lack access to timely diagnosis and treatment for TB due to a host of factors, including their immigration or legal status, language and cultural barriers, policies requiring identity documents to access services, fear of law enforcement, and a lack of awareness of available services [60][61][62][63][64][65].

Right to Be Free from Discrimination



I know so many people who are suffering from TB, but they don't want to get tested. Stigma starts right there.

Prabha Mahesh, ALERT India and Touched By TB

The right to be free from discrimination prohibits both direct and indirect discrimination against people affected by TB based on their actual or perceived health status in both the public and private spheres. This includes health care settings, employment, education, housing, family, immigration, and access to social security and public entitlements. The right to nondiscrimination also prohibits discrimination against TB key and vulnerable populations, such as mobile and migrant populations, people living with HIV, people who use drugs, prisoners, and women, who are often stigmatized or denied care because of their social or legal status. Unless explicitly mentioned, protection against disease-

based discrimination falls under the prohibition against discrimination based on “other status” or “any status” in many treaties, constitutions, and legislation [66].

■ *Legal Recognition of the Right to Be Free from Discrimination*

The right to be free from discrimination is widespread in law around the world. The *Universal Declaration of Human Rights* and seven international treaties prohibit discrimination, including the *International Covenant on Economic, Social and Cultural Rights* and the *Convention on the Elimination of All Forms of Discrimination against Women*. Six regional treaties establish the right to be free from discrimination, including the *European Convention on Human Rights* and the *Arab Charter on Human Rights*. And 147 national constitutions protect against discrimination, such as the constitutions of Afghanistan, India, Kenya, and Peru [67].


Stigmatizing TB Term		Non-Stigmatizing TB Term
People/person suffering from or infected by TB		People/person affected by TB People/person with TB
Treatment defaulter		Person lost to follow-up
TB suspect		Person to be evaluated for TB
Treatment compliance or noncompliance		Treatment adherence or non-adherence
TB control		TB prevention and care

Table 1: Stigmatizing and Non-Stigmatizing TB Terms from the Stop TB Partnership’s United to End TB—Every Word Counts: Suggested Language and Usage for Tuberculosis Communications (1st ed., 2015).

■ *The Evidence: Why We Must Eliminate Discrimination*

Discrimination is closely related to and often the result of TB-related stigma. Both stigma and discrimination have severely negative impacts on the health and well-being of people affected by TB and, by turn, public health. TB-related stigma must be reduced and eventually eliminated in order to stop discrimination against people affected by TB.

Stigmatizing language perpetuates and fuels TB-related stigma and discrimination. This includes terms such as “TB suspect” to refer to someone thought to have TB and “defaulter” to refer to someone who interrupts or stops TB treatment. The change and progression

of terminology used in the HIV epidemic and response, by example, has reflected advances in research and clinical practice and the destigmatization of the disease [68]. The Stop TB Partnership's *United to End TB—Every Word Counts: Suggested Language and Usage for Tuberculosis Communications* provides guidance on the use of non-stigmatizing, compassionate language that respects the dignity and autonomy of people affected by TB, thereby reducing TB-related stigma and discrimination (see Table 1) [69].²



The nurses at the DOT clinic shouted at us. They treated the patients like they were nothing, like they were doing us a favor by giving us our tablets.

Phumeza Tisile, TB Proof (South Africa)

Discrimination of people affected by TB occurs through person-to-person interactions, but it also operates at the structural level through discriminatory laws, policies, and practices; the discriminatory application of neutral laws and policies; the absence of legal protections; and the failure to enforce the rights of people with TB [70][71][72].

Research demonstrates that discrimination against people affected by TB is widespread, touching upon all aspects of life, including health care [73][74][75][76], employment [77][78][79][80][81][82][83][84], education [85][86][87][88], housing [89][90], the family [91][92][93][94], and social protections [95].



I've seen people kicked out of their homes, women beaten by their husbands, all because they have TB. Physicians who refused to see my TB patients on referral. Doctors who don't allow children to go back to school when they're no longer contagious, or schools that won't have them. Discrimination is widespread.

