THE UNITED REPUBLIC OF TANZANIA

MINISTRY OF HEALTH,
COMMUNITY DEVELOPMENT,
GENDER, ELDERLY AND CHILDREN

NATIONAL COMMUNITY, RIGHTS AND GENDER IMPLEMENTATION GUIDE FOR TB RESPONSES 2020

NATIONAL TUBERCULOSIS AND LEPROSY PROGRAMME (NTLP)

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GENDER IMPLEMENTATION GUIDE FOR TB RESPONSES

2020

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Abbreviations

Abbreviation	Long form description
AIDS	Acquired Immune Deficiency Syndrome
EANNASO	Eastern Afrika National Network of AIDS and Health Services Organizations
CBOs	Community Based Organizations
CHW	Community Health Workers
CLM	Community Led monitoring
CRG	Community, Rights and Gender
CSO's	Civil Society Organizations
DOT	Direct Observed Treatment
FBOs	Faith Based Organisations
GBV	Gender Based Violence
GOT	The Government of Tanzania
HIV	Human Immunodeficiency Virus
IPs	Implementing Partners
KVP	Key Vulnerable Population
MKUTA	"Mapambano ya Kifua Kikuu na UKIMWI Tanzania"
MOHCDGEC	Ministry of Health, Community Development, Gender, Elderly and Children
NGOs	Non-Governmental Organizations
NTLP	National TB and Leprosy Programme
PORALG	President Office, Regional Administration and Local Governments
PSOs	Private Sector Organizations
RCH	Reproductive and Child Health
SBC	Social Behavioral Change
TB	Tuberculosis
TTCN	Tanzania TB, Community Network
TWG	Technical Working Group
TNCM	Tanzania National Coordinating Mechanism

UKIMWI	“Upungufu wa Kinga Mwilini”
UNAIDS	Joint United Nations Programme on HIV and AIDS
USAID	United States Agency for International Development
UN - HLM	United Nations High-Level Meeting
WHO	World Health Organization

Glossary

S#	Term	Description of meaning as used in this document
1.	Community	Communities are formed by people who are connected to each other in distinct and varied ways. Communities are diverse and dynamic. One person may be part of more than one community. Community members may be connected by living in the same area or by shared experiences, health and other challenges, living situations, culture, religion, identity or values[1].
2.	Community empowerment	Is a process of re-negotiating power in order to bring about social and political changes and to gain more control. It addresses social, cultural, political, and economic determinants of health, and builds partnerships with other sectors to find solutions.
3.	Community Led Monitoring	Is a community-based mechanism by which service users and/or local communities gather, analyze and use information on an ongoing basis to improve access to, quality and impact of services, and to hold service providers and decision makers to account. *(Note: community-based monitoring is not the same as routine program monitoring).* CLM is about equipping them with planning, monitoring, organizing, assertiveness, and advocacy skills to be effective change agents and duty bearers in their respective communities. Such knowledge includes bio-medical, behavioral, and structural barriers to health service delivery; and indicators relevant to their respective CLM mechanism.
4.	Equality	Is a systemic approach and effort that aims to ensure that everyone gets the same services/care in order to enjoy full, healthy lives. It intends to promote fairness and justice among the various sub-populations and individuals in a particular society[2].

[1] Kawachiet al., 2002; Braveman and Gruskin, 2003; EQUINET, 2006
[2] Kawachiet al., 2002; Braveman and Gruskin, 2003; EQUINET, 2006

S#	Term	Description of meaning as used in this document
5.	Gender	Refers to the socially constructed characteristics of women and men – such as norms, roles and relationships of and between groups of women, men, girls and boys in all their diversity. It varies from society to society and can be changed. The concept of gender includes five important elements: relational, hierarchical, historical, contextual and institutional.
6.	Community responses	These are the Responses that are delivered in settings or locations outside of formal health facilities. They can be provided by a range of stakeholders, including community groups and networks, civil society organizations, and the private sector[3]. They include advocacy, campaigning and holding decision-makers to account; monitoring of policies, practices, and service delivery; participatory research; education and information sharing; service delivery; capacity building; and funding of community-led organizations, groups, and networks. Not all responses that take place in communities are community led.
7.	Gender Based Violence (GBV)	Is a collective term for any act, omission or conduct that is perpetuated against a person's will and that is based on socially ascribed differences (gender) between males and females. In this context, GBV includes but is not limited to sexual violence, physical violence and harmful traditional practices and economic and social violence. The term refers to violence that targets individuals or groups based on their being female or male. GBV is used as an umbrella term that encompasses different types of violence against women, including mistreatment during childbirth, FGM, and child marriage[4]
8.	Gender equality	Is the state in which access to rights or opportunities is unaffected by gender. Gender equality is achieved when women and men enjoy the same rights and opportunities

[3] Community Systems Strengthening Framework, (revised edition), the Global Fund to Fight ATM, February 2014

[4] (MOHCDGEC, 2011)

S#	Term	Description of meaning as used in this document
		across all sectors of society, including economic participation and decision-making, and when the different behaviors, aspirations and needs of women and men are equally valued and favored[5]
9.	Gender equity	Gender Equity is the process of allocating resources, programs, and decision making fairly to both males and females without any discrimination by observing those with more needs than others while addressing any imbalances in the benefits available to males and females[5].
10.	Gender integration	It refers to strategies applied in program assessment, design, implementation, and evaluation to take gender norms into account and to compensate for gender-based inequalities
11.	Gender sensitivity	It is the act of being sensitive to the ways people think about gender. It is the way decision makers; program implementers and service providers treat male or female clients when serving them while they are aware of the differences. It is an indication of gender awareness, although no remedial action is necessarily developed[6]
12.	Gender transformative	Is the process that involves acts of transforming gender relations to promote equity as a means to reach health outcomes. In its core intent, gender transformative struggles to change stereotypes, beliefs, norms and values that perpetuate gender inequity and inequality[7]
13.	KVP in the TB response	Are prisoners and incarcerated populations, people living with HIV, migrants, refugees and indigenous populations, as well as [those] experiencing significant marginalization, decreased access to quality services, and human rights violations[4].

[5] (WHO, 2015)
[6] (WHO, 2017).
[7] (UNFPA, 2017).

S#	Term	Description of meaning as used in this document
14.	Inequality	Health inequalities can be defined as differences in health status or in the distribution of health determinants between different population groups. For example, differences in mobility between elderly people and younger populations or differences in mortality rates between people from different social classes (WHO, 2017). It is a situation that prevails when equality is missing. Inequality happens when fairness and justice among the various sub-populations and individuals in a particular society are absent when such sub-populations and individuals strive to access services or care to attain their healthy lives[1]
15.	Vulnerable populations	Are those whose situations or contexts make them especially vulnerable, or who experience inequality, prejudice, marginalization and limits on their social, economic, cultural and other rights[8].
16.	Stigma	Stigma can be defined as a mark of shame, disgrace or disapproval which results in an individual being rejected discriminated against, and excluded from participating in a number of different areas of society[9].
17.	Key Vulnerable Populations in the context of TB	Are those that experience high epidemiological impact from one of the diseases combined with reduced access to services and/or being criminalized or otherwise marginalized[4].
18.	Discrimination	Is the treatment of an individual or group with partiality or prejudice. It is often expressed through action. Depending the situation in which discrimination occurs, it may be seen acting against the law because of race, sex, age, sexual orientation or religion or disease[4]
19.	Community Health Workers	These are people who are trained specifically to lender health services in the communities. There some received

[8] APCASO (2017). Strengthening Community, Rights, and Gender Concepts for Communities and Civil
[9] Society on Country Coordinating Mechanisms: Guidance Tool. Thailand: APCASO.
Gender Assessment of the National Response To TB in Tanzania

S#	Term	Description of meaning as used in this document
		formal training from health training institutions and informal through seminars and workshops
20.	Human Rights	These are a broad concept, underpinned by a set of shared common values such as fairness, respect, equality, dignity and autonomy[3].
21.	Monitoring & Evaluation	M&E is used to assess the performance of projects, institutions and programs set up by governments, international organizations and NGOs. Its goal is to improve current and future management of outputs, outcomes and impact. Monitoring is a continuous assessment of programs based on early detailed information on the progress or delay of the ongoing assessed activities (reference). An evaluation is an examination concerning the relevance, effectiveness, efficiency and impact of activities in the light of specified objectives. (Wikipedia)

Executive summary

Community, Rights and Gender responsiveness are concepts that strive in contributing to promote equity, ethics, gender equality and human rights in addressing tuberculosis. While most of other interventions for TB quality improvement model are targeted at improving TB case finding through improved TB screening, TB diagnosis and treatment, Community, Rights and Gender strive to make TB services available, acceptable, accessible, equitable and quality. This is the way that the World Health Organization (WHO) has instructed the countries to ensure Protection and promotion of human rights, ethics and equity. It is in-line with the essence that our two ministries (Ministry of Health, Community Development, Gender, Elderly and Children - MOHCDGEC and the President Office, regional Administration and Local Government - PORALG) derived the rationale and need to ensure Community, rights and gender are integrated in TB care and prevention interventions.

The goal of the National Community, Rights and Gender Implementation guide for TB services is to strengthen community response towards health seeking behavior, accurate diagnosis, treatment adherence and post treatment follow-up TB services with consideration to human rights and gender equality. The main focus is on improving TB services outcomes, by reducing barriers related to community, rights and gender inequity and inequalities in the health system, from household to community, and to health facility. Furthermore, the main emphasis is to improve accessibility, acceptability and availability of quality, TB services with human rights and gender-sensitive integrated services for target population regardless of their social-economic status.

