

### BASELINE ASSESSMENT OF COMMUNITY-BASED MONITORING OF TUBERCULOSIS INTERVENTIONS IN MALAWI



### **Final Report**

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Malawi TB CBM Assessment Report

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Finally, the DSSCC would like to stress that opinions expressed in this report are purely those of the authors based on observations and findings during the study. Therefore, DSSCC take full responsibility for any errors, misrepresentation and omissions that may be found in this report.

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# ACRONYMS

ARASA	AIDS and Rights Alliance for southern Africa
CBM	Community-based Monitoring
COVID-19	Coronavirus disease 2019
DHO	District Health Office
FACT	Facilitators of Community Transformation
GoM	Government of Malawi
KII	Key Informant Interview
МоН	Ministry of Health
NTP	National Tuberculosis Control Programme

# **Executive Summary**

Community-based approaches have been recognized as critical to preventing and treating TB. Communities are important to the TB response, globally, regionally, nationally and locally. For example, the Stop TB Partnership recommended that ending TB by 2030 should incorporate strong coalitions with civil society and community organizations and Human Rights and Gender Based Approaches. A TB response with the full integrated involvement of communities will achieve a TB free status. Community-based Monitoring (CBM) is a data driven process of drawing in, activating, motivating, capacity building and allowing the community and its representatives to directly give feedback about the functioning of public health services. In this assessment we aimed to assess the current community-based monitoring for TB in Malawi. We specifically aimed to: (a) Map and assess the community-based interventions in Malawi, (b) describe the gender and human rights barriers and enablers in accessing the Tuberculosis services in Malawi, and (c) assess the current community monitoring and evaluation tools and processes that are in place for monitoring community-based TB interventions.

The assessment was done in Karonga, Mulanje, Zomba and Nkhotakota. The assessment used a mixed methods approach (quantitative and qualitative methods of data collection). Quantitative data was collected through a Patient survey, Provider survey and review of documents while qualitative data was collected through Key Informant Interviews (KII), Focus Group Discussions (FDGs) and case studies with relevant stakeholders and beneficiaries. Structured questionnaires were used during the Patient survey, Provider survey and review of documents while Checklists were used during Key Informant Interviews (KII), Focus Group Discussions (FDGs) and case studies.

Data from the patient survey were analyzed using STATA v16.0 (Stata Corp., Texas, USA). Data were analyzed using frequencies, proportions, means, standard deviation and medians as appropriate. Data from focus group discussions and Key Informant Interviews was recorded and transcribed. To get the required qualitative data; we managed, sorted and organized qualitative data, stored, annotated and retrieved text, located words, phrases and segments of data and extracted quotes. Wherever possible, the study triangulated what was obtained in qualitative data analysis with quantitative results and relevant literature obtained through document review. The analysis also provided for gender disaggregation in order to provide understanding of how different gender groups benefitted from the project.

We received approval to conduct this study from the Malawi National health Sciences Research Committee (Protocol # 20/05/2527). We also received individual consent from all the participants in the study. The data to be analysed did not include any identifiers. We also obtained gatekeeper approval from the District Health Office, Local leaders and Facility Incharges.

The key findings of the study were:

- Most patients were aware of the services being offered by the TB sites in Malawi. The services being offered are in line with those stipulated in the Malawi national TB Annual Report for 2018:
   (a) TB screening, (b) contact investigation, (c) drug resistant (DR) TB, (d) management of drug and other commodity supply chain management and logistics, (e) community TB interventions, just to mention but a few.
- The least number of patients were diagnosed of TB using Gene Xpert. This is consistent with the NTP annual report and research done in Malawi on the low uptake of Gene Xpert.
- 54% of the TB patients accessed care from the health centers.
- The provision of nutrition products to the TB patients was very low.
- A total of 113 (46%) of the TB patients said that a hospital service charter was available at their health facilities

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- 9% of the TB patients were maltreated and the main perpetrators of the maltreatment varied by type of maltreatment
- A total of 260 (92%) TB patients were aware of COVID-19; 38% have ever been screened for COVID-19 and 97% of the patients reported that the handwashing materials were available at the facilities.
- The Malawi NTP and its implementing partners is implementing the community interventions using the HSAs, Community Volunteers and Community Health Nurses.
- The NTP IPs report to the national TB programme through the facilities that they support however different Ips have different reporting forms and reporting requirements depending on their donors.
- There has been an increasing trend in the contribution of community interventions to TB case finding in Malawi between 2016 and 2018.

Some of the conclusions and recommendations are:

- The integration of the human rights and gender are not explicitly spelt out in the programming of TB interventions in Malawi although the community interventions are explicitly spelt out.
- There is need to review the current community health structure as the very same people are being used for various community health interventions and this may make these people less efficient as they become overburdened with quite a lot of work
- The NTP should consider incorporating Social Marketing in TB programming through marketing of community-based TB interventions that have been shown to work by some IPs.
- There is need for organised way of data collection for CBM so that the same tools are used by all the IPs implementing the TB interventions.
- There is need for development of the electronic module in the DHIS2 for reporting community TB interventions for each health facility.
- To minimise misdiagnosis, there is need to consider introduction of spirometry in order to eliminate the COPD before diagnosis of TB
- There is need to civic-educate the patients on NTP policies as such policies have a direct impact on them as the immediate beneficiaries.
- There is need to civic-educate the communities especially the family members regarding maltreatment of the TB patients.
- In order to avoid using the very same volunteers and avoid discouraging some potentially active volunteers, there is need to apply participatory selection of volunteers. For example, in one project using community volunteers, the REACH Trust asked the HSAs, Chiefs and Community Volunteers. The names that were provided by all these (HSAs, Chiefs and Community Volunteers) were considered as volunteers and left out names that were not mentioned by more than one of the HSAs, Chiefs and Community Volunteers.

### 1 Background

Tuberculosis (TB) remains a public health concern in low and middle income (LMIC) settings where more than 80% of the global TB burden resides [2]. Malawi has observed a declining trend in TB due to successful implementation of the antiretroviral therapy (ART) programme because the majority of TB cases were infected with HIV [3]. The implementation and scaling up of community-based TB activities remains weak, despite the clear need, the documented cost-effectiveness of community-based TB activities and the tremendous efforts that have been expended in recent years [4]. Lack of effective collaboration between National Tuberculosis Control Programmes (NTPs) and Non-Governmental Organisation (NGOs) and other Civil Society Organisations (CSOs) and the absence of joint strategic planning, monitoring and evaluation are more the norm than the exception [4]. ENGAGE-TB emphasizes close alignment of systems, especially in TB monitoring and reporting, to ensure that national data adequately capture the contributions of community-based TB activities [4]. Both national and international consultations have been held to find missing TB cases through integrated community-based TB service delivery [5].

Community-based approaches have been recognized as critical to preventing and treating TB [6]. Communities are important to the TB response, globally, regionally, nationally and locally. For example, the Stop TB Partnership recommended that ending TB by 2030 should incorporate strong coalitions with civil society and community organizations and Human Rights and Gender Based Approaches [7]. A TB response with the full integrated involvement of communities will achieve a TB free status [8]. Community-based Monitoring (CBM) is a data driven process of drawing in, activating, motivating, capacity building and allowing the community and its representatives to directly give feedback about the functioning of public health services [9].

Community-based Monitoring involves drawing in, activating, motivating, capacity building and allowing the community and its representatives like community-based organizations (CBOs), people's movements, voluntary organizations and community representatives, to directly give feedback about the functioning of public health services [10]. Community-based monitoring process includes preparatory activities, capacity building and training of trainers, community assessment, interface meeting and finally the evaluation [10]. Therefore, CBM of TB services has the potential to address the gaps in the implementation of TB programs and thereby enhancing the transparency of service provision from the grassroot level. Community and civil society organizations engagement is a critical part of the Post-2015 End TB Strategy as it has the potential to provide for a comparative TB yield of the different TB case finding approaches [11].

The 2019 Global Tuberculosis (TB) report has placed Malawi among 30 countries with high-burden for TB and HIV, with the World Health Organisation (WHO) stating that such countries are off track to reach the 2020 milestones of the End TB Strategy. This study is in line with the Malawi Community Health Strategy objectives 2-6 as the study looks at what services are available to the community, capacity of the community health workers in provision of and monitoring of community work, engagement of community structures as well as coordination of the community structures [12]. Furthermore, this assessment is in line with the Sustainable Development Goals of ensuring Universal Health Coverage in the Malawi population [13]. With the current data challenges and weak community system, this study will bridge the community data gaps on TB and strengthen the weak community systems for TB.