Dr. Jennifer Furin, Harvard Medical School (USA)

Evidence further confirms that stigmatization and discrimination of people affected by TB have grave consequences. Stigma in health facilities, for example, undermines diagnosis, treatment, and individual health outcomes [96]. More generally, stigmatizing and discriminatory treatment of people affected by TB leads to delayed diagnosis and treatment [91][97][98][99]; challenges in treatment adherence [91][98]; increased expenses associated with testing and treatment [98][100]; diminished social status and quality of life, including poor

² The Stop TB Partnership reports that TB civil society and community groups have requested that the language guidance be updated and expanded to address a more robust set of TB terms.

mental health [87][99][101][102]; loss of income and employment [80][101][103]; difficulties finding and maintaining housing [80][90]; interruption of education [85][103][104]; and disruptions to personal relationships and difficulties in forming families [87][98][101].

Studies reveal that TB-related stigma and discrimination is especially damaging, and qualitatively different, for women as compared to men [87][93][94][98]. The Global Coalition of TB Activists' *Women & Stigma: Conversations of Resilience in the War against TB* illustrates the entrenched stigma and discrimination experienced by women affected by TB around the world [93]. In particular, women may be more vulnerable to TB-related stigma, and thus they may experience stigma at higher rates than men, with greater negative impacts on their health-seeking behavior [87][105][106]. In some cases, women are even blamed for the spread of TB, and they experience more severe disruptions to their family life, often interfering with their ability to marry in the first place [76][87][98].

The Global Coalition of TB Activists' *Childhood TB & Stigma: Conversations of Resilience in the War against TB* also demonstrates the damaging stigma and discrimination experienced by children affected by TB around the world [85]. Among other things, children's education is interrupted, they are separated from their families, sometimes for long periods, and their social development is disrupted, as they are often rejected by their friends and family because they have TB [85].

The stigmatization and discrimination of people affected by TB also endanger public health by fueling the spread of disease and impeding efforts to identify, diagnose, and treat people with TB [107][108][109][110][111].

Right to Privacy & Confidentiality

The right to privacy & confidentiality comprises the right to keep personal health information private. This means that people affected by TB have the right to privacy in all matters related to their health, including whether they have TB infection or disease. Revealing, sharing, or transferring personal health information—electronically or otherwise—is only permissible when done with the informed consent of the individual and for the purposes of their health care or to protect public health. Personal health information collected, stored, transferred, or processed during public health measures, such as public health surveillance and case notification systems, may be shared or transferred among authorized officials without the person's informed consent only if it is done in an anonymous manner without the person's name or any other personally identifiable information. In narrowly defined circumstances, when voluntary measures have been

attempted but failed, or are not possible, health care workers may be required to notify the close contacts of a person with infectious TB disease, but only if the person poses a real risk of transmitting, or is likely to have already transmitted, the disease to them. Even in these circumstances, health care workers must protect the privacy & confidentiality of the person with TB to the fullest extent possible, including not disclosing their name or other personally identifiable information to their contacts.



In my experience providing TB care around the world, there is no protection whatsoever for privacy and confidentiality. The very signs on the clinics, and the vehicles used for community work, they all reveal someone has TB.

Dr. Jennifer Furin, Harvard Medical School (USA)

The right to privacy & confidentiality must also be respected and accounted for in the design and implementation of active case finding, contact tracing, and other public health interventions to find, test, and treat people with TB. This is especially important when interventions involve entering and working in communities affected by TB.

The right to privacy & confidentiality must also be protected in health care and research settings, where personal health information and medical records are collected, stored, processed, and transmitted in digital and other forms.

To ensure that digital data containing personal health information of people affected by TB is kept confidential and secure, public health programs, research institutions, and health care providers must proactively implement policies, protocols, and practices that establish robust safeguards within electronic information systems. This includes digital technologies that support TB treatment, such as digital adherence technologies (DATs), wirelessly observed therapy (WOT), video directly observed therapy (VOT or vDOT), electronic medication monitors, ingestible electronic sensors, and use of telephonic short messaging services (SMS).

A Note on the Distinction between Privacy and Confidentiality

Confidentiality generally refers to the protection of personal information that is shared with health care workers, government officials and institutions, media organizations, employers and others with a professional, legal, or ethical obligation to keep the information confidential. Privacy refers, more broadly, to a person's interest in controlling access to information about their lives, including their health, and it protects against government interference with a person's decision-making about their health or family.

