



# KNOW YOUR RIGHTS: TUBERCULOSIS PREVENTION, DIAGNOSIS, AND TREATMENT

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## YOUR HUMAN RIGHTS AND TB

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### Why this guide?

This guide is for people with tuberculosis (TB), people at risk for TB, and the people who take care of them. It aims to explain what the global standards for TB care are, including what services you have the right to receive. This guide aims to clarify what your rights are related to TB prevention, testing, treatment, and care. Our goal is for people affected by TB to be able to recognize when they should be receiving a higher level of care, so they can ask for globally recommended standards.

### What are globally recommended standards?

The World Health Organization (WHO) is the organization of the United Nations (UN) that specializes in health. Part of the WHO's work is to guide a process that sets standards and guidelines for prevention, diagnosis, and treatment of TB. These standards support policymakers and health authorities to plan and equip their country's health programs to respect, protect, and fulfill everyone's right to health and other related human rights.

### What are human rights, and why are they important for people affected by TB?

People with TB and those at risk for TB have human rights. Governments have legal obligations under international, regional, and domestic law to respect, protect, and fulfill these human rights. Human rights are universal: everyone has them. Human rights are also indivisible, interdependent, and interrelated. That means all human rights are equally important, depend on each other, and are closely related to each other. Taking away one right affects your other human rights.

Many human rights are important for people affected by TB. These rights exist in international and regional treaties, as well as the constitutions of countries around the world. They include the Right to Life; Right to Health; Right to Non-discrimination; Right to Liberty; Right to Science; Right to Informed Consent; Right to Information; Right to Privacy; Right to Participation; Freedom from Torture and Cruel, Inhuman, or Degrading Treatment; Freedom of Movement; Freedom from Arbitrary Detention; Freedom of Association; and Freedom of Assembly.

## What does Right to Life mean for people affected by TB?

The Right to Life means that the state, that is, your country's government, may not deprive you of your life. The state also has the duty to take steps to protect your life. This means your government should take steps to end diseases and to ensure access to care, for example by taking a human-rights-based approach to eliminating TB.

## What does the Right to Health mean for people affected by TB?

The Right to Health includes two important parts. The first part is a country's health care services and health care system. The Right to Health states that health care has to be available. For TB, this means a health care system with functioning facilities for TB prevention, diagnosis, and care; with goods including TB medication and testing equipment and supplies; and with services and programs including adequate budget for health care staff and TB programs. Health care must be accessible: everyone should have access to it and cannot be denied services (which is called non-discrimination). You also should be able to reach and enter facilities that are equipped to handle TB, including, for example, local health care stations, or, if necessary, services may have to come to you. You should be able to afford health care, including your medication. And you must be able to access information about available health care options for TB and knowledge on TB. Health care has to be acceptable; this means that health care has to be appropriate to the local culture, respect ethics, and be sensitive to gender and age of a person with TB. Health care must be of good quality: health interventions for TB should be based on science and should be medically appropriate, and medicines should be of good quality.

This "availability, accessibility, acceptability, and quality" part of the right to health is often called AAAQ.

The second part of the Right to Health includes the "underlying determinants" of health. These include several human rights that relate to your health. For example, the rights to food; safe drinking water and adequate sanitation; adequate housing; healthy working conditions; and access to health education. These rights are important for prevention and treatment of TB. For you, that may mean that you should receive nutritional support in addition to medication during your TB treatment, if that would aid your healing. Or that you may need other additional support during or after you have completed your treatment, if TB has significantly changed your ability to live your life and protect your health.

Your government also must provide essential medicines. This is a "core obligation" under the Right to Health. This means that providing essential medicines is one of the most important things a government can and must do to respect, protect, and fulfill the Right to Health. The WHO has a Model List of Essential Medicines, that lists all important TB drugs in section 6.2.4 of the 19th version.

## What does the Right to Non-Discrimination mean for people affected by TB?

Your health status should never be used as a reason to treat you, your family, or the person who takes care of you any differently from others. This means that you cannot be fired from your job, refused entry into school, denied housing, or treated in a disrespectful way in a health clinic because you have TB. If you are a member of a vulnerable group, for example a person with HIV, a person who uses illicit drugs, a migrant, or a prisoner, you may not be discriminated against when you try to access TB services.

