



SUGGESTED LANGUAGE AND USAGE FOR TUBERCULOSIS COMMUNICATIONS







SUGGESTED LANGUAGE AND USAGE FOR TUBERCULOSIS COMMUNICATIONS

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### ACKNOWLEDGMENTS

The first edition of the guidance was called Every Word Counts. We emphasize that the first edition was a landmark and provided the foundation upon which Words Matter has further built upon. This updated guide is the result of the collaborative effort of many individuals, including people living with or affected by TB and activists (including through consultations hosted in Africa by African Coalition on TB and DRAF TB; in Asia by the Activists' Coalition on TB Asia-Pacific; in Eastern Europe by TBpeople; and in the Americas and Caribbean by the Americas TB Coalition), medical professionals, researchers, technical writers, technical working groups (including the STP New Tools and Vaccines Working Groups), and academic partners. We would like to thank all those who contributed to the development of this guide through participation in consultations and text review. We would also like to particularly thank the Stop TB Partnership Secretariat team, under the leadership of Dr Lucica Ditiu, for their unwavering commitment to a human rights-based TB response.

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Comments and suggestions for additions or modifications should be sent to: communications@stoptb.org



### While Tuberculosis can attack any part of the body, the power of the spoken word can penetrate much deeper, and for many people have longer lasting effects. Words Matter!

— Peter Ngo'la Owiti Stop TB Partnership Board Member Affected Community

deadliest diseases, killing three people every minute. At the time of publication, each year an estimated 10 million people developed TB and 1.5 million died from the disease. As part of efforts to end TB by 2030, we must have a shared TB language that empowers people with TB, champions human rights and innovation, and promotes accountability. As a result of the 2018 United Nations (UN) high-level meeting (HLM) on TB, the Political Declaration on the Fight Against Tuberculosis (Political Declaration) outlined commitments of the Member States to eliminate TB by 2030. In 2020. a progress report requested by the UN Secretary-General (UNSG) reinforced the recommendations to the Member States and will inform the content and implementation of the 2023 UN high-level meeting on TB's political declaration. Responding to the recommendation of the political declaration that TB-affected communities and civil society be meaningfully engaged in all aspects of the TB response, the Stop TB Partnership

communities – in collaboration with

the Developing Country Non-Governmental

Tuberculosis (TB) remains one of the world's

Organization (NGO) and the Developed Country NGO delegations to the Board of the Stop TB Partnership – developed a community report that monitored the implementation of the Political Declaration and sought to hold stakeholders accountable for targets committed to in it.

The communities' report, titled A Deadly Divide, TB Commitments vs. Realities, was issued 5 November 2020 and included a Call to Action for the UN Member States with recommendations in six critical areas for action<sup>1</sup>:

- Reaching all people through TB detection, diagnosis, treatment, care, and prevention.
- Making the TB response rights-based, equitable and stigma-free, with communities at the center.
- <u>3</u> Accelerating the development of, and access to, essential new tools to end TB.
- 4 Investing the funds necessary to end TB.
- 5 Committing to accountability, multi-sectorality, and leadership on TB.
- <u>6</u> Leveraging COVID-19 as a strategic opportunity to end TB.

In preparation for the second UN HLM meeting, proposed for 2023, it is essential that there be a unifying vocabulary that creates a shared understanding of the path forward. This will require clear communication at every level: communities, programs, governments, funders, researchers and others. This begins with acknowledging the importance of language and word choice when discussing resource allocation, program development, and monitoring and accountability. Language influences stigma, beliefs and behaviors, and it may determine whether a person feels comfortable coming forward to be tested or treated and to advocate for themselves and others. Those engaged in the development of this

guide seek to encourage more empowering, people-centered language that allows respect for the human experience and to implore people to speak openly and compassionately about TB in their homes, communities and workplaces. Words Matter has been structured across distinct, yet interrelated, sections. First, there is an introduction to unpack the difference between technical and conversational language.

Second, there is an alphabetical index, which will help users navigate this guide - particularly the glossary - efficiently and effectively. Third, there is a list of words or terms that can replace historical words or terms that are stigmatizing. Fourth, there is a discussion of words and phrases with sensitivities that TB stakeholders must note. Finally, there is a glossary that is organized across several themes: TB classification; epidemiology; prevention; diagnosis; treatment; systems; community, rights and gender; and emerging terms. This is a living document that will evolve as terms and inclusive language change. It will encourage debate and reflection among those engaged in research, writing and editing, policy development and advocacy. It is also envisaged that this guidance will be adapted and translated into different languages in recognition of the nuance across languages, cultures and contexts – and we encourage partner to explore how best to adapt and use it in their respective countries. Hopefully it will ultimately result in changes to mainstream language that protects and promotes the rights and dignity of people

with and affected by tuberculosis.



**GLOSSARY** 

### Words Matter is constructed in three sections.

The first is the **Index**, which is an alphabetized listing of all words and terms presented. The Index will allow the user to find the necessary page to understand the usage of a word or term.

Second is the Language Guide, which includes terms that are recommended for people to use when they speak about TB and related concepts in formal and informal settings. The Language Guide outlines gender-transformative, people-centered and rights-based terms that should be used when discussing TB programs, policies, financing and advocacy. The Guide is presented in two segments: The first notes words and terms that are not inclusive and supportive and in many cases are offensive; next an alternative term or phrase is provided.

Third is the **Glossary**, which lists a collection of frequently used words and terms with an explanation for their use. Efforts have been made to be as nuanced as possible in the presentation, such as distinguishing between person-centered (attention to the person) and people-centered (the person in the context of family and society). The terms are used for precision and clarity, and within the document, a distinction is also made about the difference between technical and conversational language.

# CAL VS

Change begins with our words – and it's time we use the right ones. We must communicate by using language that is sensitive to the needs of the community and not be slaves to medicalized, insensitive language just because we are used to saying it.

Stop TB Partnership – Affected Community Delegation

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# CONVERSA-IONAL LANGUAGE

<sup>-----</sup> Rhea Lobo

# TECHNICAL LANGUAGE

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# CONVERSATIONAL LANGUAGE

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Technical language is generally used to enhance communication between members of the same profession or aroup to discuss specialized content, and it assumes a certain level of knowledge and technical expertise. Context is the critical factor in determining what language is appropriate in certain settings. Words used in technical settings by researchers and health providers can have immense power to shape TB care and how people speak and think about TB if used conversationally. In addition to noting the setting for the use of words or terms, it is critical to consider cultural and regional differences that affect usage. Words such as *patient* and *cases* are not exclusive to the TB community, and when used in the correct context, they are useful as shorthand to communicate research and clinical or procedural concepts. But even in that context, it is important to be attentive to sensitivities

that can occur when an individual

in the conversation.

affected by TB is present or participating

Some words are wholly offensive, such as *illegal* or *alien*. Other words, such as *TB suspect*, are stigmatizing and harmful, transferring the "suspicion" of the disease to the person with TB and suggesting they are guilty of a crime or offense.

Understanding technical terms is key to understanding the medical aspects, progress and challenges that inform programming and advocacy for the Stop TB Partnership.

For example, an informed TB activist who understands new TB technologies is likely to be an effective advocate for new TB vaccines, diagnostics and drugs.

There are terms that persist in technical, clinical and medical settings that are not appropriate for use in informal conversation or formal statements of policy, advocacy and media. These terms have a specific meaning in a scientific setting; other technical terms have utility in many settings, as they can clarify the specific issue or concern addressed. Conversational language is generally used for social communication that can be both formal and informal. Consistent use of compassionate language in conversation can be used to establish and maintain connections and understanding. Some of these terms may be helpful to people who have recently been affected by TB or are learning about words used to describe issues related to TB. Whatever the purpose of the conversation, the language should be people-centered and acknowledge the importance of putting people

and communities at the heart of any TB discussion. People affected by TB have confronted stigma and discrimination throughout history. Language can empower

history. Language can empower and encourage people with TB to take control of their health care and become partners in their treatment and empowered equal partners in the TB response, or it can disempower and create stigma, dependency and fear. Stigma can lead people with TB to hide their need for care or avoid seeking help, making it more likely that they will become ill and infect others. Stiama can also lead to social exclusion and mental health implications. Even after the start of treatment, concern about the consequences of TB stigma often leads individuals to not complete their treatment programs. Treatment for TB can present major challenges, such as prolonged absence from work, limitations on individual and family income, paying for transportation to a medical facility or debilitating treatment side effects. all of which can lead to extreme debt. Showing compassion and understanding of the challenges faced by people with TB starts with the language TB stakeholders use. By using terms that empower people affected by TB, TB stakeholders can collectively bring the disease out of the shadows. One of the most effective tools against TB is education on how to prevent and treat it. This includes ensuring that the everyday conversational language TB stakeholders use to communicate empowers rather than isolates people with TB.



For us who have lived experience of this disease, we know the importants of language in framing all aspects of TB. This is a great "go to" document for all stakeholders working to end TB, including the recipients of services and care. Language does matter and through the adoption of, and sensitization to this guidance, we will see enhanced health seeking behavior, find more of the missing people with TB and increase treatment completion. People with TB will feel respected and feel as though they are being treated with the dignity they deserve.

----- Carol Nawina Stop TB Partnership Board Member Affected Community

# AUDIENCE

Words Matter was developed with multiple audiences in mind. The primary audiences are TB civil society, people affected by TB and health-care providers, including community health workers and program staff.