■ *Legal Recognition of the Right to Privacy & Confidentiality*

The right to privacy & confidentiality is established in law around the world. *The Universal Declaration of Human Rights* and four international treaties establish the right to privacy, including the *International Covenant on Civil and Political Rights* and the *Convention on the Rights of Persons with Disabilities*. Six regional treaties recognize the right to privacy, including the *African Charter on Human and Peoples' Rights* and the *European Convention on Human Rights*. And 175 national constitutions protect the right to privacy, such as the constitutions of Brazil, Ethiopia, Nigeria, and Pakistan [112].

The WHO further establishes that the protection for privacy & confidentiality is an important ethical principle for TB care and control, including during public health interventions such as surveillance, screening, and contact investigations and tracing [113][114][115].

■ *The Evidence: Why We Must Protect the Right to Privacy & Confidentiality*

“

Just by walking into the DR-TB clinic you are revealed. In TB, we don't use euphemisms for clinics and other services to protect privacy and to be more discreet. Like in HIV, by example, we call the clinic a 'family clinic.'

Dr. Thiloshini Govender, King Dinuzulu Hospital (South Africa)

Protecting the right to privacy & confidentiality of people affected by TB combats stigma and discrimination and encourages health-seeking behavior, thereby protecting public health. By contrast, the failure to recognize and protect privacy & confidentiality discourages people affected by TB from seeking testing, and starting and completing treatment, as they fear stigma and discrimination, and the social and economic consequences that follow. This, in turn, endangers public health by promoting the spread of disease.

The extensive evidence presented in the previous section establishes the damaging impacts to individuals and public health from stigma and discrimination against people affected by TB. The failure to design and implement robust protections for privacy & confidentiality during public health interventions, such as public health surveillance, active case finding, screening, contact tracing, and case notification, contributes to TB-related stigma and discrimination. Protecting the right to privacy & confidentiality during such measures is therefore a key safeguard against stigma and discrimination and a critical tool to promote health-seeking behavior among people affected by TB.

With that said, recent studies reveal the difficulty, if not impossibility, of truly de-identifying and encrypting data to protect against the re-identification of people whose personal information is in a dataset [116][117][118][119]. This has serious implications for digital information about people affected by TB collected, stored, transferred, and processed as part of public health interventions. Even with the most advanced security features and practices—including encrypted and password protected electronic platforms, anonymized data with coded, unique identifier systems, such as Unique Patient Identifiers (UPIs)—it may not be possible to entirely eliminate the risk of data breaches or the re-identification of people affected by TB.

Evidence from around the world demonstrates that people affected by TB have serious concerns about their privacy & confidentiality and that there are negative consequences from the failure to protect privacy & confidentiality in health care settings [77][90][120][121]. One study found that people affected by TB did not want to describe their symptoms to health care workers when they were not assured of confidentiality, leading to incorrect diagnoses and improper drug prescriptions [120]. Another found that, in order to keep their health status private, people with TB preferred paying for services in private clinics rather than accessing free treatment in public clinics [121]. For some people, this led to interrupted or incomplete treatment when they could no longer afford private care. Several other studies also show that a lack of privacy at TB clinics creates barriers to testing and treatment adherence [77][122][123]. In one, people affected by TB explained that public clinics with signs that identify the facility as a TB clinic “out” everyone who enters and leaves—correctly or incorrectly—as a person with TB [77].

50% of all people diagnosed with TB:



The only country from these six to recognize privacy and confidentiality of people affected by TB in health care settings:



(WHO Global TB Report, 2019)

Despite the above, a review of the national guidelines for the control, management, and treatment of TB in six countries—India [124], Philippines [125], Pakistan [126], Nigeria [127], Bangladesh [128], and South Africa [129]—that accounted for approximately 50% of all new TB cases in 2018 shows that only one country, South Africa,

recognizes privacy or confidentiality of people affected by TB in health care settings [7]. In fact, the word “privacy” does not appear in the guidelines of four countries that accounted for 41% of all new TB cases in 2018 [7][124][126][127][128]. The term “confidentiality” only appears in two guidelines, but neither recognizes the right to confidentiality of people affected by TB [126][127]. Instead, the term “confidentiality” is used in these guidelines in relation to voluntary and confidential counseling and testing for HIV [126][127].