This guide was developed while cognizant of existence of several gender and rights related bottlenecks to achieve the above of which the MOHCDGEC/NTLP and TB stakeholders desire to see happening in our country. Unlike most of standard guidelines, this guide includes beyond the standards and procedures for realizing community, human rights and gender integration, interventions, and key activities as well as community led monitoring. This is because; the aspects of community, rights and gender responsiveness are somehow new in our ways of delivering TB services and may need a closer guidance on their implementation.

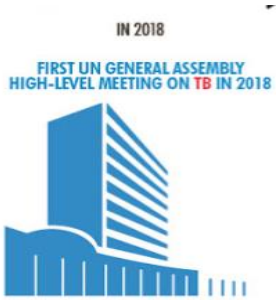
This document is intended for use by decision makers at all levels, health service providers across all levels of the service delivery, development partners and all

stakeholders who supports implementation of TB related activities. Among the targeted stakeholders include community leaders, religious leaders, influential people and the community at large. It is recommended that all those involved in managing and providing TB services to ensure that they adapt the culture of Community rights and gender responsiveness guided by this guide so that we ensure accessibility, acceptability and availability of quality TB services to all Tanzanians and ultimately achieve more client satisfaction, more facility-based delivery and accelerated reduction of stigma and discrimination to TB clients.

CHAPTER ONE: INTRODUCTION

1.1 Overview

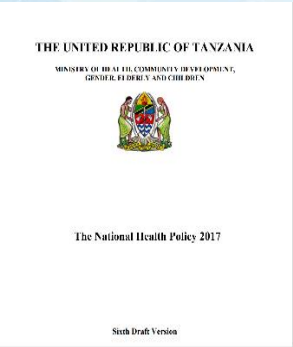
Tuberculosis (TB) throughout its long history has disproportionately affected people marginalized by poverty and social exclusion and those living in sub-standard conditions. Most of these factors are related to unrealized human rights and gender issues which hinder availability, accessibility, acceptability and affordability of TB services among marginalized communities.



Global strategies and key actors in the global TB response have explicitly acknowledged that reducing gender and human rights-related barriers to TB care and prevention services is essential in realizing End TB targets. The Global Plan to End TB 2016–2020, emphasized that countries should adopt a new radical approach that strive for equity and addressing structural, socio-economic, human rights and gender drivers in TB care and prevention services. On the other hand the End TB Strategy highlights equity, human rights and ethics as one of the four principles of the strategy. The United Nations High-Level Meeting (UN-HLM) on Ending Tuberculosis (TB) produced a historic Political Declaration, with specific, measurable milestones to achieve by 2022. One of the most important aspects of the declaration is supporting a new approach to ending TB based on human rights[10].

The Global Fund Technical Brief for Tuberculosis, Gender and Human Rights stipulates factors that hinder the effectiveness, accessibility and sustainability of TB programs and services. Those factors include underlying poverty and economic inequality, gender barriers, stigma and discrimination.

[10] UNHLM on TB key commitments. 2018. P18, P33.



The Government of Tanzania (GoT) has continued to put attention on broad aspects of human rights and gender in its health sector priorities as indicated in section 2.23 and 6.1 of the National Health Policy (2007)[11] and objective 8 of the National TB and Leprosy Strategic Operational Plan for 2020-2025. To initiate the implementation of Community, Rights and Gender (CRG), the Country has developed the National CRG Operational Plan (2020) which define priority interventions to address CRG issues.

1.2 Background

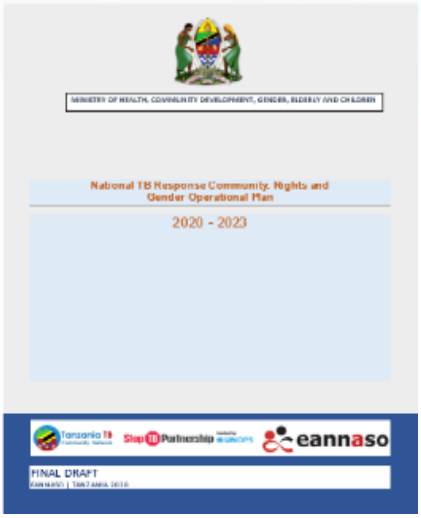
Tuberculosis (TB) remains a public health challenge in Tanzania. The Country estimates 137,000 people developed TB in 2019, with only 81,000 cases notified. Almost 41% of the people estimated to have had TB were never diagnosed posing an even greater risk of infecting family, friends and other community members. Despite national DOT coverage and higher proportion of TB patients under home based DOT, a number of challenges still exist in the control and prevention of TB in Tanzania. These include limited community awareness and engagement on TB response, delays by patients in seeking care which indicate persistence transmission of TB within the Community, passive participation of community in TB control, stigma and discrimination, gender and human rights barriers and limited accessibility of health care. This calls for community mobilization and engagement in finding TB missing cases

Tanzania conducted three CRG qualitative assessments in 2017 on Legal Environment Assessment for TB, Gender Assessment of the National Response to TB and Data for Action for TB Key Vulnerable and Underserved Populations. The assessments aimed at developing

[11] The National Health Policy, 2017

recommendations for improving community TB response to enhance availability, accessibility, and acceptability of quality TB services in the Country. The Assessments resulted into the development of National CRG Operational Plan to cover the duration of three years from 2020 to 2023.

1.3 Rationale



Tanzania is among the 30 countries with high TB burden. The country has been missing TB cases which contributed by a number of barriers to access TB services. The main barriers include low community engagement, gender and human rights related barriers. The National CRG Operational Plan (2020) realizes the need for developing National Guide for Community, Rights and Gender (CRG) implementation for TB responses[12].

The CRG Guide therefore intends to standardize the design and implementation of interventions to promote community led response in addressing CRG related barriers and their associated adverse health and social consequences among TB affected communities. The Guide will ensure that TB services are community-focused, human rights-based, and gender transformative.

1.4 Goal

Strengthen community response towards health seeking behavior, accurate diagnosis, treatment adherence and post treatment follow-up TB services with consideration to human rights and gender equality.

1.4.1 Objectives

i. To promote multisectoral collaboration and engagement for Community, Rights and Gender in TB response.
ii. To strengthen meaningful engagement of key and vulnerable populations and networks to enhancing community TB response towards availability, accessibility, acceptability and affordability to TB services.
iii. To contribute in reducing health inequities including gender and age disparities related to TB services in communities and health care settings.

[12] The National CRG Operational Plan, 2020. National TB and Leprosy Programme of Tanzania

iv. To combat stigma and discrimination in communities and health care settings.
v. To strengthen Community TB monitoring and evaluation system in relation to rights and gender transformation
vi. To advocate for reforms on TB related policies and legal framework that will enhance an enabling environment for access to quality, equitable and affordable TB services.

1.5 Intended users

The intended users for this Guide are:

i. Non-State Actors

a. TB survivors' groups and other community Based Organizations
b. Community TB networks (TTCN, MKUTA etc).
c. Community Health Workers
d. TB activists
e. Non-Governmental Organization (NGOs), Private Sector Organizations (PSOs) Faith Based Organizations (FBOs) and other Civil Society Organizations (CSO's).

ii. State Actors

a. Government Ministries, Department and Agencies

1.6 The National Community, Rights and Gender implementation Guide development process

The National Community, Rights and Gender Implementation Guide for TB response has been developed by the MOHCDGEC through National TB and Leprosy Programme (NTLP), Legal Service unit, Community Development Department-Gender Unit, Reproductive and Child Health Section in collaboration with Family Welfare Foundation, Tanzania TB Community Network (TTCN), Mapambano ya Kifua Kikuu na UKIMWI Tanzania (MKUTA), Implementing Partners, Higher Learning Institution and other stakeholders in TB control.

The workshop was conducted to agree on the Guide Framework. Participants worked on the agreed framework, then three facilitators compiled and worked more to produce the draft which was shared in the second workshop. Draft review was done, and more inputs were provided for final Draft which was submitted to NTLP for approval prior printing and dissemination.

Relevant contents have been drawn from WHO End TB strategy (2015-2030), Global Plan High Level Meeting, Global Plan to End TB: 2018-2022, Global TB Report (2020), World Health Organization. Tuberculosis and human rights information note. Guidance Tool for CRG, APCASO (2017), Stop TB Partnership: Key vulnerable populations brief: Mobile populations. Geneva, 2016. UNDP discussion paper: gender and TB (December 2015), Global Fund: Tuberculosis, Gender and Human Rights. Technical Brief. (April 2017). Global Fund Technical Brief: Community Systems Strengthening (October 2019), Hurtg.A.K. et all. 1999 IUATLD. Tuberculosis control and directly Observed Therapy from the public health/ human rights perspective. INT J TUBERC LUNG DIS 3(7):553Đ560, EANNASO CRG Guide (2019) and the existing national policies and guidelines including NTLP draft manual (2020), The National Health Policy (2007), NTLP data (2019) and the National CRG Operational Plan (2020).

CHAPTER TWO: COMMUNITY, RIGHTS AND GENDER RELATED RISK TO TB TRANSMISSION AND BARRIERS TO TB SERVICES

TB is a disease of poverty and inequality. Several people cannot access TB services due to many factors related to community issues, human rights and gender equalities that hinder the effectiveness, accessibility and sustainability of TB programs and services as explained below:

2.1Community issues related barriers to TB services

These are the barriers in relation to the community status in terms of poverty, social and economic status, health status; what they believe, traditional norms, state custody and people who use drugs; living conditions including migrants, refugees, nomads and displaced persons; occupation risks and protection; stigma and discrimination.

Underlying poverty and economic inequality.

People who live in conditions of overcrowding, inadequate ventilation and poor nutrition are at higher risk of contracting TB infection and developing TB disease, and they are likely to lack access to good-quality TB services and information about the disease. While TB medicines themselves may be free, such factors as transportation, good nutrition to optimize treatment outcomes, and initial diagnostic costs may be impeded by poverty. TB incidence and prevalence reflect poverty and inequality from community to community and may lead to deaths. Tanzania reports the average 32,000 deaths among TB patients per year[13].

