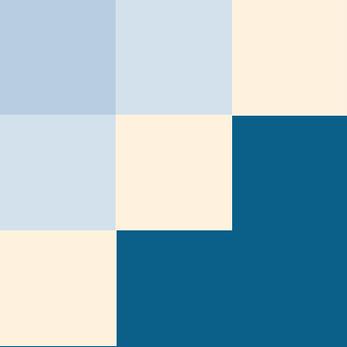




**HUMAN RIGHTS,  
INFORMED CONSENT,  
AND HIGH ETHICAL STANDARDS**  
AS A BASIS FOR  
PEOPLE-CENTERED  
TB CARE



# Acknowledgements

Brochure "Human Rights, Informed Consent, and High Ethical Standards as a basis for people-centered TB care"

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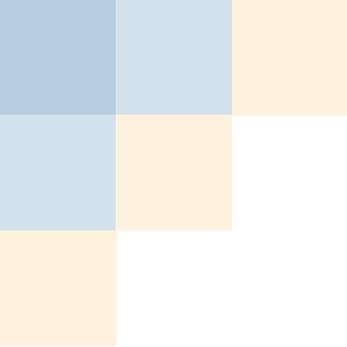
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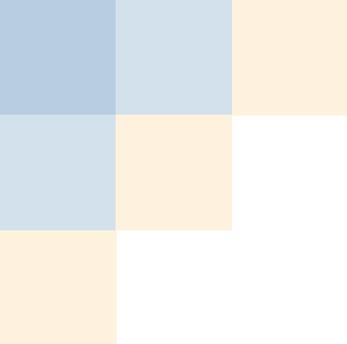
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## Abbreviation

<b>AAAQ</b>	Available, Accessible, Acceptable, Quality
<b>CSO</b>	Civil Society Organizations
<b>DOT</b>	Directly Observed Treatment
<b>DR-TB</b>	Drug-resistant TB
<b>DR-ST</b>	Drug-susceptible TB
<b>(DST)</b>	Drug Susceptibility Testing
<b>ICESCR</b>	International Covenant on Economic, Social, and Cultural Rights
<b>MDR-TB</b>	Multidrug-resistant TB
<b>Pre-XDR-TB</b>	Pre-extensively drug-resistant TB
<b>RR-TB</b>	Rifampicin-resistant TB
<b>SDG</b>	Sustainable Development Goals
<b>SMS</b>	Short message service enabling text messages via mobile phone
<b>TB</b>	Tuberculosis
<b>NTP</b>	National Tuberculosis Program
<b>PHC</b>	Public Health Center of the MOH of Ukraine
<b>SGD</b>	Sustainable Development Goals
<b>TB</b>	Tuberculosis
<b>WHO</b>	World Health Organization
<b>XDR-TB</b>	Extensively drug-resistant TB

# INTRODUCTION

The purpose of this brochure is to provide a brief overview of the up-to-date prevention, diagnosis, and treatment of TB based on human rights, high ethical standards, and a people-centered approach.

This brochure is targeted primarily at the people who most need this information - individuals directly affected by TB, their families, civil society, and the community. TB is a preventable and curable disease with timely detection, diagnosis, and provision of high-quality people-centered treatment and support services. Every person has a right to quality TB prevention, diagnosis, and treatment and they have a right to give informed consent and to be informed.

Human rights and high ethical standards are the cornerstone of people-centered prevention, diagnosis, treatment, and care of TB in which individual is well informed and involved in deciding on his/her health during the full length of TB treatment via the informed consent process. Despite this, there are still healthcare gaps in diagnosis, treatment, and new drugs, as well as gaps in the cascade of care for drug-resistant TB and human rights: A lack of a true people-centered approach, and thus violation of rights.

▶ The whole process from screening and diagnosis of TB to treatment follow-up should be a collaboration between the person with TB and medical staff as part of a care team, and the person's treatment should be informed by their values and preferences. This means that a one size fits all approach is not acceptable and belongs to the past.

People with drug-resistant TB should not be forced to stay hospitalized for a long time after they are no longer infectious to others. They should not receive just a clinic-based DOT simply because that is the only way treatment has been made available in the country. On the contrary, the solution is personalized community-based treatment and care, free of any stigma and discrimination.

