

NORAD COLLECTED REVIEWS

3/2024

# FILLING THE GAP FINALLY ADDRESSING POST-TB DISABILITIES IN SUB SAHARAN AFRICA (MALAWI, TANZANIA, SUDAN)

-

The report is presented in a series, compiled by Norad to disseminate and share analyses of development cooperation. The views and interpretations are those of the authors and do not necessarily represent those of the Norwegian Agency for Development Cooperation.

End Review KNCV

**Norad** 





Norad

# FILLING THE GAP FINALLY ADDRESSING POST-TB DISABILITIES IN SUB SAHARAN AFRICA (MALAWI, TANZANIA, SUDAN)

Cover Photo: Ken Opprann

ISBN: 978-82-8369-193-1

ISSN: 1894-518x

Published: 23.01.2024

# "Filling the gap - finally addressing post-TB disabilities in Sub Saharan Africa" (Malawi, Tanzania and Sudan)



Evaluation for LHL International (ref: 0.4.5.3 / 06/22)

June 2023



# Acknowledgements

We would like to acknowledge the excellent collaboration with all the in-country implementation partners. In Malawi, Bruce Matewere, executive director and project coordinator, Paradiso; in Tanzania, Willy Mbawala, executive director MKUTA and Florence Jared, project coordinator Kibong'oto hospital; in Sudan, Hanadi Hussein, general manager HDP.

Equally so, we thank the NTPs, district health authorities and health facility staff for their openness and rich narratives.

We received all necessary background information and had productive discussions with LHL International staff: Mona Drage, director LHL International (LHLI), Berthe Stenberg, project coordinator LHLI for Malawi, Hedvig Fiske Amdal, project coordinator LHLI for Tanzania (MKUTA), Laila Løchting, project coordinator LHLI for Tanzania (Kibong'oto), Knut Sundby, project coordinator LHLI for Sudan.

At field level, the evaluation was carried out by Emmanuel Kaonga (Malawi), Lillian Mtei (Tanzania) and Muaz Hassan (Sudan).

# **Executive summary**

The project "Filling the gap – finally addressing post-TB disabilities in Sub Saharan Africa" in Malawi, Tanzania and Sudan is an interesting project addressing an issue that has long been neglected by TB programs around the world.

To give an idea of the size of this problem, it has been estimated that the number of tuberculosis survivors in 2020 is more than ten times the estimated annual tuberculosis incidence (Dodd et al., 2021). Globally, an estimated 155 million TB survivors were still alive in 2020 (47% in South-East Asia). Of them, 18% is estimated to have been treated in the last five years and 8% in the last 2 years. For the African region, it is estimated that 25.7 million TB survivors are still alive in 2020.

The project concerns activities to improve the quality of life of persons with Post TB Lung Disease (PTLD) and mental health issues related to TB. This was done through lung rehabilitation, addressing health problems after TB treatment other than PTLD, joining TB clubs, home visits, counseling, and nutritional support. The project also addressed mental health issues. It took place from 2019 to 2022, with a no-cost extension to mid-2023.

The current evaluation follows the criteria set by the Norwegian Agency for Development Cooperation (Norad) that are used to assess the effectiveness of development programs and projects (OECD, 2010). The report is structured along the lines of the main interventions, looking at each country. These main interventions are then evaluated using the OECD-DAC criteria.

The methodology included the design of an evaluation matrix, desk reviews, interviews and focus group discussions, and the data thus generated were analyzed and synthesized.

Following a desk review of available literature, some background information is provided for each country. Overall, there is a paucity of data, with only a few articles written about post-TB disabilities in sub-Saharan Africa. This is presented in the main text.

The project had six main interventions, each of which is referred to in the paragraphs below.

Concerning the identification of people with post TB disabilities, including post TB lung disease and mental health, and mapping the scope of health problems among former TB patients and how it affects their lives (**approach 1**), the following was found.

In Malawi, the lung rehabilitation (LR) program was successful in addressing the needs of former tuberculosis (TB) patients. An app was developed to assist in data collection and support volunteers in their work, which included symptom screening, treatment adherence, and socio-economic support. After TB treatment, out of 1750 former TB patients, 70.4% experienced health problems, with lung issues being the most common. These health problems had a significant impact on daily life, income, and social interactions.

The KIDH research project in Tanzania aimed to identify individuals with post-TB lung disease (PTLD) and assess the feasibility and effectiveness of a community based pulmonary rehabilitation program. Community-based volunteers (MKUTA members) played a crucial role in identifying people with post-TB lung disease (PTLD) and post-TB disabilities (PTBD), the latter covering other TB sequelae and mental health issues. In total 625 ex-patients with remaining lung complaints were screened for PTLD, of which 11% didn't have PTLD, and a surprising 24% had recurrent TB. 419 persons were

identified with PTLD, of whom 121 underwent community-based lung rehabilitation. Limitations in access to confirmatory steps such as chest x-rays (CXR) and other investigations were taken care of by the project. The project faced delays caused by the COVID-19 pandemic. Despite these challenges, the project successfully identified numerous individuals with PTLD and witnessed their significant improvement over time.

The project in Sudan focused on PTLD, mental well-being, and Income Generation Activities (IGA), while increasing TB awareness and family involvement. The TB program collaborated with other ministries and trained health workers to identify and support individuals with TB disabilities. 760 former TB patients were assessed, with 302 participating in the PTLD program. The identification of people with PTLD was unaffected by COVID-19.

The overall assessment of the OECD-DAC criteria ranges from "good" to "excellent".

The top recommendation for this approach is the following:

Conduct or assist country-level surveys to establish an estimate of the number of people with PTLD, as the basis for national planning and preparing adequate resources to address PTLD. Alongside, a system for long term follow-up of the people who underwent lung rehabilitation should be established to get a better view on the long-term impact (Sudan)(Tanzania)(Malawi)

Concerning the **2**<sup>nd</sup> **approach**, collaboration between local health system and community-based organizations, the following was found.

In Malawi, there were mixed levels of success of collaboration, but overall the project has made significant progress, establishing collaboration between volunteers and health facility staff and bringing affected individuals back to normal functioning. Challenges included limited nutrition support in some areas and limited collaboration with other CSOs, impacting long-term benefits. Suggestions were made to connect with nutrition programs supported by Save the Children and the World Food Program. Capacity building and training were conducted for community leaders and volunteers, and efforts were made to include PTLD care in the TB management pathway.

In Tanzania, the collaboration between local health bodies and MKUTA has expanded to include the identification of people with PTLD and the implementation of lung rehabilitation. The partnership has been beneficial, but volunteers need incentives like transport and communication support. A proposal has been made to establish lung rehabilitation exercises within hospitals as well. Inclusive Health Communication training has helped MKUTA volunteers identify disabilities, with the limitation that local health authorities lack programs for these individuals. However, this presents an opportunity for future collaboration. The COVID-19 pandemic had a temporary impact on TB services, but activities are now running normally. Discussions are underway to form more PTLD clubs and institutionalize community health workers.

In Sudan, successful collaboration between local health authorities, health center workers, and volunteers has led to effective coordination through monthly meetings. The intervention focusing on health promotion for former TB patients has been well-received. Training has improved the identification of TB-related disabilities, and activities remained consistent during and after the pandemic. Ramadan initiatives and collaborations with the Sudanese Disability Union were undertaken, providing support and training for TB-affected individuals. Health communication training enhanced the relationship between medical staff and persons with PTLD/PTBD.

The overall assessment of the OECD-DAC criteria ranges from "good" to "excellent". Sustainability is felt to be a potential problem, due to budget limitations at district levels.

The top recommendation for this approach is the following:

Continue to engage community volunteers, in collaboration with the local health system, for PTBD and lung rehabilitation as they know the clients better and can follow them up easily. (Sudan)(Tanzania)(Malawi)

Concerning the **3<sup>rd</sup> approach**, the Development and implementation of a local and volunteer-based lung rehabilitation, the following was found.

In Malawi, the Pulmonary Rehabilitation Program (PRP) has been implemented successfully in nine health facilities. Trained personnel, including Health Surveillance Assistants (HSAs) and volunteers, run the program, providing lung rehabilitation exercises to individuals with lung problems post-TB. The number of persons included in the PRP was 467 in 2021- 2022. The program has shown better outcomes with a 12-week program compared to a 6-week program. Volunteers are involved in various TB-related activities and have taken ownership of the program. Despite budgetary impacts and training adjustments, the program has utilized local resources and built capacity among staff. Overall, the PRP has effectively utilized local resources, built capacity, and improved the lives of those affected by TB in Malawi.

In Tanzania, the National Tuberculosis Program (NTP) plans to conduct a survey to assess the extent of post-TB lung disabilities (PTLD). Volunteers, including MKUTA volunteers, have been engaged in various TB and HIV activities and are now involved in lung rehabilitation activities. Two successful lung rehabilitation centers have been established using minimal resources, but sustainability after funding ends is a concern. The use of community fields for exercise and advocating for exercise as a policy in TB care are suggested. Mining companies could also create exercise fields for miners who require lung rehabilitation.

In Sudan, health workers and doctors have received training in detecting and managing TB-related disabilities. Currently, 85 individuals, including staff and volunteers, are involved in a lung rehabilitation program for persons with PTLD. Volunteers also participate in other activities such as for COVID-19. Lung rehabilitation exercises are provided at treatment centers, and through medical staff supporting people at home. Transportation challenges and part-time volunteer involvement raise sustainability concerns. However, potential funding from a national organization may be available.

The overall assessment of the OECD-DAC criteria ranges from "good" to "excellent".

The top recommendation for this approach is the following:

Utilize the upcoming experience in Temeke district (urban high burden TB district, different conditions than Siha and Mirerani) to prepare a care package suitable for Tanzania conditions and other low-resource settings (Tanzania) Develop guidance and a simple booklet in local languages, as was done in the "PRP step-by-step" booklet in Malawi, to guide community health workers and other partners with establishing additional lung rehabilitation centres (Sudan)(Tanzania)(Malawi)

Concerning the **4**<sup>th</sup> **approach**, Social and medical support to people with post TB disabilities, the following was found.

Paradiso and NONM in Malawi collaborate to support individuals affected by tuberculosis (TB) through medical assessments, referrals, nutrition assistance, home visits, and financial support via TB clubs. Vocational skill development and income-generating activities were discontinued due to financial constraints. Paradiso recommends integrating care for post-TB disabilities into the TB management pathway, capacity building for health workers, and expanding the intervention. Challenges include unclear inclusion criteria for nutritional support and the need for community sensitization.

However, the successful implementation in Mchinji and Matawale suggests scaling up the program, integrating it with existing initiatives for skills training, and ensuring continuity through partnerships with other organizations.

In Tanzania, there is social and medical support for drug-resistant tuberculosis (DR-TB), but not for persons with PTLD/PTBD as such. There is a need for improvement in social support, such as food rations, income generating activities and vocational skill development. Mobile vans conducting outreach activities offer perspectives for PTLD. The COVID-19 pandemic affected social support, but capacity building did increase support for current TB patients and PTLD individuals. Social support helped clients access diagnosis, care, and treatment, but attendance at lung rehabilitation, understandably, decreased after project support ended. Efforts were made to secure payments for exercise fields and provide water and fruit to participants.

In Sudan, there is a need to address post-tuberculosis disabilities (PTBD) in policies. Volunteers provide follow-up care, counseling, and guidance to persons with PTLD/PTBD. Limited support is available beyond the National Tuberculosis Program (NTP). Efforts have been made to improve nutrition and economic conditions for persons with PTLD through production projects and food baskets. The lung rehabilitation program, conducted with the help of volunteers and staff, has had a positive impact on the mental and physical health of beneficiaries. Health workers are committed to ensuring the program's continuity through new partnerships or donors.

The overall assessment of the OECD-DAC criteria ranges from "neutral" to "excellent". Most concerns are about sustainability of social support and the collaboration that is needed for that with other local organizations.

The top recommendation for this approach is the following:

Promote that each project that involves TB community outreach services integrates PTBD/PTLD components into their existing activities. This specifically applies to integration into other programs working at community levels, for example concerning disability, income generation, nutrition, and poverty reduction. (Sudan)(Tanzania)(Malawi)

Concerning the **5**<sup>th</sup> **approach**, Capacity building of health workers and volunteers on Inclusive health communication, post TB disabilities, and lung rehabilitation, the following was found.

In Malawi, more than thousand nurses and volunteers were trained in Inclusive Health Communication, while health workers and volunteers received training on post-TB complications and support. The lung rehabilitation training proved useful in addressing PTB complications. The project aimed to scale up and integrate the intervention into other programs, with plans for data analysis as well. The COVID-19 pandemic had some impact on capacity building. Expanding the lung rehabilitation program requires additional training and mentorship for health workers, including nurses, as well as scaling up the intervention to new facilities. E-learning might be a complementary strategy to face-to-face training but is expected to have a limited penetration.

The project in Tanzania successfully trained staff in mental health evaluation and inclusive health communication, enabling them to mentor other health facility staff. Lung rehabilitation training has shown significant improvement in peoples' health and the well-being of the staff involved. Due to the pandemic, some trainings were postponed, but online training in Swahili was provided. Health professionals are actively seeking training opportunities for continued professional development. The project conducted training sessions on TB, post-TB lung disability, inclusive health communication, and physiotherapy. Trained volunteers are willing to train others, and expanding the

volunteer base is desired. Continued capacity building and mentorship are needed, and support from different donor projects can assist in this training.

The Hilat Koko center in Sudan has taken steps to improve communication with persons with PTLD/PTBD and promote their independence. The project aims to connect persons with PTLD/PTBD with the Sudanese Disability Union and government-provided social support and opportunities. In Sudan, extensive training has been provided, exceeding the targets set. The project suggests having printed guidelines available at every center for dealing with TB-related disabilities and training health workers based on these guidelines, especially in the case of staff turnover. The Ministry of Human and Social Development and the Ministry of Health show potential for continued capacity building in the country through their support and training opportunities.

The overall assessment of the OECD-DAC criteria ranges from "good" to "excellent".