The effort to use non-stigmatizing, human rights-based and gender-transformative language is ongoing and not fully embraced by all sectors. The Language Guide creates an alternative to terminology that has been in use for decades but brings with it a dehumanizing aspect to the discussion of TB and those affected. The hope is that as new writing is undertaken, research findings are described, policies are advanced and advocacy evolves, the language regularly employed is not only accurate but also respectful, peoplecentered and empowering.

It is important to remember that while Words Matter was designed with the English speaker in mind, a majority of the work in TB occurs in other languages. It is also critically important to be mindful of cultural differences and the diversity of meaning that terms carry in other languages and settings. Therefore, a nuanced consideration of the best phrasing based on context remains an important consideration. Ultimately, the purpose of Words Matter is to call attention to the impact that terms and their usage can have and to ask the user to carefully consider the power of their words.

Further efforts to inform TB stakeholders – including program managers, implementers and researchers – on the nuance and sensitivities of language should be made to ensure that the TB language guidance described in *Words Matter* can be operationalized and mainstreamed.





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# **ABBREVIATIONS** & ACRONYMS

AI	artificial intelligence
BPaL	bedaquiline, pretomanid & linezolid
C19RM	COVID-19 response mechanism
CAD	computer-aided detection
CFCS	Challenge Facility for Civil Society
CLM	community-led monitoring
CRG	community rights and gender
CRX	chest X-ray
css	community systems strengthening
DR-TB	drug resistent TB
DS	drug susceptibility
DST	drug susceptibility testing
ЕРТВ	extrapulmonary TB

HIV	human immunodeficiency virus
HSS	health systems strengthening
LTBI	latent TB infection
LtFU	lost to follow-up
MDR-TB	multidrug-resistant TB
РРМ	public-private mix
RR-TB	rifampicin-resistant TB
RSSH	resilient and sustainable systems for health
ТВ	tuberculosis
TB KVPs	TB key and vulnerable populations
UHC	universal health coverage
WGS	whole-genome sequencing
XDR-TB	extensively drug-resistant TB



For too long we did not pay attention to how we speak about TB, about people, about people infected and sick with TB, about the type of treatment outcomes, about different interventions. We did not address the fact that the way we speak can be stigmatizing, discriminatory, non-inclusive, that can hurt, upset and isolate people. We had the first language guide in 2012 and I am thrilled that our colleagues from civil society, communities, TB survivors came together to update and change the language guide. My hope is that every single one of us will read and embrace this guide and make the effort to change what has to be changed in our own language. So, I can end by saying let's use the Words Matter guide - it will make each of us much better and. I strongly believe, our TB response will be the one we want.

- Dr. Lucica Ditiu Executive Director Stop TB Partnership



SUGGESTED LANGUAGE AND USAGE FOR TUBERCULOSIS COMMUNICATIONS



# Participation in the TB response requires that each

of us has the vocabulary necessary to participate fully in discussions on policy, practices and proposed responses. Those engaged in the programmatic and clinical spheres have long shared a vocabulary that allowed for a clear understanding of the processes that comprise TB epidemiology as well as screening, diagnosis and treatment.

What follows is a list of terms that should be removed from common usage for their stigmatizing and exclusionary connotation. For example, the use

of he/him and she/her is replaced by they/them to convey a more inclusive intent. Others are terms that can be considered offensive on their face and are not appropriate for use in any setting. SUGGESTED LANGUAGE AND USAGE FOR TUBERCULOSIS COMMUNICATIONS

# DO NOT USE

TB contact is used to describe a person who was exposed to *M. tuberculosis*, either in community or due to professional duties. While the term does not have strong negative connotations, it is not person-centered.

PREFER CONTACT PERSON

# DO NOT USE

Historically an epidemiologic data category, the word *default(er)* unnecessarily and unfairly places blame on the person receiving treatment. It is important to understand the underlying reasons for a person's loss to follow-up in order to address the root cause(s).

A person who was diagnosed with TB but did not initiate recommended treatment or whose treatment was interrupted for two or more consecutive months is recognized as being lost to follow-up. People are lost to follow-up for various reasons, including systemic challenges such as access to health facilities, facility-based stigma, lack of diagnostic and treatment services, equipment and commodities, or challenges faced by the person on TB treatment such as lack of transport and poverty. Underlying reasons for LtFU translate to barriers to access to and quality of health services, which must be addressed to enable people on TB treatment to complete their regimen.

PERSON LOST TO FOLLOW-UP

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## ILLEGAL / ALIEN WORKER

Historically a reporting category for many national TB programs. Referring to a person as *illegal* is offensive on its face and is a term that should not be used. Migrants are among **TB key and vulnerable populations** (**TB KVPs**) who often have unsuccessful treatment outcomes. The term *alien* often affects their access to TB preventive and treatment services because of their noncitizen status. An unauthorized worker is one that migrates from one geographic region to another across a recognized legal boundary for employment without benefit of visa admission or following other procedural requirements. Accessing and completing TB treatment is often difficult for migrant workers. Cross-border lapses in care have been an especially thorny problem that several countries are starting to address.

### PREFER

### NONCITIZEN RESIDENT OR UNAUTHORIZED RESIDENT / WORKER

# HE/HIS OR SHE/HER

Gender-sensitive language does not presume a binary opposition such as male/female.

Avoid the use of male- (he/him/his) or female-only (she/her/her) identities as the default in all documents, including those intended for people with TB, such as an identification card or a treatment literacy pamphlet. A simple alternative is to use either pairing or a plural pronoun. For example: *"We tell every person with TB that he must practice cough hygiene"* can be written as *"We tell all people with TB that they must practice cough hygiene"*. Do not use the male default when referring to communities or professions. For example, *use businessperson* in place of *businessman* or *chair* in place of *chairman*, etc. Be fair and consistent in referring to men and women – use surnames, titles, etc., for both. Do not refer to male doctors as "Dr." and their last name and female doctors by their first

When referring to transgender persons, it is important to check which pronoun they are comfortable with.

PREFER THEY / THEM

name.

# DO NOT USE

A person who presents with symptoms or signs suggestive of TB. The term *suspect* is generally used in a criminal law context to indicate a person who is suspected of committing an offense. The term *person* with presumed TB removes that negative association.

For example, "On clinical examination, it appears that this is a person with presumed TB".

# PERSON WITH PRESUMED TB



*TB prevention and care* is the term used to define a range of TB interventions and programs. In the past, the term *TB control* was used, but its continued use is no longer recommended by the World Health Organization (WHO) because it was not "people- centered" and ignored the contribution of communities and people affected by TB. The term also had negative connotations of TB authorities' being in full control of all aspects of prevention, treatment and care of people with TB.

Additionally, priorities have shifted from an approach of "controlling" the epidemic to one that focuses on "ending" the epidemic.

For example, "We need to strengthen TB prevention and care services among rural communities".

### PREFER

TB PREVENTION AND CARE OR ENDING TB

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# DO NOT USE

With reference to those living with HIV, it is preferable to use *person living with HIV*, since this reflects the fact that an HIV-positive person may continue to live well and productively for many years. The term *people affected by HIV* encompasses family members and dependents who may be involved in caregiving or otherwise affected by the HIV-positive status of a person living with HIV.

PREFER

### PERSON LIVING WITH HIV / AIDS PLWHA / PLHIV

# DO NOT USE

Often used to describe children with TB or living with HIV or people who have acquired either through no action of their own (medically or at birth, for example). The term wrongly implies that people infected in other ways are somehow guilty.

### PREFER

### PERSON LIVING WITH HIV / AIDS

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While the person affected by TB is at the heart of this work, the consideration of their human response has been less of a focus. Accuracy at the cost of human dignity must be weighed against the final goal, which is putting an end to TB for those with, affected by and at risk of TB infection and disease. It is incumbent upon all those who engage in dialogue, research and writing, policy development and programmatic responses to weigh their word selection against the unintended perpetuation of stigma and bias.

Following are terms that have a use when discussing certain aspects of TB care, such as the process of receiving the necessary amount of treatment. While these terms have their function to accurately describe processes and a state of being, their use when applied to a distinct person can have a diminishing or stigmatizing effect. These terms are listed here to bring attention

to the need for their careful use.

### USE CAREFULLY PRESUMED PRESUMPTIVE

Historically a reporting category in many national TB programs for a person presenting with TB symptoms without bacteriological confirmation. This term places the emphasis on the disease and not the person with possible tuberculosis. This can be rephrased to focus on the person. As with the previous term, while the word can be used to describe a stage in the process of diagnosing TB, when discussing an individual, it is best to say a *person with presumed TB*.

### USE CAREFULLY BURDEN

The term *burden* refers to how much a country is affected by TB. However, it should be stressed that it is the disease, not people affected by the disease, that burdens a country, a region or the world.

### USE CAREFULLY CASE FINDING OR CASE DETECTION

Identification of newly developed TB in an active systematic way or through an inactive identification of new TB by virtue of action taken by the person experiencing symptoms.

### USE CAREFULLY PRISONER OR INMATE

Care when using *prisoners* or *inmates* is important. This is because in some contexts it can stigmatize people and it can impact perceptions regarding the right to health for all. An alternative phrase that can be used is *people deprived of their liberty*.

### USE CAREFULLY COMPLIANCE NONCOMPLIANCE

The term *compliance* is used to describe the degree to which every required dose of medicine is taken over a course of TB treatment, and it is meant to describe whether the person follows the prescribed regimen. The term *noncompliance* unfairly assigns blame to the person receiving treatment when many external factors outside a person's control (health system factors, economic factors and personal reasons) may be the cause. While adequate treatment can be achieved without the person receiving adequate treatment support, there may be a greater chance of recovery if essential support is received, such as peer support from TB survivors, access to information, access to mental health supports, and social supports that can cover income loss, transportation and other costs.