## What does Right to Liberty, Freedom of Movement, and Freedom from Arbitrary Detention mean for people affected by TB?

These rights guarantee that you cannot be imprisoned, detained, or stopped from moving around without legal proceedings. Any detention or arrest has to happen according to the law. This is important for TB when we think about whether treatment should happen in isolation. Isolation for TB treatment can be considered if it is medically necessary to protect others from TB. However, you should always be able to choose the least restrictive form of isolation possible. Basic respiratory isolation, for example, could mean wearing a specific mask until your treatment takes effect and your TB is no longer infectious. You should not be asked to stay in the hospital if wearing a mask is sufficient.

In some rare situations, your government can require you to stay in isolation even if you do not agree (involuntary isolation). This can happen only if your TB is actively infectious, if you refuse to take TB drugs or to follow infection control measures, and if there is a real risk of spreading TB to others. Involuntary isolations should never be a routine requirement and should only be used if all other measures, including extensive counseling, have been tried and failed. Involuntary isolation needs to be based on an existing law or policy, and should hold up to external review. You as the person affected also have a right to appeal the decision to be isolated. You should never be isolated in a nonmedical setting, such as a prison cell. Also, you must be provided TB treatment and basic necessities, including food, water, and the opportunity to communicate with family. Isolation should be as brief as possible, which means only as long as you TB is infectious and presents a real risk to others. Isolation should never be a requirement of receiving access to new TB drugs.

## What does Right to Privacy mean for people affected by TB?

Right to Privacy means that your health status, including whether you have TB, and your personal information should not be shared with anyone, unless you allow it or it is necessary to protect the health of others. In most places, TB is a “notifiable condition.” This means that health authorities have to report cases of TB to the national department of health. However, your personal information (like your name) should not be shared. If you have different health care providers, they may need to share information about your health with each other in order to provide you good quality care. If your TB is infectious and people you interact with are at a real risk of contracting TB, you should inform them, encourage them to get tested, and take steps to protect against the spread of TB. For example, you may choose to wear an appropriate mask in a closed family setting. Your health care provider may let people who are in close contact with you know that they need testing, without identifying who the close contact is. If you refuse or are unable to do this, your health care provider may notify these people that your TB is infectious so they can take steps to protect themselves. When there is no risk for others to contract TB, there should be absolute protection of your Right to Privacy.

## What does Right to Science mean for people affected by TB?

Right to Science means that every person should be able to benefit from new scientific findings, including new and improved prevention, diagnosis, and treatment methods. Your government should take steps to make new medication, new ways to prevent TB, and new ways of testing for TB available in your country.

Governments also have an obligation to support and advance science. That means, for example, that your government should provide funding for scientific research and support public research institutions. When your government provides funding or other incentives for research to a private company, it should also make sure that the results of that research benefit people with TB in your country and are affordable. The Right to Science is also linked to the right to participation. Communities affected by TB should be included into research processes in a respectful and meaningful manner.

## What does Right to Information mean for people affected by TB?

Right to Information means, among other things, that you—and, if you wish, the person involved in your care, like a relative or friend—need to be told about your options for medical treatment. It also means you and your community should be provided accurate information about how TB spreads, how to prevent its spread, and for how long people with TB are infectious. You should also receive counseling and all explanations that you need to consent (agree) to any medical interventions. It also means that you have the right to know the names and dosages of any medication or intervention that your doctor wants you to take; to know how long the treatment will take; and to understand all potential side effects and other ways in which a medication or intervention may affect your health or life. This is called treatment literacy. The Right to Information also means that you should receive a copy of your medical records if you want one.

## What does Right to Informed Consent mean for people affected by TB?

The Right to Informed Consent is closely linked to the Right to Information and the Right to Participation. Informed consent means that you must agree to any medical intervention before it happens, and that you must first receive complete information about the risks and benefits of the intervention. Information is the basis for your decision on whether to allow the medical intervention (for example, a specific drug regimen for TB, or whether or not you want to take preventive therapy). This means that you should always have counseling before you make a decision, and that you must be given time to think of questions and receive answers to your questions. Forced treatment for TB is never allowed.

## What does Right to Participation mean for people affected by TB?

The Right to Participation means that you as the person with TB should take part in the decisions that affect you. That, of course, includes your medical treatment. However, it also has a broader application. People affected by TB have the right to participate in deciding health policies, from the national level down to the community level. For example, this may mean that health authorities seek input from organizations that represent people with TB when evaluating a TB program, or involve the community in developing a local approach for person-centered care.