The top recommendation for this approach is the following:

Inclusive health communication, PTBDs and lung rehabilitation should be introduced as part of all TB training sessions for health care workers, using TOT and a training cascade. The national TB programs could make use of courses and curricula developed by LHL International. (Sudan)(Tanzania)(Malawi)

Concerning the **6**<sup>th</sup> **approach**, share results and advocate to regional and national health authorities, the following was found.

The Malawi project has raised awareness about post-TB disabilities (PTBD) among stakeholders but lacks specific policies and guidelines for implementation. The NTLEP suggests scaling up the intervention to other districts with financial support. Despite support from community leaders and the District Health Offices, attention shifted during the COVID-19 pandemic. The project has compiled achievements, and these are shared with relevant stakeholders. PTLD/PTBD issues are now considered for inclusion in the NSP along with a budget for continuation and roll-out. The NTLEP further considers a sub-TWG for PTLD/PTBD and is seeking support from higher policy levels.

In Tanzania, subnational health authorities are involved in the project and are familiar with the results, while national authorities have approved the project and are closely following its progress. The project has developed a care package that will be piloted in an urban district. The "4th 90%" policy in Tanzania requires further clarification for the stakeholders. Persons with PTLD/PTBD in Tanzania can advocate for themselves with support from volunteers and health authorities, and preparations are underway for a documentary about the experiences of the project. The project's dissemination of results took place in April 2023, and PTLD/PTBD is included in the revised National Strategic Plan.

In Sudan, HDP worked with the Ministry of Health. The project involved coordination between various departments, linkage of volunteers with treatment centers, and community outreach. The project continued during the pandemic with the help of the Sudanese Disability Union. The MoH only partners with the Disability Federation, but the project could consider partnering with the Ministry of Human and Social Development and the Zakat fund, which have specialized training centers at the state level and can reach families in their homes. Regular information sharing with stakeholders and the establishment of a national committee can ensure sustainability.

The overall assessment of the OECD-DAC criteria was mostly "good". Most concerns were towards the impact of advocacy efforts in Sudan, although HDP (implementation partners) fostered good coordination with local stakeholders.

The top recommendations for this approach are the following:

Strengthen advocacy work to effectively disseminate project achievements and best practices with key in-country stakeholders (national and subnational) and funders (such as GF, USAID, CDC) to lobby for policy revision to include PTBD care in the TB space and other sectors that can provide support to persons with PTBD. This includes program grant making. (Sudan)(Tanzania)(Malawi)

Distribute information on the "fourth 90" policy (90% of persons with PTLD receive social and medical support) to all national and subnational authorities in high burden countries, accompanied by advocacy and adoption strategies (Sudan)(Tanzania)(Malawi)

# Contents

Acknowledgements	2
Executive summary	3
List of figures	11
List of tables	11
Abbreviations	12
Introduction	13
Background	14
TB profile of TB in each of the countries, including what is known about PTLD and mental health issues	15
Current policies	18
Main stakeholders	19
Terms of Reference	20
Methodology	22
Findings	23
Approach 1: Identification of people with post TB disabilities, including post TB lung disease and mental health. Mapping the scope of health problems among former TB patients and how it affects their lives	23
Malawi	
Tanzania	_
Sudan	
OECD criteria assessment	
Recommendations	
Approach 2: Collaboration between local health system and community-based organizations	
Malawi	
Tanzania	28
Sudan	29
OECD criteria assessment	31
Recommendations	32
Approach 3: Development and implementation of a local and volunteer-based lung rehabilitation	33
Malawi	
Tanzania	
Sudan	
OECD criteria assessment	
Recommendations	36
Approach 4: Social and medical support to people with post TB disabilities, e.g. follow up/home visits, medical check-ups, nutritional support, transport, vocational training income generating activities, in addition to the lung rehabilitation in some sites	ı- and
Malawi	27

Tanzania	38
Sudan	38
OECD criteria assessment	40
Recommendations	42
Approach 5: Capacity building of health workers and volunteers on Inclusive health communication, post TB disabilities, and lung rehabilitation	43
Malawi	43
Tanzania	44
Sudan	44
OECD criteria assessment	46
Recommendations	47
Approach 6: Share results and advocate to regional and national health authorities	48
Malawi	48
Tanzania	48
Sudan	49
OECD criteria assessment	50
Recommendations	51
Achieved output results	52
Relevance of objectives and outcomes	54
Limitations of the evaluation	54
Conclusions and recommendations	55
References	58
Annex 1: Evaluation matrix	61
Annex 2: Data collection tools	67
Annex 3: List of persons and places visited (Muaz, Lillian, Emmanuel)	83
Malawi	83
Tanzania	01

List of figures	
Figure 1: Theory of Change	54
List of tables	
Table 1: TB profiles of Malawi, Tanzania and Sudan	16
Table 2: Mental health services in Tanzania and Sudan, selected indicators	
Table 3: Stakeholders in Tanzania, Malawi and Sudan	
Table 4: OECD-DAC evaluation criteria	
Table 5: Key findings concerning lung rehabilitation, Malawi	23
Table 6: Targets and results 2020-2022, all three countries	
Table 7: OECD-DAC criteria aaplied to the main interventions of the project, overview	

# Abbreviations

AFIDEP	African Institute for Development Policy		
BMI	Body Mass Index		
СВО	Community Based Organization		
CDC	Centers for Disease Control		
CHW	Community Health Worker		
CS0	Civil Society Organization		
CXR (-AI)	Chest X-Rays (Artificial Intelligence)		
DR-TB	Drug-Resistant TB		
GHW	General Health Worker		
HSA	Health Surveillance Assistants		
IHC	Inclusive health Communication		
HDP	Health Development Program		
IGA	Income Generating Activities		
KIDH	Kibong'oto Infectious Diseases Hospital		
LIC	Low Income Country		
LMIC	Low- and Middle-Income Country		
LR	Lung Rehabilitation		
MKUTA	Tanzania National Patient Organization (meaning "find him" in Swahili)		
MOH	Ministry of Health		
MTR	Mid Term Review		
NGO	Non-Governmental Organization		
NONM	National Organization Of Nurses And Midwives Of Malawi		
NSP	National Strategic Plan		
NTLEP	National TB and Leprosy Elimination Program		
NTP	National TB Program		
OECD-DAC	Organization for Economic Co-operation and Development -		
Development Assistance Committee			
PRP	Pulmonary Rehabilitation Program		
PTBD	Post-TB Disability		
PTLD	Post-TB Lung Disease		
SCTP	Social Cash Transfer Program		
TB	Tuberculosis		
TWG	Technical Working Group		
USAID	US Agency for International Development		
WHO	World Health Organization		
YLD	Years of Life lost due to Disabilities		

# Introduction

The project "Filling the gap – finally addressing post-TB disabilities in Sub Saharan Africa" in Malawi, Tanzania and Sudan is an interesting project addressing an issue that has long been neglected by TB programs around the world.

From the perspective of persons affected by TB, however, the impairments resulting from having had TB, and which started before, during or after TB treatment, have a big impact on their daily life. Impaired lung function or damage to other organs can lead to partial loss of function, which in turn can limit social participation. At the same time, many persons affected by TB experience mental health issues, most notably depression.

It is for this reason that the evaluation of this project is very relevant. It should inform LHL International and the wider TB community about what has been achieved, what lessons learnt are, and how this aspect of TB care can be better addressed in routine program settings.

# Background

The project concerns activities to improve the quality of life of persons with Post TB Lung Disease (PTLD) and mental health issues related to TB. This was done through lung rehabilitation, addressing health problems after TB treatment other than PTLD, joining TB clubs, home visits, counseling, and nutritional support. The project also addressed mental health issues. It took place from 2019 to 2022, with a no-cost extension to mid-2023. Its evaluation will be used by LHL International and implementation partners to redesign the project, as source of evidence to support advise on integration of PTLD and mental health issues related to TB into the general approach to TB care.

PTLD and mental health issues are a major concern for persons affected by TB. A recent systematic review found that respiratory impairment in low resource settings after being cured from TB exceeds 60%, whereas mental health issues was the case in 42% of persons affected by TB (Alene et al., 2018). For persons with MDR-TB these percentages are similar, with the addition of neurological and hearing impairments due to adverse events caused by the medication. Other studies were published pointing in the same direction, and more research and evidence is needed to put this firmly on the End TB agenda. To that end a toolkit for measurement was developed in South Africa (Abdool-Gaffar et al., 2011) and by the Union Against TB and Lung Diseases (Migliori et al., 2022).

When considering disabilities due to TB, a distinction needs to be made between impairment, activity limitation and participation restriction, in accordance with the WHO International Classification of Functioning, Disability and Health (WHODAS2)(World Health Organization, 2010). This was done accordingly by the project.

The project started in Malawi, and later Tanzania and Sudan were added. In 2021, a Mid-Term Review (MTR) was done of the Malawi project (Conroy, 2021). The project made significant progress in three areas: Inclusive Health Communication (IHC), the Pulmonary Rehabilitation Program (PRP) program, and advocacy efforts. The IHC program provided training for healthcare providers to address the specific needs of people living with post-TB disabilities. The PRP program aimed to improve the quality of life and well-being of persons with respiratory difficulties or impairments resulting from TB and its treatment, and a pilot program showed positive results. The advocacy efforts of the project have been successful in raising awareness of the project and building support among stakeholders.

The MTR found that the IHC program was successful, exceeding its targets for the first 18 months. The training materials were excellent, and the participants applied their knowledge in their daily work. Interviewees recommended that the IHC program be scaled up nationwide. The Pulmonary Rehabilitation Program PRP program was also successful, with the pilot program showing positive results, including a reduction in chest pain and coughing intensity, weight gain, improved quality of life, and mental health. The advocacy efforts of the project were successful in raising awareness and building support among stakeholders, although the MTR recommended that the project partners work with other national stakeholders to develop a broader advocacy and financing strategy.

The MTR recommended to either remove or revise the target to support people living with post-TB disabilities back into employment through the provision of cash transfers and vocational training. The evaluation of Income Generating Activities (IGAs) was needed to ensure their sustainability. The MTR suggested advocating for people living with post-TB disabilities to be included in the Social Cash Transfer Program (SCTP).

Overall, it was found that the project management team was very dedicated, with evidence of continuous efforts to innovate and respond to issues as they arise. Despite the challenging operating environment due to the COVID-19 pandemic, the project made significant progress in providing care for people living with post-TB disabilities, and the MTR recommended scaling up the IHC and PRP programs nationwide and developing a broader advocacy and financing strategy.

The current evaluation follows the criteria set by the Norwegian Agency for Development Cooperation (Norad) that are used to assess the effectiveness of development programs and projects (OECD, 2010) (see Table 4):

# TB profile of TB in each of the countries, including what is known about PTLD and mental health issues

Trends in the TB epidemic in Malawi, Tanzania and Sudan are summarized in Table 1 (WHO, 2022). In all three countries the gap between estimated incidence and notification has narrowed, and mortality rates decreased. Undernourishment and HIV are the biggest attributing factors in TB incidence, except in Sudan, where diabetes is the 2<sup>nd</sup> biggest attributing factor.

Although there is a paucity of data, it is estimated that in a high percentage of persons affected by TB suffer from respiratory impairments (DS-TB 33%, DR-TB 59% LICs and LMICs), mental health disorders (42% in LIC), hearing impairments (DS-TB 2.3%, DR-TB 15%), and neurological impairments (28-37% in DR-TB patients)(Alene et al., 2021). This means that over the years there are many persons affected by TB with lasting impact of the disease. It has been estimated that the number of tuberculosis survivors in 2020 is more than ten times the estimated annual tuberculosis incidence (Dodd et al., 2021). Globally, from the estimated 363 million people developing TB in the period 1980-2019, an estimated 155 million were still alive in 2020 (47% in South-East Asia). Of them, 18% is estimated to have been treated in the last five years and 8% in the last 2 years. For the African region, it is estimated that 25.7 million TB survivors are still alive in 2020. This prompts the need to both find people with TB earlier (with less pulmonary sequelae as a result) and provide lung rehabilitation and healthy living education as part of the care package, as this has proven to be effective in improving lung function (Pontali et al., 2022) and quality of life. However, no clear guidelines were found about how to do this when analyzing 212 guidelines and more than 3500 articles (Wanner et al., 2018). Various aspects of PTLD are not well known, such as clinical evidence, household and macro-economic- consequences, routine measurements of lung function, and in general morbidity and mortality (Quaife et al., 2020). This is an important reason that this LHL International project is deemed valuable for advancing this people-centered agenda to be included in the wider TB agenda.

There are various tools that can be used to measure the impact of TB on respiratory health, mental health and overall on quality of life:

- lung function assessment (Migliori et al., 2021).
- mental health measurements (*The World Health Organisation- Five Well-Being Index (WHO-5)*, n.d.; Topp et al., 2015)
- HRQoL (Vasantha et al., 2021)

Malawi Sudan Tanzania Incidence, New and relapse TB cases Incidence, New and relapse TB cases Incidence, New and relapse TB cases notified, HIV-positive TB incidence notified, HIV-positive TB incidence notified, HIV-positive TB incidence (Rate per 100 000 population per year) (Rate per 100 000 population per year) (Rate per 100 000 population per year) 300 900 600 300 HIV-negative TB mortality HIV-negative TB mortality HIV-negative TB mortality (Rate per 100 000 population per year) (Rate per 100 000 population per year) (Rate per 100 000 population per year) Incidence, Notified cases by age group at Incidence, Notified cases by age group an Incidence, Notified cases by age group ar sex, 2021 sex, 2021 (Number) (Number) Males Incidence Females Males Incid 365 55-64 45-54 35-44 35-44 Cases attributable to five risk factors, 20: Cases attributable to five risk factors, 202 Cases attributable to five risk factors, 202 (Number) (Number)

Table 1: TB profiles of Malawi, Tanzania and Sudan

# Some background concerning Malawi

In Malawi, it was found that PTLD is common and under-recognized, with many expatients reporting respiratory symptoms, abnormal spirometry, and bronchiectasis or destroyed lobes. Persons with PTLD also experienced declines in pulmonary function, acute respiratory events, and work-related disability up to one year after completing treatment. At TB treatment completion, 60.7% reported respiratory symptoms, with 34.2% having abnormal spirometry. One year after completing treatment this reduced to 30.7% reporting respiratory symptoms, whereas 12.2% had symptoms affecting their ability to work (Meghji et al., 2020).