The Malawi National TB Control Programme has been implementing TB activities at community level with a view to raising people's awareness of, and demand for, TB services and to strengthen community participation[14]. Activities include: (a) scaling-up the establishment of community sputum collection points to reduce distances that TB suspects travel to health facilities (there are over 1000 community sputum collection points throughout the country); (b) providing sputum transportation boxes (c) providing bicycles; and (d) providing radios to TB community clubs for health education. Despite several community TB interventions in Malawi, their monitoring and evaluation is not very strong. One of

the approaches that the NTP may use is Community Monitoring for Social Accountability using DHIS2. Community-based monitoring (CBM) systematically documents and reviews the availability, accessibility and quality of TB care and support services, for the purpose of doing advocacy with providers and policy makers to improve programs and services [7]. Therefore, in this assessment we intend to conduct CBM in Malawi and inform a stronger monitoring and evaluation of the community TB service delivery.

### 2 Purpose of this Assessment

In this assessment we aimed to assess the current community-based monitoring for TB in Malawi. We specifically aimed to:

- (a) Map and assess the community-based interventions in Malawi.
- (b) Describe the gender and human rights barriers and enablers in accessing the Tuberculosis services in Malawi
- (c) Assess the current community monitoring and evaluation tools and processes that are in place for monitoring community-based TB interventions

### 3 Study Methodology

### 3.1 Study Areas

The assessment was done in Karonga, Mulanje, Zomba and Nkhotakota. We visited the following health facilities in order to conduct the assessment:

Facility name	District	
	Mulanje District Hospital	
	Mulanje Mission Hospital	
Mulania	Mpala Health Centre	
Wuldije	Chonde Health Centre	
	Chisitu Health Centre	
	Milonde Health Centre	
	Karonga District Hospital	
	Kapolo Health Centre	
Varanga	Chirumba Rural Hospital	
Katoliga	Fulirwa Health Centre	
	Chilumba Barracks Health Centre	
	Nyungwe Health Centre	
	Nkhotakota District Hospital	
Nikhotakota	Malowa Health Centre	
INKIIOtakota	Kapiri Health Centre	
	Alinafe Health Centre	
	Zomba District Hospital	
	Naisi Health Centre	
	Makwapala Health Centre	
Zomba	Likangala Health Centre	
	Namasalima Health Centre	
	Nkasala Health Centre	
	Pilimiti Health Centre	

Table 1: Health facilities and districts that were visited for data collection for the TB CBM assessment, 2020

Matiya Health Centre
Manyaka Health Centre
Matawale Health Centre
Saint Luke's Hospital
Sadzi Health Centre

### 3.2 Data Collection Methods

The assessment used a mixed methods approach (quantitative and qualitative methods of data collection). Quantitative data was collected through a Patient survey, Provider survey and review of documents while qualitative data was collected through Key Informant Interviews (KII), Focus Group Discussions (FDGs) and case studies with relevant stakeholders and beneficiaries. Structured questionnaires were used during the Patient survey, Provider survey and review of documents while Checklists were used during Key Informant Interviews (KII), Focus Group Discussions (FDGs) and case studies. The segmentation of the interviewed respondents is shown in Table 1, by type of data collection method.

### Table 2: Segmentation of sample size by type of data collection method for the TB CBM assessment,2020

Data collection method	Number of Respondents
Patient Survey*	292
TB provider survey	28
Key Informant Interviews	6
Individual In-depth Interviews	2

\*300 respondents were interviewed but 8 records were excluded as they did not contain valid data

### 3.3 Data Analysis

The assessment employed a cross sectional study design. Data from the patient survey were analyzed using STATA v16.0 (Stata Corp., Texas, USA). Data were analyzed using frequencies, proportions, means, standard deviation and medians as appropriate. The quantitative data were presented in tables and graphs as appropriate. Detailed standalone tables and graphs were produced so that one can use them without referring to the main text.

Data from focus group discussions and Key Informant Interviews was recorded and transcribed. To get the required qualitative data; we managed, sorted and organized qualitative data, stored, annotated and retrieved text, located words, phrases and segments of data and extracted quotes. Wherever possible, the study triangulated what was obtained in qualitative data analysis with quantitative results and relevant literature obtained through document review. The analysis also provided for gender disaggregation in order to provide understanding of how different gender groups benefitted from the project.

### 3.4 Ethical Consideration

We received approval to conduct this study from the Malawi National health Sciences Research Committee (Protocol # 20/05/2527). We also received individual consent from all the participants in the study. The data to be analysed did not include any identifiers. We also obtained gatekeeper approval from the District Health Office, Local leaders and Facility Incharges.

### 4 Findings and Discussions

### 4.1 Respondent Characteristics

With reference to Table 3 and Table 4, this section presents findings on key socio-demographic characteristics of the sampled respondents that were interviewed during the survey. Socio-demographic characteristics allow us to understand in more details about the type of potential beneficiaries of the TB CBM in the selected districts and communities.

### 4.1.1 TB patient Survey

The characteristics of the patients are shown in Table 3. There were 292 patients: 54% were male, 38% were aged between 35 and 44 years, 21% were from Nkhotakota while 36% were from Zomba. A total of 280 (96% of 292) were not smoking tobacco. The main source of fuel used for cooking was firewood accounting for almost two-thirds of the interviewed respondents while the least used electricity (see Table 3). The majority of the TB patients relied on casual labour seconded by farming. A total of 127 (43% of 292) of the patients were HIV positive. Of these, 98% (125) were on ART. The majority of the TB patients were divorced. The median age of the TB patients was 38 years (interquartile range (IQR): 29-44).

#### 4.1.2 TB Provider survey

The characteristics of the TB service providers are shown in Table 4. There were 28 TB providers. Of these: 86% were male, 54% were aged at least 40 years, 79% have been providing TB service for at least 10 years, 50% had some diploma level of education, 36% were from Mulanje, and 25% were Health Surveillance Assistants. The median age of the TB providers was 40 years (IQR: 36-45). The median year of service for the TB providers was 13 years (IQR: 10-20).

Characteristics	n (%)
Total	292 (100)
Sex	
Male	159 (54)
Female	133 (46)
Age group in years	
15-24	38 (13)
25-34	75 (26)
35-44	110 (38)
45-54	43 (15)
55-64	18 (6)
65+	8 (3)
Highest education level	
None	20 (7)
Primary	161 (55)
Secondary	99 (34)
Tertiary	12 (4)
Marital status	
Never married	40 (14)
Married	167 (57)
Separated	41 (14)
Widowed	25 (9)
Divorced	19(7)
HIV status	17 (7)
Positive	127 (43)
Negative	163 (56)
Unknown	2(1)
Main Occupation	2(1)
Casual labour	121 (41)
Government employee	121 (11)
Not in public health	12 (4)
Public Health	2(1)
Miner	$\frac{2}{1}(1)$
Farmer	$\frac{1}{84}$ (29)
Self-employed	63 (22)
NGO employee	9 (3)
Patient smokes tobacco	y (5)
	12 (4)
I CS	280 (06)
Main source of fuel	280 (90)
Firewood	181 (62)
Characal	08(24)
Flactricity	70 (34) 12 (A)
District	15 (4)
Varonga	71(71)
Katoliga Nikhatakata	/1 (24)
INKIIOLAKOLA	02(21) 105(20)
	105 (36)
wiujanje	24 (18)

#### Table 3: Characteristics of patients interviewed in the TB CBM assessment, 2020

HIV=Human Immunodeficiency Virus; NGO= Non-governmental organisation

Characteristics	n (%)
Total	28 (100)
Sex	
Male	24 (86)
Female	4 (14)
Age groups in years	
<40	13 (46)
40+	15 (54)
Years of service	
<10	6 (21)
10+	22 (79)
Highest education level	
Secondary	12 (43)
Diploma	14 (50)
Degree	2 (7)
Role of provider	
Has	7 (25)
Senior has	5 (18)
Nurse or Midwife Technician	2 (8)
Medical Assistant	6 (21)
Hospital Incharge	3 (11)
Hospital Attendant	1 (4)
District TB Officer	3 (11)
District Medical Officer	1 (4)
District	
Karonga	2 (7)
Nkhotakota	4 (14)
Zomba	12 (43)
Mulanje	10 (36)

Table 4: Characteristics of providers interviewed in the TB CBM assessment, 2020

HSA= Health Surveillance Assistant; TB= Tuberculosis

# 4.2 Assessement of availability, accessibility, acceptability and quality of TB response

Here we use the human rights approach to TB framework to show how the right to health is interlinked with freedoms and entitlements that make it possible to prevent TB and increase access to quality TB diagnosis, treatment, care and support. We have adopted the framework from the STOP TB Partnership.





Source: STOP TB Partnership, Community-based monitoring of the TB response, using the OneImpact digital platform, 2020

#### 4.2.1 Services Offered at the health facilities

Health services in Malawi are provided by the public, private for profit (PFP) and private not for profit (PNFP) sectors [15]. The following governmental departments provide public services: The Ministry of Health (MOH), district, town and city councils, Ministry of Defence and Ministry of Internal Affairs and Public Security (Police and Prisons). Most PFP and PNFP services charge user fees. Government, through the ministry of health (MOH), enters into different service level agreements with the PNFP sector to provide essential services, such as maternal and child health care, especially in rural and remote areas [15] [16].