### USECAREFULLY ADHERENT NONADHERENT

Like compliance/noncompliance, the term adherent is used to describe the degree to which every required dose of medicine is taken over a course of TB treatment. This term unfairly assigns singular responsibility for treatment completion to the person receiving treatment, when many external factors outside a person's control (health system factors, economic factors and personal reasons) may be the cause. It is important to understand any impediment that may undermine the person's ability to complete the prescribed course of treatment.

### USE CAREFULLY MOBILE WORKER

The term mobile worker refers to a large category of persons who may cross borders or move within their own country on a usually frequent and short-term basis for a variety of work-related reasons, without changing their primary residence or home base. This includes any person regularly admitted as a migrant for employment, as reflected in the Migration for **Employment Convention** (Revised) 1949, No. 97. Mobile work involves a range of employment or work situations that require workers to travel in the course of their work. Mobile workers are usually in regular or constant transit, sometimes in (regular) circulatory patterns and often spanning two or more countries, away from their habitual or established place of residence for varying periods of time.

### USE CAREFULLY HIV-POSITIVE / HIV-NEGATIVE PERSON WITH TB

The human immunodeficiency virus (HIV) weakens a person's immune system, allowing TB infection to progress to TB disease or for the person to move straight into disease when exposed. A person with any bacteriologically confirmed or clinically diagnosed TB should be tested for HIV. The same is true in reverse – a person who has seroconverted for HIV should be tested for TB infection or disease so that appropriate treatment can be initiated.

### USE CAREFULLY HIV STATUS UNKNOWN PERSON WITH TB

A person with any bacteriologically confirmed or clinically diagnosed TB who has no result of HIV testing and no other documented evidence of enrollment in HIV care. If the person's HIV status is subsequently determined, they should be reclassified accordingly.

### USE CAREFULLY SPUTUM OR SMEAR POSITIVE / NEGATIVE

Smear microscopy is no longer recognized as a recommended diagnostic strategy. The preferred term is *bacteriologically positive/negative*.

### USE CAREFULLY RISK GROUPS

Any group of people in which the prevalence or incidence of TB is significantly higher than in the general population whose life circumstances increase their risk of exposure to TB disease. While the term is used in the epidemiology of TB to describe clinical risk groups when discussing an individual or group, it is best to say key and vulnerable populations.



### **PATIENT / TB PATIENT** (AND THEIR ASSOCIATES / FAMILY / COMMUNITY)

While the term *patient* means a person receiving or registered to receive medical treatment, it is widely used in respect to people with TB, even those who are not diagnosed or do not receive medical care. Also, the word implies the person's being under the authority of health system, suggesting his or her being subordinated to the authority of health workers. *Person on treatment, person receiving health care* and in some countries *client* are preferable terms and phrases.

Person affected by tuberculosis can refer to any person with tuberculosis infection or disease or who previously had tuberculosis disease, as well as their caregivers and immediate family members, and members of *tuberculosis key and vulnerable populations (TB KVPs)*, such as children, health-care workers, indigenous peoples, people living with HIV, people who use drugs, prisoners, miners, mobile and migrant populations, women, and the urban and rural poor. Example: *"The contribution of people affected by TB is important in the fight against tuberculosis"*.

As noted previously, the word patient when used in conversation or when speaking with the person "clinicalizes" them and places great focus on the treatment process rather than the person. During the period of treatment, which can be for an extended time, the person continues to live life as a *person with TB*.



Comments and suggestions for additions or modifications should be sent to: communications@stoptb.org



Important factors that affect the success of TB treatment are to what extent a person feels comfortable, the degree to which treatment approaches allow them to remain part of society, to not be a burden on the family and ideally to be able to work without fear of being isolated by illness. We will never be able to create people-centred approaches until we completely change our thinking and perception. A vivid example is when we talk about "helping a person with TB" vs. "treatment of a case" - they require a change in thinking and a change in approach. The world's fight with TB begins with how we talk about disease, the people affected and their rights.

----- Olya Klymenko Stop TB Partnership – Affected Community Delegation

# WORDS MATTER

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SUGGESTED LANGUAGE AND USAGE FOR TUBERCULOSIS COMMUNICATIONS



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# WORDS MATTER

Some words and terms have a specific meaning

in describing a process that should not be ascribed to the person contending with TB, such as the word *case*. These words and terms are used in clinical care, research, epidemiology and other aspects of TB, such as "case finding". When these words and terms are used to discuss the process, they allow rapid understanding of the topic under discussion; however, when they are employed to describe a person or circumstance, they demonstrate a lack of consideration for the person experiencing the impact of TB in their life.

# **TB CLASSIFICATION**

A new paradigm for a dynamic continuum of **TB infection** that includes additional categories between infection and active disease is receiving attention? The categories are included here so that users of this guide can become familiar with the framework.

### **TB INFECTION**

The presence of viable *M. tuberculosis* with or without progression to **active TB disease**, and none is expected unless there is serious immunologic compromise. People infected with TB bacteria have a lifetime risk of progressing to active TB of approximately 10 per cent. However, those with compromised immune systems, such as people living with HIV, **malnutrition** or diabetes or who use tobacco have a much higher risk of becoming sick with active TB disease.

### LATENT TB INFECTION

A state of persistent immune response to **TB infection** without evidence of progression to **active TB disease**.

### **INCIPIENT TB INFECTION**

Infection with viable *M. tuberculosis* that is likely to progress to active disease in the absence of further intervention but has not yet induced clinical symptoms, radiographic abnormalities, or microbiologic evidence consistent with **active TB disease**.

### SUBCLINICAL TB DISEASE

Disease due to viable *M. tuberculosis* bacteria that do not cause clinical TB-related symptoms but cause other abnormalities that can be detected using existing radiologic or microbiologic assays. The TB disease is at an initial stage, developing or beginning to happen.

### **ACTIVE TB DISEASE**

Presence of *M. tuberculosis* that has progressed from infection to active disease; in other words, what is commonly meant when we say that "a person has TB". While the most common and communicable form of TB involves the lungs, TB can affect other organ systems, bones and joints, the genitourinary tract and other sites.

### ELIMINATED TB INFECTION

*M. tuberculosis* infection has either been cleared by innate and/or acquired immune responses or has been cured with anti-TB medications. An individual with eliminated TB infection no longer has viable *M. tuberculosis* but may still have immunological evidence of prior infection.

### **PULMONARY TB**

Active TB in the lungs, as compared to **extrapulmonary TB**, where *M. tuberculosis* is present in organs other than the lung.

See Active TB disease

### **EXTRAPULMONARY TB (EPTB)**

Used to describe the presence of *M. tuberculosis* in organs other than the lungs, such as the pleura, lymph nodes, abdomen, genitourinary tract, skin, joints and bones, or meninges. Diagnosis should be based on at least one specimen with confirmed *M. tuberculosis* or histological or strong clinical evidence consistent with active extra-pulmonary TB, followed by a decision by a clinician to treat with a full course of TB chemotherapy. Tuberculous intrathoracic lymphadenopathy (mediastinal and/ or hilar) or tuberculous pleural effusion, without radiographic abnormalities in the lungs, constitutes a case of extrapulmonary TB. While a person with both pulmonary and extrapulmonary TB can be included in both categories, it is important that at a minimum it be classified as pulmonary TB because of the airborne route of infection.

### **MILIARY TB**

Used to describe a form of **pulmonary TB** with the appearance of millet seed-like lesions throughout the lungs. Miliary TB occurs when the bacilli get into the bloodstream and disperse to all parts of the body. This can cause disease in multiple sites of the body.

### **TB MENINGITIS**

A form of **extrapulmonary TB** that affects meninges - the lining of the brain.

### **POTT'S DISEASE**

A form of **extrapulmonary TB** affecting the spine, usually due to spread from other sites, often the lungs. The disease is named after Percivall Pott, the British surgeon who first described it in the late 18th century.

### **DRUG-SUSCEPTIBLE TB (DS-TB)**

Strains of *M. tuberculosis* for which all of the TB medicines will be effective so long as they are taken properly.

2 Incipient and subclinical tuberculosis: A clinical review of early stages and progression of infection. Clinical Microbiology Reviews, Vol. 31, No. 4. ASM Journals Time brings new knowledge and attitudes. The tuberculosis community embraces this moment to update and share the vocabulary we use to express our current experience. Every word not only counts, they matter!

— Paula Fujiwara Chairperson Task Force and Writing Committee Global Plan to End TB, 2023-2030

### **DRUG-RESISTANT TB (DR-TB)**

Used to describe TB that is resistant to at least one first-line anti-TB medication. What follows is a list of the various forms drug resistance in TB can occur. In many instances, resistant TB disease can be cured but it requires anti-TB medication other than those used for drug-sensitive TB and treatment can take much longer to complete.

### MULTIDRUG-RESISTANT TUBERCULOSIS (MDR-TB)

A form of drug-resistant TB, with the *M. tuberculosis* strain resistant to at least isoniazid and rifampicin, the two most powerful anti-TB drugs currently in use to treat drug-susceptible TB.

### **RIFAMPICIN-RESISTANT TB (RR-TB)**

An *M. tuberculosis* strain resistant to rifampicin detected using genotypic or phenotypic methods with or without resistance to other anti-TB medication currently in use to treat drug-susceptible TB.