In Urban Malawi, another study found that most of the tuberculosis (TB)-related morbidity occurs after treatment completion, and post-TB disability is often overlooked in estimates of disability-adjusted life years (DALYs)(Tomeny et al., 2022). At treatment completion, 55.1% of participants had cardiorespiratory disabilities, decreasing to 15.6% after 3years, with two-thirds of the disability burden experienced by women. Over 90% of projected lifetime the "years of life lost due to disabilities" (YLD) were concentrated

within the most severely affected 20% of survivors, with women experiencing two-thirds of the disability burden after 3 years.

A study report (under this project) on PTLD/PTBD amongst 170 general health workers (GHW) in Malawi who had TB in the past showed that 63% had some activity limitation, 31% had post-TB disabilities, 29% of respondents reported loss of income during TB illness, and only 16% received social support. Additionally, 31% of respondents experienced TB-related stigma (Ng'ambi, 2021).

Data collected through the so-called "Hope App" by LHL International in Malawi indicated that 70.4% of former TB patients had health problems after being cured from TB. The most were problems with the lungs (59%), pain (14.8%), and fatigue (8%). Other health issues concerned hearing problems and mental health problems. As many as 60% of the respondents (1750 people) said that this affected their daily life negatively, for 59% it affected their daily income, and for 48.5% it affected their social life negatively. Many respondents presented with multiple health problems (for instance, lung problems in combination with pain and fatigue).

In Malawi, concerning mental health problems in general, and this will reflect on the context of mental health issues in persons affected by TB as well, many people suffering from mental health conditions have no access to care due to a variety of reasons, such as non-integration of mental health services into primary healthcare, very few mental health professionals, lack of competencies of GHW in this area, inadequate resources, and high levels of societal stigma towards people suffering from mental health issues (Udedi, 2016).

A recent study about accessibility of services for people with disabilities, including respiratory impairments, showed that they? faced three main barriers to accessing healthcare (Harrison et al., 2020): the cost of transport, drugs, and services; insufficient healthcare resources; and dependence on others. The study also found that unfavorable health-seeking behavior acted as a barrier for some participants, but the attitudes of community members and healthcare workers towards disability did not have a significant impact on healthcare accessibility. This points to a health systems issue, for which inclusive health education might only be part of the solution.

The project relies on volunteers and health surveillance assistance. A study looking at their motivation, and thus related to sustainability, found that factors such as salary, accommodation, supplies and logistics, human resource management, and community links affected the motivation of HSAs (Chikaphupha et al., 2016). Lack of financial incentives, shortages of basic supplies, and heavy workload were major demotivating factors. HSAs felt that recognition, support, and a clear career pathway would improve their motivation. Although these factors were addressed in this project (training, airtime, and transport support, it does indicate the challenge of how PTLD mitigation can be successfully rolled out more widely.

### Some background concerning Tanzania

Compared to Malawi, in Tanzania there is less literature about PTLD and TB-related mental illnesses.

A cross-sectional survey of adults within 2 years of completion of TB treatment in Tanzania (related to this project) showed that 45% reported chronic respiratory symptoms, and a diagnosis of PTLD was made in 200, 91%, half of them clinically relevant. Severe chronic bronchitis and dyspnea were present in 11% and 26% of the participants. Older age, multiple episodes of TB and poverty indicators were linked with clinically relevant PTLD (Mpagama et al., 2021).

WHO published a survey handbook to estimate patient costs related to Tuberculosis (WHO, 2017), but costs after TB treatment were not well represented. In response, a study was done to adapt for the longitudinal study design of TB sequelae and the local context in South Africa, Mozambique, Tanzania, and The Gambia (Evans et al., 2021). The generic instrument was adapted for use at enrollment and at 2, 6, 12 and 24 months after enrollment, and during long-term follow-up once treatment has been completed. This provides the opportunity to repeat measures and make comparisons over time, describe changes that extend beyond treatment completion, and link cost survey data to treatment outcomes and post-TB sequelae.

# Some background concerning Sudan

Also for Sudan, not much is published about PTLD/PTBD. One cross-sectional study of persons with chronic respiratory symptoms in a Khartoum hospital OPD found that 46% of persons with previous TB had a clinical diagnosis of PTLD, representing 10% of the patient population (n=140) (Binegdie et al., 2022). There is no data on PTLD/PTBD amongst persons who completed anti-TB treatment in a representative sample.

# Current policies

Although there is an increasing body of literature related to PTLD, a literature review in 2018 found no international guidelines on how to manage PTLD (Wanner et al., 2018). The TB Sequel consortium looking into PTLD from various perspectives, does have a collaboration in Tanzania with NIMR (*TB Sequel Network*, n.d.).

Concerning mental health, the Mental Health Atlas 2020 provides country profiles for Tanzania and Sudan (not for Malawi), (WHO, 2020b, 2020a), of which some relevant indicators are listed in Table 2. It shows the paucity of mental health services and an emphasis on hospital-based services. For Tanzania, perspectives for addressing mental issues are opening as it is recognized by government to be a major issue (*Tanzania Holds Its First-Ever National Mental Health Dialogue* | *WHO* | *Regional Office for Africa*, 2022). An NGO based mental health guide for Malawi was developed (Ajayi, 2021), based on the book "where there is no psychiatrist" (Patel & Hanlon, 2018). Also, Paradiso in collaboration with AFDEP developed a policy brief about including PTBD care as a policy in the National Strategic Plan (NSP) for TB. In Sudan, based on the WHO's Mental Health Gap Action Program Intervention Guide, the MOH developed a multisectoral response to mental health issues during the Covid-19 outbreak, on which further services could be build (Shoib et al., 2022). This is relevant when considering the impact of the Inclusive Health Communication efforts of LHL International, and what role it could play in addressing mental health issues of persons affected by TB.

Table 2: Mental health services in Tanzania and Sudan, selected indicators

Indicator	Tanzania	Sudan
Mental health policy	No	Yes (since
		2009)
Human resources available	Yes	Yes
Government expenditure as % of health	4%	n.k.
budget		
Out-of-Pocket payment	>20%	100%
Mental health nurses / 100k population	0.85	0
Psychologists / 100k population	0.03	0.99
Social workers / 100k population	0.05	0.85
All mental health workers / 100k	1.31	2.05
population		
Integration into Primary Care, score out	3	3
of 5 (highest)		
OPDs with mental health services	157	12
Community based mental health	3	0
services		
OPD visits / 100k population (2020)	974	n.k.
Community based mental health	0.005	n.k.
services / 100k population		

# Main stakeholders

In the three countries, main stakeholders relevant for this project are listed in Table 3.

Table 3: Stakeholders in Tanzania, Malawi and Sudan

Country	Stakeholders		
Tanzania	MKUTA		
	Kibong'oto Infectious Diseases Hospital		
	(KIDH)		
	Ministry of Health		
	District health authorities		
Malawi	Paradiso TB Patients trust		
	National Organization of Nurses and		
	Midwives (NONM)		
	MOH		
	District health authorities		
Sudan Health Development Project (HDP)			
	MOH		
	District health authorities		

# Terms of Reference

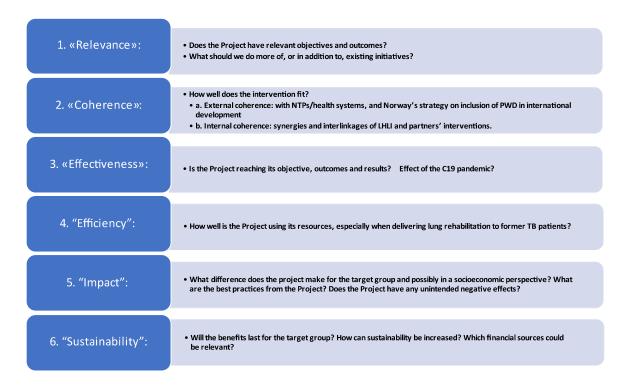
The evaluation is intended to address the following (as stated in the Terms of Reference):

LHL International and implementing partners will use this evaluation to redesign or refine, complement, and possibly expand existing initiatives, if funds become available. LHL International and implementing partners will use the evaluation as source of evidence and tool for advocacy to health authorities in Malawi, Sudan, Tanzania, and globally, providing advise on how to facilitate the integration of post TB care into general TB care and other LHL International projects.

The project interventions are in line with the Clinical standards for the assessment, management and rehabilitation of post-TB lung disease, published by the International Union Against Tuberculosis and Lung Disease for the first time in 2021. Although the project was designed and initiated prior to the Clinical standards, this evaluation should be able to contribute to the global knowledge base on post TB lung disease.

With these purposes in mind, the evaluation looked at the relevance of the project addressing post-TB disabilities, efficiency, and impact so far, following OECD DAC evaluation criteria depicted in Table 4.

Table 4: OECD-DAC evaluation criteria



These evaluation questions were applied to the main interventions of the project:

Main interventions

Identification of people with post TB disabilities, including post TB lung disease and mental health. Mapping the scope of health problems among former TB patients and how it affects their lives.

Collaboration between local health system and community-based organizations

Development and implementation of a local and volunteer-based lung rehabilitation

Social and medical support to people with post TB disabilities, e.g. follow-up/home visits, medical check-ups, nutritional support, transport, vocational training and income generating activities, in addition to the lung rehabilitation in some sites

Capacity building of health workers and volunteers on Inclusive health communication, post TB disabilities, and lung rehabilitation.

Across the OECD-DAC criteria, areas of improvement were identified, and recommendations provided with future projects and/or expansion in mind. The evaluation also intended to look at cross-cutting issues of the Norwegian government: human rights, women's rights and gender equality, climate and the environment, and anti-corruption. Human rights, women's rights and gender equality were clearly addressed at the project level. However, climate change and anti-corruption are issues far apart from the way this project has developed.

The report is structured along the lines of the main interventions, looking at each country. These main interventions are then evaluated using the OECD-DAC criteria.

# Methodology

With the evaluation matrix as basis, several methods were used to gather data and information to produce evidence to answer the evaluation questions of this assignment.

#### **Evaluation matrix**

We used an evaluation matrix (see annex 1) to determine which questions need to be asked to which target groups at the project sites, including the methods to gather such information / data, in line with the Theory of Change for this project. To answer the evaluation questions (OECD-DAC criteria), an assessment was needed of the interventions themselves, both quantitatively and qualitatively. To do this, we made interview and FGD guides (annex 2).

#### **Desk reviews**

Desk reviews were used to look at reports, documentation and other published information about PTLD and mental health of persons affected by TB in the three countries concerned.

Project- and country-relevant documentation was shared with the three field-level consultants, who extracted relevant information.

# Interviews and focus group discussions

Site visits were done in all three countries: Malawi, Tanzania, and Sudan. During these visits data and information was gathered through interviews and Focus Group Discussions.

# **Data analysis and synthesis**

Data analysis and synthesis was done by KNCV staff at the global office.

# **Indicators**

Indicators in this evaluation refer to the LHL International results framework in relation to the main activities of the project, as far as available.

# Limitations

The main limitation of this evaluation was the short duration of data/information gathering. This influenced the number of interviews and FGDs, as well as the number of sites visited. To mitigate this, a draft report was shared with LHL International, which consulted their implementation partners. In turn, the evaluation team revised and clarified emerging issues.

# **Findings**

Findings are structured along the lines of the main intervention areas, and then an evaluator's assessment is given concerning the OECD-DAC evaluation criteria of relevance, coherence, effectiveness, efficiency, impact and sustainability.

Approach 1: Identification of people with post TB disabilities, including post TB lung disease and mental health. Mapping the scope of health problems among former TB patients and how it affects their lives.

The project aimed to identify people with post-TB disabilities and provide them with support in Malawi, Tanzania, and Sudan. The program had a positive impact on the lives of the persons affected by TB in all three countries, improving their lung health, general health, and ability to work and generate income.

### Malawi

The implementation of the lung rehabilitation (LR) program in Malawi was successful in meeting the needs of former TB patients, and a mapping exercise identified the most common post-TB health problems. LHL International developed an app as a tool for data collection and a practical tool for the volunteers in their work. It includes following people from symptom screening, throughout the TB treatment and for the post TB follow up. The follow up includes treatment adherence, side effects and socio-economic support. At the end of Match 2023 information was available of 1750 persons who had completed treatment. As many as 70,4% of these persons are reported to have health problems a year after TB treatment. Lung problems affecting daily life accounted for 59%, and then there were issues like pain (14.8%), neurological problems (11.3%), overall fatigue, and mental problems. Their health problems affected their daily life in 60% of persons, for 59% it had a negative impact on income, and for 48.5% it affected their social life. Importantly, 87% of former TB patients live in extreme poverty at less than USD 1.3 per day, compared to 70.6% before TB treatment started. Unemployment increased from 8.3% before TB treatment to 19.8% after TB treatment (for the general population this is 7%).

The positive impact of the Pulmonary Rehabilitation Program shows as follows:

Table 5: Key findings concerning lung rehabilitation, Malawi

Test	Baseline	End-line
6-minute walk test (6MWT)	399,7 meters	462,2 meters
Chest pain	66,3%	8,7%
Karnofsky scale/activity	27%	0%
level score of 70 and below		(89.7% with normal
(meaning unable to carry		score)
normal activity or work)		
Dyspnea (breathlessness	62,3%	0,9%
related to activity)		
IRM (1 arm strength) (kg)	4	5.5
BMI (% of underweight)	18,2%	13%

However, at the time of the evaluation, there was a lack of interlinkages between LR programs and other organizations, and PTLD/PTBD issues were not yet reflected in the

National Strategic Plan or the Global Fund grant application, which changed after the field-level evaluation when in a dissemination meeting the MOH indicated that PTLD/PTBD issues were being incorporated in the National Strategic Plan Collaboration with other organizations supporting disabilities activities was weak, and for the longer term it is recommended to strengthen advocacy work and integration of PTLD/PTBD issues into other programs.

The project in Malawi was implemented after the COVID-19 pandemic stabilized, and the desk review found no issues with the implementation.