People in state custody and people who use drugs.

Prisoners and pretrial detention are at high TB risk because of the conditions found in closed settings, which often include overcrowding and poor ventilation. However, prisoners are often systematically excluded from TB prevention and diagnostic services. This has been a barrier for early TB diagnosis and treatment. The Government of Tanzania through NTLP has engaged the Ministry of Home affairs and established a routine TB screening system among prisoners and all people in pretrial detention.

[13] World Health Organization. Global TB report 2020. Geneva

People who use drugs in many settings face high TB risk because of overcrowding and poor ventilated living conditions at "Masikani" However, they are often excluded from TB prevention, diagnosis and care as well as information because of their unfriendly behaviors.

Migrants, refugees, nomads and displaced persons

In many circumstances, migrants, refugees, nomads and displaced persons are at particularly high risk of TB but may be excluded from services and information because of ethnic, cultural, linguistic or other discriminatory barriers, stigmatizing attitudes, illegal status, and fear of
deportation or lack of required documentation[14].

Traditional norms and Beliefs

In some places in the country, TB patients believed that TB is caused by supernatural and physical causes e.g smoking, alcohol, hard work, exposure to the cold, shared use of cooking and eating utensils, heavy labor, bewitchment and hereditary factors, breaking cultural rules that demand abstinence from sex, environmental pollution; imbalance between the physical, spiritual and social aspects. This kind of situations hinder access to TB services and increase TB transmission in communities. On other hand, there is a tendency of keeping secret on TB status despite of more than one nuclear family co-reside in the same house. Behavior promote more transmission of TB in the families and communities at large.

Stigma and Discrimination

Stigma and Discrimination have revealed to be barriers for accessing TB services among communities. The causes of stigma and discrimination in communities include moral failure, resulting in self and community driven stigmatization[15]. TB patients experience strong social stigma in many parts of the world including Tanzania due to the 'discrediting' status they receive from family and community because of the illness.

[14] Stop TB Partnership. Key vulnerable populations brief: Mobile populations. Geneva, 2016.
[15] Orr, P. (2011) Adherence to tuberculosis care in Canadian Aboriginal populations Part 1: definition, measurement, responsibility, barriers, International Journal of Circumpolar Health, 70: 2, 113-127, doi: 10.3402/ijch.v70i2.17809

When a person in a family is diagnosed with TB, she or he may be subjected to a form of social exclusion; that is, the illness may encourage separations in familial and social relations.

People with TB have a right to be free from discrimination in all settings, including health care, employment, housing, education, and migration. Despite this right, they often face stigma and discrimination because of their TB status or TB history. As TB is often associated with poverty and other socially "undesirable" behaviors and living conditions, people with TB, or suspected of having TB, may be stigmatized, and discriminated against based on their perceived socio-economic status and behaviors, as well as because of TB.

The close association between AIDS and TB in many parts of the world including Tanzania only serves to exacerbate social stigma. People living with HIV and others with compromised immunity face high TB risk. TB was estimated to cause about one third of all deaths among people living with HIV [16]. In Tanzania, 41% of TB patients were living with HIV in 2019[17]. It is well understood that HIV risk is also heightened by a wide range of human rights violations, including gender inequality and inequity. The stigma, discrimination and exclusion associated with HIV can amplify and be amplified by TB-related stigma[18].

Stigma can lead to unwillingness of individuals to disclose their status which arises from fear of loss of economic opportunities, loss of community respect, fear of transmission, shame, blame and judgement and questions of "how did you or did she/he get it" and even death. The effects of stigma can be unpredictable and can include shame and embarrassment, fear of or actual job loss, fear of infection and social isolation.

2.2Rights related barriers to TB services

Tuberculosis is a disease of poverty and inequality that particularly affects key vulnerable populations with little or no access to basic services. People affected by TB have the right to access good-quality TB prevention, testing, treatment, and care services as part of the right to health. Many of the factors that increase people's

[16] World Health Organization. HIV-associated tuberculosis (fact sheet). Geneva, 2016. At: http://www.who.int/tb/publications/tbhiv
[17] World Health Organization. Global TB report 2020. Geneva
[18] Daftary A. HIV and tuberculosis: The construction and management of double stigma. Social Science & Medicine 2012: 74: 1512–19.

vulnerability to tuberculosis (TB) or reduce their access to diagnostic, prevention and treatment services are associated with people's ability to realize their human rights[19].

Un-access to TB prevention, treatment, support and care services

Access to TB prevention, treatment, support and care services, as well as to basic necessities
such as food, housing, and social services, are fundamental human rights embedded in the right to
health.

Involuntary isolation

In several countries, laws or public health regulations allow for compulsory detention, isolation or other punishment for those who refuse TB treatment or are lost to care[20]. Such policies or practices create barriers to seeking and using health services and may constitute human rights violations. WHO suggests that, where patients are engaged respectfully and with their informed consent, unwillingness to undergo treatment is rare. In any case, as noted in WHO's Guidance on the Ethics of TB Prevention, Care and Control, detention "should never be a routine component" of TB programs.[21] In the rare case when, after all "reasonable efforts" have been made, a patient refuses care or continuation of care, a "careful limited" involuntary isolation, using the least restrictive means possible, may be justified as a last resort. Isolation must not be administered as a form of punishment, and any person subjected to it must have been informed in advance of the possibility of it.

Occupational risks without protections

People in certain lines of work including mining, health care, prisons, fishing settings and industrial settings may face high TB risk of exposure to TB or to TB-related risk factors without adequate workplace protections. In many places, mining

[19] World Health Organization. Tuberculosis and human rights information note. Geneva, https://www.who.int/tb/dots/humanrights.pdf.
[20] Mburu G, Restoy E, Kibuchi E, Holland P, Harries AD. Detention of people lost to follow-up on TB treatment in Kenya: the need for human rights-based alternatives. Health and Human Rights 2016; 18(1):43-54.
[21] World Health Organization. Guidance on ethics of tuberculosis prevention, care and control. Geneva, 2010.

relies on poorly paid workers in remote locations where state regulatory mechanisms do not hold mining companies to account for inadequate workplace safety[22] .

2.3Gender related barriers to TB services

Gender refers to the social attributes and opportunities associated with being male or female. Gender determines what is expected, allowed, and valued in a woman or a man in each context. In most societies there are differences and inequalities between women and men in responsibilities assigned, activities undertaken, access to and control over resources, as well as decision-making opportunities.

Women decision – making power

Gender barriers and negative norms impair women's decision – making power when it comes to their health; they are not free to decide when, where and how to access health services.

> Traditionally, the wife needs an approval from a husband to get help for a sick child or for herself. If the wife acts on her own or decided to sell something to afford health services for herself, she can be beaten of face divorce.

Some studies have found that women have less access to TB treatment and prevention services than men and are unlikely to undergo sputum smear examination. Social factors may account for gender differences in use of TB services. Women in some contexts have difficultly accessing TB services because male family members are unwilling to pay for these services, women's health may not be considered as important as that of male family members, or because TB in women is more stigmatized than in men[23].

> In some communities, a woman who is found to have TB may be divorced by her husband or, if unmarried, may have difficulty in finding a husband.

Gender-insensitive health care infrastructure

Gender-insensitive health care infrastructure also has an impact on women's access to services. Although women are less likely to delay seeking care, once they do access TB services, women generally wait longer than men for diagnosis and

[22] Stop TB Partnership. Key vulnerable populations brief: Miners. Geneva, 2016.
[23] A sputum smear in this case is a laboratory test that looks for mycobacterium tuberculosis in a sputum sample. Sputum is the material that comes up from air passages when you cough deeply.

treatment. Women who attend TB services have also complained about a lack of privacy in health centres when receiving Directly Observed Treatment (DOT), and women with children may not be able to attend TB services regularly due to a lack of child-care facilities. Moreover, while most countries rely on passive case-finding approaches to TB, several studies have argued that this method may not be appropriate or effective for women.[24]

Gender-specific occupations

Gender-related barriers to TB services may take many forms, affecting both men and women. Overall, men face higher risk of developing TB than women, and there are more TB deaths among men. Men are also more vulnerable to TB due to gender-specific occupations. In many places, men are more likely to have jobs, such as mining or blasting, with exposure to particulates. Men may be more likely to migrate for work, which may cause interruptions in TB treatment.

Gender related behaviors

Men may also be more likely to smoke, use drugs and/or alcohol consumption in many societies, both independent risk factors for TB. On the other hand, women may have less access to TB treatment and prevention services than men, and in some settings, have been less likely to undergo sputum smear examinations.[25]

Gender differences in access to healthcare

Women are being underreported in most cases, perhaps due to inadequate care-seeking related to time and financial constraints, insufficient access to income, and gender inequalities, social status, social cultural norms and low level of education. In Maasai customs, a cow has more value in the homestead than a woman, and a lactating mother cannot leave the house for six months. As such, if she contracts TB, she cannot be diagnosed in a health facility. In addition, married women in Turkana cannot remove the beads on their bodies which may make TB screening difficult[26]

[24] UNDP discussion paper: gender and TB. December 2015
[25] Global Fund. Tuberculosis, Gender and Human Rights. Technical Brief. April 2017. Geneva, Switzerland
[26] KELIN, (2018). Tuberculosis: A Gender Assessment in Kenya, Nairobi: KELIN

Women face greater socio-cultural and financial barriers to access TB care, given their subordinate position in relation to men. Travel and treatment costs can have a more limiting effect for women, due to their financial dependence, lower income, and lack of control over the family resources. Traditional gender roles that grant men a higher status as the 'breadwinner' or the 'pillar of the family', cause women to be perceived as less important. Women's health is therefore not prioritized, and they may receive less support for their healthcare, compared to other family members.