High ethical standards are part of the End TB Strategy adopted by the WHO and Stop TB Partnership. Treatment and care must be people-centered, accessible, acceptable, affordable, and appropriate. To best serve the needs of people with TB and their loved ones, it is preferable that care and support services be based in their communities. Finally, care should be based on ideas of social justice and equity and aim to enable all people and especially the most vulnerable, to adhere to treatment.

People-centered care places the focus on the well-being, values, and convenience of the individual being treated and their loved ones. It is a collaboration between them, and the medical staff aimed at making treatment easier to adhere to, less disruptive, and without the economic and time costs that so often accompany TB treatment.

Evidence-based TB treatment programs should collaborate extensively with those individuals undergoing TB treatment, as well as communities and civil society, thereby empowering the individual to play an active role in decision-making processes during the full length of TB diagnosis, treatment, and care. Continuous feedback from the individual about the treatment helps to improve the quality of that treatment and adapt it to the person's needs.

**Drug susceptible TB treatment is relatively simple, safe, and well-tolerated.** However, it does take a long time. The treatment of drug-resistant TB is more complex, takes much more time,

but with proper management and support is tolerated and successful, especially with one of the new oral TB treatment regimens.

TB treatment, no matter whether the bacteria affecting the individual is drug-susceptible (i.e., responds to the normal drugs for treating TB) or drug-resistant, is not easy for the individual with TB as it takes a long time and affects one's life. Sometimes, even relatively safe TB drugs can have serious side effects or interact with other drugs individual is taking. To support individuals with TB to successfully complete treatment, countries are implementing not only strict requirements of DOT, but also person-friendly alternatives (community-based treatment) within the people-centered approach. Ensuring the conditions which enable the individual to adhere to their treatment regimen is of utmost importance.

An individual enrolled in TB treatment needs to be treated with respect and dignity and empowered and fully supported not only by his/her medical team but also by family, community, and the whole of society. Designing modern people-centered TB treatment, care, and support programs based on human rights and ethics, and linking these services with other supportive interventions (monetary, necessities, informational, emotional etc.) will significantly increase the number of successfully treated individuals.

In this brochure, we are highlighting the importance of informed consent during the whole TB treatment pathway including for the new oral and old injectable treatment regimens for DR-TB. This brochure aims to provide useful information and an overview of people-centered approaches in TB for civil society and TB affected communities, as well as policy and decision-makers. We hope that after reading this document, individuals affected by TB will feel more comfortable discussing their treatment options and progress with medical personnel, family, and community members and will be more engaged in making decisions on their health.

In early 2021, the WHO updated the definitions of XDR-TB and pre-XDR-TB to take into account the newer drugs and treatment regimens that are available as well as changes to WHO guidelines that deprioritized injectable antibiotics in favor of more effective and better tolerated ones.

**Pre-extensively drug-resistant TB (Pre-XDR-TB)** - TB caused by Mycobacterium TB (M. TB) strains that fulfill the definition of multidrug-resistant and rifampicin-resistant TB (MDR / RR-TB) and [which are also resistant to any fluoroquinolone](#).

**Extensively drug-resistant TB (XDR-TB)** - TB caused by Mycobacterium TB (M. TB) strains that fulfill the definition of MDR / RR-TB and which are also resistant to any fluoroquinolone and at least one additional Group A drug (levofloxacin, moxifloxacin, bedaquiline, or linezolid).

The definition of multidrug-resistant TB (MDR-TB) remains the same.

**Multidrug-resistant TB (MDR-TB)** - Resistance of Mycobacterium TB strains to at least isoniazid and rifampicin [with or without resistance to other drugs](#)

**Rifampicin-resistant TB (RR-TB)** - [Resistance to rifampicin with or without resistance to other first-line anti-TB drugs](#).