Best practices for identifying eligible persons for the LR program have been established in Malawi, including an accurate screening tool, involvement of local personnel like physiotherapists, and trained volunteers/HSAs as facilitators. The screening tool for mental health issues was sufficient as screening tool (not for distinguishing different types of mental health issues). Some persons with PTLD provided false information to be recruited into the program, but mostly it concerned other complications, and they were then referred to other services for care and support. The project in Malawi is collaborating with HSAs and volunteers to identify beneficiaries for the LR program and trained local providers to sustain these activities.

Paradiso and NONM are implementing the LR program with financial support from LHL International in Malawi, but they are seeking local funding opportunities, including integrating PTLD activities into other programs that receive funding from GF. The Inclusive Health Communication (IHC) course is already available online, accessible to all and free of charge. Overall, there is a need to incorporate it in TB guidelines, sensitize first-line healthcare workers, and fund TB-related community efforts to improve early identification of PTLD. The recommendation is to strengthen advocacy work, developing policy and guidelines, and integration of PTLD issues into other programs.

#### Tanzania

The KIDH research project in Tanzania found that MKUTA members, who are community-based volunteers, all of them former TB patients, were able to identify people with post-TB lung disease (PTLD). However, confirmation of the extent of the disease was challenging due to a lack of access to confirmatory steps like chest x-rays (CXR) and other investigations in Mirerani Some persons had to travel at least 35 kilometers to get a chest x-ray done at KIDH, which was unavoidable as the project in Tanzania took place in the context of a research project. In Mirenani, with big mining communities, CXR was deemed important as well. Transport costs for participants were covered by the project. In future roll-out, in first instance in Temeke, CXR will be part of the assessment, but in further roll-out assessment can be effectively done without CXR (as was shown in Malawi).

To improve early identification of PTLD, it is necessary to sensitize first-line healthcare workers and fund TB-related community efforts in Tanzania.

The Multisectoral Accountability Framework was launched in Tanzania on World TB Day in March 2023 to address social and economic challenges faced by TB and PTLD/PTBD individuals. In early 2023 LHL International disseminated project results to authorities and partners, which led to inclusion of PTBD/PTLD in the National Strategic Plan for TB.

The project was the first to systematically identify persons with PTLD/PTBD in Tanzania, but delays caused by the COVID-19 pandemic limited follow-up visits. This, together with fact that the project duration was limited, made that follow-up visits for participants in Tanzania could only be done until six months, instead of the intended nine or 12-month visits. However, some further follow-up will be done through the long-term "regular" LHL International project with MKUTA. Despite these challenges, numerous persons with

PTLD/PTBD were identified within a short period. However, confirmation of PTLD can be challenging going forward, as there were no nearby centers capable of performing the confirmatory tests, including spirometry and chest x-ray. All had these confirmatory tests performed at KIDH, as part of the PTLD research project there. Spirometry is not planned to be used outside research settings. From the work done, however, PTLD diagnosis can effectively be based on the person's history, activity level, symptoms and simple tests such as the 6-minutes walk.

Persons with PTLD/PTBD in Tanzania have shown significant improvement and have been able to resume their normal income-generating activities, leading to an overall improvement in the economic status of the family and community. Some persons with PTLD/PTBD have become volunteers themselves after experiencing the benefits of the program and aim to assist others who are in similar situations and improve their own health.

In total 625 ex-patients with remaining lung complaints were screened for PTLD, of which 11% didn't have PTLD, and a surprising 24% had recurrent TB. Out of 419 identified PTLD persons in Tanzania, only 121 underwent community-based lung rehabilitation. Those not recruited, mostly due to being too far away from the sites of community-based rehabilitation, were counseled and trained in performing the exercises at home. Persons identified with PTLD started showing positive results at three months, and most graduated by six months. A few with severe PTLD took longer to recover, usually those with associated silicosis and/or smokers. Those who had poor performance in lung rehabilitation had a relapse of symptoms, which were alleviated when more effort was put into exercise. Community-based organizations could secure funding from different donors and partners to sustain their case finding activities aimed at identifying individuals with PTLD and mental health issues.

## Sudan

The project in Sudan addressed PTLD, mental well-being, and Income Generation Activities (IGA) and at the same time had a positive impact on raising awareness about TB transmission and the need to keep family members informed. The TB program in Sudan coordinates with other ministries, and disabilities are considered part of non-communicable diseases, and the program coordinates with the Ministry of Social Welfare. The staff's role was to share information about PTLD and connect TB-affected persons with other entities. The recommendation is to organize monthly meetings between project staff and the disability federation at the local, regional, and federal levels.

In Sudan, 760 former TB patients were assessed for PTLD, of which 302 were included in the PR program. The identification of persons with PTLD in two clinics in Sudan appears not to have been affected during or after the COVID-19 pandemic. Health workers in Sudan have been trained to identify TB disabilities at an early stage and successfully built the capacity of volunteers to understand that TB disability is not contagious, contrary to their prior beliefs.

Ex-TB patients without disabilities in Sudan expressed a desire for a similar project to support them, but they were informed that they could continue with their lives as usual after receiving treatment, unlike those with disabilities.

To sustain the project's impact, an effective monitoring and evaluation system is necessary. Additionally, organizing a bazaar to showcase the productivity of ex-patients' projects could increase patient participation. It was suggested to explore financial sources to sustain or enhance collaboration between the health system and community-based organizations by strengthening coordination between relevant parties and expanding the network of partners.

# OECD criteria assessment

Approach 1: Identification of people with post TB disabilities, including post TB lung disease and mental health. Mapping the scope of health problems among former TB patients and how it affects their lives.

OECD criteria	Score	Why do you give this score?
Relevance	Excellent  Excellent	Malawi: Ability to identify right persons for LR <u>Tanzania</u> : PTLD persons were identified and channelled towards rehabilitation that caused remarkable improvement
Relevance	Excellent	Sudan: In view of the numbers of persons affected by PTLD/PTBD, this is very relevant, also according to stakeholders (staff, and affected persons)
	Good	Malawi: Collaboration was observed
Coherence	Good	<u>Tanzania</u> : Ability of CBO in assisting the regular health system came into play
	Good	<u>Sudan</u> : Varying levels of collaboration between project staff and health authorities, collaboration with health facility (HF) staff generally okay or very good
Effectiveness	Excellent	<u>Malawi</u> : The project had been competently identifying people affected by TB and changing their life through social and medical support and lung rehabilitation.
	Excellent	<u>Tanzania</u> : Once identification was made, rehabilitation done with improvement
	Good	<u>Sudan</u> : Results were very as reported by the implementation partner, and confirmed by affected persons themselves
	Excellent	Malawi: Very transparent in using the resources
Efficiency	Good	<u>Tanzania</u> : The experience gained from the operational research enabled KIDH to develop a package of care for use at community level and address logistical challenges in diagnostic capabilities at the peripheral level, which will be piloted in Temeke.
	Neutral	Sudan: Overall, TB budgets are decreasing in Sudan. It is felt that if more budget was put into advocacy to the Ministries of Health and of Social Welfare, more domestic funding might have been secured.
	Excellent	Malawi: Changed lives of persons with PTLD/PTBD for the better
Impact	Excellent	<u>Tanzania</u> : The community and individual lives have improved remarkably, and awareness of PTLD/PTBD and the ability to overcome it is known
	Excellent	<u>Sudan</u> : According to all account, the impact is excellent, and the combination of interventions reinforcing each other
	Good	Malawi: Use of local resources
Sustainability	Good	<u>Tanzania</u> : The project has built capacity at the community level that can be scaled-up countrywide while the NTLP has included PTLD/PTBD in the revision of the NSP with funding application in the GF round 7.
	Good	<u>Sudan</u> : Sustainability depends on policy making and funding, there are some perspectives in terms of interest and local resources. Interventions are low-cost

### Recommendations

## Top recommendation:

Conduct or assist country-level surveys to establish an estimate of the number of people with PTLD/PTBD, as the basis for national planning and preparing adequate resources to address PTLD/PTBD. Alongside, a system for long term follow-up of the people who underwent lung rehabilitation should be established to get a better view on the long-term impact (Sudan)(Tanzania)(Malawi)

# Other recommendations:

With the help of the Hope App, developed by LHL International, build up a national-level database of people with PTLD/PTBD, preferably as integral part of DHIS2. (Sudan)(Tanzania)(Malawi)

For screening, involve nurses and equip nearby facilities with molecular diagnostics to exclude active TB and simple tests to diagnose PTLD (6 minutes test, possibly mobile CXR-AI) to reduce the need for referral for diagnosis and enable confirmation of PTLD. Regular meetings of relevant actors would facilitate such a system. (Sudan)(Tanzania)(Malawi)

Improving the lung function of persons with PTLD has priority, as this is underlying all other problems. Nutritional and income support are facilitating factors, but part of a comprehensive approach. (Sudan)(Tanzania)(Malawi)

Develop guidelines and criteria for nutrition support and entry into income-generating activities (Sudan)(Malawi)

# Approach 2: Collaboration between local health system and community-based organizations

Collaborative activities are very project and donor dependent. Sometimes there are so many activities and they work nicely, and when funding ends these services cease. There is a need for continuity to maintain the service to the affected community, which makes collaboration with the local health system and community-based organizations very important. In this chapter we look at it for each individual country.

#### Malawi

When looking at collaboration between health facilities and project volunteers, there are varying levels of success across different districts. In Matawale, Zomba, there was a strong collaboration between project volunteers and health center staff on LR. A positive side effect was that other disabilities activities were implemented at facility level, with volunteers multi-tasking and helping to identify children with undernourishment in the community who were then supported with food rations by Save the Children. It was felt this was an additional impact of the training the project offered. In Kaigwazanga, Mchinji, health staff was collaborating well with project volunteers on TB-related activities, but the person in-charge was not fully aware of what the volunteers did.

Overall, the project has made significant progress in implementing interventions in target health facilities in impact districts. Collaboration has been established between lung rehabilitation (LR) volunteers and health facility staff in the implementation of the intervention, specifically in the identification and management of PRP sessions, and inclusion of PTBD care into the TB management pathway. The intervention has been successful in bringing back those affected to normal functioning.

However, there were also challenges observed in the implementation of the project. In some areas, nutrition support was found to be inadequate for LR clients, and there was a lack of collaboration between the project and other CSOs, jeopardizing long-term benefits for beneficiaries. It is suggested to better connect programs supported by the World Food Program, e.g. through Save the Children. The pandemic had a delaying effect on the identification of persons with PTLD/PTBD, as implementation started after the pandemic had stabilized.

Despite these challenges, good working relationships were established between volunteers and health workers, which is essential for the successful implementation of the LR program. Capacity building and training of community leaders and volunteers has been conducted to increase their knowledge on LR issues, and Paradiso and NONM are facilitating the inclusion of PTLD/PTBD care in the TB management pathway, conducting capacity building and training for health workers and volunteers countrywide, and conducting studies covering PTLD/PTBD issues and other challenges faced by people affected by TB, such as mental issues and income recovery. However, further advocacy is needed to ensure policy and guidelines for PTLD/PTBD care are embedded in the NSP and integrated with other programs, and to establish the burden of PTLD/PTBD. Although data about more than 2000 former TB patients (in 7 out of 750 sites in the country) is indicative for the problems faced by them (70% had health problems, for 60% of these daily life and income was negatively affected), it is felt that a national policy is even better served by a representative national PTLD/PTBD survey. This also refers to what is needed for planning by the NTP.

## Tanzania

In Tanzania, the collaboration between local health bodies and MKUTA was extended to include finding people with PTLD (Post-Tuberculosis Lung Disease) and implementing the LR (Lung Rehabilitation) aspect of the project. This enhanced the interaction between the two, with each side complementing and appreciating the efforts of the other.

However, there is a need for incentives such as transport and communication to enable volunteers to deliver lung rehabilitation exercises with ease. A proposal has been made to establish lung rehabilitation exercises within the hospital for patients attending the Chronic Lung Clinic and those who are oxygen-dependent to prevent development of PTLD.

While CSOs in Tanzania primarily deal with TB and HIV-related conditions, the Inclusive Health Communication training provided by LHL International assisted MKUTA volunteers to be able to identify people with disabilities in the community. Unfortunately, the local health authorities do not yet have any programs in place for the various persons with disabilities identified by MKUTA. However, this is an opportunity for the country to utilize these trained volunteers for related work in the future.

The COVID-19 pandemic has resulted in a slight reduction in TB case notifications and services in Tanzania. However, activities are now running normally, and various targets are being reached.

The long-standing collaboration between the local health systems and community volunteers in Tanzania was utilized in this project by capacitating the volunteers in PTLD/PTBD. Consequently, the project activities were conducted as part of their normal TB work activities. In these two districts, MKUTA played a significant role in notifying up to 60% of the TB patients and referred persons with PTLD/PTBD. There was an increase in TB case notification since MKUTA intensified home visits, with 24% of ex-patients being diagnosed with active TB (relapse). The collaboration between the entities increased during the follow-up of project participants, and there is a need to find ways to sustain this. Community health workers are close to the PTLD/PTBD persons and can monitor their progress closely, report challenges and enable health workers to recommend other needed interventions.

In Tanzania, there is no system to follow up persons with PTLD/PTBD, and the long-term benefits are unknown. Those who could not join the project also had no follow-up and/or support for PTLD/PTBD related issues. The national authorities plan to include five interventions to address PTLD/PTBD, such as awareness creation, identification of recurrent TB in PTLD persons, screening and diagnosis, rehabilitation, and conducting a survey concerning the burden of PTLD/PTBD. The authorities also plan to apply for funding for these interventions in the next Global Fund cycle.

There have been discussions among volunteers and persons with PTLD/PTBD to form PTLD/PTBD clubs that would enable them to attend joint exercise sessions and counseling. Additionally, there is a need to institutionalize community health workers and develop certification and identification cards to recognize them officially. Support in transport, such as motorcycles or transport allowances, is necessary to enable home visits and sample transportation.

