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UNITED TO END TB EVERY WORD COUNTS

SUGGESTED LANGUAGE AND USAGE FOR
TUBERCULOSIS COMMUNICATIONS

FIRST EDITION



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

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This guide is the result of the collective contributions and inputs from many individuals, including medical professionals, academics, activists, and people with TB. We would like to thank all those who contributed to the development of this guide.

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PREFACE

Tuberculosis (TB) remains one of the world's most deadly diseases, killing three people every minute. Each year 9 million people develop TB and 1.5 million die from the disease. In 2014, the World Health Assembly unanimously approved a new End TB Strategy to end the global tuberculosis epidemic by 2035 – the first time governments have set a goal to end TB.

A main component of the End TB Strategy is 'Integrated, Patient Centered Care and Prevention', and a key paradigm shift in the upcoming Global Plan to End TB 2016-2020 is 'changing the mindset, language, and dialogue on TB' which will put people with TB at the centre of the global TB response.

This should start with acknowledging that the language commonly used to speak about TB must evolve. Language influences stigma, beliefs and behaviors, and may determine if a person feels comfortable with getting tested or treated. Just as the HIV/AIDS community would avoid using terms such as 'AIDS control' or 'AIDS suspects', the TB community should shift to more empowering, people-centred language to help bring TB out of the shadows and encourage people to speak about it in their homes, communities, and workplaces.

The detrimental effect of stigmatizing language was detailed by several TB experts

from around the world in an article in the June 2012 issue of the International Journal of Tuberculosis and Lung Disease, “Language in tuberculosis services: can we change to patient-centred terminology and stop the paradigm of blaming the patients?”¹

The authors describe how judgmental terms such as ‘TB suspect’ can powerfully influence attitudes and behaviour at every level – from inhibiting people to seek treatment to shaping the way policy-makers view the challenge of addressing the disease. The article also observes that the powerfully negative connotation of words such as ‘defaulter’ and ‘suspect’ place blame for the disease and responsibility for adverse treatment outcomes on one side — that of people with TB.

Another call to action was made in an editorial in the *British Medical Journal* in March 2015, “End stigmatizing language in tuberculosis research and practice”, noting that despite the growing advocacy movement to stop stigmatizing TB language, it remains commonplace in articles, abstracts, and meetings.² The authors call for a change in the language used by the scientific and medical communities as a key starting point.

These recommendations have been developed for use by everyone involved in the fight against TB. The use of appropriate language has the power to strengthen the global response to the TB epidemic.

This is a living document which will evolve as language changes, will encourage debate and reflection, and will ultimately aim to mainstream language that respects the dignity of people with tuberculosis.

¹ Zachariah, R et al. Int. J. Tuberc. Lung Dis. 2012; 16 (6):714-7

² Frick, M, von Delft, D, Kumar, B. BMJ 2015;350:h1479

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Introduction

Introduction

TECHNICAL LANGUAGE

This section includes terms used in technical, clinical, and medical settings.

Words such as ‘control’ and ‘cases’ are not exclusive to the TB community, and when used in the correct context, are useful as shorthand to communicate research and concepts.

Other words, such as TB suspect, are stigmatizing and harmful, transferring the ‘suspicion’ of the disease to the person with TB and suggesting the person is guilty of a crime or offence.

Context is the critical factor in determining what language is appropriate in certain settings. Words used in technical settings by researchers and health providers have immense power to shape TB care and how people speak and think about TB.

Organizations such as the Community Research Advisors Group (CRAG) and the Treatment Action Group (TAG) have led efforts to encourage the elimination of stigmatizing terminology in TB. Other organizations, such as The International Union Against Tuberculosis and Lung Disease, have taken strong steps to encourage the appropriate use of language, including introducing the use of language guidance in 2015 for those submitting abstracts to their Annual Conference.



Introduction

CONVERSATIONAL LANGUAGE

This section includes everyday terms that people use to speak about TB and related concepts.


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.

One of the most effective tools against tuberculosis is education on how to prevent and treat TB. This includes ensuring everyday conversational language we use to communicate is empowering rather than isolating people with TB. Newspaper headlines such as 'TB Patient Jailed as Public Health Menace' spread fear and misinformation.

Usage of terms such as 'defaulter' can have far reaching impact. In some settings people with TB face social exclusion which leads to poor quality of life, low self-esteem, and clinical depression.