Research also indicates that people affected by TB have serious concerns about privacy & confidentiality in employment and education settings. One study identified the right to privacy in the workplace as one of the two major concerns held by people with TB in the study [120]. In another study among health care workers, the majority of participants believed TB screening and treatment should be kept confidential in the workplace, regardless of where the testing occurred [130]. A study among secondary students found that they kept their TB status secret from their teachers, demonstrating a strong preference for privacy at school [76]. Another study of students revealed the need for privacy in school settings in documenting the discriminatory treatment of a child with TB, who was excluded from school activities even though she was undergoing treatment and not infectious [87].



Right to Information

Somebody has to do something for TB awareness in prisons, to break the silence.

Karabo Rafube, Preacher and Prisoners’ Rights Activist (South Africa)

The right to information comprises the right to seek, receive and communicate information. This means that people have the right to information about TB that is readily available, easily accessible, and understandable. All information about TB must be gender- and culturally-sensitive, imparted in a non-technical manner, in a language understood by the person receiving it, by trained counselors, including people who have themselves survived TB. National TB programs must pay special attention to people who are illiterate when developing and communicating information about TB.

The right to information can be understood as an integral component of and, in fact, a necessary condition for health literacy. It includes a right to information about TB infection and disease, including prevention, symptoms, disease transmission, infection control, the duration of infectiousness, drug-resistance, and that TB is a curable disease. The right to information also includes information about TB

prevention, testing, and treatment services—i.e., “treatment literacy.” Treatment literacy—a central component of the HIV response—includes knowledge about the highest-quality TB diagnostics and drugs available, the length, benefits, and risks of TB treatment, all possible treatment side effects, and the risks of interrupting or stopping treatment.

“

We must break down the jargon in TB.

Dr. Govender Thiloshini, King Dinuzulu Hospital (South Africa)

Health Literacy

People’s knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention, and health promotion to maintain or improve the quality of their lives.

WHO, Health Literacy: The Solid Facts (Ilona Kickbusch et al. eds., 2013).

■ *Legal Recognition of the Right to Information*

The right to information is established in law around the world. The *Universal Declaration of Human Rights* and five international treaties recognize the right to information, including the *International Covenant on Civil and Political Rights* and the *International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families*. Six regional treaties establish the right to information, including the *American Convention on Human Rights* and the *Convention on Human Rights and Biomedicine* (the Oviedo Convention). And 94 national constitutions enshrine the right to information, such as the constitutions of Malawi, the Philippines, South Sudan, and Venezuela [131].

■ *The Evidence: Why We Must Fulfill the Right to Information*

“

Nothing. Nothing. Nothing. They gave me no information when I was diagnosed with TB.

Dr. R. Gopa Kumar, Uniworld Foundation and Touched By TB (India)

Fulfilling the right to information for people affected by TB promotes health-seeking behavior, reduces delays in diagnosis, supports treatment initiation and adherence, and protects public health. Without knowledge about TB infection and disease, people affected by TB may not recognize symptoms, resulting in delays in diagnosis

and treatment and spread of the disease. Plus, they may not know that TB is a curable disease or that they are no longer contagious shortly after starting treatment. Both may discourage health-seeking behavior and lead to stigma and avoidable anxiety or depression. Without information about TB treatments, including the length of the regimen, the risks of stopping or interrupting treatment, and the side effects, people are less likely to adhere to and successfully complete the therapy.



I needed someone to counsel me when I found out I had TB. Even as a trained counselor, myself, all my coping strategies went for a toss. I needed help.