The time constraints related to the heavy workload of women, their domestic social responsibilities and their role as caretakers can also restrict their access to healthcare.

Women's lack of independence reduced decision-making power and restricted mobility also constitute important limitations for seeking healthcare. This is illustrated by the fact that women often need to ask permission to their husbands

TB-related perceptions, attitudes and stigma among women

Most of the studies provide evidence that women do confront greater TB-related stigma and social consequences than men. Other studies reveal that women had more experiences and greater fear of social isolation, rejection, abuse, harassment, humiliation, conflict with spouses and family members, abandonment, divorce and difficulty in finding marriage partners (probably related to the ideas that TB is hereditary or that it affects pregnancy and breastfeeding). Some studies linked this with a particular interest among women in keeping their TB diagnosis a secret and feeling inhibited and ashamed of discussing their illness with family.[27]

[27] Susan van den Hof1 et al, 2010)

Gender differences on Knowledge about TB

Studies found differences between men and women regarding the sources of information about TB.

While men had more access to TB information direct through media, such as TV, radio, newspapers and public announcements, women had access through relatives and friends. Furthermore, people who received TB information through friends and relatives had lower knowledge scores than those who received it direct through TV, radio or public announcements. This lead to misconception towards TB and its services.

CHAPTER THREE: COMMUNITY, RIGHTS AND GENDER INTEGRATION IN TB CARE AND PREVENTION

3.1 Legal and Policy Framework

Management of Tuberculosis in the country has a legal basis which calls for putting in place various mechanisms/measures to control the disease. Currently there is no specific law enacted to address TB issues in the Country. However, the Constitution of the United Republic of Tanzania and the National Health Policy of 2007 enshrine various basic rights which by virtual of being a human being, everyone is entitled to enjoy them including TB patients.

The Constitution appeals the need to address TB issues in the Country. This is evidenced under Article 8(1)(b) of the said Constitution which clearly states that the primary objective of the Government shall be the welfare of the people. Therefore, addressing TB which is recognized as one of the challenges towards people's health, is in line with the efforts to meet the requirement of the Constitution. On the other hand, the constitution stipulates various basic rights which correlate to the control of TB in the Country. Such rights are stipulated below:[28].

[28] The constitution of the United Republic of Tanzania. 1977.

Figure 1: Rights provided for under the Constitution of United Republic of Tanzania, 1977

Even if people know their rights, they may not be able to assert them without assistance from legal or paralegal professionals. TB-related rights literacy helps people to know their rights under health regulations and national law as well as their human and patient rights with respect to TB, either can be part of larger information campaigns or community systems strengthening activities or can be more targeted. Rights literacy can be crucial, especially for marginalized populations already prone to discrimination and exclusion and without good access to mainstream information sources. It is best to combine rights literacy with measures that improve access to legal services or with measures to combat problematic policies and laws.

The Health policy of 2007 acknowledges TB as one of the challenges affecting people's health in the community. As a strategy to control the disease, the Government under the Policy commits itself to put in place and improving TB related laws, guidelines and strategies[29].

Apart from the national legal framework, Tanzania is a signatory to various International Instruments which also appeal to taking measures towards controlling TB. Such instruments include Universal Declaration on Human and people's Rights and Declaration on the rights of people affected by tuberculosis. People affected by tuberculosis by virtue of being human beings have all the rights to have their rights protected and promoted. Therefore, the instruments advocate for various rights such as right to life, right to equality, right to work, right to freedom of movement, right to freedom of association, right to privacy and right to participate in public affairs[30].

3.2 Address gender inequality and remove human rights barriers in the TB response[31]

Tanzanian community like in any other communities facing gender and rights barriers to TB services. The following are the proposed ways to improve TB outcomes by reducing those barriers:

3.2.1 Reducing stigma and discrimination

i) *Assessing stigma and discrimination*: stigma indexes tools may be used to assess the type and level of TB-related stigma in a given population, e.g. in

[29] The National Health Policy 2007. section 5.3.2 (a)(b) & (c)(i)(ii).
[30] Declaration on the Rights of People affected by Tuberculosis. 2019. Stop TB partnership
[31] Global Fund. Tuberculosis, Gender and Human Rights Technical Brief. April 2017

health care settings, in communities, and whether stigma is worse in some locations or some population groups than in others. This information will be crucial for designing effective anti-stigma measures.

ii) *Addressing stigma and discrimination in the community and workplace:* Basic non-judgmental information on TB should be accessible to the lay public and to employers and employees, to counter stigma and discrimination and help de-stigmatize people vulnerable to or affected by the disease, empower patients and their communities to know their rights, and ensure access to services for all. Mass media or other awareness-raising activities can help address stigma in the community or workplace, especially if they are informed by an understanding of the origins of stigma and the nature of misconceptions that may feed stigma. Information campaigns through patient support groups, clubs or "budd" programs in the workplace, and mobilizing and informing anti-stigma champions among political, religious, cultural or thought leaders may be used and they may focus on assuring TB patients are not fired when they are ill.

iii) *Addressing stigma in health care settings:* Programs may be designed to help health care

workers understand and address their own concerns about TB risk on the job, as well as stigmatizing attitudes toward patients[32]. This will ensure confidentiality and privacy of patients with TB as an important aspect of stigma reduction in health facilities and increases uptake of health services by those who need them.[33]

iv) *Addressing stigma and discrimination in education:* TB-related stigma can lead to

discrimination and exclusion in education[34] and it has been demonstrated that school-based

information programs have been effective in some settings.[35]

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[32] International HIV/AIDS Alliance, Zambart Project and STAMPP-EU. Understanding and challenging TB stigma: toolkit for action. Brighton, UK, 2009; Stop TB Partnership. Good practice: Stop TB Partnership challenge facility for civil society – financial support to community initiatives for positive change. Geneva, undated.

[33] Stop TB Partnership. Key vulnerable populations brief: Health Care Workers. Geneva, 2016.

[34] Cremers AL, de Laat MM, Kapata N, et al. Assessing the consequences of stigma for tuberculosis patients in urban Zambia. PLoS ONE 2015; 10(3):e0119861.

[35] Gothankar JS. Tuberculosis awareness program and associated changes in knowledge levels of school students. International Journal of Preventive Medicine 2013; 4(2):153-7.

3.2.2 Reducing gender-related barriers to TB services

i) *Understand the populations at risk of TB and living with TB* by assessing gender-related barriers to services in each community and systematic collection of gender-disaggregated data on incidence, prevalence, and services to inform targeted outreach to men and women, training of health workers and other health system strengthening. The assessments will highlight regulations, laws and policies as well as program practices that fail to take into account gender-related drivers of risk. For instance, if men's (or women's) working hours impede seeking health services, useful measures may include:

- mobile services,
- increasing budgets to allow for longer hours of service at fixed facilities,
- advocacy with community leaders, men's and women's groups and others on the importance of access to services for all.

If men are disadvantaged as migrant workers or workers exposed to particulates or are more likely to use drugs, advocacy and targeted extension of male-friendly services can help.

3.2.3 Introducing TB-related legal services

Even if people know their rights, they may not be able to assert them without assistance from legal or paralegal professionals. In some circumstances, access to legal assistance may be the most direct and effective way for marginalized persons to get access to TB services, to be protected from compulsory treatment, or involuntary isolation, or to address stigma and discrimination. Community-based and peer-led legal counselling or services may be particularly effective. TB survivors' groups in their working councils, MKUTA and TTCN at national level may take lead to improve access to TB related legal services and advocate for equality and equal quality TB services. This approach may bring legal remedies to people with TB facing delays in receiving their medications in health facilities, helping to establish mobile services for remote populations, and cutting wait times for severely ill persons.

Programs aiming to improve access to justice should be attentive to barriers to legal services faced by women as a result of unequal household-level

decision-making power and resource control as well as inequality under the law.

3.2.4 Monitoring and reforming policies, regulations and laws that impede TB services

Policies and laws can hinder access to TB services and can be reformed through advocacy, community mobilization and awareness-raising, and litigation.

3.2.5 Knowing your TB-related rights

Larger information campaigns mostly lead to TB-related rights literacy which help people to know their rights under health regulations and national law as well as their human and patient rights with respect to TB. It is best to combine rights literacy with measures that improve access to legal services or with measures to combat problematic policies and laws. Patients' rights programs can also be effectively combined with training of health care workers in nondiscrimination, gender-responsiveness, confidentiality, and informed consent. Health workers, mine workers, prison staff and others who may be exposed to TB on the job may also benefit from rights literacy programs.

3.2.6 Sensitization of lawmakers, judicial officials and law enforcement agents

Judges may also play important roles in protecting and fulfilling the rights of TB patients as well as caregivers. Training of police, judges, and other law enforcement and judicial personnel may be an essential activity to ensure the effectiveness and uptake of TB services. Training of police is likely to be best received when it includes practical information on how police can protect themselves from TB on the job.

3.2.7 Training of health care providers on human rights and ethics related to TB

While health workers might be expected to be models for the community in respecting the rights of people affected by or at risk of TB, this is not always the case. Health workers may need support to overcome their own stigma and

fears of acquiring TB, as well as to appreciate the importance of non-discriminatory provision of health care, informed consent, confidentiality and privacy, patient-centered care, patient rights and meaningful participation of patients in decision-making about their care. Training is one strategy for improving knowledge, attitudes, and practices of health workers. It may be combined with integration of human rights and ethics elements in performance reviews or other incentives, as well as with patients' rights education. Training is unlikely to be effective if health workers perceive that they have inadequate supplies of medicines or diagnostics or otherwise poor workplace support, or if they feel their own privacy and confidentiality rights are inadequately protected[36].

3.2.8 Ensuring confidentiality and privacy

Not only with respect to the workplace but also in health care facilities, educational institutions and other settings, measures may be undertaken to reform policies, practices and laws that undermine confidentiality and privacy with respect to TB status. Practices assessment in this area is crucial.