# 1. HUMAN RIGHTS, ETHICS, AND ENSURING EQUITY ARE ESSENTIAL FOR SUCCESSFUL TREATMENT OF PEOPLE WITH TB

**Human rights belong to every person. All these rights are very important and interrelated.**

- The right to health is a most fundamental right of every human.
- All States are obliged to protect and allow the realization of human rights including the right to health.
- Respect for human rights in the delivery of TB care is no less important than the TB treatment and care itself.
- Every person affected by TB has a right to free evidence-based TB treatment and must have easy access to people-centered, quality diagnosis, and care and medications.
- TB services must be available, accessible, acceptable, and of good quality (known as AAAQ framework).
- For TB treatment and care to be people-centered, the broader dimensions of accessibility (non-discrimination, physical, economic, and information) must be met.

Human rights are due to every human being. International treaties and national constitutions, set up and protect the human rights of all people, including people affected by and living with TB. The Universal Declaration of Human Rights adopted by the United Nations General Assembly in 1948 stipulates that **all human beings are born free and equal in dignity and rights**.

A most fundamental human right is the right to health. The International Covenant on Economic, Social and Cultural Rights, (ICESCR), article 12, defines the 'right to health' as the '**right of everyone to the enjoyment of the highest attainable standard of physical and mental health**'. This treaty has been ratified by almost all countries and is legally binding.

Human rights are often interrelated. For example, the right to health guarantees the right of access to good quality health services. It is very closely related to other rights such as access to clean drinking water, nutritious food, housing, sanitation, and education.

The right to health (article 12 of the ICESCR) is related to and dependent upon the realization of other rights, such as human dignity, equality, privacy, non-discrimination, non-stigmatization, informed consent, the freedoms of association, assembly, and movement, work, adequate standard of living (housing, food, clothing), **and especially the right to be involved, informed and benefit from scientific progress**.

One important part of the right to health is what is called the AAAQ framework. This means that health goods and services must be Available, Accessible (to all without discrimination as well as affordable and not too far away), Acceptable, and of good Quality. **These are enforceable minimal specific standards<sup>1</sup>** that should be upheld by all TB programs.

<sup>1</sup> The ICESCR is legally binding in almost all countries. A complaint has to pass through the local courts first and if it is not resolved there it can be escalated to international courts.

In the right to health, accessibility has four dimensions related to human rights - non-discrimination, economic accessibility (affordability), physical accessibility, and information accessibility.

For example, clinic-based / hospital-based DOT would likely not be physically or economically accessible for people with TB living in a rural area if they must travel a long distance and pay for transportation. Nor would it be acceptable for individual with TB raising children at home who, due to their low income, is unable to pay the additional costs of transportation to the treatment center. Also, visiting the treatment center is time-consuming and could leave them insufficient time to deal with the children. A discriminatory attitude could keep them away from treatment or the job market. Even if TB diagnosis, treatment, and care may be available at a bare minimum standard in their country, to be people-centered, the broader dimensions of accessibility must also be met.

All these international declarations are legally binding on governments and organizations implementing TB programs. In respecting, promoting, and ensuring that the rights to health, privacy, participation, information, non-discrimination, non-stigmatization, freedom of movement, and other human rights such as the possibility to benefit from research outcomes (more effective diagnostics, new TB medications, vaccines, regimens, interventions) **are related to improved interventions, treatment, and prevention outcomes**. Diagnosis, prevention, treatment, and care for people affected by TB must be based on human rights and ethics and **promoting equity to ensure that individual's needs come always first**.

According to WHO guidelines, human rights are legal guarantees that protect people with TB against actions that interfere with fundamental freedoms and human dignity. The guideline emphasizes the importance of families, civil society, the community, and the government in motivating and empowering **people to take part in planning and making decisions about their TB treatment and care**. This guideline highlights the need and obligation to incorporate human rights and ethical principles into the provision of TB treatment and care. It means that treatment programs should resonate with the needs of people with TB, and be linked with support services that motivate, encourage and help them to complete treatment successfully.

▶ All people on treatment should be treated with respect, dignity, and empathy, allowing them to make informed decisions about their health.

WHO published a comprehensive guideline entitled '**Ethics guidance for the implementation of the End TB Strategy**' in 2017 to be sure that TB strategies and programs globally are designed and implemented following human rights and high ethical standards and are tailored to people.