#### Sudan

In Sudan, collaboration between local health authorities, health center workers, and volunteers from the Health Development Program has been successful through monthly meetings to coordinate efforts. The new intervention has been well-received, with a focus on health promotion for TB patients after completing their treatment. The community, community leaders, women's groups, and civil society are needed to reach people affected by TB. Health workers and volunteers were trained to identify TB-related disability as early as possible. The number of activities remained steady during and after the pandemic.

During Ramadan, initiatives and projects were undertaken for the Sudanese Disability Union, and volunteers from other organizations helped train TB-affected individuals in lung rehabilitation exercises. After training in health communication, volunteers provided

psychological support and followed up with persons with PTLD/PTBD, improving the relationship between medical staff and them considerably. Ex-TB patients without disabilities expressed a desire for a similar project to support them.

It was suggested that larger projects, such as a chicken farm that could support 5-10 ex-patients and their families, could increase funding and participation. CBO programs could be explored to find areas where ex-patients fit, such as youth programs. Due to insufficient government funding, not much financial support can be expected domestically. Strengthening coordination between stakeholders and partnering with the TB program for training or with advocacy groups for people with disabilities could help expand the circle of partners and reduce expenditures.

# OECD criteria assessment

Approach 2: Collaboration between local health system and community-based organizations

organizations		
OECD criteria	Score	Why do you give this score?
Relevance	Good	Malawi: Whereas collaboration was very strong between Paradiso and the local health system, this collaboration was not extended to other existing CSOs such as Save the Children, United Purpose or Emmanuel International.  Tanzania: Community based organizations could identify and refer those in need to the health
	Excellent	system
	Good	<u>Sudan</u> : The volunteers cannot implement this in isolation, but would be able to with the permission of health facility (HF) staff and health authorities
	Good	<u>Malawi</u> : Collaboration was observed happening with the health system during implementation especially using the existing referral system
Coherence	Excellent	<u>Tanzania</u> : Excellent results came out of the collaboration between MKUTA and KIDH, with involvement of the Mirerani Health Centre and relevant district staff.
	Neutral	Sudan: Very mixed picture. The collaboration mechanism was not all that clear and parties didn't clarify it in discussions that took place. No written minutes for example, or clear frequency of meetings. Evaluator felt it was not quite adequate between the 3-4 parties (HDP, HF staff, health authority's locality, TB program federal).
	Good	<u>Malawi</u> : Collaboration between the health system and volunteers was delayed due to the Covid-19 pandemic
Effectiveness	Good	<u>Tanzania</u> : MKUTA identified persons got the required intervention, and a good collaboration was established with the local health authorities.
	Good	<u>Sudan</u> : In the sites where collaboration was good, there was enthusiasm and dedication, the project really added to existing practices
	Good	Malawi: The project used the resources well despite the limited funding
Efficiency	Good	<u>Tanzania</u> : Persons identified by MKUTA were picked up by the health system immediately because of the prior arrangements and training.
	Neutral	<u>Sudan</u> : The four involved parties (HDP, HF staff, health authority's locality, TB program federal) did not appear to be very clear each other's role, be it that collaboration was judged positively by them
Impact	Good	<u>Malawi</u> : The project changed the lives of the target group through the support and services the project was rendering. The effective referral system is a good example of the best practice that the project has contributed to.

	Good	<u>Tanzania</u> : Collaboration between MKUTA and the local health facilities has improved with positive results
	Neutral	<u>Sudan</u> : It was reported that other CSOs were little involved, and that to quite some extent the project has operated on its own. This is understandable given the duration of the project, but important for the longer term.
Sustainability	Good	<u>Malawi</u> : The project was using the local volunteers in the implementation of its activities, and this assures continuity of the intervention if this financially supported during roll-out.
	<b>y</b> Good	<u>Tanzania</u> : Funding for CBO activities is thought to be an important factor to sustain the collaboration between CBO and the health services
	Neutral	Sudan: In most cases other CSOs have not picked up the intervention yet, nor funding has become available, which endangers sustainability. However, the advocacy work of the project, sharing results and the model with key stakeholders, and which was extensive, is expected to lead to a stakeholder-supported sustainable future of the project activities

# Recommendations

### Top recommendation:

Continue to engage community volunteers, in collaboration with the local health system, for PTBD and lung rehabilitation as they know the clients better and can follow them up easily. (Sudan)(Tanzania)(Malawi)

# Other recommendations:

LHL International and partners should assist the national programs in formulating and developing an all-round, effective and efficient intervention to the benefit of people with PTLD and mental health issues (Sudan: is covered by policies as mentioned earlier, but focus here on collaboration issue (SOPs and so on, and governance issues) (Tanzania)(Malawi)

Dependence on donors should be avoided to ensure continuity of services. The local health authorities, in collaboration with CSOs, should devise ways to ensure such services are not interrupted, such as expanding already existing systems. (Sudan)(Tanzania)(Malawi)

Build intergovernmental partnerships with CSOs, women's groups, NGOs, social welfare schemes and the private sector. In Tanzania, the recently launched MAF offers opportunities for local health authorities to establish such linkages. (Sudan)(Tanzania)(Malawi)

# Approach 3: Development and implementation of a local and volunteer-based lung rehabilitation

### Malawi

In Malawi, the Pulmonary Rehabilitation Program (PRP) has been implemented successfully in nine health facilities. The program is run by trained personnel, including Health Surveillance Assistants (HSAs) and volunteers who are members of TB Clubs formulated by Paradiso within the facility's catchment area. The volunteers were recruited based on their eligibility and trained in lung rehabilitation exercises. The program has been piloted in collaboration with a physiotherapist to help people with lung problems post-TB, with preliminary results indicating that the 12-week program has better outcomes than a 6-week program. The program is managed locally, with volunteers conducting exercises and training, and healthcare staff conducting medical assessments.

The volunteers are involved in other TB-related activities such as sputum sample collection, home visits to support TB patients, and follow-up of persons affected by TB. The program was affected by the COVID-19 pandemic with implementation starting after the pandemic had stabilized. The number of persons included in the PRP was 467 in 2021- 2022.

The involvement of volunteers in the program has enhanced their ownership of the program. The number of persons that could be trained reduced, due to the budgetary impact of the (necessary) inclusion of physiotherapists (after the initial budget was approved) in the planning phase, the extension of the training from five to seven days, and the decision to go for a 12-week LR scheme rather than only 6 weeks. The program utilizes local resources and builds the capacity of local staff to ensure the sustainability of the intervention. However, funding is crucial for the success of the intervention, and incentives for volunteers are felt to remain key in motivating them to continue producing results. The volunteers and HSAs gain experience in planning and managing the program, but there is a need to integrate services and facilitate policy development to support the implementation of the intervention. Overall, the program has been successful in utilizing local resources, building capacity, and improving the lives of persons affected by TB in Malawi.

# Tanzania

In Tanzania, the National Tuberculosis Program (NTP) plans to conduct a survey to determine the extent of the problem of post-TB lung disabilities (PTLD/PTBD). The country has not previously utilized volunteers for lung rehabilitation activities, with physiotherapists in hospitals sometimes providing this service to inpatients. However, the use of volunteers is a new intervention in Tanzania, with MKUTA volunteers involved, who were already engaging in other TB and HIV activities such as contact tracing, screening for TB in HIV households, and ensuring adherence to TB and HIV medication. Volunteers in Mirerani are also actively involved in case finding in mines, conducting frequent health education sessions.

Two successful lung rehabilitation centers have been established in Tanzania, one on community-owned grounds and the other on private grounds, using minimal resources. This included reimbursement of transport costs and provision of nutritional support to participants. However, there is a concern that the program may not be sustainable when funding ends, and the people with PTLD/PTBD might deteriorate. To address this, MKUTA could scale-up volunteer training and mentorship, and physiotherapists from local hospitals could conduct the required training and mentoring. Health authorities are aware and were informed about the project. It received a positive response, but no promises were made about continuation of the project after it will have ended.

Community fields have been utilized for exercise in Tanzania, and exercise could be made a policy in TB care and treatment. Additionally, the mining companies should create exercise fields in mining areas to cut costs for miners who would otherwise need to travel for lung rehabilitation exercises. Free entry on certain days for privately owned grounds could also be requested as part of Corporate Social Responsibility, which would help create a culture of exercise for people with other non-communicable diseases like diabetes.

### Sudan

In Sudan, health workers and doctors have been trained in early detection and management of disabilities, including the provision of free follow-up tests, such as hearing tests. Previously, there was no lung rehabilitation program, but efforts are being made to understand the prevalence and types of disabilities among ex-patients. Currently, 85 people, including 28 staff and 57 volunteers, are involved in helping persons with PTLD to improve lung efficiency, reduce coughing, expand airways, and sleep comfortably. Volunteers were not involved in the lung rehabilitation program before or during the pandemic but now have collected valuable information. In addition to the lung rehabilitation program, volunteers and staff are involved in other projects, including COVID-19 and routine TB activities.

The lung rehabilitation exercises were provided as routine check-up patients at treatment centers, and medical staff were trained to help persons with PTLD continue the program at home.

The transportation of persons with PTLD/PTBD to the rehabilitation centers is an issue and adds a financial burden. Volunteers discovered people with PTLD/PTBD in a center that was not initially included in the program, and although they will continue to work, continuity cannot be guaranteed due to their volunteering in their spare time. However, a national organization might be able to provide funding if the medical staff at the center request support for a specific issue.

#### OECD criteria assessment

Approach 3: Development and implementation of a local and volunteer-based lung rehabilitation

OECD criteria	Score	Why do you give this score?
	Excellent	Malawi: The use of local volunteer system had been so excellent to bring tangible achievements that the project has so far contributed to the management of post TB client
Relevance	Excellent	<u>Tanzania</u> : This is needed as it is the main part of PTLD treatment and management, and was thought out well and implemented
	Excellent	<u>Sudan</u> : Health services cannot do this in addition to the workload they already have, so the added support from volunteers has shown to be crucial
	Excellent	<u>Malawi</u> : The use of local volunteers has been so effective in the implementation of the intervention at community level
Coherence	Excellent	<u>Tanzania</u> : The project established one centre with the village and another with a private individual and entered an agreement with minimal maintenance costs
	Good	<u>Sudan</u> : In several sites, HF staff have adopted the interventions and collaborated well with them
	Excellent	<u>Malawi</u> : The use of local volunteers residing within impact areas has been cost effective in the implementation of the intervention.
Effectiveness	Excellent	<u>Tanzania</u> : This was achieved well, and the developed areas were utilized effectively
	Excellent	<u>Sudan</u> : Without exception, the intervention has been judged by affected people and health staff and volunteers alike as being effective in the rehabilitation of persons with PTLD
	Excellent	<u>Malawi</u> : The project has been efficient and economical as it was using locally available resources
Efficiency	Good	<u>Tanzania</u> : Most PTLD persons could utilize the communal grounds as exercise fields, but there were some minor limitations.
	Good	<u>Sudan</u> : In all sites, the activities showed a good progress, indicating good use of available budget
Impact	Excellent	<u>Malawi</u> : The use of local volunteers has brought a significant impact on people affected by TB at community level through continuous psychosocial support rendered by the trained volunteers
	Excellent	<u>Tanzania</u> : The persons needing the service were all satisfied
	Excellent	Sudan: In all sites, results were very positive
	Excellent	<u>Malawi</u> : The project was using the local volunteers as trainers to develop skills of other volunteers within the project, and this assures continuity of the intervention
Sustainability	Good	<u>Tanzania</u> : Community grounds are available and can be utilized at no costs. Advocacy is required to establish exercises as a need to all
	Good	<u>Sudan</u> : The intervention is relatively low cost, while addressing a rather great need. It is likely that it will be picked up for expansion.

#### Recommendations

#### Top recommendation:

Utilize the upcoming experience in Temeke district (urban high burden TB district, different conditions than Siha and Mirerani) to prepare a care package suitable for Tanzania conditions (and other low-resource settings) (Tanzania)

Develop guidance and a simple booklet in local languages, as was done in the "PRP step-by-step" booklet in Malawi, to guide community health workers and other partners with establishing additional lung rehabilitation centres (Sudan)(Tanzania)(Malawi)

#### Other recommendations:

Local authorities can easily identify additional CBO volunteers to expand lung rehabilitation efforts at the community level (Sudan)(Tanzania)(Malawi)

When establishing lung rehabilitation centres, prepare for a high demand, as people with lung disabilities caused by other than TB might want to join, especially people suffering from COPD (Sudan)(Tanzania)(Malawi)

Suggest to local area authorities and corporations (especially mining companies) to identify community fields which can be used free of charge for exercises and other health related activities at community level (Tanzania)

Approach 4: Social and medical support to people with post TB disabilities, e.g. follow-up/home visits, medical check-ups, nutritional support, transport, vocational training and income generating activities, in addition to the lung rehabilitation in some sites

#### Malawi

In Malawi, Paradiso and NONM are working together to provide medical and social support to people affected by tuberculosis (TB). The project offers medical assessments, referrals, nutrition support, home visits, and financial support for income-generating activities (IGA) through TB clubs. The clubs provide an opportunity to meet people in a similar situation and in effect provide moral support for people affected by TB. However, there are concerns about the accuracy of identifying eligible clients for nutritional support and the frequency of such support. Inclusion criteria seem to be primarily based on expressed need rather than objective criteria such as BMI or otherwise. Other nutrition projects have a frequency of support of every two weeks or monthly, whereas the project provides this on a quarterly basis. The vocational skill development and IGA initiatives had to be discontinued due to financial limitations.

Paradiso recommends the inclusion of PTLD/PTBD care in the TB management pathway, capacity building for health workers, and scaling up the intervention to more facilities. The NTLEP and most CSOs are not paying much attention to PTLD/PTBD, although NTP, AFIDEP, Paradiso and NONM have been involved in drafting a policy brief, but at the time of the evaluation this was not disseminated yet. For inclusion in the National Strategic Plan for TB an approved policy would be needed. The NTLEP is trying to engage the Ministry of Gender and Social Welfare to consider including persons with disabilities in the social cash transfer, which then can include persons with PTLD/PTBD.

A total of 2011 people have been screened for post TB complications in Malawi, revealing that 70% had such health problems. Medical assessment was done for 726 former TB patients, 467 persons affected by TB received pulmonary rehabilitation, 90 nutritional supports, and 146 have joined the local TB Clubs of Paradiso. Paradiso volunteers carried out 515 home visits.