3.2.9 Programs in prisons and other closed settings

It is well established that the course of TB epidemics in prison is an important determinant of TB epidemics in society,[37]which indicates that TB services in prison should be part of all national TB prevention and care efforts. Training of prison medical personnel, as well as guards and other prison staff, on the basics of TB prevention and care has revealed to be effective according to the results from the current ongoing program which is conducted between MoHCDGEC - NTLP and Ministry of Home Affairs in Tanzania. The challenge identified is the follow up for post release care. To overcome the challenge coordination of prison care among prisons and with post-release care in the community should be the key to enabling people in state custody to begin TB treatment without fear of interruption when they are transferred or released.[38] Peer-based, patient-centered approaches should be encouraged

[36] Health and Development Networks, Stop TB Partnership, AIDS Care Watch, Development Cooperation Ireland. Fighting TB on the front lines: Highlights and recommendations from the Stop-TB eForum 2005. Dublin, 2005.
[37] UN Commission on Crime Prevention and Criminal Justice. United Nations Standard Minimum Rules for the Treatment of Prisoners (the Mandela Rules). UN doc. E/CN.15/2015/L.6/Rev.1, 21 May 2015 (see rule 24).
[38] Dara M, Acosta CD, Melchers NV, et al. Tuberculosis control in prisons: current situation and research gaps. International Journal of Infectious Diseases 2015; 32:111-7.

in prison as in other settings. TB constituencies like TB survivals clubs/ groups and community TB network like Tanzania TB Community Network (TTCN) can be a link between prison settings and post release tb services.

3.2.10 Mobilizing and empowering patient and community groups

People's meaningful participation in decision-making about health policies and programs that affect them is an integral element of the right to health. TB services should not be delivered in a "top-down" fashion rather, that the best outcomes depend on empowering people to be meaningful participants in TB prevention, diagnosis and treatment, to know their rights as patients, and to play a "watchdog" role in monitoring the quality and reach of services[39]. Community system activities should contribute to the empowerment of patients and the public in interacting with TB service providers[40]

Some activities include:

- support to patient peer groups;
- capacity-building to enable people, including men, women and young people, to take an active role in identifying and addressing TB risks in households, communities and workplaces;
- creating platforms for formal participation of patients and patient groups in health decision-making;
- building the policy advocacy capacity of current and former TB patients; and
- building capacity and opportunity for community health committees or TB patient groups to monitor and report on the quality of TB.

[39] Macq J. Empowerment and involvement of tuberculosis patients in tuberculosis control: Documented experiences and interventions. Geneva: World Health Organization and Stop TB Partnership, 2007.
[40] Global Fund to Fight AIDS, TB and Malaria. Community systems strengthening information note. Geneva, 2014; also, Global Fund, Community systems strengthening: technical brief [when available].

3.3 TB response

3.3.1 Public health versus Human rights perspectives

Despite the clear connection between TB, human rights and gender, for many years back, the TB program in Tanzania like many other countries has been based on a bio-medical or public health-based approach. **A biomedical perspective** for TB care and prevention concentrates on reducing the transmission of tuberculosis by targeting the most contagious persons (bacteriological confirmed TB cases) by finding these cases and treating them until they are eventually cured. This indicates the control of infections concentrate on disease rather than 'well-being'. From a biomedical perspective, only people with pulmonary tuberculosis are regarded as being infectious to others, and because control needs to prevent transmission to the wider public, public health interventions are targeted at cases of *infectious* TB mostly.

For instance, the focus on directly observing patients take their medication (DOT), without taking into account the economic and social factors that are associated with the disease, a patient in this situation may be forced to discontinue treatment because she cannot travel to the clinic every now and then for DOT, either because she lacks resources herself or because her household has refused to support her; a patient may not be able to tell her family that she has TB (and therefore cannot ask for support) because a TB diagnosis may precipitate divorce or obviate her marriage chances; she is feeling too unwell to travel and sometimes long distances over difficult roads; and/or she simply cannot afford to take the time out of daily life (work, responsibilities for child care, etc.). Such a program is unlikely to achieve the hoped-for results.

A **"Human Right based perspective"** note that before the obstacles to a particular treatment regimen can be cleared away, patients must understand the system, and the system must be consistent with the underlying health beliefs and social norms of the community. The program will also need to take account of the practical realities of everyday life which play a role in the ability of people to adhere to any treatment regimen[41].

The Human Rights-Based approach is a conceptual framework that can be applied to programmatic interventions design. According to APCASO, there are several guiding factors informing the human Rights based approach which form the acronym **PANELS**[42]. These factors include:

- **P**articipation of all stakeholders including affected communities and excluded groups.
- **A**ccountability for monitoring progress and mechanisms for measuring violations of rights.
- **N**on-discrimination and ensuring that no one is left behind and needs of the most vulnerable are included.
- **E**mpowerment by building capacity and placing people at the center of the process rather than treating them as passive recipients.
- **L**inkage to legally enforceable rights and protections
- **S**ustainability and ensuring local ownership and strengthening partnerships among stakeholders.

[41] Hurtg.A.K. et all. 1999 IUATLD. Tuberculosis control and directly Observed Therapy from the public health/ human rights perspective. INT J TUBERC LUNG DIS 3(7):553Ð560

[42] APCASO (2017). Strengthening Community, Rights, and Gender Concepts for Communities and Civil Society Society on Country Coordinating Mechanisms: Guidance Tool. Thailand: APCASO.

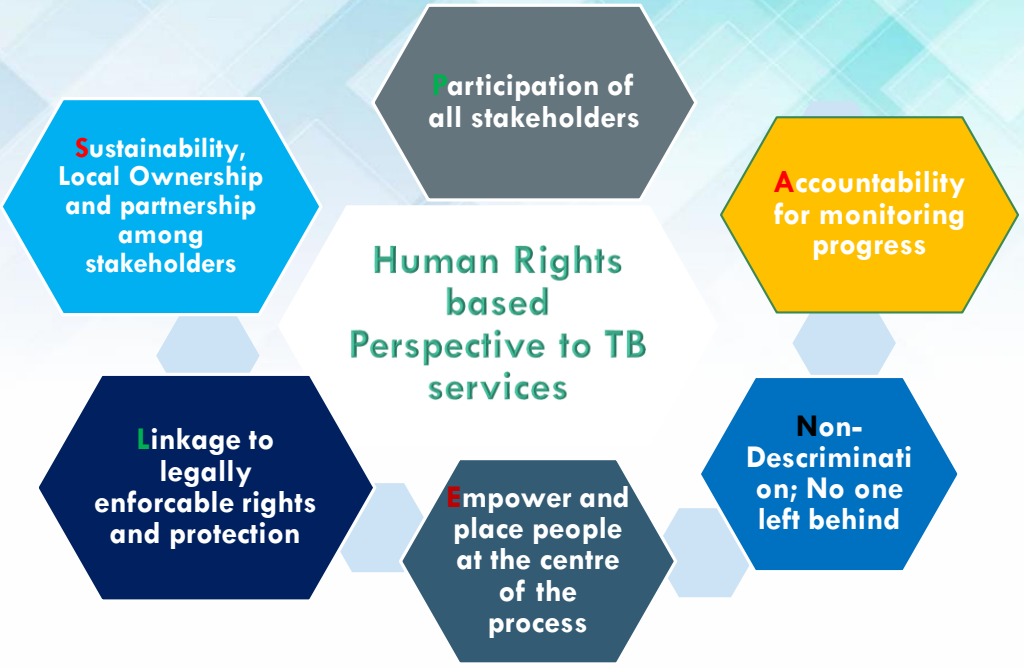


Figure 2: Human Rights perspective to TB services

3.3.2A human rights-based and gender-responsive approach

A human rights-based and gender-responsive approach to addressing TB and other health problems means integrating human rights and gender equality norms and principles – including non-discrimination, transparency and accountability in the design, implementation, monitoring, and evaluation of programs. It also means empowering vulnerable groups and key vulnerable populations, putting in place necessary programs to address their vulnerabilities and needs, ensuring their participation in decision-making processes which concern them, and ensuring that there are mechanisms for complaint and redress when rights are violated. Human rights-based services should be informed by a thorough assessment and analysis of where human rights barriers and gender inequality exist and whom they affect. They can help ensure that users of health services and those most affected by TB are brought together in non-threatening and meaningful consultation with government, service providers, community leaders and others in civil society. The perspectives and voice of those affected by the disease are irreplaceable, including in determining priorities for reducing gender inequality and human rights barriers and in devising and implementing the most effective prevention and treatment services. Where there

are established national human rights bodies or ombudspersons, those institutions may also play an important role in ensuring the respect, protection and fulfillment of the rights of people needing and using TB services.

Gender integration in TB care and prevention entails the collective efforts from different key stakeholders in making sure that all stakeholders are informed, aware and understand the concept of gender and begin to reflect on their own attitudes to transform and advance equality and equity in all aspects of life but specifically to TB care and prevention related interventions. It includes empowering women, men, adolescent girls and boys in TB related issues and advocating for reducing all forms of GBV among TB patients and their families, stigma and discriminations and gender imbalances.