This guidance promotes people-centered treatment and follows the aims of the SDG 'Leave no one behind' - **end poverty, discrimination, exclusion and reduce the inequalities and vulnerabilities that limit the possibilities of individuals, families, and whole communities**.

It means that every individual affected by TB matters and must have free of charge and easy access to people-centered, quality diagnosis, treatment, and care. The WHO ethical guidance states that all TB services must be free, although there might technically be low costs charged that are still be in keeping with the right to health if they are not so great as to create an accessibility barrier (economic accessibility).

The guidance says clearly that the government has an ethical obligation to ensure access to free TB diagnosis, prevention, care, quality drugs for treatment, and provide the wide variety of social support that individual may need during treatment not only to drug-susceptible but also drug-resistant TB. It encourages people affected by TB to demand their rights and high ethical standards throughout the whole length of their treatment and care.

## 2. ADHERENCE TO HUMAN RIGHTS TO SCALE UP PEOPLE-CENTERED TB CARE

Civil society has many roles in the fight against TB. Some of the important ones are promoting evidence-based and people-centered screening, diagnosis, treatment, and care, and [advocating for the rights of affected TB communities and individuals and for increased resources](#). Usually, civil society knows well the community affected by TB and the local circumstances. CSOs are accepted locally while being able to collaborate with governmental and other institutions. These are the main reasons why CSOs have been engaged in scaling up people-centered TB services, usually in close collaboration with the national TB program.

Historically, TB treatment and care have been structured around hospitalization and observation that was believed to be clinically necessary as well as more convenient for medical staff. These approaches never met the needs of all people with TB and often placed a great burden on the most vulnerable people. Luckily, decades of research on infectiousness, adherence support, individual preferences, reduction of perceived treatment burden as well as advocacy on human rights and the people-centered care model have improved approaches to TB screening, diagnosis, treatment, care, and any other supports needed. Despite this, not all people who need TB treatment and care have access to innovative and rights-based services and supports.

Also, evidence shows that not all individuals, families, communities, and those planning and implementing TB programs are fully aware of the patient's rights nor of ethical standards and new treatment regimens. To solve this problem, in 2019, TB survivors, human rights experts, and civil society organizations including the Stop TB Partnership drafted and adopted the [Declaration of the Rights of People Affected by TB](#).

This declaration is based on the right to health, the right to science, and WHO's ethical guidance. Most importantly, the declaration acknowledges that while everyone has human rights, including the right to health, those rights must be understood, recognized, claimed, and the declaration drafted by people affected by TB does this fully.

The main aim of the declaration is to inform, promote and protect human rights and ensure people affected by TB have equitable access to science-based TB prevention, diagnosis, and treatment, including highly effective and tolerated medications, and care that resonates with their needs and is free from any form of stigma and discrimination. This declaration demonstrates clearly how important it is to involve people with TB and TB survivors in all aspects of TB prevention, diagnosis, and care.

This document stresses that all people with TB have the right to be treated with respect, dignity and to receive prevention, diagnosis, and treatment that meet international standards. This includes access to rapid diagnosis and the best available medicines for treatment. It also includes the absolute necessity of informed consent for all aspects of TB care.

This declaration demonstrates to us all that governments and national TB programs are obliged to protect, fully support, and promote the human rights, including the right for

health, of people affected by TB and offer them accessible, people-centered, gender-responsive and effective treatment with effective medications and support services.

## ***Adherence to human rights is no less important than the TB treatment and care itself for achieving a successful treatment outcome.***

*According to the Declaration of the Rights of People Affected by TB, healthcare for TB is defined as "integrated care with all the most effective, high quality health goods and services associated with preventing, diagnosing and treating TB infection and disease, including pulmonary, extrapulmonary, drug-susceptible and drug-resistant TB, with the least harmful side effects, including, but not limited to diagnostics, drugs, counseling and other psychosocial support services, long-term hospitalization and ongoing care for partial or permanent disability, when required, community-based care, palliative and end-of-life care, monitoring for and management of adverse events during treatment, and other therapeutic interventions and devices, including emergency care, delivered by trained health care workers in a respectful, dignified, culturally-sensitive, nondiscriminatory manner, free from coercion and stigmatization, over the entire course of infection or disease and covering the entire lifespan for people requiring continuing care".*

This comprehensive definition consists of the full list of essential services that people with TB may need due to their illness and special needs during the whole duration of their treatment and care. It also defines how these services must be provided and by whom.