Prabha Mahesh, ALERT India and Touched By TB

Studies from around the world show that a lack of information on TB infection and disease, including about symptoms and how the disease spreads, has serious consequences. A systematic literature review of factors that contribute to TB disease identified multiple studies that found a lack of knowledge about TB and its mode of transmission puts people at higher risk for TB disease [132]. These studies identified TB key and vulnerable groups—mobile and migrant populations and health care workers—as lacking knowledge about the disease and its transmission [133][134][135][136][137]. Other studies have also found that limited knowledge about TB is a barrier to services among migrants, rural populations, and persons with disabilities [138][139][140]. Another systematic review and meta-analysis also found that a lack of knowledge about TB disease and its causes and symptoms in low- and middle-income countries contributes to delays in seeking care and diagnosis, causes people to self-medicate and hide their illness, and results in discrimination within communities, thereby reducing the effectiveness of national TB programs [141]. Other research found that a lack of knowledge about the cause and mode of transmission of TB was a barrier to treatment adherence [142]. A population-based study found that almost twice as many people who lacked knowledge about TB symptoms used less-qualified health care providers and self-medication when they first sought care than people who knew about the symptoms [143]. Finally, a cross-sectional survey found that TB-related stigma among people with TB, as measured by a validated scale, was statistically associated with less knowledge about TB [144].

Evidence from around the world also demonstrates that a lack of knowledge about TB treatments negatively affects treatment access, adherence, and completion. A systematic review of studies from developing countries found that a lack of knowledge about the duration of TB treatment and the consequences of stopping treatment were associated with treatment non-adherence and being lost to

follow-up among people with TB [145]. Cross-sectional studies have found that poor knowledge about TB treatment and the disease were significantly associated with treatment non-adherence [146][147].



The best counselors are those who have survived the disease. They can form a real bond of trust and have the experience needed to support people with TB through treatment.

Dr. Jennifer Furin, Harvard Medical School (USA)

Another systematic review and meta-analysis of trials and observational studies found that education and counseling for people with TB were associated with higher rates of treatment adherence, treatment completion, and cure [148]. The review considered education and counseling interventions that aimed to provide “adequate knowledge” and ensure “patient understanding” of the “disease process and risks and benefits associated with treatment adherence” [148]. Another study found that an intervention that promoted treatment literacy through treatment support groups reduced the number of people with TB who were lost to follow-up [149]. Several studies have also found that peer counseling, sometimes combined with other interventions, improves TB treatment adherence and outcomes, including among adolescents and people who use drugs [150][151][152].

Right to Liberty

The right to liberty protects people affected by TB from arbitrary or discriminatory detention, including for involuntary isolation or treatment. Involuntary detention, hospitalization, or isolation of a person with TB is a deprivation of liberty in all cases. In accordance with the right to liberty, involuntary isolation is only permissible as a measure of last resort, in narrowly defined circumstances, for the shortest duration possible, and only to protect the public’s health—never as a means of convenience or punishment. Involuntary isolation should not be an ordinary part of a national TB program’s disease response.

Forced treatment of people with TB during involuntary isolation or hospitalization, or under any other circumstances, is never ethically justified and, in all cases, is a violation of human rights.

According to the WHO, involuntary hospitalization or isolation for TB is only permissible when, based on accurate medical evidence that a person:

- ✓ Is known to be contagious, refuses effective treatment, and all

reasonable measures to ensure adherence have been attempted and proven unsuccessful; **OR**

- ✓ Is known to be contagious, has agreed to ambulatory treatment, but lacks the capacity to institute infection control in the home, and refuses inpatient care; **OR**
- ✓ Is highly likely to be contagious (based on laboratory evidence) but refuses to undergo assessment of his/her infectious status, while every effort is made to work with the person to establish a treatment plan that meets their needs [113].

In addition, in accordance with the UN Economic and Social Council's *Siracusa Principles*, the deprivation of liberty involved in the involuntary hospitalization or isolation of people with TB is only justified when it is:

- ✓ In accordance with national law in force at the time of the deprivation;
- ✓ Based on, and proportionate to, a legitimate objective in response to a serious threat to the health of the population or individual members;
- ✓ Strictly required by the exigencies of the situation;
- ✓ The least restrictive means available to achieve the objective; **AND**
- ✓ Not arbitrary, abusive or discriminatory [153].

In the exceptionally rare circumstances when the involuntary isolation of a person with infectious TB disease is medically required and legally and ethically permissible, isolation must occur in a medically appropriate or home-based setting. Involuntary isolation of people with TB in a prison cell or within a prison's general population is never appropriate or justifiable [113][154]. And the government must provide people with TB who are involuntarily isolated with, among other things, medical care, including good quality TB testing, treatment, and counseling services, sufficient nutritious food and water, and access to social support. A person deprived of their liberty because of TB must also have the right to challenge their confinement in a court of law, to receive a timely judicial determination, and to redress and compensation if their confinement is found to be unlawful.