### MDR-TB/RR-TB

Indicates that an Xpert positive result for RR-TB is presumptively treated as MDR-TB. RR-TB, along with MDR-TB, has been an area of growing concern to human health worldwide and poses a threat to achieving the end of TB.

# EXTENSIVELY DRUG-RESISTANT TB (XDR-TB)

Describes *M. tuberculosis* strains of MDR-TB that are resistant to isoniazid and rifampin, a fluoroquinolone and a second-line injectable or bedaquiline or linezolid.

### PRE-XDR-TB

Describes *M. tuberculosis* strains that fulfill the definition of multidrugresistant TB (MDR-TB) and are also resistant to any fluoroquinolone.

### TOTALLY DRUG-RESISTANT TB (TDR-TB)

A generic term for tuberculosis strains that are resistant to a wider range of drugs than strains classified as extensively drug-resistant tuberculosis. The term was first presented in 2006, when it showed that TB was resistant to many second-line anti-TB medications and possibly all the medicines used to treat the disease. However, the term *totally drug resistant tuberculosis* is not yet recognized by the WHO. These cases are defined as extensively drug resistant tuberculosis (XDR-TB), according to WHO definitions?

### HIV-NEGATIVE

The results of a blood test for HIV show no evidence of infection with HIV (e.g. absence of antibodies against HIV). Synonym: seronegative. It is important to note that the test result of a person who has been infected but is in the "window" between HIV exposure and detection of antibodies will also be negative. *HIV-negative* may also be used to describe a person's HIV status (i.e. "an HIV-negative person").

### **HIV-POSITIVE**

The results of a test for HIV show the presence of antibodies against HIV. Antibodies can be detected through a blood test or gingival exudate test (commonly known as a saliva test). Synonym: seropositive. *HIV-positive* may also be used to describe a person's HIV status (i.e. "an HIV-positive" person).

# **EPIDEMIOLOGY**

### CASE

Used widely in public health to refer to an instance of disease, and in that context has it a specific meaning. It should be applied with sensitivity in health-care settings to avoid dehumanizing people with TB. A person is not a case but a fellow human being. People seeking or receiving care may find it demeaning if they overhear a health worker describing them as cases.

→ Consult Language Guide for recommended usage

### DEFINITE CASE OF TB

A bacteriologically confirmed TB case – a person with TB whose biological specimen is positive by culture, or **WHO-approved rapid diagnostics** (such as **GeneXpert**® MTB/RIF<sup>4</sup>, Truenat® and other molecular methods). With advancements in new TB diagnostics, WHO discourages case identification using smear microscopy for testing and case detection.

→ Consult Language Guide for recommended usage

### **TB BURDEN**

Disease burden is the impact of a health problem as measured by financial cost, mortality, morbidity, or other indicators. *TB burden* refers to how much a country is affected by TB. It can be described by saying how many people with TB they have in a year, or how many people in the country die of TB each year, or how many people with TB there are at any given point in time.

### LISTS OF HIGH-TB-BURDEN COUNTRIES<sup>5</sup>

WHO periodically provides a global list of high burden countries for TB. TB-HIV and multidrug/rifampicin-resistant TB (MDR/RR-TB), with 30 countries in each category and each category accounting for 86 per cent to 90 per cent of the estimated global incidence rate. Twenty of the 30 countries are selected on the basis of the estimated absolute number of new (incident) cases, and 10 countries are determined on the basis of the most severe burden in terms of incidence that are not already in the top 20 and that meet a minimum threshold in terms of their absolute number of cases: i.e. 10,000 new cases per year for TB and 1,000 new cases per year for HIV-associated TB and rifampicinresistant TB.

- The categories are:
- The 30 high-TB-burden countries.
- The 30 high-TB/HIV-burden countries.
- The 30 high-MDR/RR-TB-burden countries.

- 4 The Xpert MTB/RIF that detects mycobacterium tuberculosis complex (MTBC) and resistance to rifampin (RIF) in less than two hours
- 5 WHO global lists of high burden countries for tuberculosis (TB), TB/HIV and multidrug r/ifampicin-resistant TB (MDR/RR-TB) 2021 - 2025. Background document. https://cdn.who.int/media/docs/default-source/hqtuberculosis/who\_globalhbcliststb\_2021-2025\_background document.pdf?stvrsn=fbb864c2\_9

<sup>3</sup> World Health Organization Tuberculosis: Totally Drug-Resistant TB. https://www.who.int/news-room/questions-and-answers/ item/tuberculosis-totally-drug-resistant-tb

### **MISSING PEOPLE WITH TB**

People with TB who are "missed" each year by health systems receive neither the diagnosis nor treatment they need, and they are not notified by the national surveillance systems. According to WHO, in 2020 close to half of all people with TB were missed, did not access the care they needed and were not reported. There are many different reasons for this, depending on the context and the country. Some patients may have poor access to TB treatment and health services in general; other countries do not have TB services available in all facilities. There may be a shortage of health workers in some cases, or existing health workers may not have the appropriate skills and training to be able to TB?

### NOTIFICATION

Health workers are obligated to register the name of each person diagnosed with TB, usually in an official registry, and data on the number of cases are then reported at regular intervals to national health authorities. This process is important. because it allows every country to track the TB epidemic and progress in addressing it. However, people working in health services should be sensitive to the implications for people affected by TB if they should overhear that their "case" has been "notified". They should be prepared to explain why notification is important for society as a whole. The confidentiality of people who are notified is essential.

### TB INCIDENCE

The estimated number of people falling ill with TB during a period of time (usually a year), expressed as the rate per 100,000 population.

### **TB PREVALENCE**

The proportion of individuals in a specific population who are ill with TB at a specific point in time. Usually given as the number of people with TB per 100,000 population.

### TB KEY AND VULNERABLE POPULATIONS (TB KVPS)

Subpopulations that are more prone to TB either due to more environmental (overcrowding, poor ventilation), biological (immunologically suppressed, poor nutrition or behavioral risks (directly through airborne transmission or indirectly through behavior that increases the risk of non-TB diseases that suppress immunity) or because of legal, human rights, gender or other social barriers in accessing public health services. TB KVPs need to be defined in country contexts but can include prisoners; people living with HIV; migrants, internally displaced people and refugees; people who use drugs; health-care workers; children; people with diabetes; urban poor and people living in slums; the elderly; miners and people with silicosis; and those who work with or live near animals, amonast others?

### **TB TREATMENT OUTCOMES**

The results or consequences of TB treatment. For all forms of TB, outcome definitions have many similarities, so treatment outcomes are standardized to permit comparisons across clinicians, time and sites; they rely heavily, but not exclusively, on bacteriologic end points; and they are mutually exclusive and exhaustive.

### **TB TREATMENT SUCCESS**

Sums two positive treatment outcomes: **TB cure** and **TB treatment completion**.

### **TB CURE**

Refers to a person with bacteriologically confirmed TB at the beginning of treatment who was smear- or culturenegative in the last month of treatment and on at least one previous occasion.

### **TB TREATMENT COMPLETION**

Refers to a person with TB completed treatment without evidence of failure, but with no record to show that sputum smear or culture results in the last month of treatment and on at least one previous occasion were negative, either because tests were not done or because results are unavailable.

### LOSS TO FOLLOW-UP

This means that a person diagnosed with TB either did not start treatment or that their treatment was interrupted for two or more consecutive months.

### NOT EVALUATED

Refers to people with diagnosed TB for whom no treatment outcome is assigned. This includes people "transferred out" to another treatment unit as well as those for whom the treatment outcome is unknown to the reporting unit.

### **TB TREATMENT FAILURE**

Signals when a person with drug-sensitive TB remains bacteriologically positive at five months or longer after the initiation of anti-TB treatment.

# DRUG-RESISTANT TB TREATMENT FAILURE

Signals when the person remains bacteriologically positive within the maximum duration of the intensive phase and indicates that the bacterium is resistant to at least one first-line anti-TB drug. If no maximum duration is defined, an eight-month cutoff is generally observed. This is based on the current treatment regimens and may change. WORDS MATTER – GLOSSARY

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### **TB RELAPSE**

Signals that a person on treatment who has become (and remained) bacteriologically negative while receiving therapy but after completion of therapy becomes bacteriologically positive again or has clinical or radiographic deterioration that is consistent with active tuberculosis.

### **TB RECURRENCE**

Signals the reappearance of TB due to either reactivation of the same strain (i.e. true relapse) or reinfection with a new strain. Recurrence due to reinfection has become an area of intense study because of its perceived significance in high-TB-endemic settings, particularly those with high rates of human immunodeficiency virus (HIV) coinfection.

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6 WHO, Global Tuberculosis Report 2021

- https://www.who.int/publications/i/item/9789240037021
- 7 The Global Fund to Fight AIDS, Tuberculosis and Malaria. Q&A: The Hunt for TB's "Missing Millions." https://www.theglobalfund.org/en/blog/2019-03-21-qa-the-hunt-for-tb-missing-millions
- 8 TB CRG Assessments. Citro, B. et al. Building the Evidence for a Rights-Based, People-Centered, Gender Transformative Tuberculosis Response: An Analysis of the 51op TB Partnership Communities, Rights and Gender Tuberculosis Assessment Vol 23/2, December 2021, pp 253-267 https://www.hhrjournal.org/2021/12/building-the-evidence-for-o-rights-based-people-centered-gender-transformative-tuberculosis-responsean-analysis-of-the-stop-th-partnership-community-rights-and-gender-tuberculosis-assessment

# PREVENTION

### BACILLUS CALMETTE-GUÉRIN (BCG) VACCINE

Bacillus Calmette-Guérin vaccine, commonly known as BCG, is currently the only approved TB vaccine. BCG protects infants and young children against severe forms of TB, including miliary TB and TB meningitis. BCG is the world's most widely used vaccine. WHO estimates that the BCG vaccine saves the lives of more than 40,000children each year. Developed in France, it was first used in humans in 1921. At the time, BCG vaccine represented a resounding success, and over the years, it has contributed to decreased mortality in children and shown a certain level of protective effects against nonmycobacteria tuberculosis, like like Hansen's Disease (leprosy).