This definition has been drafted by the best possible experts - the global TB community (e.g., TB survivors) - relying on their own experiences, needs, best practices and science. Thus, it is understandable why the definition is so long. At the same time, it is a rich source for decision-makers for service design.

# 3. INFORMED CONSENT

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*“Very few of us were informed of the potential for hearing loss when we were given an injectable”*

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Article [“Hear us! Accounts of people treated with injectables for drug-resistant TB”](#)

**The process of informed consent starts from screening and TB diagnosis and continues during the whole of TB treatment.**

- Informed consent is systematic, continuous, and mutual communication between the person in treatment and their medical staff or care team.
- Ideally, the entire care team (including the doctor, nurses, and other medical staff) should be part of the informed consent process.
- It ensures that people in TB treatment and care are well informed about their treatment (options, length, possible outcomes, medications used, and side-effects that may occur) to make informed decisions about their treatment during the whole treatment process and consider other services that might support cure.
- Informed consent helps to build trust between a person with TB and his/her medical doctor.
- A person can give written or verbal informed consent.
- A person has the right to refuse any medicines, procedures or treatment and care entirely.

Informed consent is a necessary part of rights-based and person-centered TB treatment and care. In accordance with the WHO Ethical Guidance, informed consent is defined as **‘the process of engaging individuals as partners in the delivery of health services by giving them sufficient and relevant information to enable them to make decisions for themselves’**.

Informed consent helps to build trust between individual and care team and maintain a good relationship between the individual under treatment and their medical care provider. It should be voluntary, respecting a person’s autonomy, self-determination, and dignity. Informed consent is not simply a document that is signed or a one-time agreement.

It is a process that should last for the entirety of TB diagnosis and treatment. It gives an individual enrolled in TB treatment the right to discuss all matters related to their treatment along with their medical team and make informed choices based upon their values and preferences.

The WHO guideline on systematic screening for active TB mentioned above, says that people screened for TB have the right to informed consent. During the informed consent process, all treatments and procedures, including their benefits and risks, should be explained to the individual concerned in plain language. This includes providing explanations for why certain medications are recommended and what their adverse reactions might be. It is important for individual to ask questions to have the best possible understanding about everything relevant to their treatment. Also, participants being

screened for TB should go through the informed consent process [to allow them to make an informed decision](#). They have the right to get test results as part of the information accessibility section of the right to health. Every person has the right to refuse any procedure. Even if a person refuses treatment, testing, or any other procedure, a professional who gives test results has an ethical obligation to explain the consequences of refusal in understandable terms.

A great time to start the informed consent process is right after diagnosing TB and while defining a personal treatment plan. The informed consent allows the individual undergoing treatment to ask for clarification of anything related to his/her health conditions and treatment (including regimens, side effects) and affecting his/her living arrangements and other aspects of life. As a rule, Informed consent should be well documented, carefully monitored and renewed regularly. Done this way, it helps to set up a mutually beneficial, trusting partnership between individual undergoing TB treatment and the medical staff for monitoring treatment progress.

Also, there is a high probability that decisions made by individual during difficult moments such as when being told of the diagnosis of TB, will be voluntary and understood if he/she is well informed about the benefits and possible side effects of the proposed treatment, and the risks of not being treated. In this way, the goals and obligations of both sides become clear.

It is an individual's right to be continuously well informed about the progress of their treatment, and the regimen being used. While research shows that not all doctors know or agree that a [person being treated for TB has a right to informed consent](#), the individual does indeed have this right, as guaranteed in the right to health and as stressed in [WHO guidance and strategy](#).

If it is culturally acceptable, it is preferable to use written informed consent, although individual can give verbal informed consent if that is more acceptable to them.

There is a need to bear in mind that just reading (or not reading) and signing an informed consent document is not informed consent. It is not the signature or the document itself that matter most. It is the understanding of individual who is undergoing the process of informed consent that is most important. Treatment providers have an ethical duty to provide all information about TB treatment (including risks, benefits, and alternatives, side-effects, and interactions between medications) before obtaining individual agreement. During the informed consent process, it is necessary to discuss openly not only the side effects of medications but also interaction with other drugs that can make treatment less effective. However, It is vital that individual be aware of side-effects to ensure best treatment outcomes.