To change from overreliance on biomedical interventions, the NTLP has increased focus on adequate consideration of the socio-cultural aspects of the community with consideration of rights and gender transformative to shed more light on TB care and prevention. To operationalize that, three blocks of CRG will be integrated TB services as illustrated below:

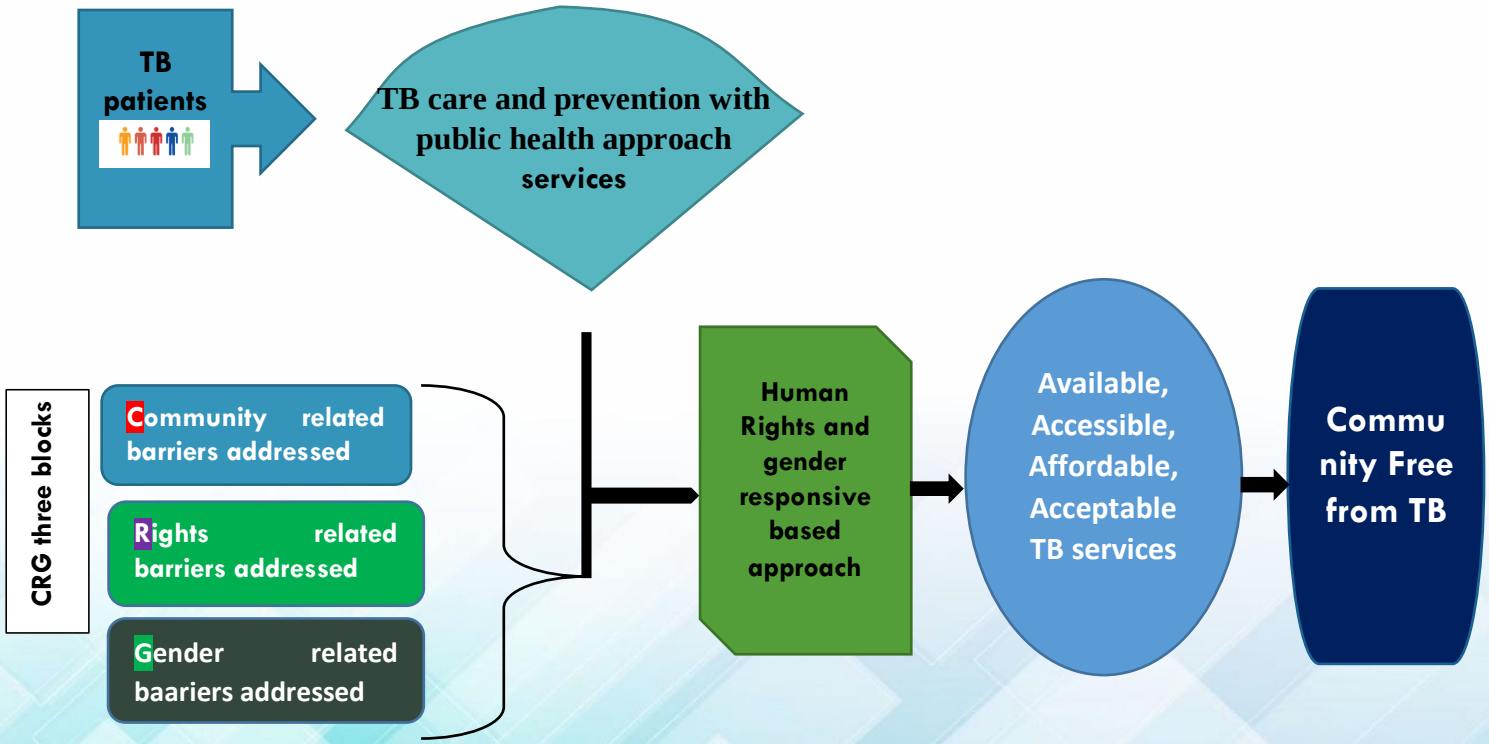
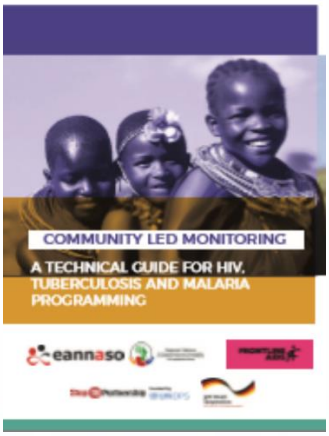


Figure 3: *From Public health approach to human rights based approach for quality TB services*

3.3.3 Community Led Monitoring (CLM)[43]

Community Led Monitoring (CLM) is often referred to as Community Based Monitoring (CBM). It is defined as "Mechanisms that service users or local communities use to gather, analyze and use information on an ongoing basis to improve access to quality and the impact of services, and to hold service providers and decision makers to account" It:

- holds both government and non-state service providers accountable for responding to intended beneficiaries' needs.
- strengthens community engagement and ownership.
- fills public health system information gaps; responds to human rights and gender-related barriers.
- monitors budgets; and
- prevents stockout and expiry of commodities.



This is mostly achieved by routinely collecting data to establish gaps in service delivery; and to respond to the identified limitations in the quality of services such as availability of health workers, commodity stocks outs; gender and human rights barriers to services.

CLM recognizes communities have unique attributes that can be nurtured and tapped to improve planning and health service delivery at community level. Among these are the capacity to advocate effectively, play the 'Watch dog" role, utilize experiences to advise on what works and what does not. Communities are effective implementers of testing and screening, adherence support, stigma reduction, social accountability, and many other services[44]. Community TB constituents and networks; and individual community members should act as 'community level quality assurance advocates' who identify and document gaps and constraints in equity, access and quality of prevention, treatment

[43] EANNASO CRG Guide: Community Led Monitoring. A technical Guide for HIV, Tuberculosis and Malaria. 2019
[44] EANNASO CRG Guide: Community Led Monitoring. A technical Guide for HIV, Tuberculosis and Malaria. 2019

services and challenges adversely affecting service delivery; and use the information to influence and advocate for positive changes and improvements at all levels namely the facility, councils, regional and national level policy reform; and inform decision and program design by NTLP.

CLM beneficiaries

Beneficiaries at community level include people living and affected by TB, key and vulnerable populations specific to TB who either account for high incidence and prevalence rates, or for the majority of missing cases. Key affected populations under TB include miners, health care workers, community health workers, children, prisoners, urban slum dwellers and the rural poor, fisher folks, traditional healers

CLM is NOT monitoring and evaluation: CLM should not be equated to routine monitoring and evaluation undertake by implementing partners who engage communities to attain their perceptions and feedback on services rendered to them.

Principles of community led monitoring (CLM)

Community empowerment: This is a process of re-negotiating power to bring about social and political changes and to gain more control. It addresses social, cultural, political, and economic determinants of health, and builds partnerships with other sectors to find solutions. CLM involves sensitizing and building capacity within communities to know their respective epidemics and understand programs and grants; CLM is about equipping them with planning, monitoring, organizing, assertiveness, and advocacy skills to be effective change agents and duty bearers in their respective communities. Such knowledge includes bio-medical, behavioral, and structural barriers to health service delivery; and indicators relevant to their respective CLM mechanism.

Community led and driven: Community led organizations include key vulnerable population (KP) led organizations. “Community led and driven” means that people affected by TB must be an integral part of the decision to establish CLM mechanisms and should meaningfully participate at all levels – including in setting objectives, defining what CLM will monitor, selecting data collectors, and recording information. Lastly their holistic involvement should entail meaningful participation in analysis and interpretation or making sense of collected information, and using it for advocacy, decision making, priority setting, policy change and program improvement.

Objective and transparent: CLM mechanisms uphold the principal of impartiality and neutrality. Community led organizations which are active implementers of interventions and service providers do not qualify as potential CLM implementers. This is because such organizations will be 'subjective' and have 'conflict of interest'. This could undermine overall effectiveness and credibility of the CLM mechanism. Advocacy may not make sense because the conflicted implementer cannot advocate to themselves to change things they are already perceived to be in control of. CLM also fosters a culture of information exchange reflecting the needs of affected communities for optimum healthcare decision making.

Collaborative with active stakeholder engagement: CLM is a community led, objective and collaborative mechanism undertaken by communities either independently or in collaboration with service providers and other possible partners such as researchers, academics and think tanks. Service providers may either be grassroots health facilities, clinics or civil society organizations undertaking community level service delivery. Where a CLM mechanism is implemented as a collaborative initiative between the community led organization, health facilities and other service providers, the relationship should be cordial, mutually beneficial, and free of mistrust. Trust is built when all stakeholders are clearly oriented on CLM processes during its planning stages, to build consensus. Relevant stakeholders consist of health facilities, health medical officers, health management teams, police and other law enforcement agencies, elected members of parliament, legislative officers, linked offices at national level and members of their oversight committees. Stakeholder engagement should be initiated at the beginning or launch of the CLM mechanism, throughout the course of implementation and at forums disseminating or advocating around CLM findings.

Action oriented and transformational: The goal of CLM is to stimulate positive and corrective action that improves access, uptake, and the quality of health services. Feedback should always strive to be constructive. CLM assesses current health practices to identify, document and communicate identified gaps within a reasonably short time. It transforms findings into advocacy action at various levels. Such information may also show whether a program is achieving intended results. Feedback loops for CLM mechanisms i.e. from identification of barriers and limitations to advocacy should last between three to six months, or shorter.

Promotes accountability for health investments and results: Through continuous monitoring, CLM mechanisms promote accountability for investments at community level. Through corrective action and improvements, they promote value for money and results which are critical in the strengthening RSSH and in facilitating impact.

Provides a complementary source of information: CLM mechanisms provide and generate alternative and complementary information through a structured process that entails routine data collection and monitoring of the availability of tools, equipment, materials, supplies and stock of medicines, and health workers with the required competencies and skills mix to match community health needs; the accessibility of health facilities and services including the gender and human rights barriers to TB services; the acceptability of health services. CLM amplifies the voice of communities and service beneficiaries through a structured and constructive process, with short feedback loops that leads to improvements in the access, uptake, and the quality of health services.