### **TB VACCINES**

Vaccinations intended for the prevention of TB. Immunotherapy as a defense against TB was first proposed in 1890 by Robert Koch. Today, the only effective TB vaccine in common use is the **Bacillus Calmette-Guérin (BCG) vaccine**, first used on humans in 1921. Other TB vaccines are at various stages of development.

### **TB INFECTION CONTROL**

TB infection control (also referred to airborne infection prevention and control, or AIPC) includes vital practices to reduce the risk of *M. tuberculosis* transmission by reducing the concentration of infectious droplet nuclei in the air and the exposure of susceptible individuals to such aerosols. TB prevention and control consists of a combination of measures designed to minimize the risk of *M. tuberculosis* transmission within populations. A three-level hierarchy of controls has been shown to reduce and prevent the risk of transmission and exposure to *M. tuberculosis*:

- Administrative policies and protocols: management policies and protocols that are intended to reduce the risk of exposure to persons with infectious TB.
- Environmental controls: measures to prevent the spread of infectious droplet nuclei and reduce their concentration, such as ultraviolet light and negative pressure rooms.
- Respiratory protection controls: use of personal protective equipment in situations that pose a high risk of exposure to *M. tuberculosis*.

In all settings, particularly those in which people are at high risk for exposure to TB, policies and procedures for TB control should be developed, reviewed periodically and evaluated for effectiveness to determine the actions necessary to minimize the risk of transmission of TB. Researchers, advocates, and policy makers all share a common vision of TB elimination. Through writing grants and manuscripts, as well as communicating with scientists, advocates, and policy makers, language is integral to the work of the researcher. By avoiding offensive and stigmatizing language, the researcher can enhance the humanity and power of the work, and ultimately ensure the successful development and implementation of those tools so desperately needed in the fight against TB.

---- Dr. David Lewinsohn Chair, Stop TB Partnership Research Working Group

### **TB PREVENTIVE TREATMENT (TPT)**

A course of one or more anti-tuberculosis medicines given with the intention of preventing the development of TB disease. TPT is only given to people who are infected with TB bacteria or have been exposed to it and are at a higher risk of developing TB disease than the general population. TPT is considered one of the most critical public health measures to protect both individuals and the community from TB. There are various TPT regimens, which are prescribed depending on circumstances like age, pregnancy, drug-to-drug interactions, drug-resistance profile of TB the person was exposed to, as well as availability.

Isoniazid given daily for six to nine months has been the most widely used TPT regimen worldwide. Other regimens include rifampicin given alone for four months ("4R") or with isoniazid for three months ("3HR"). The availability of dispersible tablets of HR makes this an attractive option for children. Rifapentine can be given together with isoniazid in a weekly dose for three months ("3HP") or daily for one month ("1HP"). There are also regimens recommended for people who had contact with drug-resistant TB (DR-TB). More details on the best circumstances in which to give one regimen over another may be found in the WHO guidelines on TPT<sup>®</sup>.

WORDS MATTER – GLOSSARY

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<sup>9</sup> WHO operational handbook on tuberculosis. Module 1: prevention - tuberculosis preventive treatment. https://www.who.int/publications/i/item/9789240002906

# DIAGNOSIS

### SCREENING FOR TB DISEASE

The identification of people in a predetermined target group who may have **active TB disease** using tests, examinations or other procedures that can be applied rapidly. This screening should efficiently distinguish persons with a high probability of having TB from those who are unlikely to have TB. Among those whose screening is positive, the diagnosis needs to be established by using one or several diagnostic tests and additional clinical assessments, which together have high accuracy. Screening is an approach for active TB case-finding among people who may not seek care.

Systematic TB screening is sometimes used interchangeably with "**active TB case-finding**". It should be distinguished from testing for TB infection (with a TB skin test or interferon-gamma release assay).

### **TB CASE FINDING**

A system for locating people with active TB disease. Depending on the approach used, there may be active case-finding or passive case-finding, and best results are achieved through a combination of both.

### **ACTIVE CASE-FINDING**

Proactive screening and testing in communities and TB KVPs, often using mobile X-ray units and rapid molecular tests. The term is sometimes used synonymously with "systematic screening".

→ See Screening for active TB disease

### PASSIVE CASE-FINDING

Patient-initiated pathway to TB diagnosis involving:

- 1 a person with TB disease who experiences symptoms that they recognizes as serious;
- 2 the person has access to and seeks care, presenting spontaneously at an appropriate health facility;
- 3 a health worker who correctly assesses that the person fulfills the criteria for presumptive TB;
- 4 successful use of a diagnostic algorithm with sufficient sensitivity and specificity to diagnose TB.

Reliance on passive case-finding leaves a high risk of late diagnosis and **missing people with TB**.

### **CONTRACT TRACING**

Also referred to as contact investigation, contact tracing is a systematic process to identify those who had contact with a person with an infectious form of TB (often referred to as "TB contacts" or "contact persons"), assess them for TB infection and disease, and provide appropriate treatment if TB infection or disease is confirmed. These may be people who live in the same household. Contact tracing is an **active case-finding** intervention.

### **CASE DETECTION**

Used to describe when a person's TB is diagnosed and reported within the national surveillance system and then to WHO.

→ Consult Language Guide for recommended usage

### **TB NOTIFICATION**

The process of reporting on **definite cases** of TB to relevant health authorities, which in turn report them to the **World Health Organization (WHO)**.

### BACTERIOLOGICALLY POSITIVE PULMONARY TB

Bacteriological confirmation of TB in a person from whom a biological specimen is positive by rapid molecular test (GeneXpert®, Truenat®), or culture. Smear microscopy is no longer recommended as a diagnostic by the World Health Organization (WHO).

### BACTERIOLOGICALLY NEGATIVE PULMONARY TB

Clinically diagnosed TB in an individual who does not fulfill the criteria for bacteriological confirmation but has been diagnosed with active pulmonary TB by a clinician or other medical practitioner, who has prescribed a full course of TB treatment.

### **RAPID MOLECULAR TESTS FOR TB**

The use of rapid molecular assays (e.g. **GeneXpert**®, Truenat®) as the initial test to diagnose TB is recommended by WHO instead of sputum smear microscopy, because they have high diagnostic accuracy and will lead to major improvements in the early detection of TB and drug-resistant TB.

### **GENEXPERT**<sup>®</sup>

The instrument employed in automated **rapid molecular test for TB**. This is the specific trade name for the instrument by Cepheid, and others instruments exist.

### **TB GENOTYPING**

A laboratory-based approach to analyze the genetic material (e.g. DNA) patterns that helps distinguish different strains of M. tuberculosis. TB genotyping combined with epidemiologic data helps identify groups or individuals with TB disease involved in the same chain of recent transmission, thus informing contact investigations. It also allows more accurate monitoring of progress toward eliminating TB transmission.

### **DRUG SUSCEPTIBILITY TESTING (DST)**

A process of determining whether a person's TB organism has any resistance to first-line anti-TB medications to ensure they are prescribed the appropriate medications to cure their TB. The results of DST are important, as they help health practitioners determine effective treatment regimens for a person's TB disease.

### PHENOTYPIC DST

Drug susceptibility testing (DST) that determines if a strain is resistant to an anti-TB medication by evaluating its growth on culture (or metabolic activity) in the presence of the medication.

### WHOLE-GENOME SEQUENCING (WGS)

A current alternative to the WHO-approved probe-based methods for TB diagnosis and detection of drug resistance, genetic diversity and transmission dynamics of *Mycobacterium tuberculosis* complex (MTBC). WGS can support the investigation of TB outbreaks. The technique has been applied to estimate the timing and directionality of transmission and to exclude cases from an investigation.

### **NEXT-GENERATION SEQUENCING**

Recent advances in DNA sequencing technology that give a substantial reduction in costs and a substantial increase in the rate of processing and accuracy. The technology is used to determine the order of nucleotides in entire genomes or targeted regions of DNA or RNA.<sup>®</sup>

### CHEST X-RAY (CXR)

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Chest radiography, also commonly referred to as chest X-ray (CXR), is a rapid imaging tool that allows for the identification of lung abnormalities. CXR is an essential tool for early detection of TB, and it's therefore fundamental to achieving the targets set out in WHO's End TB Strategy and the Global Plan to End TB 2023–2030.

### **TB CULTURE TESTS**

A process for the diagnosis of TB through a test where sputum is cultured and tested to find germs (such as TB bacteria) that can cause disease. A sample of sputum is added to a substance that promotes the growth of bacteria. If no bacteria grow, the culture is negative. If bacteria grow, the culture is positive. If TB bacteria grow, the culture is positive. If TB bacteria grow, then the person usually has tuberculosis disease. The process can take several weeks, thereby delaying access to early diagnosis and treatment. For this reason, access to **rapid molecular tests for TB** should be available to all.