Individual has the right to refuse any specific medicines and procedures or treatment and care entirely. A reason for this might be personal or if a particular adverse reaction or the risk of it, such as hearing loss, is unacceptable to the individual. In situations like this, it is a individual's right to ask if there are other treatment options. Even in situations where individual completely refuses medication, procedures, or treatment entirely, it is important that they be fully informed and counseled about the consequences of refusal and their further options. Evidence shows that refusal of TB treatment is related to [insufficient provision of information, counseling, and support](#). The treatment provider has an ethical obligation to support treatment adherence. Support from family and community is also pivotal to successful completion of TB treatment.

It is not legal to force individual to participate in the treatment, to take medication or to go through any procedure if they refuse. However, some countries have laws allowing for the involuntary isolation of people who pose a public health risk. It is necessary to inform the individual about the consequences they pose to their family and community **if not enrolled in treatment and how it negatively affects their health**. With proper counseling, people who initially refuse treatment, may give their consent once they understand its importance.

**Right to healthcare, medications, health-related information, and participation in health-related decision-making.**

- The right to timely and appropriate health care and medications.
- States must ensure the right to health and provide culturally appropriate, gender-responsive, physically accessible health care and support services for people affected by TB.
- Lack of finance is not an excuse for not ensuring the right to health.

The International Convention on Economic, Social, and Cultural Rights General Comment No. 14 is an important document related to the right to health. It stipulates the right to timely and appropriate health care and the underlying determinants of health (safe water, sanitation, food, clothing), **access to health-related information, and participation in health-related decision-making**. For example, the right to health includes available, accessible, non-discriminating, affordable, and good quality, and gender-sensitive health services. The right to health consists of the right to prevention, treatment, and control of diseases.

General Comment No. 14 emphasizes that States have three obligations - to respect, protect and fulfill. In short, this means that states respect the enjoyment of the right to health, prevent third parties from interfering in the above-mentioned rights and adopt appropriate measures (including legislative, administrative, budgetary, judicial, promotional, and other) towards the full realization of the right to health. This UN document states clearly that States must ensure the right to health and culturally appropriate, physically accessible health care services considering the needs of various vulnerable groups, supporting people in making informed decisions about their health, treatment and care. Even lack of finance by the State is not an excuse for not fulfilling the right to health and providing people with TB medicines on **the WHO Essential Medicines List (EML)**. It is considered a "core obligation". All of the medicines commonly used to treat both drug-resistant and drug-susceptible TB are on the EML.

***People-friendly informed consent process***

Article 12 of the Declaration of the Rights of People Affected by TB stipulates that everyone affected by TB has the right to verbal or written informed consent for testing, treatment, and participation in research projects. This declaration requires that all information provided during the informed consent procedure should be gender and age-specific, culturally sensitive, easily understandable, and non-technical, comprehensive, and communicated in a language understood by the person under TB treatment. Information provided to the person during TB treatment should be sufficient for her/him to make informed decisions about themselves. Informed consent does not replace any other interventions (e.g., psychological counseling) or activities meant to support a persons' adherence to TB treatment.

## 4. PEOPLE-CENTERED CARE AND SUPPORT

TB treatment and support services designed to fit best with the unique needs of individuals undergoing treatment and their families, include:

- People-friendly household or community-based treatment services instead of lengthy clinic-based treatment.
- Individual with TB disease should be an equal partner, not a patient, and needs a supportive, caring, and trustful atmosphere during treatment.
- Mental health services are related to better treatment outcomes and should be available to all people undergoing TB treatment.
- A multi-disciplinary medical team providing people-friendly treatment, care, and social support is a basis for successful TB treatment.