The referral system used in the project helped link clients with comorbidities to other facilities for necessary services, and involving healthcare providers in project activities facilitated the identification of hidden health problems. However, the criteria for recruiting people with PTBD /PTBD into the nutrition support program were unclear, according to the desk review.

Local health workers and volunteers are essential for sustaining the implementation of the intervention. In Mchinji, the involvement of health center staff is limited, and most participants wanted to continue the LR program after having finished 12 weeks. Some persons with PTLD/PTBD had a focus on incentives rather than the benefits of the lung rehabilitation program, which is not surprising given the fact that 87% of persons affected by TB were under the poverty line of 1.3 USD/day. Sensitization of the community on the program is needed, and a focal person should monitor LR activities implementation. In Matawale, integrating LR into existing programs and combining it with vocational skills is suggested. Both locations report success and recommend scaling up the program's implementation.

However, the continuity of social and medical support is a challenge due to the limited involvement of other organizations. Paradiso suggests integrating this program into other programs providing food rations, and the NTLEP proposed integrating counseling with the practice for persons with MDR-TB.

#### Tanzania

In Tanzania, social and medical support for DR (drug-resistant) TB patients includes a stipend for upkeep and transportation, as well as nutritional support during in-patient treatment. However, social support, particularly food rations and vocational skill development, needs improvement. Income-generating activities for persons with TB are important since many come from poor families and had a late diagnosis of TB. There is a suggestion for the involvement of Tanzania Social Action Fund (TASAF) and similar initiatives to help identify families living in poverty. Six diagnostic TB mobile vans do regular zonal outreach active case finding activities with support from USAID, EGPAF, and other community bodies. This is also the case for the mining areas. LHL International supports the use of the mobile van located at KIDH. However, social and medical support is not homogenous and is dependent on donors and is seasonal, and these initiatives do not provide services for people with PTLD/PTBD.

The NTLP (National Tuberculosis and Leprosy Program) has a program for social and medical support to DR patients only, and other CSOs conduct active case finding, contact tracing, and adherence follow-up. Social support to TB and HIV patients in Tanzania was impacted by the COVID-19 pandemic due to difficulties in entering households for fear of infection, resulting in a decline in case notification. However, social and medical support provided to TB patients and persons with PTLD/PTBD has increased due to capacity building provided to volunteers, carried out by the project.

Lack of financial support hinders recovery of persons with PTLD/PTBD and the sustainability of the lung rehabilitation program in Tanzania. Efforts should be made to sustain funding to ensure the program's effectiveness, including applying for funding during the next round of Global Fund and/or putting aside funding from other projects. Persons with PTLD/PTBD propose that exercise should be made a policy for TB care and treatment to prevent the development of PTLD/PTBD.

Social support provided by this project in Tanzania helped people access diagnosis, care, and treatment for lung-related issues, including attendance at lung rehabilitation. Although LR duration (6 months) was followed according to protocol, some patients wanted to continue to attend LR afterwards. Some did and others did not, the latter often because of lack of transportation. Those continuing, and with the help of the volunteers organized regular exercises at the fields. Volunteers who help with the process need to be fairly compensated for their time and resources and require additional training and formalization of their work. Persons with PTLD who previously could not perform economic activities due to their conditions became productive after improved lung functioning.

Some participants in Tanzania could not continue with exercises at the end of the 24 weeks, the duration of the LR protocol. Although some participants wanted to continue afterwards, some did not as this would have meant paying out of their pocket, reflecting the state of poverty amongst many participants. Others did not continue due to the lack of nutritional support they had enjoyed during the period of project support. However, and importantly, MKUTA managed to secure payments for the private exercise field in Mirerani for an extra six months and provide drinking water and fruits to participants who continued exercises in the no-cost extension period. The observation underlines the importance of combining LR with nutrition and transport support.

#### Sudan

In Sudan, there is a need to recognize post-tuberculosis disabilities (PTBD) as a significant threat to persons affected by TB and address it in policies. Volunteers provide follow-up care, psychological counseling, and guidance to ex-TB patients, motivated by a

desire to help those in need. They suggest providing additional support such as hearing aids and wheelchairs could be helpful.

An organization in Sudan is supporting the disabled community by providing educational services, awareness about disability, and services such as wheelchairs and walking sticks. However, there are no other actors supporting ex-TB patients other than the NTP, and they are focusing on the medical part.

To improve the nutrition and economic situation of persons with PTLD/PTBD in Sudan, 35 production projects and 1200 food baskets were provided, particularly to those with limited income.

The program in Sudan trains 20 ex-patients per week on lung rehabilitation exercises, with the help of volunteers and staff under a project coordinator. The program had a significant impact on persons' mental and physical health, with beneficiaries regaining hope, love for life, and the ability to run successful businesses.

The health workers who participated in the program are now aware of TB disabilities and have promised to ensure its continuity through new partners or donors.

#### OECD criteria assessment

Approach 4: Social and medical support to people with post TB disabilities, e.g. follow-up/home visits, medical check-ups, nutritional support, transport, vocational training and income generating activities, in addition to the lung rehabilitation in some sites

OECD criteria	Score	Why do you give this score?
	Excellent	Malawi: Social and medical support was really addressing a gap among people affected by TB through the strong referral system, the screening of ex-TB patients and the linkages between the service providers within the health system
Relevance	Excellent	<u>Tanzania</u> : Social and medical support was optimal during the project
	Good	<u>Sudan</u> : It has become clear that the combination of LR, IHC and support for income generating activities (small business development) are complementary to each other, and reinforce each other through motivation
	Neutral	<u>Malawi</u> : Neutral because the social support was inadequate and not linked to other institutions providing similar services
Coherence	Neutral	<u>Tanzania</u> : This was project dependent and did not involve other partners
	Neutral	<u>Sudan</u> : Whereas medical support has been fair, socio- economic support has been largely dependent on the project and received little support from other local arrangements
Effectiveness	Good	<u>Malawi</u> : Based on interviews, improvements can be made concerning standardized inclusion criteria for nutritional support and monthly nutrition support. Also, more intensive involvement of trained medical staff during screening of people affected by TB who would improve identification of major comorbidities and offer support at the same service delivery point or refer.
	Good	<u>Tanzania</u> : Support provided was effective as it enabled them to participate and improved health of the intended population
	Excellent	<u>Sudan</u> : Without exception, all interviewed affected persons indicated the positive effect of this intervention
Efficiency	Excellent	<u>Malawi</u> : Social and medical support was so efficient and brought change among people affected by TB through rehabilitation, referral and social support
Efficiency	Excellent	<u>Tanzania</u> : Resources were used well and were quite efficient as long as they continued
	Good	<u>Sudan</u> : Medical and social support has been fair, although there were few reports of some people claiming PTLD related disabilities to get the incentives (nutrition support and IGA)
	Excellent	<u>Malawi</u> : The intervention brought significant improvement in the lives of people as you are able to live a normal life after completing the intervention
Impact	Good	<u>Tanzania</u> : The support enabled the participants to attend the LR and improved their health significantly. At the end of their rehabilitation period of 24 weeks, several participants continued with the help of MKUTA.
	Good	Sudan: Although impact on the longer term is unknown, impact on the short term has helped many affected persons (and families) to counter catastrophic expenditure due to PTLD/PTBD
Sustainability	Neutral	Malawi: There are strong links within the public health system on medical issues, however, concerning social and

	nutritional support there is need to link with other institutions.
Good	<u>Tanzania</u> : Once the support stopped, most activities couldn't continue. However, there is a good perspective for sustainability of provision of such support with the planned roll-out in Temeke district and inclusion of PRLD in the National Strategic Plan for TB.
Not so good	<u>Sudan</u> : TB affects mostly persons of lower socio-ecomic status, a situation that likely is not changing much with short term social support. There are no strong indications that income support will be taken over by existing social protection schemes, nor that persons with PTLD/PTBD are easily categorized under "persons with disabilities"

#### Recommendations

#### Top recommendation

Promote that each project that involves TB community outreach services integrates PTBD/PTLD components into their existing activities. This specifically applies to integration into other programs working at community levels, for example concerning disability, income generation, nutrition, and poverty reduction. (Sudan)(Tanzania)(Malawi)

#### Other recommendations:

Map stakeholders and actors that provide social & medical support for disabled people (Sudan)(Tanzania)(Malawi)

Conduct cost-effective studies about the effectiveness of this intervention at community level. Preferably including assessment on acceptability and affordability in the event that social and/or medical support is unavailable (Sudan)(Tanzania)(Malawi)

Lobby for assistance to those who cannot afford hospital level care, as some don't have funding for investigations, so they return home (Sudan)(Malawi)

Discuss the use of the existing mobile vans approach to support confirmatory diagnosis of persons with PTLD (specific for Tanzania)

Expansion of these interventions by MKUTA to cover all regions where they have a presence, starting with mining districts. MKUTA could mentor other CSOs to scale up this intervention (specific for Tanzania)

Lobby with the Ministry of Gender to access district-level safety nets and soft loans. For example, this might be done through National Economic Empowerment Fund (specific for Malawi)

## Approach 5: Capacity building of health workers and volunteers on Inclusive health communication, post TB disabilities, and lung rehabilitation

#### Malawi

In Malawi, the project provided training in Inclusive Health Communication for nurses and volunteers at the national level, and training in lung rehabilitation to health staff and volunteers at nine sites. In total, 1054 nurses and volunteers were trained in Inclusive Health Communication (with an eLearning version available in English and Chichewa), 298 health workers and volunteers oriented on post TB, complications and support. Also 56 people (CHWs/HSAs and volunteers) were trained in lung rehabilitation, managing the PRP, as well as the assessments pre and post the program. To assess former TB patients for post-TB complications, 137 people were trained. Feedback from staff discussions in Mchinji, Kaigwazanga, and Zomba, Matawale, indicated that the LR training was useful in resolving PTB complications, such as shortness of breath, high blood pressure, and psychological effects. However, suggestions were made to improve the training, including the involvement of health professionals, guidance on how to follow up with participants discharged from PRP, procurement of enough equipment, strengthening nutrition support, and utilizing physiotherapy trainers from within the district. The project's low-cost intervention was supported by Paradiso and health authorities, who wished to scale it up and integrate it into other programs. The plan includes analyzing data with the district team during quarterly review meetings and training more health workers to bring the services closer to the community when rolling out the interventions.

The project adjusted the delivery of training content based on feedback from district partners, including increasing the number of training days to accommodate slower learners, conducting mentorship sessions, and coaching volunteers on using inclusive health communication skills with persons with PTLD/PTBD. Nurses and clinicians had little time for the baseline assessment process. For that reason TB officers (who don't have medical training) were trained, and in most cases a nurse would be available for difficult assessments.

The COVID-19 pandemic delayed all aspects of the project implementation, including capacity building of volunteers and health workers, although some training continued with preventive COVID-19 precautions..

The LR program in Malawi has primarily been run by HSAs and volunteers, without the involvement of nurses and clinicians, although the latter have played a crucial role in providing services to those with comorbidities. Paradiso recommends including nurses and clinicians in the program through training and mentorship and providing refresher training and additional healthcare workers. E-learning is new in Malawi. In 2022 there were 4 million internet users, with a penetration of 20% of the population, a number that is growing<sup>1</sup>. Internet use amongst health workers, HSAs and volunteers is unknown, possibly limiting perspectives for eLearning (the IHC course).

To expand the LR program, more health workers need to be trained, mentored, and provided with refresher training. Additionally, the intervention needs to be scaled up, which will involve training staff in new facilities.

\_

<sup>&</sup>lt;sup>1</sup> <u>Digital 2022: Malawi — DataReportal – Global Digital Insights</u>

#### Tanzania

The project in Tanzania has successfully trained staff in mental health evaluation and inclusive health communication, empowering them to mentor other health facility staff. Those trained in lung rehabilitation have seen significant improvement and also their own health and wish for all staff to receive training and refresher courses. The project recommends applying for funding in the next Global Fund application to sustain transport allowance for lung rehabilitation participants and extend services to other areas of the country, particularly mining communities most affected by silicosis and with populations likely to have PTLD with delayed diagnosis and treatment.

Due to the need for social distancing during the pandemic, many trainings in Tanzania were put on hold, with an increase in online training, in Swahili, for those who could attend. However, for lower cadre health personnel, general training and continued education sessions did not happen. Healthcare professionals are actively seeking online and physical training to safeguard their registration through continued professional development and these training could be accredited for that. In October 2021 and May 2022, different training sessions were conducted utilizing the same trainers for different cadres, including mental health training conducted by experts from Dar es Salaam who conducted separate sessions for all cadres.

Initially, PTLD was referred to specialists in major hospitals, but now, they can be referred to the local level for lung rehabilitation. The project conducted a one-week training in October 2021 on TB, post-TB lung disability, inclusive health communication, and physiotherapy, followed by a refresher training in May 2022 on IEC, mental evaluation, and the Hope APP, the latter reducing the paper load related to recording and reporting.

The trained volunteers are willing to train others, and MKUTA is seeking to increase the volunteer base and include younger volunteers for the lung rehabilitation exercises. There is a need for continued capacity building for trained individuals to mentor colleagues, and different projects from donors can help with this training.

#### Sudan

The Hilat Koko center in Sudan has implemented measures to improve communication with ex-TB patients with disabilities and encourage their independence. They are sharing their experiences, and there were awareness sessions on disabilities and regular workshops on health communication for all workers in the center. A worker involved in research is looking to write a paper on how the program has supported ex-TB patients with disabilities in Sharg Alneel locality. The project aims to connect persons with PTLD/PTBD to the Sudanese Disability Union and government-provided social support and opportunities.

In Sudan, 1267 individuals have been trained to deal with post-TB disability, and 2600 staffs oriented about how to do medical assessments of former TB patients, well above the targets that were set. For IHC, 350 people were trained. The Ministry of Human and Social Development in Sudan supports development and training, and the MoH sponsors courses related to health, including nursing and special cases like this. The MoH has an Institute of Public Health where they provide free training. These are opportunities for the project's sustainability.