### **COMPUTER-AIDED DETECTION (CAD)**

A form of **artificial intelligence (AI)** used to analyze chest radiography (CXR) for the presence of abnormalities suggestive of pulmonary TB; it can improve the feasibility and performance of CXR for TB screening and triage. CAD technologies for TB detection are recommended for use by WHO for adults aged 15 years or older, in place of human readers for interpretation of digital chest radiography in both screening and triage for TB disease.

### **TB PHENOTYPING**

A molecular biological test to determine drug-resistant TB by targeting the main mutations responsible for the strain. Reliable and rapid results can be obtained but require appropriate infrastructure to reduce the possible contamination of the culture.

# TREATMENT

Treatment of TB is focused on both curing the person with TB and minimizing transmission of *M. tuberculosis* to others. Thus, successful treatment of TB has benefits for both the person and the community where they live. Treatment outcomes, used in reporting, are provided in the **Epidemiology** section above.

### FIRST-LINE TREATMENT

Anti-TB medicines used for the treatment of drug-susceptible (DS) TB. As of 2022, the standard first-line regimen consists of isoniazid (INH or H), rifampicin (RIF or R), pyrazinamide (PZA or Z) and ethambutol (EMB or E) for six months. Use of **streptomycin** (SM) is no longer recommended as part of the first-line treatment. Some countries are now rolling out shorter regimens for treatment of DS-TB, which consist of eight weeks of daily treatment with rifapentine (RPT), INH, PZA and moxifloxacin (MOX), followed by nine weeks of daily treatment with RPT, INH and MOX.

### SECOND-LINE TREATMENT

Anti-TB medicines used for the treatment of **drug-resistant tuberculosis (DR-TB)**. The second-line anti-TB medications include multiple classes of medications, such as fluoroquinolones and injectables (aminoglycosides and capreomycin) that have been in use for some time. However, because of adverse side effects and painful administration,

the injectables have given way to newer anti-TB medications such as bedaquiline (BDQ), delamanid and linezolid. A novel antibacterial agent, pretomanid, has been approved by the US Food and Drug Administration (FDA) to treat XDR-TB or treatment-intolerant/nonresponsive MDR-TB. (See **Bedaquiline, pretomanid and linezolid (BPaL)**). Drug development is ongoing, and new drugs and regimens are being studied.

### BEDAQUILINE, PRETOMANID & LINEZOLID (BPAL)

A six-month oral regimen composed of bedaquiline, pretomanid and linezolid for treating **extensively drug-resistant tuberculosis (XDR-TB)**.

### The Stop TB Partnership has, once again, provided the TB community with a critical tool in the fight to end TB. Words Matter allows

a common vocabulary to be shared across the range of groups dedicated to the eradication of stigma and the effective participation by those affected by TB in achieving the 2030 goals.

- Deliana Garcia Stop TB Partnership Board Member Developed Country Non-Government Organizations

### BEDAQUILINE

An oral medication used to treat multidrug-resistant TB (MDR-TB) and extensively drug-resistant tuberculosis (XDR-TB) together with other medicines (see, for example, Bedaquiline, pretomanid and linezolid (BPaL)). In 2013, the World Health Organization (WHO) recommended bedaquiline for treatment of MDR-TB, which made it the first new anti-TB drug in 40 years.

### RIFAMYCINS

A group of antibiotics that are synthesized either naturally by the bacterium *Amycolatopsis rifamycinica* or artificially. Rifamycins are particularly effective against mycobacteria and are therefore used to treat tuberculosis, leprosy and mycobacterium avium complex (MAC) infections. The rifamycin group includes rifamycin, as well as the rifamycin derivatives (rifampicin, rifabutin, rifapentine and others).

### FLUOROQUINOLONES

A group of quinolone antibiotics that contain a fluorine atom in their chemical structure and are effective against both gram-negative and gram-positive bacteria. A number of fluoroquinolones are used as part of TB treatment, including levofloxacin and moxifloxacin. The early-generation fluoroquinolones ciprofloxacin and ofloxacin are no longer recommended for use in **drug-resistant tuberculosis (DR-TB)** care, while gatifloxacin is currently unavailable in quality-assured formulations!

### **STREPTOMYCIN**

An antibiotic medication used to treat a number of bacterial infections. It was the first antibiotic for TB. Streptomycin is now considered a second-line anti-TB medicine and used only as a substitute for amikacin when amikacin is not available or there is confirmed resistance to it<sup>2</sup>.

# SYSTEM

### **ARTIFICIAL INTELLIGENCE (AI)**

The theory and development of computer systems that can perform tasks that to date have required human intelligence, such as speech recognition and visual perception. Advancements in medical and computer sciences have facilitated the training and use of AI algorithms to recognize tuberculosis-related abnormalities on chest radiographs (CXR) with great efficacy. AI and **computer-aided detection (CAD)** have been used for diagnosis by identifying either the presence or absence of TB.

### **HEALTH CARE**

A constellation of preventive, curative and palliative services and interventions delivered to individuals or populations. In most countries, these services account for most of the employment, expenditure and activities that would be included in the broader **health sector** or **health system**.

### **HEALTH SECTOR**

The combined public and private health services (including those for health promotion, disease prevention, diagnosis, treatment and care), health ministries, health-related nongovernmental organizations, health-related community groups and health-related community groups and health-specific professional organizations, as well as institutions that directly provide inputs into the health-care system, such as the pharmaceutical industry and institutions.

### **HEALTH SYSTEM**

The combination of organizations, people and actions whose primary intent is to promote, restore or maintain health. It involves a broad range of individuals. institutions and actions that help to ensure the efficient and effective delivery and use of products and information for prevention, treatment, care and support to people in need of these services. The private sector accounts for a significant component of the health system in some countries and plays an important role in the context of TB it accounts for a significant proportion of TB services and is often the first point of care for persons on TB treatment.

Also see Health System Strengthening (HSS)

# HEALTH SYSTEMS STRENGTHENING (HSS)

A process that enables a health system to deliver effective, safe, inclusive and high-quality interventions to those who need them. Areas that require strengthening are typically the service delivery system, health workforce, health information system, systems to guarantee equitable access to health products and technologies, and health financing systems, as well as leadership, governance and accountability.

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**NORDS MATTER – GLOSSARY** 

<sup>12</sup> WHO Consolidated Guidelines on Drug-Resistant Tuberculosis Treatment, 2019. https://apps.who.int/iris/rest/bitstreams/1211676/retrieve

### RESILIENT AND SUSTAINABLE SYSTEMS FOR HEALTH (RSSH)

Systems that respond to epidemics and provide basic health services to ensure prosperous and stable communities and nations.<sup>10</sup> RSSH combines the concepts of HSS and **community systems strengthening (CSS)** into a more holistic and integrated concept<sup>44</sup> and articulates the elements of a responsive people-centered approach that goes beyond the sometimes narrow approaches of the formal health system.<sup>5</sup>

### **TB RESPONSE**

Efforts to prevent and treat TB. It includes a mix of biomedical, public health targets and socioeconomic interventions, along with research and innovation at the global and country level. At country level, the TB response is normally led by the National TB Program (NTP). The WHO End TB Strategy and the Stop TB Partnership's Global Plan to End TB: 2023–2030 provide clear guidance on TB responses that should lead to ending the epidemic.

### **GOOD GOVERNANCE**

The process whereby public institutions conduct public affairs, manage public resources and guarantee the realization of human rights in a manner essentially free of abuse and corruption, and with due regard for the rule of law.<sup>®</sup>

### PUBLIC-PRIVATE MIX (PPM)

A comprehensive approach for the systematic involvement of all relevant health-care providers in TB prevention and care to promote the use of International Standards for TB Care<sup>v</sup> and achieve national and alobal TB targets. PPM encompasses diverse collaborative strategies, such as public-private (between the national program and the private sector), public-public (between the national program and public sector care providers such as general hospitals, prison or military health services and social security organizations) and private-private (between an NGO or a private hospital and the neighborhood private providers) collaboration. Health-care providers outside the scope of NTPs, including the private and informal sector, are often the first point of care for TB patients. However, these providers are not always fully engaged, despite evidence that PPM approaches increase detection and good treatment outcomes. PPM also implies engaging relevant care providers in the prevention and management of multidrug-resistant tuberculosis (MDR-TB) and in the implementation of TB-HIV collaborative activities.

### INTERVENTION

Different activities in different contexts. In medical treatment, an intervention is an action taken that may improve or worsen a person's health. When describing programs at the community level, the use of the term "intervention" can convey "doing something to someone or something," and as such, it undermines the concept of participatory responses. Preferred terms include "programming", "program", "activities", "initiatives", etc. The word "intervention" occurs in three other definitions: structural interventions, health-care interventions and health-care strengthening. Its use in these contexts is appropriate.

### **NEW TB TOOLS**

Upgraded tools used to prevent, diagnose and treat TB. The new tools that are under development include new **TB vaccines** that are effective for all ages, all forms of TB and are safe; and new TB diagnostics capable of identifying TB and drug resistance, TB in children and people living with HIV (PLHIV), and **extrapulmonary TB** and using specimens besides sputum. New TB anti-TB medications under research and development seek to produce friendlier, effective, affordable, less toxic and shorter treatment regimens for TB and **multidrug-resistant tuberculosis (MDR-TB)**.

### **PRISON SETTINGS**

Settings, where people are restrained from the open community that include jails, prisons, pretrial detention centers, forced labor camps and penitentiaries. It is critical that access to TB prevention, diagnosis, treatment, care and support extends to these settings.