According to the TB patient survey, the most common service offered was TB diagnosis. The least common service was nutritional support with 17% of the patients recognising this as being available. A more detailed list of the services is presented in Figure 3 and Figure 4. The findings from the provider interviews are consistent with what we observed amongst the patients where the nutrition support was the least offered across the health facilities selected. A higher proportion of female provider indicated more services being

available as compared to the male providers of TB. Similarly, more female patients generally indicated higher proportions of services available at the selected health facilities. However, in both cases the differences observed were generally not statistically significant. The TB provider survey also shows that 11% of the health facilities had poor ventilation, non-functioning weighing scales and sitting accommodation. However, only 96% of the health facilities had functioning laboratories to carry out TB investigation.

The services that are available at the selected health facilities are based on the Malawi Medical Council list of available services at the health facility depending on the care level. Most of the health facilities providing TB services will be able to perform sputum microscopy. However, advanced tests are only done at the tertiary hospitals and district hospitals. The services being offered are in line with those stipulated in the Malawi national TB Annual Report for 2018: (a) TB screening, (b) contact investigation, (c) drug resistant (DR) TB, (d) management of drug and other commodity supply chain management and logistics, (e) community TB interventions, just to mention but a few [17]. An illustration of services available at one of the TB center visited is shown in Figure 2.

Figure 2: An illustration of TB and HIV testing services at one of the sites visited



The findings from KIIs and IDIs were also consistent with the quantitative results and those of the desk review indicating that the services were available at community level through established sputum collection centres, at health centre and district hospital levels:

"On TB, as an HSA in my catchment area, when I have a patient, I do follow him/her up on drug adherence. And when the patient is not adhering to drugs, we coordinate with TB office. We do patient follow up when we have other TB patients in my catchment area who need to submit sputum every 2 months... Yeah, there are community sputum collection centers and there are volunteers that were trained by other NGOs to conduct door to door exercise for sputum collection". IDI Chonde

and

"...community TB interventions as you have mentioned, we are having community sputum collection points, .... Three volunteers were trained on how to collect sputum, and how they can fill in laboratory forms and bring the specimen here at the facility for sputum examination using microscopy." KII, Kaporo Health Centre, Karonga



### Figure 3: Services available at health facilities as reported by TB patients that responded to TB CBM assessment, 2020

### Figure 4: Services available at health facilities as reported by TB providers that responded to TB CBM assessment, 2020



#### 4.2.2 Access and barriers to TB treatment

The methods of TB diagnosis by the HIV status of the TB patients are shown in Table 5. The majority of TB patients were diagnosed using sputum smear microscopy (73%). Amongst the HIV positive and HIV negative TB patients, sputum smear microscopy was reported as the major form of TB diagnosis followed

by Chest X-ray method (see Table 5). However, the National TB guidelines require that all HIV positive presumptive TB patients be screened using Gene Xpert method in order not to miss out most of the TB cases [18]. Similar low uptake of Gene Xpert amongst the population in Malawi has been observed and this may lead to lower detection of the TB cases amongst the HIV positive TB cases especially if tests with lower sensitivity are used instead of Gene Xpert [17] [19]. All persons diagnosed with TB are put on TB treatment in order to reduce mortality and morbidity due to TB [20].

Diagnosis	Positive (n=127)	Negative (n=163)	Overall (n=290)*
Sputum Smear/Microscopy	57%	86%	73%
TB Culture	2%	2%	2%
X-Ray	43%	16%	28%
Gene XPert	12%	4%	7%
Clinical diagnosis	3%	0%	1%
TB=Tuberculosis			

Table 5: Methods of TB diagnosis by HIV status of the patient, 2020

\*2 records had no documentation of HIV status

TB treatment in Malawi is provided to patients at no fees. The major supplier of the TB drugs to the various health facilities is the National TB Control Programme with support from the Global Fund. The Government of Malawi also supports the logistics and supply chain management of the TB through support by the National Budget for the Ministry of Health.

The places where the TB patients received their treatment is provided in Figure 5. Most of the TB patients receive TB treatment from the health centres. The least received TB treatment from the central hospitals. Based on literature in Malawi, the major provider of health care including TB in Malawi is Malawi Government accounting for almost 70% of the TB sites [16]. The second major provider is CHAM which account for almost 30%. In CHAM facilities, the patients may provide some consultation fees for TB treatment however the TB drugs are provided free of charge.



#### Figure 5: TB treatment places provided by patients interviewed in TB CBM, 2020

Although both oral and injectable TB drugs are provided to TB patients depending on TB type and susceptibility, in this survey all the respondents were on oral TB drugs. In this study we found out that 69% of the TB patients were educated on the side-effects of TB drugs. This is consistent with the National TB Programme manual for TB management in which the patients need to be informed of the possible side-effects related to the TB drugs [20]. We also observed that 74% of the TB patients experienced side-effects. The different side-effects experienced by the TB patients are shown in Table 6. The most common side-effect was dizziness (43% of 292). Except for dizziness, most men did not experience the side-effect as compared to the females (see Table 6). Amongst the patients with side-effects, 8% interrupted TB treatment as a result of having side-effects when taking TB drugs. The actions taken by TB patients that experienced the side-effects are: seeking care at TB clinic (48%), doing nothing (17%), informing the HSA (11%), and seeking advice from community volunteer or nurse (6%).

Side-effect	Male	Female	Both sexes
Nausea	22	30	26
Vomiting	10	16	12
Fever	10	12	11
Rash/Itchiness	17	23	20
Fatigue	29	29	29
Bloody nose	1	0	1
Dizziness	49	36	43

#### Table 6: Side-effects experienced by the TB patients in Malawi, 2020

https://kf.kobotoolbox.org/#/forms/afZ49JieMUZXUcCdg7StrV/landing

Bruising	4	6	5
Yellow Skin/Eyes	16	17	16
Pain in Abdomen	37	33	35
Dark/Brown Urine	42	31	37

Almost all the TB patients (99%) of the TB patients were able to receive their TB drugs in the past month. Among those who did not receive TB treatment, the major barrier was long distance to the health facility. There are also studies on care-seeking that have cited distance to the health facilities as a major barrier for care seeking in similar settings. Therefore, there is need for the Government of Malawi together with its implementing partners to devise some community interventions that will minimise the travel barrier to accessing TB treatment. One such approach would be to use outreach clinics especially in hard-to-reach areas. The other long-term plan would be to open community hospitals in hard-to-reach areas. All the patients that were on ART have been able to access their ART. The main reason is that there is consistent supply of ARVs in Malawi through the support from the Global Fund since 2004.

#### 4.2.3 Nutrition Support to TB patients

Undernutrition is an important risk factor for TB and TB causes undernutrition [21]. This bi-directional association leads to a high prevalence of undernutrition among people with TB. Proper TB treatment helps restore normal weight and nutrition. However, the time to full nutritional recovery can be long and many TB patients are still undernourished after TB treatment is completed [21]. Therefore, it is important to do a nutritional assessment at the time of TB diagnosis and provide nutritional care accordingly. To this end, WHO has issued guideline on nutritional care and support for people with TB [21]. An illustration of nutrition support to persons with TB is shown in

Figure 6.



Figure 6: Illustration of nutrition support being given to child diagnosed of TB

Source: https://www.who.int/tb/nutrition/en/

Despite the vital role nutrition has on TB treatment success, 12 (4%) of the 292 TB patients indicated having received nutrition support. Similarly, 4 (14%) of the 28 providers indicated that they received the nutrition support for TB patients. Furthermore, 96% of the providers indicated that they did not have enough supply of nutrition support for TB patients in the next month.

Findings from the qualitative interviews also indicated that nutrition supplies were provided to the patients however there was huge stock out levels. For example: -

"Nowadays the support on food supplements was phased out but when in stock we have a program known as adult nutrition and our TB patients benefit from this program." KII – HSA Chonde Community Hospital

and

"Only those that are admitted at the hospital are given soya porridge, beans and milk." IDI- Kapili, Nkhotakota

#### 4.2.4 Human Rights, Gender and TB-related Stigma

Globally men are significantly more at risk of contracting and dying from TB than women [22]. In 2017 close to 6 million adult men contracted TB and around 840,000 died from it. This compares with an estimated 3.2 million adult women who fell ill and almost half a million who died from TB. TB can

however have particularly severe consequences for women, especially during their reproductive years and during pregnancy. Maternal and child health services present a strategic entry point for increasing access to TB services, for both women and their families [22].

A total of 113 (46%) of the TB patients said that a hospital service charter was available at their health facilities. We note that the burden of TB is much higher in males than females and this is a sharp opposite of diseases like HIV/AIDS. A total of 132 of 292 TB patients have been denied some services as a result of disclosing their TB status. Of these; 14% were denied housing, 2% denied place of worship or marriage and 1% denied land ownership. The following patient charter was captured at one of the health facilities and it is available in English and Chichewa languages as shown in Figure 7.