■ *Legal Recognition of the Right to Liberty*

The right to liberty is established in law around the world. The *Universal Declaration of Human Rights* and five international treaties recognize the right to liberty, including the *International Covenant on Civil and Political Rights* and the *International Covenant on the*

Elimination of All Forms of Racial Discrimination. Six regional treaties establish the right to liberty, including the *African Charter on Human Peoples' Rights* and the *American Convention on Human Rights*. And 150 national constitutions enshrine the right to liberty, such as the constitutions of Argentina, Mali, Papua New Guinea, and Uganda [155].

■ *The Evidence: Why We Must Protect the Right to Liberty*

“

I've had to isolate people with TB on occasions. The most important thing is that it didn't work very well. It never fixes the problem. There is usually a reason someone isn't taking their meds. How do we identify and address those reasons? This is the work we must do, to treat the patient and protect the public—not deprive them of their liberty.

Dr. Jennifer Furin, Harvard Medical School (USA)

Protecting the right to liberty of people affected by TB promotes improved individual and public health outcomes by encouraging health-seeking behavior and reducing stigma. Despite this, there is a lack of national laws and policies that explicitly protect the right to liberty in the context of TB and that establish clear rules and guidelines for the rare circumstances when involuntary isolation is permissible. For example, legal environment assessments conducted with two countries that account for more than 30% of the global disease burden revealed that neither country has a national law or policy on the isolation of people with TB [77][156]. While both countries have legislation granting government the power to restrict liberty and movement in the context of infectious diseases, neither has a law or policy specially tailored to TB [77][156]. The laws authorizing restrictions on liberty in these countries, and others, do not meet the standards described above established by the WHO and UN Economic and Social Council. And, among other things, they do not account for the fact that people with latent TB infection are not contagious, the short duration for which people with TB disease undergoing treatment are infectious, the availability of inexpensive and effective TB infection control measures, and that TB is curable.

“

We should not use the criminal justice system to limit the rights of people affected by TB. We need a separate process, with the right to appeal the decision to deprive someone's liberty. We must only limit rights in a rights-based manner.

Dr. Thiloshini Govender, King Dinuzulu Hospital (South Africa)

Involuntary isolation has grave social, economic, and physical and

mental health consequences for people affected by TB and their communities. In a report to the UN Human Rights Council on the deprivation of liberty and confinement in penal and medical contexts, the UN Special Rapporteur on the Right to Health explained:

“Confinement as a response to tuberculosis increases stigmatization of people with the disease, driving those most at risk underground and away from health care. Confining people with tuberculosis not only puts them at risk by placing them in settings often characterized by inadequate access to treatment and support, but also fuels the spread of the disease within these settings. As a particularly stark example, incarceration has been utilized to isolate persons with tuberculosis, punishing them for not adhering to the treatment, even though violations of the right to health led to their non-adherence in the first place. Confinement inappropriately places the burden of tuberculosis treatment and care on the person, effectively isolating and criminalizing those who are sick instead of providing the health care and support needed to complete treatment. These practices must be brought to an end” [157].

[UN Special Rapporteur on the Right to Health, Mr. Dainius Pūras](#)

Confinement of people with TB may exacerbate existing social inequalities and disadvantages among people affected by TB [157]. Evidence shows that people detained due to TB are more likely than other people with TB to come from socially disadvantaged groups, including the homeless, mobile and migrant populations, people living with HIV, people who use drugs, people with mental illness, and racial or ethnic minorities [158][159][160][161]. A person in confinement for TB is excluded from fully participating in the social and economic activities of their life [162][163][164]. They may be unable to earn income or they may lose their employment entirely, leading to negative financial consequences for themselves and their families [162][163]. Research shows that prolonged isolation for treatment of drug-resistant TB induces feelings of fear, anger, self-blame, depression, and suicide [162].

Evidence also demonstrates that people confined due to TB are likely to experience stigma and social exclusion from their communities, friends, and families [113][157][162][163][164]. The extensive research presented in the previous sections on the damaging impacts to individual and public health from TB-related stigma and discrimination is therefore relevant here, as well. Protecting the right to liberty and implementing isolation policies in accordance with the WHO and UN Economic and Social Council guidelines therefore serve as key protections against stigma and discrimination and crucial tools to promote health-seeking behavior among people affected by TB.