There is a clear worldwide trend to replace hospital-based treatment, even for MDR-TB, that [is inconvenient for the person being treated, with more convenient and people-friendly household or community-based treatment services.](#)

People-centered TB care should be available and easily accessible. Ideally, it should be moved closer to individual (in household or community settings) rather than forcing them to travel to and between different medical or care facilities to get their medication and social or other support. The treatment of MDR-TB and extensively drug-resistant TB is more complex, takes quite a long time, and should also be delivered in people-friendly household or community-based settings. It is found that treatment of adverse effects, intensive adherence interventions, and nutrition supplement consumption lead [to better MDR-TB treatment success. Individualized treatment regimens have better treatment outcomes compared to standardized regimens.](#)

Successful drug-resistant TB treatment needs good cooperation between various treatment, care, and supportive intervention providers. Ideally, it is a multi-disciplinary medical team able to create a supportive, caring and trusting atmosphere where individual with TB disease is an equal partner rather than a patient. Committed healthcare workers trained to provide [people-friendly care along with social support are one factor for successful MDR TB treatment.](#)

A recent meta-analysis of studies shows social support as related [to higher treatment success rates among people with DR-TB.](#) The analysis also showed that the most significant interventions leading to better treatment outcomes were monetary and other economic incentives (travel reimbursement, nutrition bonus, rewards for taking medications correctly, free treatment, service packages covering most of the treatment cost, food distribution). Health literacy consultations, whether at the person's home or at hospital, and advice on possible adverse effects of DR-TB medications and how to take medications correctly helped to improve treatment success. Companionship support from family treatment supporters (family, friends, relatives) or social groups also increases confidence in completing the treatment program. Supervision of TB medication intake and participation in different social events including celebration of milestones in TB treatment also improve treatment success. Therefore, it would be wise to implement these interventions with treatment programs.



Despite [WHO's recommendation of ambulatory TB treatment](#), some countries continue to insist on people with multi-drug resistant TB participating in lengthy hospital-based treatment. It has long been known that people, whether with DS-TB or DR-TB become rapidly non-infectious once treatment has begun, and thus are able to maintain their everyday life, taking outpatient treatment for TB.

Mandatory hospitalization of people with TB, violates their rights and negatively affects their mental health. It should be avoided and replaced with people-centered outpatient TB treatment [accompanied by supportive interventions and provision of mental health services](#). [Mental health services are not yet widely available to people undergoing TB treatment, although they should be. Mental health problems are associated with worse TB treatment outcomes. Individuals who, in addition to having TB, are depressed, are more likely to drop out of treatment or die.](#) Thus currently, there is an urgent need to develop mental health services for people affected by TB to support their mental health during and after TB treatment.

WHO TB guidelines list specific instances where hospitalization is recommended, but these are limited to specific clinical reasons and not applicable for most people with DS or DR-TB. If hospitalization is necessary, it should, like all other aspects of TB prevention, diagnosis, and treatment, be explained through an informed consent process and end as soon as individual is no longer infectious.

## 5. SCREENING AND DIAGNOSIS: MAINTAINING PRIVACY AND CONFIDENTIALITY

**WHO recommends routine systematic screening for TB to find and diagnose all people with active TB as fast as possible and provide them with treatment and support.**

- The aim of screening is to speed up detection and diagnosis of all people with active TB and to provide them with treatment
- TB screening programs and household contact management should be person-centered, free of stigmatization and discrimination, meet the needs of people of different gender, health (including disabled people), and income level, free of charge and able to motivate people diagnosed with TB to start treatment.

[WHO guidelines on systematic screening for active TB](#) recommend regular screening of people who belong to TB risk groups, following screening principles. In simple words, systematic screening for TB means routine identification of people who may have active TB.

TB screening should follow high ethical standards based on human rights, as used for screening for infectious diseases in general. As WHO guidelines point out, TB screening programs should be people-centered and designed to minimize discomfort and pain and be free of stigmatization and discrimination. Moreover, screening programs should meet the needs of people of different gender, health (including disabled people), and income status. Programs should also be free of charge and link with and motivate individuals diagnosed with TB to start treatment as soon as possible. The main ethical principles related to TB screening are the use of informed consent, maintaining privacy and confidentiality, and full protection of vulnerable populations.