The human rights and gender of the patients are reported in Table 7. While the majority of the patients were being treated with dignity by the providers, the least of the patients understand the National TB control policies. The human rights, gender and stigma situation was better for the males than the female patients.

Table 7: Human Rights and Gender issues reported by the TB patients in Malawi, 2020
---

	Femal		
Human right	Male	e	Total
Patients are treated with respect and dignity	96	95	96
The health information of patients is confidential and is not discussed with			
other people	81	86	83
Patients are educated on TB before beginning treatment	86	84	85
Patients are educated on what tests will be used to diagnose them and what		60	60
each	67	69	68
Patients are educated on what health services are available to them and how	75	70	72
Patients are educated on the treatment ontions for their TB including the	15	70	15
risks	69	69	69
Patients are given information on their rights for receiving testing and	0,5	0,2	0,7
treatment	74	72	73
Patients receive timely responses to reasonable requests for services and			
inform	74	70	72
Patients access to healthcare is not based on their gender	90	91	90
Patients access to healthcare is not based on their religious beliefs	93	93	93
Patients access to healthcare is not based on their political identity	92	91	92
Patients access to healthcare is not based on their marital status	96	95	95
Patients access to healthcare is not based on their citizenship	86	86	86
Patients access to healthcare is not based on their current health status	92	89	91
Patients access to healthcare is not based on their mental	95	89	92
Patients access to healthcare is not based on their race/ethnicity	94	92	93
Patients access to healthcare is not based on their income level	94	89	92
Patients access to healthcare is not based on their sexual orientation	92	89	90
Patients are given appropriate and professional quality testing and treatment	91	93	92
Patients are free from physical and mental abuse and/or neglect while			
seeking	84	83	84
Patients are given complete and current information concerning diagnosis,	-	-	-
treatment	70	70	70
Patients are not coerced or forced into taking TB treatment	85	79	82
TB patients are able to refuse treatment	60	62	61
Patients are able to freely review their records at their request	62	52	58
Patients are able to actively participate in decisions regarding medical care	62	55	59
Patients understand what TB is	67	66	66
Patients understand the policies of the NTP	18	22	20
Patients understand their treatment options and treatment options and	10	40	
alternatives, including the risk	49	42	46
Patients consent to all medical protocols and procedures	57	45	51
Patients understand the hospital service charter	44	39	42

It was reported by respondents that there was still greater level of non-acceptability of TB in the community as evidenced by continued high cases of stigma and discrimination. One key informant

pointed this out when he compared how communities perceive TB patients and health care workers and attributed the trend as a result of lack of information to the public on TB as in this quote:

"Because of lack of information there is stigma among the communities especially relatives they usually stigmatize the TB patients by avoiding eating together and doing other household activities with them. For us as the health workers we are treated well by the communities because they always expect us to provide them our services, and they consider us as their solution to their health problem" KII Malowa

We learnt that despite rising stigma and discrimination cases, efforts were being made through communitybased health workers to array fears of contracting TB from people that were on TB treatment. The quote illustrates this perspective:

"On discrimination, if people realize that a member of the community has diagnosed with TB, they do discriminate the patients, it only takes us the community volunteers to civic educate them not to discriminate TB patients. We tell them that when someone starts TB treatment there is no any risk of transmitting TB" IDI Kapili

Participants also highlighted efforts that were being undertaken on community sensitization being put in place to ensure confusion around covid-19 and TB was countered as in the following quote:

"Those suffering from TB are given messages that Covid-19 has great impact on those with weak bodies because of low immunity. Please follow precautionary measures you have learned at health facility like hand washing, observing social distance and also staying home".

In the opinion of some respondents, especially health workers, misunderstanding and misinterpretation of the patient rights as contained in the patient charter was contributing to poor quality of care. It was learnt that because the charter was in English, it was difficult for patients to appreciate their rights and responsibilities. Such participants recommended the need for translated patient charter into the vernacular language. The quote below illustrate:

"Community should be sensitized on patient charter. The charter needs to be interpreted into vernacular language so that the patients should well understand it" KII Malowa

Some respondents feared that continued misunderstanding and misinterpretation of the patient charter among both the patients and health workers was detrimental to provision of quality TB care in the country:

"The patient charter will be effective if the patients are informed about their rights because if the patients and health providers do not understand the patients charter this will obviously affect the implementation of the charter" KII Malowa

Interestingly, some community health volunteers mentioned that they were not knowledgeable of the patient charter. Volunteers are instrumental in the provision of community – based health care to TB patients. The quote illustrates:

"In short I would say I don't know much about it if you noticed In my previous explanation I didn't explain much because I really don't know it" IDI\_Milonde.

#### 4.2.5 Mistreatment because of TB

From the patient survey, we noted that 9% of the patients have not been treated fairly because they have TB. The major form of maltreatment was isolation from the family members while the least was abandonment by the loved ones.

	Member responsible for the maltreatment			
Maltreatment type	Family n=11	Friends n=11	Community n=12	Total n=34
Exclusion from public	18	18	17	18
Isolation from family	18	36	8	21
Lack caregiver	9	9	25	15
People avoid contact	27	9	17	18
Abandonment by loved	9	27	0	12
Intimidation/Name calling	18	0	33	18
Total	100	100	100	100

Table 8: Maltreatment reported by the TB patients in Malawi, 2020

#### 4.2.6 Impact of COVID-19 on TB services

The World Health Organization declared COVID-19 a global pandemic on 11 March 2020. Malawi registered the first case on 2 April 2020. From this survey, a total of 260 (92%) TB patients were aware of COVID-19. One hundred and thirteen (38%) have ever been screened for COVID-19. A total of 28 (10%) of the TB patients indicated that the TB services were disrupted due to COVID-19. A total of 7% of the 292 TB patients indicated that HIV services were disrupted due to COVID-19. Half of the TB patients indicated that HIV services were disrupted due to COVID-19. Half of the TB patients indicated that the the transformation of transformation of the transformation of the transformation of transformation of the transformation of the transformation of transfor

while 58% of the providers indicated that their hospitals had enough PPE for COVID-19. Below is an illustration of PPE usage at one of the health facilities visited.

### Figure 8: Illustration of persons in the masks in the era of COVID-19 at one of the health facilities, 2020



A total of 97% of the TB patients indicated that the health facilities have handwashing facilities and this is consistent with the providers who indicated that all health facilities had handwashing facilities. However, 40% of the TB patients stated that the handwashing facilities provided were not enough at these health facilities. Below is a sample of a handwashing facility at one of the health facilities visited.



Figure 9: Handwashing set-up equipment at one of the health facilities, 2020

Findings from qualitative investigations indicated that the TB and HIV patients were being given drugs over longer time periods than they should have been in the absence of COVID-19. This was being done by the facilities in order to minimise the likelihood of the patients to meet any potential cases and hence being infected by COVID-19 virus. There was knowledge of COVID-19 was found to be good among the respondents especially community health volunteers as one explained:

"Even a child knows about COVID 19, it is a disease which if don't wash your hands and touch your nose or eyes you are definitely going to contract it if you have touched something with the virus". IDI\_Kapili

However, some respondents in some districts narrated that COVID-19 had negatively impacted TB services because it was observed that most patients were not coming up for TB services citing the facilities were being overcrowded by COVID-19 patients. This is well illustrated in the quote below:

"COVID -19 has killed so many people. People are scared to go at the health facilities to provide sputum for TB testing because the facility is overcrowded" KII\_Malowa

Whereas in some districts especially in the Northern region, participants were of the view that COVID-19 had not disrupted TB services in any way as illustrated by this respondent:

Aaaaaah, there is nothing that has changed, TB programme is as fixed as it was. If anything, we just encourage these people to put on mask, in fact, its mandatory now..." KII\_Chirumba

Some respondents indicated that COVID-19 had brought in confusion as it was similar to TB. We get this perspective from the following:

"It has impacted so much and we are at risk because these two diseases (TB and Corona) seem to be similar. Sometimes we might think we are working with a TB patient not knowing what the person is harboring. IDI Milonde"

### 4.3 Community-based TB interventions in Malawi

There are several community interventions being implemented by the National TB Control Programme (NTP) and the implementing partners. The NTP operates and oversees a total of 1500 sputum collection points in various communities in Malawi [17]. Besides the NTP has a pool of the Community Volunteers, Health Surveillance Assistants (HSAs) and Community nurses that support the TB service implementation at community level. The services range from sputum collection to treatment follow-up in the communities for TB patients. Some NTP IPs, implement community-based TB interventions include DAPP, FACT, ECM, CHC, REACH Trust, Paradiso TB Patient Trust, World Vison and Action Aid. The specific community health sensitization sessions on TB, sputum collection and patient referrals, treatment support for TB patients, nutrition support through various strategies like procurement of food rations to improving the livelihoods of the households with TB patients through introduction of backyard gardens, spectrometry, and implementation research on TB.