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Appendix

Key Informant Interview Questionnaire for People Affected by TB

Personal Information:

1. Please tell me your full name, age, where you live, and your current profession.

History with TB:

2. Can you briefly explain your history with tuberculosis, including where you lived and what you were doing in your life at the time you were sick?

Challenges Faced Before and During TB Treatment:

3. What are some of the challenges or barriers you faced when you were sick, in terms of getting diagnosed, starting treatment, and adhering and completing treatment?
4. Were you provided comprehensive, accurate information about the nature of TB infection and disease, and about your treatment, after your diagnosis?
 - a. If so, what information were you given and by whom?
 - b. If not, what information were you provided, by whom, and what do you believe was lacking?
5. Were you isolated during your TB treatment?
 - a. If so, please tell me about that experience, including where the isolation occurred, who ordered the isolation, what you were provided during your isolation, and whether you were isolated against your will.

Human Rights:

6. From your experience, can you please tell me your thoughts about human rights and how they relate to tuberculosis?
7. After you were diagnosed with TB, was your privacy respected, meaning was your diagnosis kept private among only you, your doctors, and close contacts?
 - a. If so, how was your privacy protected and who was the primary person responsible for protecting it?
 - b. If not, please tell me what happened and how your privacy was not protected.

8. Did you experience any discrimination during or after the time you had TB, such as in employment or education?
 - a. If so, please tell me about your experience.
9. Are there any particular human rights that you believe are particularly important, given your experience with TB and understanding of the TB response more broadly?
 - a. If so, please tell me which human rights you think are important and why.

Recommendations for TB Policymakers and Program Implementers:

10. If you could speak directly to TB policymakers and program implementers in your country and at the WHO, what are the three things you would tell them to do in order to improve the TB response?

Final Thoughts:

11. Is there anything else you believe it is important for the GCTA to know in order to create an effective Technical Brief on TB and human rights for policymakers and program implementers?

Key Informant Interview Questionnaire for TB Health Care Providers

Personal Information:

1. Please tell me your full name, age, where you live, and what kind of health care worker you are.

TB Healthcare:

2. Where do you practice medicine, in what jurisdictions, and in what kinds of health facilities?
3. Can you briefly explain the kind of health care you provide for people affected by TB, including the kinds of services?
4. What are your thoughts, based on your clinical experience, about the effectiveness of Directly Observed Therapy as the primary treatment strategy for TB?

Challenges Faced Before and During TB Treatment:

5. What are some of the challenges your TB patients face in getting diagnosed, starting treatment, and adhering and completing treatment?
6. In your experience, are people with TB provided comprehensive and accurate information about TB infection and disease, and about their treatment?
 - a. If so, what does this information entail and from whom do they receive it?
 - b. If not, what kinds of information is generally lacking for people affected by TB?
7. Have you had to recommend the isolation of a patient with TB during your practice?
 - a. If so, please tell me about that experience, including the reasons why the isolation was needed, where the patient was isolated, for how long, and under what conditions.

Human Rights:

8. Based on your experience as a TB health care provider, can you please tell me your thoughts about human rights and how they relate to TB?
9. In your experience, are your TB patients' privacy and confidentiality respected, meaning their diagnosis is kept private among the patient, their care providers and their close contacts?
 - a. If so, how does this happen in practice?

- b. If not, please tell me the different ways that you've seen privacy and confidentiality not being protected.
10. Have you witnessed first-hand or heard from any of your patients that they have experienced discrimination because they had TB?
 - a. If so, please tell me what you witnessed or heard from your patients.
 11. As a TB health care provider, are there any human rights that you believe are particularly important for people affected by TB?
 - a. If so, please tell me which rights you think are important and why.

Recommendations for TB Policymakers and Program Implementers:

12. If you could speak directly to TB policymakers and program implementers in your country and at the WHO, what are the three things you would tell them to do in order to improve the TB response?

Final Thoughts:

13. Is there anything else you believe it is important for the GCTA to know in order to create an effective Technical Brief on TB and human rights for policymakers and program implementers?