TB is often associated with factors that can themselves create stigma: HIV, poverty, drug and alcohol misuse, homelessness, a history of prison and refugee status. TB is sometimes perceived as a sign of HIV positivity and HIV-associated stigma is transferred to TB-infected individuals.

Change begins with how we speak about TB in our homes, in the media, in communities, and in healthcare settings.



CONVERSATIONAL LANGUAGE

Introduction

COMPASSIONATE LANGUAGE

This section includes language that puts people with TB first and acknowledges their key role as influencers, educators, and champions in the fight against TB.


People affected by TB have suffered from stigma and discrimination throughout history. Language can empower and encourage people with TB to take control of their condition and become partners in their treatment, or create stigma, dependency, and fear.

Stigma can lead people with TB to hide their condition or avoid seeking help, making it more likely that they will become ill and infect others. Even after the start of treatment, concern about the consequences of TB stigma often leads individuals to drop out of treatment programs.

Treatment for TB involves major challenges, such as prolonged absence from work, 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 we use.

By using terms that empower people affected by TB, we can collectively bring TB out of the shadows.





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Technical Language



TECHNICAL LANGUAGE

This section includes terms used in technical, clinical, and medical settings.



case

Although this term is used widely in public health to refer to an instance of disease, it should be used 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'.

case detection

When a person's TB is diagnosed and reported within the national surveillance system and then to World Health Organization (WHO).

definite case of TB

Having *Mycobacterium Tuberculosis* complex

identified from a clinical specimen, either by culture or by molecular tests, such as Xpert MTB/RIF or line probe assay. In countries that lack the laboratory capacity to routinely identify *M. Tuberculosis*, pulmonary TB with one or more initial sputum smear examinations positive for acid-fast bacilli is also considered to be a "definite" case, provided that there is a functional external quality assurance system with blind rechecking.

extensively drug-resistant TB (XDR-TB)

A form of drug-resistant TB in which bacteria are resistant to isoniazid and rifampicin, the two most powerful anti-TB drugs, plus any fluoroquinolone and at least one injectable second-line drug.

extra-pulmonary TB

TB involving organs other than the lungs, such as 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 (EPTB), followed by a decision by a clinician to

treat with a full course of TB chemotherapy. Unless a case of EPTB is confirmed by culture as caused by *M. Tuberculosis*, it cannot meet the “definite case” definition.

health care

Preventive, curative, and palliative services and interventions delivered to individuals or populations. In most countries these services account for the majority of employment, expenditure, and activities that would be included in the broader health sector or health system (see following entries).

health sector

The health sector encompasses organized public and private health services (including those for health promotion, disease prevention, diagnosis, treatment, and care), health ministries, health-related non-governmental organizations, 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 teaching institutions.

health system

A health system consists of all organizations, people, and actions whose primary intent is to promote, restore, or maintain health. It involves the 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.

health systems strengthening

A process that enables a health system to deliver effective, safe, 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.



high-burden country

This term refers to the WHO list of countries that together have 80% of all TB cases arising each year. This expression should be used with caution and sensitivity in order to avoid stigmatization.

human immunodeficiency virus (HIV)

HIV is the virus that weakens the immune system, ultimately leading to AIDS. Since HIV means human immunodeficiency virus, it is redundant to refer to the 'HIV virus'.



intervention

The term 'intervention' means different things in different contexts. In medical treatment, an intervention may save a person's life. When describing programmes at the community level, use of the term 'intervention' can convey 'doing something to someone or something' and as such undermines the concept of participatory responses. Preferred terms include 'programming', 'programme', '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.

multidrug-resistant tuberculosis (MDR-TB)

MDR-TB is a specific form of drug-resistant TB, due to bacilli resistant to at least isoniazid and rifampicin, the two most powerful anti-TB drugs.



notification

Refers to the obligation of health workers to register the name of each person diagnosed with TB, usually in registry. 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 the whole society. The confidentiality of people who are notified is essential.

malnutrition

Refers to the situation of people whose diet does not provide adequate calories and protein for growth and maintenance and includes both undernutrition and overnutrition. Undernutrition increases risk of developing TB disease.

nutritional support

Nutritional support aims at ensuring adequate nutrition and includes assessment of the dietary intake, nutritional status, and food security of the individual or household, offering nutrition education and counselling on how to ensure a balanced diet, mitigate side-effects of treatment and infections and ensure access to clean water, and providing food supplements or micro-nutrient supplementation where necessary.