Although at national level, there is a gender differences in the burden of TB in the population with the males being more at risk than the females [23], the programming of TB interventions do not explicitly include the assessment of human rights of the individuals. However, the programming by the NTP and the CSOs working on TB have involved the communities in identification of the needs through participation in the Grant Making Processes at National level. For example, DAPP, MANASO and Paradiso have been involved in the Global Fund (GF) Grant making process.

Community based monitoring of TB services was being conducted through a number of governance structures that were established at community level as demonstrated in this quote:

"...So, we report on the number of people that provided their sputum in the community.... We have structures such as VDCs, Support groups and CBOs which we share our reports with at community level. IDI Kapili

Additionally, monitoring of TB community-based interventions was being conducted within the partnership of health centre personnel, district health officers and community health volunteers as narrated in the quote that follows:

"In terms of monitoring we do together with our colleagues from the district at least once in a quarter. They provide us with fuel to go and supervise the sputum collection points on how they are performing their work and also, we have quarterly meetings with those sputum collection points volunteers. So, in terms of monitoring as well as supervision we are doing quite well, but in terms of reporting, we report to the district TB officer.KII\_Kaporo

The National TB Control Programme 2018 Annual report reports 19702 presumptive TB referrals from community outlets [17]. The yield among presumptive TB referrals has slightly improved. Quality of samples, proper follow up samples referred from community outlets are some of the key challenges in community TB intervention. A total 758 cases were contributed by community referrals and this contributed 4.8% of all notified TB cases in Malawi in 2018.



Figure 10: Trend in number of presumptive TB cases from community

#### Source: 2018 Annual TB Report, National TB Control Programme, Malawi

Trained community health volunteers performed door-to-door visits to screen all available household members in TB high risk areas for symptoms suggestive of TB (defined as any cough, unintentional weight loss, fever, night sweats), collect sputum and facilitate specimen transport to the laboratories. This intervention is being implemented in Nsanje, Balaka, Mulanje, Chiradzulu, Mangochi, Mwanza, Blantyre and Lilongwe. A total of 30 high burdened sites were identified for this exercise.

Year	Notified TB cases	% contribution
2016	288	1.7
2017	738	4.4
2018	758	4.8

#### Table 9: Contribution of community TB referrals to overall notified TB cases in Malawi, 2016-2018

Source: 2018 Annual TB Report, National TB Control Programme, Malawi

### 4.4 Monitoring and evaluation of community based TB interventions

Each of the health facility implementing TB interventions conducts some monitoring and evaluation. The quality of monitoring and evaluation being done is dependent on the leadership and availability of key staff in monitoring and evaluation. The monitoring and evaluation that is being done at facility level is governed by the National TB Control Programme (NTP). The NTP provides the data collection tools in the form of registers and laboratory forms. During every quarter, the facilities are visited for onsite supervision, data collection and mentorship. During each of the quarter, action points are made in order to improve the service being received by the TB patients. The quarterly data are entered in an Epi Info database developed by the NTP and later electronically uploaded in District Health Information System version 2 (DHIS2).

Besides the NTP tools, the different partners of NTP also have different additional data collection tools in addition to the standard tools provided by the NTP. The different data collection tools are as a result of different funding requirements. Therefore, different NTP partners working on community interventions have different indicators altogether.

### 4.5 Patient satisfaction with TB services

The patient survey found out that 97% of the TB patients were satisfied with the services that they received. Consistent with quantitative results, we found that the community members were appreciative of the services provided to them and they were satisfied:

"Some people in the community appreciate the work we are doing, they found it very helpful when we are collecting sputum in the community and deliver to the health facility on their behalf so the relationship is well with communities. For those have TB sometimes they are not well treated because people believe that they will spread the TB virus". IDI-Kapiri

# 5 Challenges in the Implementation of Coomunity TB interventions

Some of the challenges in the implementing of community TB interventions are:

- High workload for the HSAs and Community Nurses as well as the District TB Officers
- Data not being validated there by leading to misclassification of the TB cases. For example, a TB patient who is a walk in being classified as being referred from OPD. Besides, the patients being regarded as having TB yet they have other chronic airways diseases hence leading to poor

treatment outcomes as there is misdiagnosis. Interviews with the REACH Trust indicated that in one of their implementation research, the patients were misclassified as having TB yet they had TB. Treating someone for TB if they do not actually have TB may be a critical human rights violation and costly to both the patient and the NTP.

- Weaker social science research on leveraging community interventions in increasing access and availability of TB services to the communities.
- The lack of incentive scheme for volunteers lead to fatigue as the volunteers need to make ends meet and also support the TB patients
- The limited funding to support the community TB programmes
- Long turnaround time of sputum sample results from communities to laboratory and back to the presumptive TB patients
- Shortage of staff supporting the community interventions has seen the community interventions not being fully implemented after project expiration
- Poor documentation of data being collected at community level
- Community members not going for follow-up screening for TB
- Most of the data management is still paper-based making it difficult to quickly track the patents in the continuum of care at community and facility level
- Each IP is using their own data collection tools and therefore it becomes hard to consolidate such data
- Most of the TB programming do not consider life after TB. Life after TB is not as rosy as before TB treatment since the patient and their families will have lost some finances and property as part of expenses in treatment care and support.

### 6 Opportunities

There exist myriad opportunities for CBM of TB in Malawi:

- The Global Fund is now pushing for implementation of rights- and biomedical-based programming of TB interventions
- The NTP already has community health staff like the HSAs (providing mentoring and supervision to the volunteers), Community Volunteers and community Health Nurses.
- There exists reporting arrangement of the community TB data collected by the volunteers. These volunteers report to HSAs and the HSAs report to the DTOs who later report to the NTP.
- The availability of the community structures across several health facilities. Most of the NTP IPs, make use of these community structures: VHCs, VDCs, SHAGs, HCACs, etc.

### 7 Sustainability of the CBM

Some of the sustainability mechanisms of the CBM are:

- Coming up with the incentive mechanisms for the volunteers. This could be done through provision of lunch allowances and fuel
- The IPs should co-create projects and implement with the NTP
- Using of the community structures and CHWs like HSAs, CHN, DTOs, SHAGS, VDCs, etc

### 8 Conclusion and recommendations

In conclusion, most of the TB-related services are available to the communities in the selected districts. The Malawi NTP is implementing several TB interventions supported by the implementing partners. Although partners use different monitoring and evaluation tools, such tools feed to the national database for TB including community interventions. Most of the patients are aware of their human rights with respect to accessing the healthcare and services are provided in Malawi irrespective of gender bias. Irrespective of the impact of nutrition on the health status of the TB patients, there is limited integration of nutrition in TB programming in Malawi due to erratic supply of nutrition products. Almost all the patients that accessed TB services were satisfied with the services that they received. The community TB services make use of community health workers and most of these are overburdened with huge workload making the implementation of community interventions below expectation. Some of the recommendations in this CBM are:

- The integration of the human rights and gender are not explicitly spelt out in the programming of TB interventions in Malawi although the community interventions are explicitly spelt out.
- There is need to review the current community health structure as the very same people are being used for various community health interventions and this may make these people less efficient as they become overburdened with quite a lot of work
- The NTP should consider incorporating Social Marketing in TB programming through marketing of community-based TB interventions that have been shown to work by some IPs.
- There is need for organised way of data collection for CBM so that the same tools are used by all the IPs implementing the TB interventions.
- There is need for development of the electronic module in the DHIS2 for reporting community TB interventions for each health facility.
- To minimise misdiagnosis, there is need to consider introduction of spirometry in order to eliminate the COPD before diagnosis of TB
- There is need to civic-educate the patients on NTP policies as such policies have a direct impact on them as the immediate beneficiaries.
- There is need to civic-educate the communities especially the family members regarding maltreatment of the TB patients.
- In order to avoid using the very same volunteers and avoid discouraging some potentially active volunteers, there is need to apply participatory selection of volunteers. For example, in one project using community volunteers, the REACH Trust asked the HSAs, Chiefs and Community Volunteers. The names that were provided by all these (HSAs, Chiefs and Community Volunteers) were considered as volunteers and left out names that were not mentioned by more than one of the HSAs, Chiefs and Community Volunteers.