The training in Sudan has helped health workers identify TB disabilities early, and volunteers have received psychological support to understand that the disability caused by TB is not contagious, breaking the stigma associated with TB. The training for Sudanese Disability Union's workers helped them understand that the disability caused by TB is not contagious, which they used to believe. Although medical doctors have a high turnover rate, there has been no turnover in healthcare providers at the two project

implementation centers and at the central level, and the project works with medical assistants.

The project in Sudan recommends having printed guidelines available in every center on how to deal with disabilities and training health workers based on these guidelines, even if staff turnover occurs. The Ministry of Human and Social Development supports development and training, and the MoH sponsors courses related to health, including nursing and special cases like this, indicating that there is potential for continued capacity building in the country.

#### OECD criteria assessment

Approach 5: Capacity building of health workers and volunteers on Inclusive health communication, post TB disabilities, and lung rehabilitation

OECD criteria	Score	Why do you give this score?
Relevance	Excellent  Excellent  Excellent	Malawi: The project created a pool of trainers who are providing IHC training at HF level. The LRP training was carried out by physiotherapists and Paradiso/NONM.  Tanzania: The intended workers and volunteers were trained adequately  Sudan: Capacity building has been very good, and training
		content to the point
Cohorongo	Excellent	<u>Malawi</u> : The availability of in-district physiotherapists assisted training of local volunteers at HF, no external support was needed.
Coherence	Excellent	<u>Tanzania</u> : Project staff have used their training to mentor and train other non-project staff
	Excellent	<u>Sudan</u> : Support in capacity building from HF staff has been really good, in the majority of the sites
Effections	Excellent	<u>Malawi</u> : The project was effective in building skills of local volunteers using the local trainers.
Effectiveness	Excellent	<u>Tanzania</u> : Training was conducted as intended after COVID- 19 restrictions were eased
	Excellent	Sudan: Volunteers and health staff have been able to upgrade their skills and apply it
Efficiency	Excellent	<u>Malawi</u> : The project was so cost effective in building skills of the local volunteers at community level using local trainers and locally available resources
·	Good	<u>Tanzania</u> : Training of the different health cadres was done collectively with good utilization of the trainers. The online IHC and Hope APP training were very effective.
	Good	Sudan: Simply good value for money
Impact	Excellent	<u>Malawi</u> : The approach of capacity building of local volunteers at community level helped in bringing services closer to where they were most required, and this helped to change the lives of people affected by TB
	Good	<u>Tanzania</u> : The practice of training in groups, online training, and continued mentorship worked well
	Excellent	<u>Sudan</u> : All three main interventions (LR, IHC and Socioeconomic support) made a big difference for persons with PTLD/PTBD
	Good	<u>Malawi</u> : The use of local trainers assures continuity of the intervention beyond the project life span
Sustainability	Good	<u>Tanzania</u> : Training capacities in the project area have been developed and KIDH also improved its capacities in PTLD. However, but for sustainability, the NTLP needs to include these modules in the training for the different cadres of health workers
	Good	<u>Sudan</u> : Given modest funding, this activity can be expanded, and the NTP can make use of existing trained volunteers and staff to expand the effort

#### Recommendations

#### Top recommendation:

Inclusive health communication, PTBDs and lung rehabilitation should be introduced as part of all TB training sessions for health care workers, using TOT and a training cascade. The national TB programs could make use of courses and curricula developed by LHL International. (Sudan)(Tanzania)(Malawi)

#### Other recommendations:

Through different professional bodies, include IHC and different aspects of PTLD/PTBD in short online courses that could provide CPD points. Such an approach would also be useful in future pandemic situations. Despite limitations, online training should be encouraged as much as possible. (Sudan)(Tanzania)(Malawi)

Utilize trained staff and volunteers from this project as trainers of trainers in the future when scaling up this intervention. (Sudan)(Tanzania)(Malawi)

Extending the successful IHC training beyond the scope of PTBD could assist other programs in identifying and tackling issues relevant for discrimination/stigma related to other disabilities. (Sudan)(Tanzania)(Malawi)

### Approach 6: Share results and advocate to regional and national health authorities

The projects in Malawi, Tanzania, and Sudan have highlighted the need for sharing their achievements and best practices with national health authorities and other key partners. There is a draft policy brief available for PTLD/PTBD in Malawi and it needs to be shared with NTLEP. There is also a need for resources and funding for the implementation of the intervention after the development of the policy.

#### Malawi

The Malawi project has made efforts to raise awareness about post-TB disabilities (PTBD) among key stakeholders during 53 events, but there is a lack of policy and guidelines to implement the intervention, and financial resources may be needed for smooth implementation. The National Tuberculosis and Leprosy Program (NTLEP) suggests scaling up the implementation of the project to other districts with financial support to sustain the intervention. Paradiso suggests including PTBD care into the TB management pathway, capacity building for health workers, scaling up the intervention to more facilities, and more advocacy for the intervention.

During the launch and other meetings, the Malawi project created awareness about PLTD/PTBD among key stakeholders. However, the need to provide support to persons affected by TB is not prioritized in other programs that promote livelihood. The NTLEP recommends linking them to other programs that promote livelihood like social cash transfer and food supplementation programs. However, the awareness about the need for interlinkages is low among the zonal office and other sectors, and only seven health facilities are implementing the intervention across the country.

The project's advocacy meetings were delayed considerably by the COVID pandemic as implementation started after the pandemic had stabilized. In Zomba and Mchinji, community leaders and the DHO had good interest and support towards PTBD activities, but attention shifted during the COVID pandemic. The Malawi project has compiled achievements and best practices which will be shared at a dissemination workshop at the end of the project. At the time of the evaluation, the project kept the NTP well-informed through a national NTP research conference in Blantyre (2021), a stakeholder meeting on post TBG in Lilongwe in 2021, internationally the Union conference in 2022, and members of the Malawi TB caucus. However, at the time of the evaluation the NTP stated that PTLD/PTBD was not part of the NSP yet, as there was no standing policy about it yet. Shortly after the evaluation, however, it became clear that PTLD/PTBD does now feature in the most recent NSP revision, together with a needed budget for continuation and roll out of PRP.

The NTLEP suggests reflecting PTBD issues in the NSP and guidelines, establishing a sub-TWG, and seeking support from higher levels such as the ministry or parliamentarians. The project in Malawi has achieved significant progress in improving the lives of people affected by TB, which can be used to advocate for policy change and the inclusion of PTBD care in the NSP.

#### Tanzania

In Tanzania, two projects have been identified: one focused on identifying and providing lung rehabilitation to persons with post-TB lung disabilities in two districts (this project), and another being conducted by NIMR in Mbeya studying the pathogenesis of post-TB lung disease. Tanzania urgently needs policies to address PTLD/PTBD, and the National Tuberculosis and Leprosy Program (NTLP) is awaiting the project report to provide relevant information for the upcoming revision of the National Strategic Plan. Tanzania has a well-established system for obtaining approval from national authorities for project activities, which then trickles down to the implementers. Related to this, dissemination

of project results was done in April 2023, with the national NTLP coordinator confirming inclusion of PTLD/PTBD in the revised National Strategic Plan.

Subnational health authorities are involved in the project in Tanzania and are familiar with the results. National level authorities approved project conduct and are closely following up on the conduct of the project, awaiting the final report. The Tanzanian national authorities are aware of the utilization of exercise fields within the community for lung rehabilitation by the project, as they are of the project's ability to increase TB case notification and capacity building for volunteers and health facility staff. They appreciate the management of mental health issues and counselling offered by trained staff. Local health authorities and implementing partners need to decide on a package of remuneration for volunteer community health workers to sustain the work of finding people with TB and PTLD/PTBD.

The project in Tanzania was able to identify active TB patients among ex-TB patients, and even some MKUTA members were diagnosed with active TB. A care package based on project experience has been developed and will be piloted in an urban district (Temeke in Dar es Salaam), with a focus on monitoring symptomatology, the 6-minute walk, and chest x-ray.

More information is needed on the policy of the 4th 90% in Tanzania. Persons with PTLD/PTBD in Tanzania could advocate for themselves through testimony at local and national meetings, with assistance from volunteers and health authorities. PTLD/PTBD persons and volunteers in Tanzania are eager to share their experiences with lung rehabilitation, and a documentary is in preparation.

#### Sudan

In Sudan, HDP worked with the Ministry of Health to train volunteers and care providers at treatment centers to address disabilities caused by TB. The project involved coordination between various departments, linkage of volunteers with treatment centers, and community outreach. Ex-patients were educated about TB-related disabilities, volunteers provided psychological support, and patients' rights were addressed. However, policies need to change to include vocational training and income-generating opportunities for people who have overcome their disabilities.

The project continued during the pandemic with the help of the Sudanese Disability Union. Although the government's attention towards it is increasing but not meeting expectations. However, health authorities are present in meetings and activities, and coordination with the MoH prevented delays in project implementation. Interviewees suggested to establish a committee for people with TB disabilities at the national level to ensure information sharing and collaboration with stakeholders.

The MoH only partners with the Disability Federation, but the project could be more effective by also partnering with the ministries of human and social development and the Zakat fund, which have specialized training centers at the state level and can reach families in their homes. Regular information sharing with stakeholders and the establishment of a national committee can ensure sustainability.

#### OECD criteria assessment

Approach 6: Sh		and advocate to regional and national health authorities
OECD criteria	Score	Why do you give this score?
	Good	<u>Malawi</u> : Interim results of the project were shared, as was the project's MTR No results have been shared so far awaiting end of project evaluation
Relevance	Excellent	<u>Tanzania</u> : Project made all the necessary communications with the national and subnational authorities and have been updating them
	Good	<u>Sudan</u> : Advocacy at national and district levels differed, but also received a high priority from all actors
	Good	<u>Malawi</u> : Interim results have been shared at national level with relevant stakeholders, and the MOH indicated that PTBD/PTLD will have a place in the NSP for TB
Coherence	Excellent	<u>Tanzania</u> : Ongoing sharing of results has been optimal, and PTBD/PTLD issues are included in the NSP for TB
	Neutral	<u>Sudan</u> : Advocacy and sharing was primarily a function of the project and much less so by other local actors taking part in this project
	Good	<u>Malawi</u> : Interim results of the project were shared, as was the project's MTR
Effectiveness	Good	<u>Tanzania</u> : The information has been shared within the regions and at national and international level (Union 2022), but not widely circulated to non-project regions. PTBD is included in the NSP.
	Neutral	Sudan: The project has not yet led to policy formulation
Efficiency	Excellent	<u>Malawi</u> : There has been a compilation of success stories and achievements pending dissemination
	Excellent	<u>Tanzania</u> : Interaction with subnational players was ideal
	Neutral	Sudan: Cannot judge this really, and efforts differed per site
	Good	<u>Malawi</u> : Results of the project have led to the inclusion of PTBD in the revision of the NSP.
Impact	Good	<u>Tanzania</u> : Communication of any intervention to national and other stakeholders from the outset results into buy-in
	Neutral	<u>Sudan</u> : In Sudan it seems that advocacy has caught the attention of the NTP, but it is not clear to what extent this will be successful.
	Good	Malawi: Results of the project have led to the inclusion of PTBD in the revision of the NSP.
Sustainability	Good	<u>Tanzania</u> : With good awareness of national and regional players, cooperation on ways to assure sustainability happens
	Good	<u>Sudan</u> : Advocacy and dissemination of results after the end of the project will be done during the rest of the partnership period between LHL International and HDP, at least till 2025.

#### Recommendations

#### Top recommendation:

Strengthen advocacy work to effectively disseminate project achievements and best practices with key in-country stakeholders (national and subnational) and funders (such as GF, USAID, CDC) to lobby for policy revision to include PTBD care in the TB space and other sectors that can provide support to persons with PTBD. This includes program grant making. (Sudan)(Tanzania)(Malawi)

Distribute information on the "fourth 90" policy (90% of persons with PTLD/PTBD receive social and medical support) to all national and subnational authorities in high burden countries, accompanied by advocacy and adoption strategies (Sudan)(Tanzania)(Malawi)

#### Other recommendations:

Write policy briefs, as was done in Malawi for PTBD and LR, about how to provide support for persons with PTLD and mental health issues (Sudan)(Tanzania)(Malawi)

Document and compile all best practices for the purpose of dissemination at national and international level. A good example is the documentary made in Malawi (Sudan)(Tanzania)(Malawi)

#### Achieved output results

The project has used a results framework to summarize the level of implementation of activities as compared to the targets that were set. Final results are awaited at the end of the project after June 2023, but here interim results are presented.

Table 6: Targets and results 2020-2022, all three countries

	MA	LAWI	TAN	ZANIA	SUI	DAN
Post TB disability	Total target 2020- 2022	Total result 2020 - 2022	Total target 2020- 2022	Total result 2020 - 2022	Total target 2020- 2022	Total result 2020 - 2022
Impact: The burden of TB is reduced						
Overall project outcome: The rights and needs of people with post-TB disability in countries is met						
a) Zero increase in unemployment due to post TB disabilities	0	0				
b) Reduced proportion of people experiencing activity limitations due to TB one year after treatment						
completion	0	10.3%	40%	40%		
c) Number of people with post TB disabilities that access care and support	2780	1172	500	554		700
c) Number of people with post 16 disabilities that access care and support	2/00	11/2	300	334		700
Lower outcome 1: The health system is able to manage patients with post-TB disability						
	CE0/	81%	50%	67%	60%	050/
1 A. % increase in knowledge among trained health workers and treatment supporters (pre-test vs post-test)	65%	47	50%	6/%		85%
1B. Number of post -TB support groups	48		1	1	255	130
1C. Pulmonary rehabilitation program in place		1	1	2	36	4
1D. Number of post TB disability friendly clinics established	0	9	2	2	4	
1E. E-learning course on inclusive health communication established in local language	0	1	0	1	2	0
Output 1.1. Health workers and treatment supporters have the required skills to care for and support former						
Tb patients with disabilities						
Number of people trained in post TB complications and support	1194	774	65	40	350	1267
Number of people trained in inclusive health communication	1565	1054	40	40	400	350
Number of people oriented on undertaking medical assessment of post TB patients	350	137	30	40	150	2600
Number of assessments of clinics conducted	7	0			4	4
Output 1.2. Post-TB patients with disability are reached with medical rehabilitation						
Number of former TB patients undergoing a medical assessment	1325	726	200	554	400	760
Number of people included in the pulmonary rehabilitation program	337	467	100	121	17	902
An App for registration, assesment and support plan is developed	1	1	1	1	1	1
Number of people registered in the app	3380	2011			800	334
Lower outcome 2: Post TB disability patients ' rights are a priority						
2A.Number of research and advocacy influencing policy change and/or change of practice	5	6	1	1	1	1
2 B. Number of abstracts and presentations submitted and held at national and international conferences	6	23	3	2	3	2
Output 2.1. Relevant authorities are informed about post TB disabilities, activity limitations and needs	2	2	1	4	2	2
Assessment of burden of post TB disabilities undertaken	31	3 53	3	1	16	68
No of advocacy meetings			3	1		
A briefing on post TB disability in national TB caucus held	4	2			2	1
Operational research conducted and conclusions shared with authorities	0	0	1	1	0	2
Output 2.2. Post-TB patients with disability are reached with social support		0:-			0	
Number of people with post TB disabilities followed up by treatment supporters	1880	615			600	320
Number of people with post TB disability that receives nutritional support	600	90		121	400	1200
Number of people with post TB disability reached with skills training	162	0	15	0	400	600
Number of people with post TB disability participating in income generating activities	473	146			60	40

Some data were not accessible when writing this report, but the overall picture is a very positive one.