3.3.4 Designing community led monitoring (CLM) mechanisms[19]

CLM is process oriented, hence has several interlinked stages. This section guides on how to design and cost CLM mechanisms. CLMs are best designed by implementing civil society and community led organizations. Empowering these organizations and beneficiaries on their respective patient rights, and equipping them with planning, monitoring, organizing, assertiveness, and advocacy skills is important. This creates effective change agents and duty bearers that can actively improve service delivery. A CLM mechanism comprises of seven main inter-linked phases, namely:

1. *Community and government orientation, community empowerment, and capacity building phase:* communities as right holders and government as duty bearers are oriented on CLM which is a mechanism through which communities can claim their rights and through which governments are held accountable. communities and networks are oriented and empowered
   on their respective rights, on prevention and treatment for TB and the expected service to be delivered to them. Communities are also equipped with organization and advocacy skills.
2. *Planning and conceptualization phase*: involving community mobilization and entry: Civil society and communities do not rush into implementation CLM

mechanisms; but first plan and invest first in their own empowerment and design of these mechanisms before initiating the implementation phase.

3. *Stakeholders analysis and engagement:* A rapid mapping of key stakeholders and service providers should be done. This will help identify the focal persons at all levels. It will also be useful in identifying early and advocating with people who may otherwise act as detractors to the CLM mechanism. It is also important to determine the roles of each group of stakeholders.
4. *Capacity building, Development and pre-test of software and tools:* As part of capacity building, communities should be mobilized and empowered on the package and quality of TB services to expect from health facilities and community Health workers. This knowledge and literacy are important since it helps draw lessons on what works and what does not, while facilitating corrective action. In addition to sensitizing community members, data collectors and other staff should be trained on CLM objectives, tools and required monitoring and reporting skills to allow data collectors to immediately flag out key issues and gaps such as commodity stock-ots, closure of facilities, availability of key TB diagnostic infrastructure and any other relevant areas, depending on the main scope or objectives selected for the CLM. Training package should include practical simulation exercises on the use of electronic technologies e.g. One Impact and tools that will be adopted.
5. *Data collection, analysis and reporting:* Data analysis software may be required, and staff trained on their use. Once findings are generated and analyzed, validation meetings should be planned (and budgeted earlier) to relay information to community members and other stakeholders, summarize an advocacy agenda and discuss how to use findings for advocacy and triangulation of information available to decision makers. Such community-led meetings facilitate community ownership and grow members into key drivers of change.
6. *Influencing and advocacy phase*: The dissemination and advocacy forums for the reports should provide space for the audience to respond to the key issues and define when corrective action will be taken.
7. *Follow up stage:* When recommended actions by decision makers, oversight bodies and policymakers are followed up with intended implementers.
8. *Monitoring and review phase:* Where implementation of emerging actions and the eff activeness of the CLM mechanism is continually analyzed and improved. Periodic (monthly, quarterly, and annual) reviews of the CLM mechanism should be used to monitor implementation progress, identify, and resolve challenges and

continue to adapt the CLM mechanism Reviews provide a good opportunity for end beneficiaries and communities to appreciate CLM and their power as influencers or positive change makers. Reviews provide an opportunity to document best practices, lessons learned and inform future programming for CLM mechanisms.

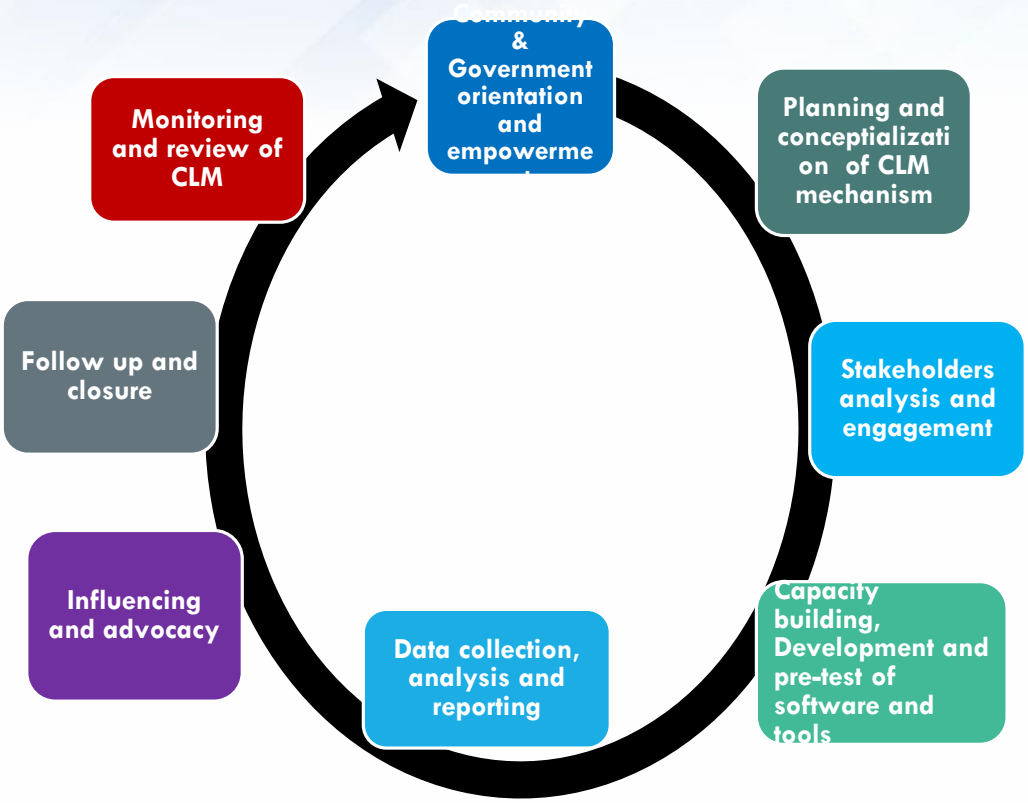


Figure 4: CLD designing conceptual framework. Source: EANNASo, 2019

3.3.5 Community linkage, monitoring, response towards equitable and quality TB services

Community response is actions and strategies that seek to improve the health and human rights of their constituencies, that are specifically informed and implemented by and for communities themselves and the organizations, groups, and networks that represent them. It is how communities act on the challenges and needs that they face; it is a multidimensional - can combine community-based service delivery with roles in advocacy, monitoring, research, governance and accountability and it makes

a vital contribution to national responses to TB, working alongside other sectors to develop evidence-based approaches, apply good practice and implement normative guidance. It brings a unique added value in comparison to others especially effective at ensuring health equity, in particular for key and vulnerable populations, addressing the social determinants of health (such as human rights and gender equity), implementing safe, high-quality and people centered services, and holding decision-makers to account.

Community response often provide support that would not otherwise be available. An example is a community health worker (CHW) program for TB, where the workers are based in and contracted by a government hospital, serve as a link between medical staff and community members, and focus on TB contact tracing and case finding.

Community Led Response

Community-led responses include 'key and vulnerable population-led responses. These are implemented by entities for which most of the governance, leadership, staff, spokespeople, membership and volunteers reflect and represent the experiences, perspectives and voices of key and vulnerable populations. The response presented through advocacy and research of which council, regional and national level advocacy activities will be led by community organizations, networks and civil society actors, particularly those representing marginalized, under-served and key and vulnerable populations [45].

[45] Global Fund Technical Brief: Community Systems Strengthening, October 2019

Community led advocacy and research activities can be:

- Qualitative, quantitative, and operational community-led research that takes into account human rights, gender and age considerations, and the production, publication and dissemination of reports and communication materials.
- Mapping of legal, policy and other barriers that hinder/limit community responses (including barriers that impede registration, funding of community organizations).
- Data collection and analysis to inform development and/or improvement of key and venerable population programs.
- Research and advocacy to sustain/scale-up access to services by key and vulnerable populations, including public financing for the provision of services by community led and based organizations (e.g. costing of services and implementation arrangements; analysis of the legal and policy context, tendering and selection processes, and monitoring of implementation).
- Capacity building to develop and undertake campaigns, advocacy and lobbying, for improved availability, accessibility, acceptability and quality of services and social accountability.
- Capacity building to develop and implement advocacy campaigns for domestic resource mobilization for the three diseases and Universal Health Coverage.

, engagement and representation in policy processes, decision-making and accountability

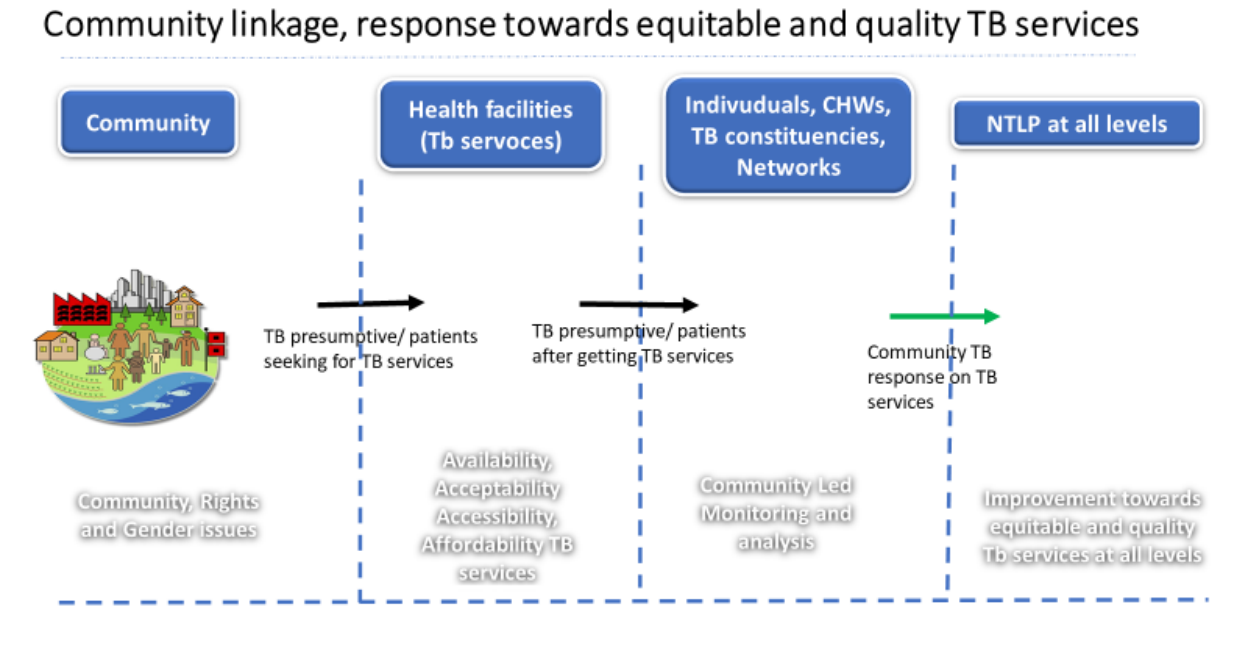


Figure 5: community led monitoring, linkage and response towards equitable and quality TB services