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# 10 Annex

# 10.1 Patient questionnaire Patient\_Questionnaire\_CBM 15June2020

Patient CBMF Questionnaire

# **Section 1: Basic Information**

### Enumerator

- 🔘 Enock Manda
  - Wanangwa Sichinga
- ) Ngale Mantchondo
- 🔵 Tambulani Harawa
- ) Beatrice Nindi

## District

- 🔵 Karonga
- () Nkhotakota
- 🔿 Zomba
- Mulanje

Name of facility from wher the patent gets TB treatment

Name of community health worker

**TB Treatment Card Number** 

Name of the patient

Age of

https://kf.kobotoolbox.org/#/forms/afZ49JieMUZXUcCdg7StrV/landing



) Female

(

# Highest education qualification

- None
- Primary
- Seconday
- Tertiary

# Marital status

- Never Married
- Married
- Separated
- Widowed
- Divorced

# What is your HIV status

- Positive
- Negative

) Unknown/Never tested

## On ART

Yes

# Main occupation

- Casual labour
  - Government employee- not in public health
- NGO employee
- 🔵 Miner
- Public Health Employee
- Self employeed
- Farmer

## Do you smoke

- 🔵 Yes
- No No

https://kf.kobotoolbox.org/#/forms/afZ49JieMUZXUcCdg7StrV/landing

I	Main source of fuel	
	◯ Firewood	
	Charcoal	
	C Electricity	
	Gas	
	Other	
	Other fuel source	

# Section 2: Physical Environmental

What services does your health facility provide?

	TB Diagnosis
	HIV Diagnosis
	Malaria Medications
	Patient Follow-up
	TB Medications
	HIV Medications
	Referrals to Hospital
	Nutritional Support
	Malaria Diagnosis
	Counseling
	Other
Specify	/ other services
Please	describe your living conditions (well-ventilated? Dirt floors? Roofing? Crowded?
	well-ventilated
	Dirt floors
	Dirty Roofing
	Crowded
How m	any individuals are living in your house?

How many rooms does your house have?

o mul	tiple people sleep in the same bed?
$\bigcirc$	Yes
$\bigcirc$	No
Secti	on 3: TB Cases
Please	check the corresponding box on whether the following statements are YES or
lave y	ou been tested for TB in the past one month?
$\bigcirc$	Yes
$\bigcirc$	No
ave y	ou been diagnosed with TB in the past 1 month?
$\bigcirc$	Yes
$\bigcirc$	No
ow w	ere you diagnosed with TB?
	Sputum Smear/Microscopy
	TB Culture
	X-Ray
	Clinical diagnosis
	Gene XPert
re yoເ	a currently on TB treatment?
$\bigcirc$	Yes
$\bigcirc$	No
/ere y	ou diagnosed with TB before starting TB treatment?
$\bigcirc$	Yes
$\bigcirc$	No
ave y	ou been tested for HIV in the past 1 month?
	Yes

	Yes
	No
re you	a currently on HIV treatment?
	Yes
	No
/ere y	ou diagnosed before starting HIV treatment?
	Yes
	No
ave ye	No ou been tested for malaria in the past 1 month
ave y	No <b>ou been tested for malaria in the past 1 month</b> Yes
ave yo	No <b>ou been tested for malaria in the past 1 month</b> Yes No
ave yo	No ou been tested for malaria in the past 1 month Yes No ou been diagnosed with malaria in the past 1 me
ave ye	No ou been tested for malaria in the past 1 month Yes No ou been diagnosed with malaria in the past 1 mo
ave yo	No ou been tested for malaria in the past 1 month Yes No ou been diagnosed with malaria in the past 1 mo Yes No
ave you	No ou been tested for malaria in the past 1 month Yes No ou been diagnosed with malaria in the past 1 mo Yes No u currently on malaria medications?
ave you	No ou been tested for malaria in the past 1 month Yes No Yes No Yes Yes Yes Yes

# Section 4: Drugs

# Where do you receive your TB drug supply?

District hospital



- Central Hospital
- Health Center
- Health Post
  - ) Other

Specify other places

Did the dector evolution to you shout the TP drugs that you are surrently taking?							
Did the doctor explain to you about the TB drugs that you are currently taking?							
What TB drugs are you currently taking?							
Ethambutol							
Isoniazid							
Rifampacin + Isoniazid + Pyrazinamide							
Capreomycin							
Kanamycin							
Rifampacin + Izoniazid							
Amikacin							
Rifampacin + Izoniazid + Pyrazinamide + Ethambutol							
Clofazimine							
Ethionamide							
P-aminosalicylate sodium salt							
Cycloserine							
Linezolid							
Levofloxacin							
Moxifloxacin							
Protionamide							
Pyridoxine							
Pyrazinamide							
Delamanid							
Other							
Specify other TB drugs							
How do you receive your treatment?							
Orally (pill)							
Injected (with needle)							
Have you ever been told by doctors that your TB treatment has failed?							
Yes							
ttps://kf.kobetoolbox.org/#/forms/afZ49JieMUZXUcCdg7StrV/landing							

6/36

Have you ever been told by doctors about potential side effects from your TB treatment?						
$\bigcirc$	Yes					
$\bigcirc$	No					
Have y	ou ever experienced side effects from your TB treatment	:?				
$\bigcirc$	Yes					
$\bigcirc$	No					
Have y	ou ever been refered to a Dictrict or Central Hospital for	TB care?				
$\bigcirc$	Yes					
$\bigcirc$	No					
lf you l	nave experienced side effects, which ones have vou had?					
	Nausea					
	Vomiting					
	Fever					
	Rash/Itchiness					
	Fatigue					
	Bloody nose					
	Dizziness					
	Bruising					
	Yellow Skin/Eyes					
	Pain in Abdomen					
	Dark/Brown Urine					
	None					
	Tingling/Burning/Numbness in hands and feet					
	Other					
Specify	v other side-effects					

ļ	Have th	ese side	effects eve	er discouraged	you from	taking your	TB	medecines?

	Yes
What a	No action did you take after experiencing these side-effects?
	Seek care at TB clinic
	Explained to HAS
	Explained to Community Volunteer or Nurse
	Stopped taking drugs
	Did nothing
	Continued TB drugs
Have y	ou been UNABLE to receive your TB drugs in the past mo

# nth?

$\bigcirc$	Yes								
$\bigcirc$	No								
Have y	ou ever shared the TB drugs with your friends?								
$\bigcirc$	Yes								
$\bigcirc$	No								
Have y	Have you heard any of your friends sharing the TB drugs in the community?								
$\bigcirc$	Yes								
$\bigcirc$	No								
lf yes,	what was the reason for NOT being able to receive them?								
	Distance								
	Cost								
	Fear/Stigma								
	Drug Stock Out								
	Food/water fetching								
	Other								
Specify other reasons for not accessing treatment									

If you selected drug stock out, what drugs that you have taken have been stocked out and how many times- maximum of 4?

		E(	(100)	– Ethambutol 100 mg
			$\bigcirc$	Ethambutol
)	z na	(	$\bigcirc$	Isoniazid
			$\bigcirc$	Rifampacin + Isoniazid + Pyra i amide
			$\bigcirc$	Capreomycin
			$\bigcirc$	Kanamycin
			$\bigcirc$	Rifampacin + Izoniazid
			$\bigcirc$	Amikacin
			$\bigcirc$	Rifampacin + Izoniazid + Pyrazinamide + Ethambutol
			$\bigcirc$	Clofazimine
			$\bigcirc$	Ethionamide
			$\bigcirc$	P-aminosalicylate sodium salt
			$\bigcirc$	Cycloserine
			$\bigcirc$	Linezolid
			$\bigcirc$	Levofloxacin
			$\bigcirc$	Moxifloxacin
			$\bigcirc$	Protionamide
			$\bigcirc$	Pyridoxine
			$\bigcirc$	Pyrazinamide
			$\bigcirc$	Delamanid
			$\bigcirc$	Other
		N	umbe	er of times stocked out in last month

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			$\bigcirc$	Ethambutol
)	ΖNέ	C	$\bigcirc$	Isoniazid
			$\bigcirc$	Rifampacin + Ison azid + P razinamide
			$\bigcirc$	Capreomycin
			$\bigcirc$	Kanamycin
			$\bigcirc$	Rifampacin + Izoniazid
			$\bigcirc$	Amikacin
			$\bigcirc$	Rifampacin + Izoniazid + Pyrazinamide + Ethambutol
			$\bigcirc$	Clofazimine
			$\bigcirc$	Ethionamide
			$\bigcirc$	P-aminosalicylate sodium salt
			$\bigcirc$	Cycloserine
			$\bigcirc$	Linezolid
			$\bigcirc$	Levofloxacin
			$\bigcirc$	Moxifloxacin
			$\bigcirc$	Protionamide
			$\bigcirc$	Pyridoxine
			$\bigcirc$	Pyrazinamide
			$\bigcirc$	Delamanid
			$\bigcirc$	Other
		Ν	lumbe	er of times stocked out in last month

ć

- 12	п.	

|--|

			Ethambutol
<b>'</b> Z	z na	C	O Isoniazid
			🔘 Rifampacin + Isoniazid + Pyra i amide
			Capreomycin
			Kanamycin
			🔘 Rifampacin + Izoniazid
			O Amikacin
			Rifampacin + Izoniazid + Pyrazinamide + Ethambutol
			Clofazimine
			C Ethionamide
			O P-aminosalicylate sodium salt
			O Cycloserine
			C Linezolid
			C Levofloxacin
			Moxifloxacin
			O Protionamide
			O Pyridoxine
			O Pyrazinamide
			O Delamanid
			O Other
		N	umber of times stocked out in last month

I

Z	E (150/75/400/275)
(	) Ethambuto
l oniazid + Pyrazinamide	Isoniazid
(	Rifampacin + so
(	Capreomycin
(	Kanamycin
(	Rifampacin + Izoniazid
(	Amikacin
(	Rifampacin + Izoniazid + Pyrazinamide + Ethambutol
(	Clofazimine
(	Ethionamide
(	P-aminosalicylate sodium salt
(	Cycloserine
(	Linezolid
(	Levofloxacin
(	Moxifloxacin
(	Protionamide
(	) Pyridoxine
(	) Pyrazinamide
(	Delamanid
(	Other
Nur	nber of times stocked out in last month

I.