### **PROGRAM INTEGRATION**

The combination of different kinds of services or operational programs to maximize outcomes, such as by organizing referrals from one service to another or offering one-stop comprehensive and integrated services. In the context of TB care, integrated programs may include testing for HIV and diabetes, asking about tobacco use, testing, counseling and treatment; sexual and reproductive health; primary care; maternal and child health; alcohol use, nutritional status and mental health.

### SOCIAL DETERMINANTS OF HEALTH

The conditions, defined by the **World Health Organization (WHO)**, in which people are born, grow, live, work and age, including the **health system**. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices. WORDS MATTER - GLOSSARY

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### SOCIAL PROTECTION

The public and private initiatives that provide income or consumption transfers to the poor and the marginalized, protect the vulnerable against livelihood risks and enhance the social status and rights of the marginalized; with the overall objective of reducing the economic and social inequities.

### **UNIVERSAL ACCESS**

The maximal coverage of TB prevention, diagnosis, treatment, care and support services for those who require them. Basic principles for scaling up toward universal access are that services must be equitable, accessible, affordable, comprehensive and sustainable over the long term. Because different settings often have distinctly different needs, targets for universal access are set nationally.

Applicant Handbook – A Practical Guide to Preparing a Funding Request Following Receipt of an Allocation Letter. 2017

<sup>13</sup> https://plataformalac.org/wp-content/uploads/2018/03/advocating-for-community-responses-en.pdf

<sup>14</sup> The Global Fund to Fight AIDS, TB and Malaria.

<sup>15</sup> The Global Fund to Fight AIDS, TB and Malaria (2016): Building Resilient and Sustainable Systems for Health Through Global Fund Investments. https://www.theglobalfund.org/wnapphing/tunding/resources/ 16 United Malions Office of the High Commission for Human Rights

Ib United Nations Office of the High Commission for Human Rights https://www.ohchr.org/en/issues/development/goodgovernance/pages/goodgovernanceindex.aspx

International Standards for Tuberculosis Care, International Union Against TB and Lung Disease, 2014 – (3rd Ed.).

https://theunion.org/technical-publications/international-standards-for-tuberculosis-care

# UNIVERSAL HEALTH COVERAGE (UHC)

The process by which all people receive the health services they need without coping with financial hardship when paying for them. The full spectrum of essential, quality health services should be covered, including health promotion, prevention and treatment, rehabilitation and palliative care. As TB is a disease that disproportionally affects the poorest members of society, UHC is an important element in treating TB. However, UHC alone is not sufficient for effective and equitable TB care and prevention. Social protection interventions that prevent financial hardship associated with TB, including income losses and expenditures such as home care. transport and food, are also important.

### OUT-OF-POCKET HEALTH EXPENDITURES

Out-of-pocket payments for healthcare, including gratuities and in-kind payments, can lead to catastrophic expenditures and push people into poverty. Out-of-pocket expenses are higher either where national health programs do not provide TB services close to the TB-affected persons or where health facilities do not have crucial TB diagnostic and treatment services and commodities. The need to pay out-of-pocket expenditures can also mean that individuals and households do not seek care when they need it.

### STOP TB PARTNERSHIP (STBP)

Founded in 2001, the Stop TB Partnership is a United Nations-hosted organization that takes bold, smart risks to serve the needs and amplify the voices of the people, communities and countries affected by TB. The Stop TB Partnership brings together expertise from a broad spectrum of country, regional and global partners in the shared mission to revolutionize the TB space and end TB by 2030. The Stop TB Partnership works to advocate, catalyze and facilitate sustained coordination and collaboration among partners; to support the development, replication and scale-up of innovative approaches and tools; and to facilitate equitable access to TB diagnostics, treatment, care and support for all in need.

## WORLD HEALTH ORGANIZATION (WHO)

Founded in 1948, WHO is the United Nations agency that connects nations, partners and people to promote health, keep the world safe and serve the vulnerable so that everyone, everywhere can attain the highest level of health. The Global TB Programme works toward the goal of a world free of TB, with zero deaths, disease and suffering from the disease. The Global TB Programme's mission is to lead and guide the global effort to end the TB epidemic through universal access to people-centered prevention and care, multisectoral action and innovation.

### GLOBAL FUND TO FIGHT AIDS, TUBERCULOSIS AND MALARIA (GLOBAL FUND)

A partnership designed to accelerate the end of AIDS, TB and malaria as epidemics. The Global Fund mobilizes and invests more than US\$4 billion a year to support programs run by local experts in more than 100 countries. In partnership with governments, civil society, technical agencies, the private sector and people affected by the diseases, the Global Fund is working to challenge barriers and embrace innovation.

### UNITAID

A global health agency engaged in finding innovative solutions to prevent, diagnose and treat diseases more quickly, cheaply and effectively in low- and middle-income countries. Its work includes funding initiatives to address major diseases such as HIV/AIDS, malaria and TB, as well as HIV co-infection and co-morbidities such as cervical cancer and hepatitis C, and cross-cutting areas, like fever management.

### UNITED NATIONS HIGH-LEVEL MEETING ON THE FIGHT AGAINST TB (UN HLM ON TB)

The first-ever UN General Assembly high-level meeting on TB, held on 26 September 2018, endorsed an ambitious and powerful political declaration to accelerate progress towards WHO's End TB targets. This declaration was subsequently adopted by the General Assembly on 10 October 2018.<sup>6</sup> A second UN HLM on TB will take place in 2023.

### USAID

United States International Agency for International Development (USAID).

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 Political Declaration of the High-Level Meeting of the General Assembly on the Fight Against Tuberculosis: United to End Tuberculosis: An Urgent Global Response to a Global Epidemic. https://digitallibrary.un.org/record/1649588/Hies/A\_RES\_73\_3-EN.pdf



# COMMUNITY, RIGHTS AND GENDER

### COMMUNITY, RIGHTS AND GENDER (CRG)

The meaningful engagement of TB-affected communities in the TB response; the overcoming of social, policy and legal barriers to TB services; and the application of human rights and gender approaches in planning, implementation, monitoring, evaluation and governance of TB programs.

### COMMUNITY, RIGHTS AND GENDER (CRG) ASSESSMENT

A community-led and country-owned process that, through an inclusive and multisectoral approach, generates strategic evidence and information on rights and gender related to barriers to services and informs the development of a national costed TB CRG action plans toward rights-based, gender-transformative and people-centered TB responses.

### COMMUNITY ENGAGEMENT

A process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impacts and outcomes.<sup>9</sup> For community engagement to be meaningful, it must be financially supported and include the inclusive, informed and coordinated participation of people with or who have survived TB, TB affected persons and TB key and vulnerable populations (TB KVPs), and civil society in TB policy and program prioritization, design, implementation, monitoring, review and evaluation. Community engagement also includes their participation in advocacy, human rights, demand generation and social accountability for interventions that contribute to building systems for health.

### COMMUNITY SYSTEMS STRENGTHENING (CSS)

Interventions that support the development and reinforcement of informed, capable, coordinated and sustainable structures, mechanisms, processes and actors through which community members, organizations and groups interact, coordinate and deliver their responses to the challenges and needs affecting their communities. Community systems strengthening is increasingly recognized in international commitments and normative guidelines. However, in some countries, interventions to strengthen community systems remain insufficiently acknowledged, prioritized, funded or integrated into national and disease-specific plans and budgets.

### COMMUNITY-BASED PROGRAMS/ INTERVENTIONS

Approaches that are local in their presentation and rely on the community to identify the issues to be addressed, design the response and participate in delivering the action.

### COMMUNITY-LED PROGRAMS/ INTERVENTIONS

Approaches that are local in their focus and leadership. While engagement and participation are essential for both community-based and community-led processes, the act of initiating the action, followed by oversight and accountability on the part of the community rather than a government or academic institution, is the core of community-led programs and interventions.

### COMMUNITY-LED MONITORING (CLM)

A system that increases accountability for health and social programs. It involves people who have the most at stake – recipients of services – in monitoring access to and quality of services and working to co-create solutions that improve them. CLM is based on routine and systematic oversight of local and national health and social systems and on consultations with community members to identify service gaps and areas for improvement and to inform advocacy campaigns and strategies.

# CHALLENGE FACILITY FOR CIVIL SOCIETY (CFCS)

The leading grant mechanism on TB community, rights and gender (CRG), conceptualized and coordinated by the Stop TB Partnership for grassroots and TB-affected community organizations. It also supports TB-affected communities and civil society working at the national, regional and global levels to increase demand and accountability while transforming the TB response to be community-led and guided by principles of human rights and gender equality. WORDS MATTER - GLOSSARY

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### **HUMAN RIGHTS**

The universal and inalienable as well as indivisible and interdependent rights of the person.<sup>20</sup> Human rights are entitlements for all human beings – they are not granted by any state. These universal rights are inherent to us all, regardless of nationality, sex, national or ethnic origin, color, religion, language or any other status. They range from the most fundamental – the right to life – to those that make life worth living, such as the rights to food, education, work, health and liberty.