3.4 CRG implementation stakeholders and their roles

A stakeholder is a party that has an interest in a company and can either affect or be affected by the business[46]. Stakeholders in implementing CRG operational plan in Tuberculosis (TB) response includes:

- *People living and affected by TB*
- *Community Health Workers:* These are people who are trained specifically to lender health services in the communities. There some received formal training from health training institutions and informal through seminars and workshops
- *Health care Workers:* These are health care professionals that include Doctors, Nurses, Pharmacists, Laboratory technologists, Radiologists and Medical Social Workers.
- *Community leaders:* These are leaders within the community which pray important roles for the communities' welfare. Community leaders include; Village chair persons, Village and Ward Executive Officers.
- *Religious leaders:* These are religious leaders from different denominations. This includes Christian religious leaders and Muslims
- *Traditional healers***:** These are people within the communities which provide healing to people through use of traditional therapies
- *Community members:* These are key stake holders and direct beneficiary of health services including TB prevention and care services.
- *Community Networks for TB (TTCN & MKUTA)*
- *Community TB Technical Working Group*
- Ministry of health, Community Development, Gender, Elderly and Children/ NTLP
- Development partners and Implementing Partners (Ips)

[46] Stakeholder Management - Manage risk, (2020) Meet Atium, the Integrated Issue & Stakeholder Management Platform. tsc.ai

3.4.1 Stakeholders and their roles

Stakeholders	Roles
People living TB and TB survivals	• Be at the forefront of ending stigma. They can share their experiences and challenges in the mainstream TB community as well as through survivor groups and other peer networks. • Information sharing and compliance to the treatment plan. Patients should provide all relevant information to the physicians. • Contribute to ending TB. help the patients with possible TB in the community by convincing them to seek the medical advice as early as possible.
Community Health Workers	• Health education and active case finding of patients with TB symptoms in relation to Gender and Rights to TB services • Sputum sample collection from the presumptive cases • Linkage of patients in the community to health facilities and support systems • Tracing defaulters of the treatment and helping them resume to treatment
Health Care Workers	• Provision of health and psychosocial care to the societies • Carrying out TB interventions in their localities • Generating and compiling the reports in regard to TB services • Conducting screening campaigns in the societies
Community leaders	• Protecting rights of community members and their properties • Dissemination of official information including health information. • Advocacy to developmental activities at their localities.

Religious leaders	• Influencing their followers on religious, development and health issues • Advocating peace and fairness to their followers • Advise to government and governmental leaders on health issues
Traditional healers	• Identification of patients with TB symptoms • Referral and linkages of presumptive TB cases to CHW/Health Facilities • Keeping records of presumptive cases and referred cases.
Community members.	• Receiving health and TB services positively • Participating in planning and implementation of TB interventions • Supporting their friends and relatives on TB treatment (Treatment supporters) in different aspects such as Direct Observed Treatment (DOT), financial support, nutritional support and psychosocial support. • Reporting presumptive cases to visiting CHWs and accompanying them to visit health facilities to both presumptive and TB patients.
Community TB networks	• Promoting capacity building of civil society members and representatives of communities affected by TB to intensify `the information sharing, dialogue and consultation on the implementation of CRG Activities. • Development of framework for CLM to enable communities monitor availability, affordability, accessibility of TB services • Expand the effectiveness of ACSM approaches to increase TB case detection, service usage and engagement of civil society.

	• Identify key TB related issues in the community and advocate for programs that reduce human rights and gender-related barriers to accessing services. • Develop a policy advocacy agenda and engage communities to hold discussions with key decision makers. • Catalysing greater collaboration between civil society, NTLP, POLAG at all levels in all activities and projects for improved outcomes including meaningful engagement of civil society and affected communities in policy development; • Soliciting funds from donors
Community TB Technical working Group	• Provide technical and strategic guidance on the implementation of CRG • To guide the inclusion of CRG in research, policy and clinical practices. • Improving prevention, detection and management of TB at community level in line with the National guideline and standards • Soliciting funds from different sources for TB interventions
Ministry of health, Community Development, Gender, Elderly and Children	• Soliciting Funds to facilitate implementation of the programme activities • Developing guidelines and directives for smooth running of the programme activities • Providing technical support to all programme activities implementers • Overseeing, monitoring and evaluation of ongoing TB control services
Implementing Partners	• Soliciting funds from donors • Support implementation of TB activities

	• Capacity building to staff and community key stakeholders
Development partners	• Soliciting funds from different sources for TB interventions • Providing technical support in different aspects • Monitoring the programmatic performance

CHAPTER FOUR: MONITORING AND EVALUATION

Monitoring and Evaluation is used to assess the performance of projects, institutions and programs set up by governments, international organizations and NGOs. It must be detailing how to ensure robust monitoring of all activities, including capacity-building, that also include intervention areas to be monitored and evaluated, for real time throughout the life of the program, project or activity interventions.

4.1 Monitoring and Evaluation

Implementation of this guide will contribute in promoting community, human rights and gender revealing and preventing barriers towards access and linkage to provision of health services among targeted populations. Furthermore, it will enable key stakeholders to address CRG interventions in-line with TB care and prevention services.

Community health care workers, CSOs, TB constituents and networks will also be considered as champions in addressing gender norms, community engagement and efforts to promote CRG described in this document. The matrices below provide areas of focus and key interventions and activities that will lead to achievement of Community human rights and gender in implementation of community intervention as stipulated in this document.

SN	ACTIVITIES	OUTPUT	OUTCOMES	INDICATORS	MEANS OF VERIFICATION	ASSUMPTION	STAKEHOLDERS
Key result area number 1: An enabling policy and legal environment							
1	Review of policies and guidelines that promote CRG to TB Care and prevention services in the country	Reviewed TB care and prevention documents	Inclusion of CRG into TB policies and prevention documents	Number of Policy and guidelines documents that promote CRG to TB care and prevention	Activity report	Availability of funds	NTLP partners, and related sectors
Key result area number 2: Reduced stigma and discrimination							
1	Conduct baseline Stigma index assessment in Tanzania	Stigma Index Assessment report	Magnitude of TB related stigma in Tanzania	Stigma Index known in Tanzania	Assessment report	Available funds	NTLP, NIMRI, implementing partners
	Conduct community-based assessment system to monitor self-stigmatization among TB patients	Electronic Applications for data collection;	Number of self-stigmatized cases reported	Percentage of people diagnosed with TB who experienced self-stigma that	Analyzed data from a known set system	Data collection system in place.	TB constituents, community TB networks, Tb patients

		questionnaires	among community members	inhibited them from seeking and accessing TB services		Availability of funds	
	Conduct health facility-based assessment system to monitor self-stigmatization among TB patients	Electronic Applications for data collection; questionnaires	Number of TB patients reported stigma at HFs	Percentage of people diagnosed with TB who report stigma in health care settings that inhibited them from seeking and accessing TB services	Analyzed data from a known set system	Data collection system in place. Availability of funds	TB constituents, community TB networks, Tb patients
	Conduct community-based assessment system to monitor self-stigmatization among TB patients	Applications for data collection; questionnaires	TB patients reported stigma at community settings	Percentage of people diagnosed with TB who report stigma in community settings that inhibited them from seeking and accessing TB services	Analyzed data from a known set system	Data collection system in place. Availability of funds	TB constituents, community TB networks, Tb patients
	Implement women focused Social behavioral change interventions	SBC strategies	Increased percentage of women seeking for TB services	Percentage of female TB patients notified in a specified period increased by 10%	Analyzed data from ETL register (% of presumptive cases & TB cases notified among women)	Functioning ETL	NTLP, regions, districts, TB constituents, community TB networks, TB patients
Key result Area number 3: Enhanced community engagement							
	Implement TB care and prevention activities through community engagement	Various Community TB interventions implemented	Increased % of TB cases attributed from community referrals	40% or more of TB patients notified through community referrals in a specified period	Analyzed data from ETL register (community contribution in TB case notification)	Functioning ETL	NTLP, regions, districts, TB constituents, community TB networks, TB patients
Key Results Area Number 4: CRG informed TB response							
	Develop and disseminate SBC materials addressing human rights and Gender issues Related to TB	SBC materials developed and disseminated	Increased community awareness on TB	Number and type of SBCC materials developed and distributed to addressing human rights and Gender issues Related to TB	SBC materials in place	Availability of funds	NTLP, IPs, CSOs

	Review and develop guidelines that promote CRG to TB Care and prevention services in the country	Reviewed TB care and prevention documents	Inclusion of CRG into TB policies and prevention documents	Number of guidelines documents that promote CRG to TB care and prevention	Activity report	Availability of funds	NTLP partners, and related sectors
	Develop CLM system to conduct community monitoring of TB services	CLM electronic/ paper-based system developed	Community feedback on TB services in place	Number of Community-Led monitoring reports presented to TNCM, TWG, Local government (village, ward and council)	CLM system in place	Availability of funds	TB constituents, community TB networks, TB patients

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