I

Iso	iazid 300 mg
(	Ethambuto
oniazid + Pyrazinamide (	Isoniazid
(	Rifampacin + so
(	Capreomycin
(	Kanamycin
(	Rifampacin + Izoniazid
(	Amikacin
(	Rifampacin + Izoniazid + Pyrazinamide + Ethambutol
(	Clofazimine
(	Ethionamide
(	P-aminosalicylate sodium salt
(	Cycloserine
(	Linezolid
(	Levofloxacin
(	Moxifloxacin
(	Protionamide
(	) Pyridoxine
(	) Pyrazinamide
(	Delamanid
(	Other
Nu	nber of times stocked out in last month

I

Strepto		omycin
	$\bigcirc$	Ethambuto
l pniazid + Pyrazinamide	$\bigcirc$	Isoniazid
	$\bigcirc$	Rifampacin + so
	$\bigcirc$	Capreomycin
	$\bigcirc$	Kanamycin
	$\bigcirc$	Rifampacin + Izoniazid
	$\bigcirc$	Amikacin
	$\bigcirc$	Rifampacin + Izoniazid + Pyrazinamide + Ethambutol
	$\bigcirc$	Clofazimine
	$\bigcirc$	Ethionamide
	$\bigcirc$	P-aminosalicylate sodium salt
	$\bigcirc$	Cycloserine
	$\bigcirc$	Linezolid
	$\bigcirc$	Levofloxacin
	$\bigcirc$	Moxifloxacin
	$\bigcirc$	Protionamide
	$\bigcirc$	Pyridoxine
	$\bigcirc$	Pyrazinamide
	$\bigcirc$	Delamanid
	$\bigcirc$	Other
N	lumbe	er of times stocked out in last month

Where do you receive your HIV drug supply?

TB Clinic
HIV clinic
ANC
PNC
Community Testing
Moonlight Testing
VMMC
Other

#### Specify other places

What HIV drugs are you currently taking?

ARVs
IPT/INH
СРТ
Other

Specify other drugs

Have you been UNABLE to receive your HIV drugs in the past month?

Yes

No No

If yes, what was the reason for NOT being able to receive them?

Distance
Cost
Fear/Stigma
Drug Stock Out
Food/water fetching
Other

Specify other reasons for not accessing treatment

http://www.wooden.org////ormo/are-reasonace/coodag.or//whatamag-

If you selected drug stock out, what drugs that you have taken have been stocked out and how many times?

### Drug out of stcok (1)



Number of times out of stock (1)

### Drug out of stcok (2)

- () ARVs
- () IPT/INH
- CPT
- O Other

Number of times out of stock (2)

### Drug out of stcok (Otherspecify)

- () ARVs
- () IPT/INH
- C CPT
- ) Other

Number of times out of stock (OtherSpecify)

Have drug stock outs discouraged you from seeking TB and/or TB/HIV services?

$\bigcirc$	Yes
$\bigcirc$	No

# **Section 5: Nutritional Supports**

Have you received nutritional food supply from the DOT center?

Yes
No If yes, did you receive food supply from the DOT center this month?
Yes
No
If yes, what food items were you supplied with this month?

Date	sup	plied
------	-----	-------

yyyy-mm-dd

Name of Food supplied (1)

Quantity of food

Name of Food supplied (2)

Quantity of food

Name of Food supplied (3)

**Quantity of food** 

Name of Food supplied (4)

**Quantity of food** 

How often do you receive nutritional support from your DOT center?
Daily
Weekly
Monthly
Quarterly
Annually
Do you believe the supplied food is enough?
Yes
No

# Section 6: Access and Availability of Services

Are you aware of any DOT facilities in your community?

Yes

How far is your house/village to the facility where you receive treatment?

How long does it take to travel to the facility where you receive treatment? *Time in minutes* 

What mode of transportation do you use to travel to the facility?

	Walk
	Bike
	Motorbike
	Car
	Hospital ambulance
	Other
Cuasifu	
specity	other transport modes

### How many times do you come to collect your TB and/or HIV drugs at the facility?



#### How much do you pay from your house to the facility to take your treatment or drug?

In Malawi Kwacha for both trips (going and coming)

How long do you wait at the health facility to see a physician or nurse?

How long do you wait at the health facility to receive treatment?

If yes, how many tablets do you take per day/week/month (answer as many as you can)



#### How often do you pay

- everytime
- sometimes
- rarely

### Do you receive worse care if you don't pay

- Yes
  - No

#### When going for TB test



- When going for TB test
- When diagnosed with TB
- When picking up medicine/ treatments
- When 2nd TB test performed
  - When 3rd TB test performed

#### How much do you pay in Kwacha

#### How often do you pay

- everytime
- sometimes
  - rarely

#### Do you receive worse care if you don't pay

- Yes
- ) No

#### When diagnosed with TB

- Doctor Referral Appointment
- When going for TB test
- When diagnosed with TB
- When picking up medicine/ treatments
- When 2nd TB test performed
- When 3rd TB test performed

#### https://kf.kobotoolbox.org/#/forms/afZ49JieMUZXUcCdg7StrV/landing

How much do you pay in Kwacha

How of	ften do you pay
	everytime
	sometimes
	rarely
Do you	receive worse care if you don't pay
	Yes
	No
When	picking up medicine/treatments
	Doctor Referral Appointment
	When going for TB test
	When diagnosed with TB
	When nicking up modicing/ treatment

- When picking up medicine/ treatments
- When 2nd TB test performed
- When 3rd TB test performed

# How much do you pay in Kwacha

# How often do you pay

- everytime
- sometimes
- rarely

### When 2nd TB test performed

- Yes
- No

#### **Doctor Referral Appointment**

- Doctor Referral Appointment
- When going for TB test
- When diagnosed with TB
- When picking up medicine/ treatments
- When 2nd TB test performed
- When 3rd TB test performed

### How much do you pay in Kwacha

#### How often do you pay

- everytime
- sometimes
- rarely

#### When 3rd TB test performed

- Yes
- No No

#### **Doctor Referral Appointment**

- Doctor Referral Appointment
- When going for TB test
- When diagnosed with TB
- When picking up medicine/ treatments
- When 2nd TB test performed
- When 3rd TB test performed

## How much do you pay in Kwacha

#### How often do you pay

- everytime
- sometimes
- rarely

Do you	receive	worse	care	if you	don't	рау
	Yes					
	No					

#### What sources do you get your information on TB from?

Radio	
Internet	
Television	
Newspaper	
Government Heath Worker	
NGO Heath Worker	
HSA	
Community volunteer	
Friend/Relatives	
Other	

#### Specify other information sources

### Do you trust your TB service providers (physicians, nurses, etc)?

)	Yes
_	

) No

### Why or why not?

Do you trust government community health workers?

$\bigcirc$	Yes
$\sim$	

	$\left( \right)$	$\mathbf{)}$	No
--	------------------	--------------	----

Why or why not?

# Section 7: Human Rights, Gender, and Stigma

	Housing
	Place of Worship
	Marriage
	Employment
	Insurance
	Microfinance
	Travel
	Land Ownership
	Education
	Government Services
	Medical Services for non-TB illnesses
	Other
Currif	
specity	y other

# Have you ever been denied services, received worse servicesor discriminated against in any way?

# Have you ever disclosed your TB status to anyone?

$\bigcirc$	Yes
$\bigcirc$	No

Were you denied any services as a result of disclosing your TB status?

	Housing		
	Place of Worship		
	Marriage		
	Employment		
	Insurance		
	Microfinance		
	Travel		
	Land Ownership		
	Education		
	Government Services		
	Medical Services for non-TB illnesses		
	Other		
Snecif	vother		
lobecity office			

# Has anyone disclosed their TB status to you?

Yes

### Are TB patients treated unfairly in your community?



If YES, how are they mistreated?