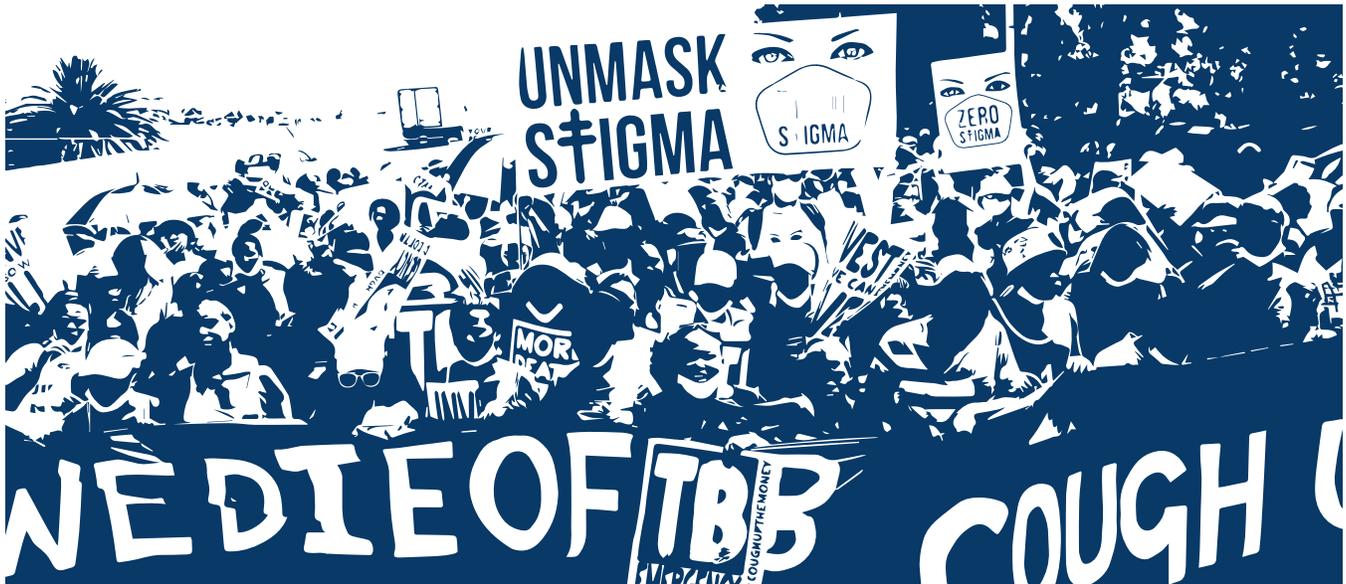


Photo Credit: David Harrison for Treatment Action Campaign

## What do Freedom of Association and Freedom of Assembly mean for people affected by TB?

The Right to Participation is one reason why Freedom of Association and Assembly also play a role in TB. Freedom of Assembly allows groups of people to come together, for example to discuss input to a community health issue. Freedom of Association allows you and other people affected by TB to form and register organizations (for example, community groups that provide support to people affected by TB) or to advocate for the rights of people with TB.

## What is person-centered care?

Person-centered care means that everything to do with TB prevention, diagnosis, and treatment should consider the whole person. This includes respecting each person's human rights and thinking about social and economic factors, not only about the medical information. Your treatment plan should be made to address your specific situation. It should protect your rights, not violate them. TB affects more than one person. That is why we think about family- and community-centered care as well. The people helping to take care of family or community members living with TB need to be informed about prevention, diagnosis, and treatment just like the person with TB does.

## What does this mean for families and communities?

Families and communities play important roles in TB prevention, diagnosis, and treatment. That's why community-based organizations (CBOs) and support groups are important. You have the right to Freedom of Association and Freedom of Assembly. This means that you, other patients, and your community have the right to meet to share information. You have the right to form organizations that support people with TB, their caregivers, and their community.

## What can I do if my rights are violated?

You have the right to make a complaint. Health authorities should have a channel for you to make a complaint. You also have the right to receive a response. If you do not receive a response, or if you receive a response that does not address your concerns or needs, you may have the right to take them to court. This depends on your country's laws, and you should contact a legal professional or legal aid organizations. There are organizations that specialize in rights violations around the right to health. That includes your rights in access to treatment, for example, and the other rights laid out in Section I, "Your Human Rights and TB."

Many countries have human rights ombudsmen or national human rights institutions. These are independent groups that exist to monitor, protect, and restore human rights and can receive complaints from individuals about human rights violations. You can look up whether your country has a national human rights institution by checking the directory here: <https://nhri.ohchr.org/EN/Pages/default.aspx>. In some situations, it may be faster to reach out to a local patient advocacy organization if you think that your rights have been violated and want to receive information on your options.