<sup>18</sup> Community engagement: a health promotion guide for universal health coverage in the hands of the people. WHO, 2020 https://www.who.int/publications/i/item/9789240010529

<sup>20</sup> See UN Universal Declaration of Human Rights (1948), available at https://www.un.org/en/about-us/universal-declaration-of-human-rights

### HUMAN RIGHTS-BASED APPROACH TO TB

An approach to TB that entails promoting and protecting the rights of people affected by TB, including the rights to life, health, nondiscrimination, privacy, informed **consent**, housing, nutrition and water.<sup>21</sup> The approach focuses on identifying, mitigating and overcoming human rights- and gender-related barriers to TB services. The right-to-health framework has been adapted to TB to include accessibility, availability, acceptability and quality; stigma and discrimination; freedoms (e.g. to privacy, confidentiality); key and vulnerable populations; gender; participation; and legal remedies. It articulates the domestic and international legal obligations of governments and nonstate actors to ensure that quality testing and treatment for TB is available and accessible without discrimination.

### SOCIAL JUSTICE

A central concept of equality and human rightsrights that examines how these rights are manifested in the lives of individuals. It aims to redress inequities based on gender, race, religion, age, sexual orientation, economic status and other characteristics. Achieving social justice is critical in health care to ensure that all individuals can maintain their highest level of health and wellness.

%20Response\_Policy%20Brief%20(2020).pdf.

### MALNUTRITION

The state of people whose diet does not provide an appropriate balance of nutrients and food for health maintenance and includes both undernutrition (underconsumption) and overnutrition (overconsumption). Malnutrition is a strong driver of the TB epidemic and increases the risk of developing TB disease.

### **NUTRITIONAL SUPPORT**

Efforts to ensure adequate nutrition for a person or family. It can include assessment of the dietary intake, nutritional status and food security of the individual or household and the offering of nutrition education and counseling. In the context of TB, it is important to ensure a balanced diet that can mitigate the side effects of treatment and the disease. Additionally, it is important to ensure access to clean water and to provide food supplements or micronutrient supplementation where necessary.

### CONFIDENTIALITY

The principle that guides the practice between individuals or institutions and those they serve is that information about them – in particular, their state of health and diagnoses, health-care services received and treatment – will not be shared with anyone else without the written consent of the individual.

### CONSENT

The agreement between people or institutions and those they serve for something (e.g. an intervention) to happen. For example, a person consents to be screened for TB. An informed consent to an intervention means that the consenting individual was adequately informed about and understands the reason for the intervention, possible side-effects and other consequences, as well as alternatives to the intervention.

### PRIVACY

The ability of a person to determine which information about them is shared and with whom.

### PERSON-CENTERED APPROACH TO TB CARE

An approach that considers the needs, perspectives and individual experiences of the person affected by TB while respecting their right to be informed and receive the best quality of care based on their individual needs. It requires the establishment of mutual trust and partnership in the treatment recipient/care provider relationship and creates opportunities for the person to provide input into and participate in the planning and management of their own care. There is convincing evidence that a person-centered approach improves treatment outcomes while respecting human dignity.

Please also see people-centered approach to TB care, which is the preferred term.

### PEOPLE-CENTERED APPROACH TO TB CARE

WHO's definition of "care that is focused and organized around the health needs and expectations of people and communities rather than on diseases. People-centered care extends the concept of patient-centered care to individuals, families, communities and society. Whereas patient-centered care is commonly understood as focusing on the individual seeking care the patient - people-centered care encompasses these clinical encounters and includes attention to the health of people in their communities and their crucial role in shaping health policy and health services.22"

### **STIGMATIZATION (OR STIGMA)**

A process of devaluation whereby a person is discredited, seen as a disgrace or perceived to have less value or worth in the eyes of others. Some common examples of stigma related to TB include assuming that people with TB also have HIV, that they must be a drug user and/or that they must bave done something bad to deserve the punishment of having TB. This devaluation is then used to justify social isolation and discrimination against the person with TB<sup>2</sup>.

### DISCRIMINATION

The treatment of a person in a manner that is different, unjust, unfair or prejudicial, often based on their belonging - or perceived belonging to a particular group. TB-related discrimination occurs when someone is treated differently to their disadvantage because they are known to have or have had TB or to be closely associated with people with TB, such as their spouse or other members of their household. Some TB-related discrimination examples include not being attended to at hospitals or clinics after TB was diagnosed; being kicked out of home by family members upon knowledge of TB diagnosis; not being served by neighborhood market vendors; being fired by employers upon knowledge of TB diagnosis; and being blocked from returning to school despite being on treatment and without any coughing<sup>24</sup>

WORDS MATTER - GLOSSARY

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<sup>21</sup> See KELIN et al., Nairobi Strategy on TB and Human Rights, available at https://stoptb.org/assets/documents/communities/ Nairoby/TBStrategy/FINAL.pdf; TBpeople, Declaration of the Rights of People Affected by TB, available at https://stoptb.org/assets/documents/communities/ FINAL%20Declaration%20n%20th#%20Right%20df%20People %20Affected%20by%20TB%2013.05.2019.pdf; GCTA Activating a Human Rights-Based TB Response, available at https://stoptb.org/assets/document/communities/ Activating20A%20Humar%20Right%20Based%20Tuberculosis

<sup>22</sup> World Health Organization People-Centred Health Care: A Policy Framework. 2 December 2013. https://www.who.int/publications/i/item/9789290613176

<sup>23</sup> Stop TB Partnership TB Stigma Assessment https://stoptb.org/assets/documents/communities/STP%20TB%20 Stigma%20Assessment%20Data%20Collection%20Instruments.pdf 24 Ibid

### **EMPOWERMENT**

The action taken by people to overcome the obstacles of structural inequality that have previously placed them in a disadvantaged position. Social and economic empowerment is a process aimed at mobilizing people to achieve equitable welfare and equitable access to resources and to become involved in decision-making at the domestic, local and national levels. In the context of TB, empowerment is about supporting communities of TB-affected persons and TB survivors to form strong communityand country-level networks with the membership equipped with knowledge, tools and skills. These can include advocacy, resource mobilization, community-based and community-led delivery of services, and community-led monitoring to meaningfully engage in and contribute to all components of the TB response.

### GENDER

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GLOSSARY

**WORDS MATTER -**

The socially constructed set of norms, roles, behaviors, activities and attributes that a given society considers appropriate or valued for women, men and transgender people. Gender is often simplistically understood as relating to biological sex and referring only to men and women. However, some people do not fit into or associate with these binary categories in terms of biology and identity.

### **GENDER-SENSITIVE APPROACH**

An approach that includes laws, policies, programs or training modules that recognize that there are differentgendered actors (women, men, girls, boys, transgender and gender-diverse individuals) within a society and that these individuals are constrained in different and often unequal ways and may therefore have differing and sometimes conflicting perceptions, needs, interests and priorities.<sup>\*\*</sup>

### GENDER-TRANSFORMATIVE APPROACH

An approach that entails programs, laws, policies or training modules that are tailored to respond to the differentgendered risks, needs and barriers to services for all people (women, men, girls, boys, transgender and genderdiverse individuals). In the context of TB, a gender-transformative approach examines, questions and changes harmful gender norms and inequalities to gain improved rights and health for all people affected by TB.

### **GENDER-SPECIFIC**

Any program or tailored approach that is specific to the person's gender identity/ gender expression. Gender-specific programs may be justified when analysis shows that one group (i.e. transgender) has been historically disadvantaged socially, politically and/or economically.

### **GENDER-INCLUSIVE LANGUAGE**

The promotion of gender-responsive language that serves to address gender inequalities that exist in societies. This means speaking and writing in ways that do not discriminate and that challenge, rather than perpetuate, gender stereotypes. This is equally important in the TB context, where the use of gender-inclusive language can help move toward gender-responsive TB responses in general.

25 See TB & Gender: A Stop TB Partnership Discussion Paper, available at https://stoptb.org/assets/documents/global/awards/ tbreach/TB-REACH\_Gender2021-web.pdf

# EMERGING TERMS

### COVID-19

An infectious disease caused by the SARS-CoV-2 virus. COVID-19 was first reported to the WHO on 31 December 2019. On 30 January 2020, WHO declared the COVID-19 outbreak a global health emergency. On 11 March 11 2020, WHO declared COVID-19 a global pandemic.

### **BI-DIRECTIONAL TESTING**

The delivery of simultaneous diagnostic testing for more than one disease. In the context of the COVID-19 pandemic and the TB epidemic, it entails an integrated diagnostic testing approach to detect COVID-19 and TB, most frequently in high-TB-burden countries. Bidirectional testing for COVID-19 and TB is justifiable because both are respiratory diseases with similar symptoms and the presence of TB increases the risk of COVID-19 infection and affects its severity. Diagnostic testing platforms exist that can test for both TB and COVID-19. With early detection and treatment, both diseases have the greatest potential for improved outcomes and reduced transmission

# COVID-19 RESPONSE MECHANISM (C19RM)

A special initiative of the **Global Fund to Fight AIDS, TB and Malaria** to provide countries with additional funding to respond to COVID-19 to mitigate its impact on HIV, TB and malaria programs and to initiate and strengthen improvements in health and community systems. All countries receiving funding from the Global Fund were eligible to receive C19RM funding, including multicountry programs and noneligible countries in crisis.

# WORDS MATTER

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SUGGESTED LANGUAGE AND USAGE FOR TUBERCULOSIS COMMUNICATION



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Words Matter for me is one of those game changers in the TB landscape because language puts our words in focus, gives structure to our thoughts and helps us to communicate effectively. So when we change our language, we change our thoughts and if the TB community wants to address social determinants and eliminate barriers to TB care including stigma, human rights, and gender and make it people-centered then we require a shared inclusive vocabulary. Words Matter!

----- Austin Obiefuna Stop TB Partnership Board Member – Vice Chair