people affected by TB

Encompasses people ill with TB and their family members, dependents or communities and healthcare workers who may be involved in caregiving or are otherwise affected by the illness.

prevalence

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

prison settings

Prison settings can include jails, prisons,

pre-trial detention centres, forced labour camps and penitentiaries. It is critical that access to TB prevention, treatment, care and support extend to these settings.

programme integration

This term refers to joining together different kinds of services or operational programmes in order to maximize outcomes, e.g. by organizing referrals from one service to another or offering one-stop comprehensive and integrated services. In the context of TB care, integrated programmes may include HIV testing, counselling and treatment; sexual and reproductive health, primary care and maternal and child health.

public-private partnership (PPP)

A comprehensive approach for systematic involvement of all relevant healthcare providers in TB prevention and care to promote the use of International Standards for TB Care and achieve national and global TB targets. PPM encompasses diverse collaborative strategies such as public-private (between the national programme and the private sector), public-public (between national programme and public sector care providers such as general hospitals, prison or military health services and social security organizations), and private-private (between

national programme 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 neighbourhood private providers) collaboration. PPP also implies engaging relevant care providers in prevention and management of MDR-TB and in the implementation of TB/HIV collaborative activities.

pulmonary TB

A case of TB involving the lung parenchyma. Miliary TB is classified as pulmonary TB because there are lesions in the lungs. Tuberculous intrathoracic lymphadenopathy (mediastinal and/or hilar) or tuberculous pleural effusion, without radiographic abnormalities in the lungs, constitutes a case of extrapulmonary TB.

A person with both pulmonary and extrapulmonary TB should be classified as having pulmonary TB.

screening

This refers to the systematic identification of people with active TB in a predetermined target group by the application of tests, examinations or other procedures that can be applied rapidly. Among those

with potential TB, the diagnosis needs to be established through the application of diagnostic tests and clinical assessment with high combined specificity.

sputum smear-positive pulmonary TB


Defined as the presence of at least one acid fast bacillus in at least one sputum sample in countries with a well-functioning external quality assurance system.

sputum smear-negative pulmonary TB

Defined by two sputum specimens negative for acid-fast bacilli and radiographical abnormalities consistent with active TB or sputum that is culture-positive for *M Tuberculosis*.

social determinants of health

The social determinants of health are defined by WHO as the conditions 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. The social determinants of health are mostly



Language can empower and encourage people with TB to take control of their condition and become partners in their treatment. It can also create stigma, dependency, and fear. Stigma can lead people with TB to hide their condition or avoid seeking help, making it more likely that they will become ill and infect others.

Even after the start of treatment, concern about the consequences of TB stigma may lead individuals to drop out of treatment programs.

responsible for health inequities, the unfair and avoidable differences in health status seen within and between countries.

It is well established that social determinants play a powerful role in the global TB epidemic. Poverty for example, greatly enhances a person's risk for becoming ill with TB; and overcrowded living conditions enhance TB transmission.

surveillance

Surveillance is the continual analysis, interpretation, and feedback of systematically collected data, generally using methods distinguished by their practicality, uniformity and rapidity rather than by accuracy or completeness.



TB control

Depending on the context, 'control' may create the perception that experts are in full control of all aspects of prevention, treatment and care of people with TB. It is useful to examine the term 'control' critically so as to avoid neglecting the resources of communities and people with TB.

The WHO End TB Strategy endorsed by all governments outlines a shift from 'controlling' TB globally to ending TB as a public health problem by 2035, with 'integrated, patient

centred care and prevention' as a central pillar of the strategy.

The term 'TB Prevention and Care' can be used as an alternative.

TB infection

About one-third of the world's population have *Mycobacterium Tuberculosis*, which means people have been infected by TB bacteria but are not ill with disease and cannot transmit the disease. People infected with TB bacteria have a lifetime risk of falling ill with TB of approximately 10%. However persons with compromised immune systems, such as people living with HIV, or people with malnutrition or diabetes or who use tobacco have a much higher risk of becoming sick with active TB disease.

universal access

Universal access implies maximal coverage of TB prevention, treatment, care, and support services for those who require them. Basic principles for scaling up towards 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.

Universal Health Coverage


Universal Health Coverage (UHC) means that 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 tuberculosis is a disease that disproportionately affects the poorest members of society, UHC is an important element for treating tuberculosis. 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.