The best way to protect different risk groups from stigmatization and discrimination during screening and diagnosis is to assess risks, including privacy and confidentiality, and eliminate these before implementation of any activity. Most importantly, in designing screening, as in diagnosis, treatment, and care programs, the involvement of people affected by TB is important to be sure that all elements of the program fully meet their needs, support their recovery, protect their rights and ensure dignity of the individual.

# WHAT TO REMEMBER:

Every individual affected by TB has a right to effective evidence-based, and people-centered TB prevention, diagnosis, and treatment, and supportive services, which should be based on social justice and equity, and aimed to succeed with the treatment.

Drug resistance continues to be a serious problem. Evidence shows that drug resistance is often the result of poorly implemented medical or public health interventions, not just inadequate TB treatment adherence.

The golden rule - TB treatment and care must be Accessible, Acceptable, Affordable, and Appropriate.

People-centered TB treatment places the focus not only on treatment but also on the well-being, values, and convenience of the individual being treated, and their loved ones. It is based on cooperation among them and the medical staff (care team), and aims to make a long-lasting treatment better tolerable, easier to adhere to, less disruptive, and without extra economic cost and waste of valuable time.

All people affected by TB have a right to be engaged with an informed consent process to be well informed and thus able to make decisions about his/her health.

Ideally, treatment care teams should encourage individuals undergoing TB treatment to participate in decision-making processes related to their treatment via the informed consent process and to ask regularly for feedback to improve treatment and adapt it to the individual's needs.

There is an urgent need to modernize TB treatment and care. "One size fits all" is not an acceptable approach if we are aiming to provide people with TB globally with a human-rights-based and people-centered treatment that helps them complete their TB treatment.

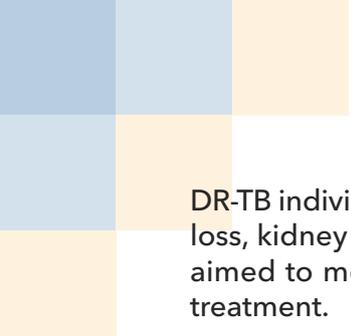
DOT is widely used in TB clinics and hospitals, but the latest evidence shows that it is not associated with better treatment success compared to other treatment approaches, and it is far from being people-centered and fails to consider psychological, structural, and other factors related to better treatment outcomes.

DOT is far from being convenient for individuals in treatment. It forces people to spend their valuable time and limited income traveling back and forth to receive TB medications; it places the greatest burden on already very vulnerable people and is especially burdensome for women who may have additional care responsibilities that make treatment adherence difficult.

To best serve the needs of people with TB and their loved ones the best solution is personalized community-based treatment and care, which is free of any stigma, and discrimination.

The whole TB treatment process must be a good collaboration between person and care team (medical and other personnel), where the informed consent process assists them to make informed decisions about their health, such that treatment is guided by their values and preferences.

Information shared regularly during the informed consent process should be gender- and age-specific, easily understandable, and non-technical, culturally sensitive, complete, and communicated in a language understood by the individual under TB treatment.



DR-TB individuals with HIV co-infection have an elevated risk for the development of hearing loss, kidney damage, and depression. There is an urgent need to provide specific services aimed to monitor and improve their heart, renal, and mental health problems during TB treatment.

There is a need to develop mental health services for people affected by TB to support their mental health during TB treatment and consequently improve the treatment success rate.

Treatment adherence can be increased by providing people in TB treatment with other supportive person-friendly services - food and /or food supplements, grocery store vouchers, a living allowance, housing, mental health support, friendly home visits, or supportive communication by phone, SMS, or voicemail.

The use of virtual TB treatment services by digital means where people can upload or record live video, offers an important option and is more desirable and less disruptive compared to classical DOT for some people as we learned during the COVID-19 pandemic.

However, these innovative solutions raise human rights-based concerns about privacy and people's dignity, which need to be addressed, and all these new solutions should be designed in a form that is acceptable for the individual with TB and their loved ones. Not all people can use TB treatment solutions provided virtually. They may not be appropriate for people with certain disabilities or people who lack experience with cellular phones or the internet, or if they live in a place where internet service is poor

TB treatment programs should collaborate extensively with communities, CSOs, and people affected by TB, and ask for feedback to improve and innovate treatment, care, and supportive services.

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