#### Exclusion from public or family function

- Exclusion from public or family functions
- Isolation from family members and friends
- Lack caregiver
- People avoid contact
- Abandonment by loved ones
- Intimidation/Name-Calling

#### which member mistreates

- Family
- Friends
- Community

#### Isolation from family members and friends

- Exclusion from public or family functions
- Isolation from family members and friends
- Lack caregiver
- People avoid contact
- Abandonment by loved ones
  - Intimidation/Name-Calling

#### which member mistreates

- Family
- Friends
- Community

### Lack of care giver

- Exclusion from public or family functions
- Isolation from family members and friends
- Lack caregiver
- People avoid contact
- Abandonment by loved ones
- Intimidation/Name-Calling

#### which member mistreates

- Family
- Friends
- Community

### People avoid contact

- Exclusion from public or family functions
- Isolation from family members and friends
- Lack caregiver
- People avoid contact
- Abandonment by loved ones
- Intimidation/Name-Calling

#### which member mistreates

- Family
- Friends
- Community

### Abandonment by loved ones

- Exclusion from public or family functions
- Isolation from family members and friends
- Lack caregiver
- People avoid contact
- Abandonment by loved ones
- Intimidation/Name-Calling

#### which member mistreates

- 📄 Family
- Friends
- Community

### Intimidation/Name-Calling

- Exclusion from public or family functions
- Isolation from family members and friends
- Lack caregiver
- People avoid contact
- Abandonment by loved ones
- Intimidation/Name-Calling

#### which member mistreates

- Family
- Friends
- Community

### Exclusion from public or family functions

- By Family Members
- By Friends
- By Community

#### Isolation from family members and friends

- By Family Members
- By Friends
- By Community

### Lack caregiver

- By Family Members
- By Friends
- By Community

### People avoid contact

- By Family Members
- By Friends

By Community

https://ĸt.kopotoolpox.org/#/torms/afZ49JieMUZXUcCdg7StrV/landing

Abandonment by loved ones	
By Family Members	
By Friends	
By Community	
Intimidation/Name-Calling	
By Family Members	
By Friends	
By Community	
If you have to pay for TB serv	rices, are you informed of the actual amount of charges that you are liable for?
Yes	
No	

Do you have access to all bills for services, regardless of how you paid?

	Yes
	No

Section 8: Patient Rights

Please tell us on a 5-point scale how much you agree or disagree to each of the following statements, where a "1"

### Patients are treated with respect and dignity

$\bigcirc$	Strongly disagree
$\bigcirc$	Disagree
$\bigcirc$	Neutral
$\bigcirc$	Agree
$\bigcirc$	Strongly agree

The health information of patients is confidential and is not discussed with others without the patient's consent



Pati n	ts e
Q	St are educat d on TB before beginning treatment
	rongly disagree
$\bigcirc$	Disagree
$\bigcirc$	Neutral
$\bigcirc$	Agree
$\bigcirc$	Strongly agree

Patients are educated on what tests will be used to diagnose them and what each test diagnoses

- Strongly disagreeDisagree
- Neutral
- 🔵 Agree
- Strongly agree

Patients are educated on what health services are available to them and how to access these services

- Strongly disagree
- Disagree
- O Neutral
- () Agree
- Strongly agree

Patients are educated on the treatment options for their TB, including the risks and benefits associated with each option

- () Strongly disagree
- () Disagree
- () Neutral
- Agree
- () Strongly agree

Patients are given information on their rights for receiving testing and treatment services

Strongly disagree
 Disagree
 Neutral
 Agree
 Strongly agree

# Patints c t e s

Ston dige
# Patints c t e s

Ston di ge

# Patients c t s

Ston di ge

# 10.2 Provider questionnaire Provider\_Questionnaire\_CBM 15June2020

Patient CBMF Questionnaire

# Gender for

(

O Male

) Female

# Medical Training



Secondary

Diploma

O Degree

Masters

O PhD

#### Years of service

Number of times gloves stocked out in last

Gloves available

#### Sputum Collection Cups

🔵 Yes

) No

Number of times Sputum cups stocked out in last

Sputum collection Cups available

**Microscope Slides** 

🔵 Yes

) No

Number of times slides stocked out in last

Slides available

**Protective Masks** 

🔵 Yes

) No

Number of times masks stocked out in last

Protective Masks available

### Syringes

$\bigcirc$	Yes
$\frown$	

() No

Number of times syringes stocked out in last

Syringes available

IV Bags

YesNo

Number of times IV bags stocked out in last

IV Bags available

Medical Bandages/Dressings

🔵 Yes

) No

Number of times bandages stocked out in last

Medical Bandanges available

#### Patient Beds

Yes

Number of times beds stocked out in last

**Patient Beds available** 

#### Thermometers

Yes

Number of times thermometers stocked out in last

Thermometers available

#### Stethoscopes

) Yes

) No

Number of times stethoscopes stocked out in last

Stethoscopes available

#### Disinfectant

'es

) No

Number of times disinfectants stocked out in last

**Disinfectant available** 

### **Other supplies**

Yes

() No

Lab Technicians on duty at any time?

Nurses on duty at any time?

Physicians on duty at any time?

TB Microspistst on duty at any time?

How many hours per day is your facility open to patients?

\_\_\_\_

\_

How many of these are males

How many of these are children (aged below 15 years)

How many of these are males

How many of these are children (aged below 15 years)

\_

Number of times stocked out in last month

How many TB patients are you currently supplying nutritional support to?

# Exclusion from functions or workplace

- By Family Members
- By Friends
- By Community
- Other health workers

### Isolation

- By Family Members
- By Friends
- By Community
- Other health workers

#### Lack caregiver

- By Family Members
- By Friends
- By Community

Other health workers

### People avoid contact

- By Family Members
- By Friends
- By Community
- Other health workers

#### Abandonment by loved ones

- By Family Members
- By Friends
- By Community
- Other health workers

### Intimidation/Name-Calling

- By Family Members
- By Friends
- By Community
- Other health workers

#### Do patients have to pay for any services at your facility?

- ) Yes
- ) No

If you have to pay for TB services, are you informed of the actual amount of charges that you are liable for?

- Yes
- No No

#### Do you have access to all bills for services, regardless of how you paid?

- Yes
  - No

#### Exclusion from functions or workplace

- By Family Members
- By Friends
- By Community
  - Other health workers

### Isolation

- By Family Members
- By Friends
- By Community
- Other health workers

## Lack caregiver



- By Friends
- By Community
- Other health workers

## People avoid contact

- By Family Members
- By Friends
- By Community
- Other health workers

## Abandonment by loved ones

- By Family Members
- By Friends
- By Community
- Other health workers
#### Patients



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Patients	с	t	e	s	t
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() N	t				
O Ag	ĵ				

Patients	с	t	е	s	t	
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() N	t					
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O Ag	ç				

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How many of these have been diagosed of COVID19?

# 10.3 Key informant interview guide

**District:** 

**Facility Name:** 

#### **Respondent Name:**

#### **Position:**

# **GENERAL CBM**

- 1. What community TB or Lung health interventions do you implement?
- 2. What are the monitoring, evaluation and reporting processes put in place
- 3. What challenges faced in implementing the community interventions
- 4. What are the things NTP needs to strengthen in implementing CBM?
- 5. Do you have any other comments relevant to CBM?

### HUMAN AND GENDER RIGHTS

- 6. How are people with TB/ those working with TB patients perceived in society?
- 7. What are perceptions of the effectiveness of existing programs combating stigma and discrimination?

### **PATIENT CHARTER**

- 8. What can you say about the patient charter?
- 9. What are the enablers and barriers to the implementation of patient's charter?
- 10. What are your suggestions to improve the implementation of the charter? **COVID-19 Information**
- 11. What do you know about COVID-19?
- 12. What can you say about the impact of COVID-19 on TB services?
- 13. What kind of sensitization is there on COVID-19 preventative measures?
- 14. What can you say regarding screening about COVID 19?

# 10.4 In-depth interview guide

#### **District:**

**Facility Name:** 

**Respondent Name:** 

**Position:** 

### **GENERAL CBM**

1. What community TB interventions do you implement?

- 2. Are you aware of any structures in your community that can facilitated monitoring and accountability of the TB program?
- 3. Do the TB patients receive nutritional support? Is there any other support being provided to the TB patients?
- 4. Would you say TB patients are denied services, receive worse services or discriminated against in other ways?
- 5. Are you updated on the various programs that take place within your community?
- 6. What is the reporting arrangement for various community interventions within your community?

# HUMAN RIGHTS AND GENDER

- 7. How are people with TB/those working with TB patients perceived in society?
- 8. What are your perceptions of the effectiveness of existing programs combating stigma and discrimination?

# PATIENT CHARTER

9. Can you share more light on the service charter?

# COVID 19

- 10. What do you know about COVID-19?
- 11. What can you say about the impact of COVID 19 on TB services?
- 12. What kind of sensitization is there on COVID 19 preventive measures?