The WHO Post-2015 global TB strategy highlights the key role of UHC and includes a target for “Zero TB affected families facing catastrophic costs due to TB” by 2035.

vulnerability

Vulnerability refers to unequal opportunities, social exclusion, unemployment, or precarious employment and other social, cultural, political, and economic factors that make a person more susceptible to TB. The factors underlying vulnerability may reduce the ability of individuals and communities

to avoid TB risk and may be outside the control of individuals. These factors may include: lack of the knowledge and skills required to protect oneself and others; accessibility, quality, and coverage of services; and societal factors such as human rights violations or social and cultural norms. These norms can include practices, beliefs, and laws that stigmatize and disempower certain populations, limiting their ability to access or use TB prevention, treatment, care, and support services and commodities. These factors, alone or in combination, may create or exacerbate individual and collective vulnerability to TB.



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Conversational Language



CONVERSATIONAL LANGUAGE

This section includes terms that may be used when people speak about TB and concepts related to TB.



cocktail of drugs

A colloquially used term to describe the mix of drugs that people with TB, especially those with MDR-TB, need to take to achieve a cure. This term is not recommended, because it could be perceived as making light of the often harsh difficulties associated with MDR-TB treatment.

migrant worker

A migrant worker is a person who migrates from one country or area to another in pursuit of job opportunities. This includes any person regularly admitted as a migrant for employment, as reflected in the Migration for Employment Convention (Revised) 1949, No. 97. Accessing and completing TB treatment is often difficult for migrant workers.

Cross-border lapses in care have been an especially thorny problem that a number of countries are starting to address.

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 place of habitual primary residence or home base. 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.

out-of-pocket health expenditures

Informal payments for healthcare, including gratuities and in-kind payments, which can lead to catastrophic expenditures and push people into poverty. The need to pay out-of-pocket expenditures can also mean that individuals and households do not seek care when they need it.



person with suspected TB/TB suspect

A person who presents with symptoms or signs suggestive of TB. The term 'suspected' is associated with 'suspicion', suggesting the person is guilty of a crime or offence. The term 'person to be evaluated for TB' or 'person with TB symptoms' is preferable.

person-centered approach to TB care

It is recognized that the simple act of watching a person affected TB swallow pills every day does not represent comprehensive care. This approach considers the needs, perspectives and individual experiences of people affected by TB, while respecting their right to be informed and receive the best quality of care based on individual needs. It requires the establishment of mutual trust and partnership in the patient-care provider relationship and creates opportunities for people to provide input into and participate in the planning and management of their own care. There is convincing evidence that patient-centered approach improves treatment outcomes while respecting human dignity.



people suffering with TB

This term implies that the individual is powerless with limited control over his or her life. The term people with TB is preferable to describe people who are ill with active TB.

people living with HIV

With reference to those living with HIV, it is preferable to avoid certain terms: 'AIDS patient' should only be used in a medical context (most of the time a person with AIDS is not in the role of patient); It is preferable to use 'people living with HIV' (PLHIV), since this reflects the fact that an infected person may continue to live well and productively for many years. Referring to people living with HIV as 'innocent victims' (which is often used to describe HIV-positive children or people who have acquired HIV medically) wrongly implies that people infected in other ways are somehow deserving of punishment. It is preferable to use 'people living with HIV' or 'children living with HIV'. 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.

person to be evaluated for TB

This is a highly preferable term to 'TB suspect', the term currently under wide usage, to describe a person who presents with symptoms or signs suggestive of TB.

stigma and discrimination

'Stigma' is derived from the Greek meaning a mark or a stain. Stigma can be described as a dynamic process of devaluation that significantly discredits an individual in the eyes of others. Within particular cultures or settings, certain attributes are seized upon and defined by others as discreditable or unworthy. When stigma is acted upon, the result is discrimination that may take the form of actions or omissions.

Discrimination refers to any form of arbitrary distinction, exclusion or restriction affecting a person, usually but not only by virtue of an inherent personal characteristic or perceived belonging to a particular group—in the case of TB, a person's confirmed or potential illness with TB disease—irrespective of whether or not there is any justification for these measures. The term 'stigmatization and discrimination' has been accepted in everyday speech and writing and may be treated as plural.



compliance / non-compliance

The terms compliance and non-compliance are used to describe the degree to which every required dose of medicine is taken over the course of a TB treatment. These terms unfairly assign blame to the person receiving treatment when many external factors outside a person's control (health system factors, economic reasons) may be the cause.

The term adherence should be used as an alternative.



For many people affected by TB, treatment involves major challenges, such as taking an absence from work, 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 we use to speak to and about people affected by TB.



Compassionate Language



COMPASSIONATE LANGUAGE

This section includes language that puts people with TB first and acknowledges their key role as influencers, educators, and champions for efforts against TB.

community systems strengthening

The term ‘community systems strengthening’ refers to initiatives that contribute to the development and/or strengthening of community-based organizations in order to increase knowledge of and access to improved health service delivery. It usually includes capacity-building of infrastructure and systems, partnership-building, and the development of sustainable financing solutions.



defaulter ► person lost to follow-up

The word default(er) is used in three different ways, all of which unnecessarily and unfairly place blame on the patient. The first is the initial/pre-treatment defaulter. This refers to a person whose diagnosis of TB disease has been confirmed, but who does not appear in the TB patient register and is therefore not

registered as having started treatment. In practice, such a person has sought care from the health services, and has been diagnosed with TB, but does not end up being registered. The term treatment defaulter is also used to describe a patient who starts TB treatment that is interrupted for two consecutive months or more. The third attribution, treatment after default, refers to a patient who is declared as having interrupted TB treatment for two months or more, and then returns to the TB services.

In all three of these situations, it is generally poor quality of health services and lack of a patient-centred approach that leads to treatment interruption or failure to begin treatment, and it is incorrect to shift the blame and place it on people with TB by labelling them defaulters. The term person lost to follow-up for treatment non-completion should be used as an alternative.

empowerment

Empowerment is 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 equality of welfare and equal access to resources and become involved in decision-making at the domestic, local, and national level.

gender-sensitive

Gender-sensitive policies, programmes, or training modules recognise that both women and men are actors within a society, that they are constrained in different and often unequal ways and that consequently they may have differing and sometimes conflicting perceptions, needs, interests, and priorities.

gender-specific

The term 'gender-specific' refers to any programme or tailored approach that is specific for either women or men. Gender-specific programmes may be justified when analysis shows that one gender has been historically disadvantaged socially, politically, and/or economically.



HIV-infected

People should be referred to as 'HIV-positive' if they know they are HIV-positive or as 'having undiagnosed HIV infection' if they do not. The term 'HIV-infected' is not recommended.

HIV-negative

A person who is HIV-negative shows no evidence of infection with HIV on a blood test (e.g., absence of antibodies against HIV). Synonym: seronegative.

The test result of a person who has been infected but is in the window period between HIV exposure and detection of antibodies will also be negative.

HIV-positive


A person who is HIV-positive has had antibodies against HIV detected on a blood test or gingival exudate test (commonly known as a saliva test).
Synonym: seropositive.

people affected by TB

This term encompasses people ill with TB and their family members, dependents, communities and healthcare workers who may be involved in care-giving or are otherwise affected by the illness.

people with TB (PWTB)

This term encompasses people who are ill with active TB. The term people (or person) with TB recognizes that a person with TB should not be defined solely by their condition, and may be preferable to the word 'patients' in certain contexts (e.g. non-medical and community settings).



“It’s hard to believe we label people as TB suspects when we consider someone might have TB. I would not like to be called a suspect. Unless we are able to understand the challenges and needs people with TB are facing, policies and interventions will never be tailored to their needs.

We should be humble and honored we serve those affected by TB - and accountable to them.”

- Dr. Lucica Ditiu
Executive Secretary
Stop TB Partnership



Key Terminology

EVERY WORD COUNTS: KEY TERMINOLOGY

case

Although this term is used widely in public health to refer to an instance of disease, it should be used 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'.

compliance / non-compliance ► adherence

The terms compliance and non-compliance are used to describe the degree to which every required dose of medicine is taken over the course a TB treatment. These terms unfairly assign blame to the person receiving treatment when many external factors outside a person's control (health system factors, economic reasons) may be the cause.

defaulter ► person lost to follow-up

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centred approach that leads to treatment interruption or failure to begin treatment, and it is incorrect to shift the blame and place it on people with TB by labelling them defaulters. The term person lost to follow-up for treatment non-completion should be used as an alternative.

TB control ► TB prevention and care

The term 'control' may create the perception that TB experts are in full control of all aspects of prevention, treatment and care of people with TB. It is useful to examine the term 'control' critically so as to avoid neglecting the resources of communities and people with TB.

TB suspect ► person to be evaluated for TB

TB suspect is sometimes used to define a person who presents with symptoms or signs suggestive of TB.



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