The overall project outcome in terms of the number of people with post TB disabilities that access care and support has exceeded the targets, indicating a very effective set-up of the project. Activity limitation became less. To measure unemployment was difficult. The level to which the health system was able to manage persons with post-TB disabilities has been successful, with some caution about setting up support groups,

although from the field visits it is very clear this is a big success and the main motivating factor for people with PTBD/PTLD to participate.

Targets to improve health workers skills were impacted by the COVID-19 pandemic, but overall very good results were booked.

The number of persons with PTBD reached exceeded the targets that were set in all three countries. The Hope app to record them is in use in all three countries as well, which is a nice accomplishment and ready for further roll-out and possible adoption elsewhere.

Giving priority to the rights of persons with PTBD was underlined with several publications and advocacy events, as was planned or exceeded.

Informing authorities has happened according to plan, with the number of advocacy meetings exceeding the targets. The evaluators deem this very important, as without such "voice" about the project and the plight of persons affected by TB, the important work of this project is easily overlooked. The project is commended for these efforts.

The number of persons affected by TB reached with social support was affected by the Covid-19 pandemic in Malawi, but not in Sudan. A mixed picture is seen here, mostly due to contextual factors and budgetary limitations. Being an essential part of the approach to PTBD/PTLD, for rolling out social support local partnerships and interprogrammatic collaboration must be sought.

#### Relevance of objectives and outcomes

For the most part the Theory of Change (TOC) underlying this project still stands and this evaluation underlines its relevance. The TOC is depicted below. However, including the process of transforming practice into policy and roll-out of the approach might benefit the project. This applies both to the lower part of the TOC (situational analysis) and the upper part of the TOC, namely, how to get from a successful project to improvements at scale (nation-wide). In practice this has happened, at least in Malawi and Tanzania, where PTLD/PTBD issues have been included in the National Strategic Programs for TB. This is to the credit of the local implementation partners, with the support of LHL International.

Impact: The burden of TB is reduced in Malawi, Sudan, Tanzania and Zambia Overall outcome: The rights and needs of people with post-TB disability in Malawi, Sudan, Tanzania and Zambia are met The health system is able to manage patients with post-TB disability Post-TB disability patients' rights are a priority in Malawi, Sudan, Tanzania & Zambia Advocacy Health workers, treatment for right to supporters and Community based Improving quality health. correctional officers have of care and support groups for people with post-TB the required skills to care and labour support for rights/ disabilities for and support former Tb people with post-Project working patients with disabilities intervention conditions for people with post TB screening of TB identify the burden health workers orkers disabilities and needs of post correctional officers and TB disabilities treatment supporters are Screening of former trained Shortage of HW leads to Health workers are at higher Health workers (HW) have limited knowledge on risk of contracting TB demotivated and burn-out post-tb disabilities People with post-TB disabilities have Situational analysis reduced income, due People with post-TB disabilities lack People with post-TB disabilities face Limited data stigma and social exclusion on the level adaptation at work / oss of job and stigma MoH and National TB Programs does not prioritize people with post-TB disability. They are left behind in all aspects; health, social and economic

Figure 1: Theory of Change

#### Limitations of the evaluation

#### Malawi

Poor road conditions because of heavy rains affected selection of districts – districts with poor road conditions were not included on the list of districts to be visited.

#### Tanzania

The evaluation was conducted well, and project management was very keen to provide a conducive environment. However, time wasn't enough to organize and conduct productive focus group discussions with the PTLD/PTBD persons themselves. As such, most of the interviews were one-on-one except for the FGD immediately after participation in LR exercises.

#### Conclusions and recommendations

Overall, the project is having a very positive impact on the lives of people affected by PTLD/PTBD, in all three countries. The combination of interventions (lung rehabilitation, inclusive health communication, nutrition support, and income support) has particularly been beneficial, and it is difficult to assess the impact of individual, stand-alone interventions. It is therefore recommended that interventions are offered as a package, while exploring the impact of stand-alone interventions. In particular income support needs rethinking when rolling out the approach, exploring better linkages to local income support initiatives.

In terms of the OECD-DAC criteria, here follows an overview of what the evaluators thought of it after having spoken with diverse stakeholders in the three countries:

Table 7: OECD-DAC criteria applied to the main interventions of the project, overview

	Malawi	Tanzania	Sudan
Approach 1: Identification of people with	· ·	the state of the s	-
TB lung disease and mental health. Mapp among former TB patients and how it affe			olems
among former 18 patients and now it arre	ects their live	5.	
Relevance	Excellent	Excellent	Excellent
Coherence	Good	Good	Good
Effectiveness	Excellent	Excellent	Good
Efficiency	Excellent	Good	Neutral
Impact	Excellent	Excellent	Excellent
Sustainability	Good	Good	Good
<b>Approach 2: Collaboration between local</b>	health systen	and commun	ity-based
organizations			
Relevance	Good	Excellent	Good
Coherence	Good	Excellent	Neutral
Effectiveness	Good	Good	Good
Efficiency	Good	Good	Neutral
Impact	Good	Good	Neutral
Sustainability	Good	Good	Neutral
Approach 3: Development and implement	ation of a loc	al and volunte	er-based
lung rehabilitation	1		
Relevance	Excellent	Excellent	Excellent
Coherence	Excellent	Excellent	Good
Effectiveness	Excellent	Excellent	Excellent
Efficiency	Excellent	Good	Good
Impact	Excellent	Excellent	Excellent
Sustainability	Excellent	Good	Good
Approach 4: Social and medical support t			The second secon
e.g. follow-up/home visits, medical check vocational training and income generating			
rehabilitation in some sites	g activities, ii	addition to t	ne lung
Relevance	Excellent	Excellent	Good
Coherence	Neutral	Neutral	Neutral
Effectiveness	Good	Good	Excellent
Efficiency	Excellent	Excellent	Good
-			<u>!</u>

	Malawi	Tanzania	Sudan
Impact	Excellent	Good	Good
Sustainability	Neutral	Good	Not so good
Approach 5: Capacity building of health w health communication, post TB disabilities			nclusive
Relevance	Excellent	Excellent	Excellent
Coherence	Excellent	Excellent	Excellent
Effectiveness	Excellent	Excellent	Excellent
Efficiency	Excellent	Good	Good
Impact	Excellent	Good	Excellent
Sustainability	Good	Good	Good
Approach 6: Share results and advocate to authorities	regional and	d national hea	lth
Relevance	Good	Excellent	Good
Coherence	Good	Excellent	Neutral
Effectiveness	Good	Good	Neutral
Efficiency	Excellent	Excellent	Neutral
Impact	Good	Good	Neutral
Sustainability	Good	Good	Good

The in-country evaluators made several recommendations for each of the six project approaches. They can be found under the respective chapters, and here the top recommendations are listed:

Main approach	Top recommendation
Approach 1: Identification of people with post TB disabilities, including post TB lung disease and mental health. Mapping the scope of health problems among former TB patients and how it affects their lives.	Conduct or assist country-level surveys to establish an estimate of the number of people with PTLD/PTBD, as the basis for national planning and preparing adequate resources to address PTLD/PTBD. Alongside, a system for long term follow-up of the people who underwent lung rehabilitation should be established to get a better view on the long-term impact (Sudan)(Tanzania)(Malawi)
Approach 2: Collaboration between local health system and community-based organizations	Continue to engage community volunteers, in collaboration with the local health system, for PTBD and lung rehabilitation as they know the persons better and can follow them up easily. (Sudan)(Tanzania)(Malawi)
Approach 3: Development and implementation of a local and volunteer-based lung rehabilitation	Utilize the upcoming experience in Temeke district (urban high burden TB district, different conditions than Siha and Mirerani) to prepare a care package suitable for Tanzania conditions (and other low-resource settings) (Tanzania)  Develop guidance and a simple booklet in local languages, as was done in the "PRP step-by-step" booklet in Malawi, to guide community health workers and other partners with establishing additional lung rehabilitation centres (Sudan)(Tanzania)(Malawi)

Main approach	Top recommendation
Approach 4: Social and medical support to people with post TB disabilities, e.g. follow-up/home visits, medical check-ups, nutritional support, transport, vocational training and income generating activities, in addition to the lung rehabilitation in some sites	Promote that each project that involves TB community outreach services integrates PTBD/PTLD components into their existing activities. This specifically applies to integration into other programs working at community levels, for example concerning disability, income generation, nutrition, and poverty reduction. (Sudan)(Tanzania)(Malawi)
Approach 5: Capacity building of health workers and volunteers on Inclusive health communication, post TB disabilities, and lung rehabilitation	Inclusive health communication, PTBDs and lung rehabilitation should be introduced as part of all TB training sessions for health care workers, using TOT and a training cascade. The national TB programs could make use of courses and curricula developed by LHL International. (Sudan)(Tanzania)(Malawi)
Approach 6: Share results and advocate to regional and national health authorities	Strengthen advocacy work to effectively disseminate project achievements and best practices with key incountry stakeholders (national and subnational) and funders (such as GF, USAID, CDC) to lobby for policy revision to include PTBD care in the TB space and other sectors that can provide support to persons with PTBD. This includes program grant making. (Sudan)(Tanzania)(Malawi)  Distribute information on the "fourth 90" policy (90% of persons with PTLD/PTBD receive social and medical support) to all national and subnational authorities in high burden countries, accompanied by advocacy and adoption strategies (Sudan)(Tanzania)(Malawi)

#### References

- Abdool-Gaffar, M. S., Ambaram, A., Ainslie, G. M., Bolliger, C. T., Feldman, C., Geffen, L., Irusen, E. M., Joubert, J., Lalloo, U. G., Mabaso, T. T., Nyamande, K., O'Brien, J., Otto, W., Raine, R., Richards, G., Smith, C., Stickells, D., Venter, A., Visser, S., ... COPD Working Group. (2011). Guideline for the management of chronic obstructive pulmonary disease--2011 update. *South African Medical Journal = Suid-Afrikaanse Tydskrif Vir Geneeskunde*, 101(1 Pt 2), 63–73. https://doi.org/10.7196/samj.4490
- Ajayi, O. (2021). The Malawi Quick Guide to Mental Health By The Scotland–Malawi Mental Health Education Project SMMHEP. 2020. eBook. 90 pp. *BJPsych Bulletin*, 45(4). https://doi.org/10.1192/bjb.2021.13
- Alene, K. A., Clements, A. C. A., McBryde, E. S., Jaramillo, E., Lönnroth, K., Shaweno, D., Gulliver, A., & Viney, K. (2018). Mental health disorders, social stressors, and health-related quality of life in patients with multidrug-resistant tuberculosis: A systematic review and meta-analysis. *Journal of Infection*, *77*(5), 357–367. https://doi.org/10.1016/j.jinf.2018.07.007
- Alene, K. A., Wangdi, K., Colquhoun, S., Chani, K., Islam, T., Rahevar, K., Morishita, F., Byrne, A., Clark, J., & Viney, K. (2021). Tuberculosis related disability: a systematic review and meta-analysis. *BMC Medicine*, 19(1). https://doi.org/10.1186/S12916-021-02063-9
- Binegdie, A. B., Brenac, S., Devereux, G., Meme, H., Sony, A. E. L., Gebremariam, T. H., Osman, R., Miheso, B., Mungai, B., Zurba, L., Lesosky, M., Balmes, J., Burney, P. J., & Mortimer, K. (2022). Post-TB lung disease in three African countries. *International Journal of Tuberculosis and Lung Disease*, 26(9), 891–893. https://doi.org/10.5588/IJTLD.22.0261
- Chikaphupha, K. R., Kok, M. C., Nyirenda, L., Namakhoma, I., & Theobald, S. (2016). Motivation of health surveillance assistants in Malawi: A qualitative study. *Malawi Medical Journal*, 28(2), 37–42. https://doi.org/10.4314/mmj.v28i2.2
- Conroy, A. C. (2021). MID TERM REVIEW OF THE POST TB DISABILITIES PROJECT Finally Addressing the Gap.
- Dodd, P. J., Yuen, C. M., Jayasooriya, S. M., van der Zalm, M. M., & Seddon, J. A. (2021). Quantifying the global number of tuberculosis survivors: a modelling study. *The Lancet Infectious Diseases*, *21*(7), 984–992. https://doi.org/10.1016/S1473-3099(20)30919-1
- Evans, D., van Rensburg, C., Govathson, C., Ivanova, O., Rieß, F., Siroka, A., Sillah, A. K., Ntinginya, N. E., Jani, I., Sathar, F., Rosen, S., Sanne, I., Rachow, A., & Lönnroth, K. (2021). Adaptation of WHO's generic tuberculosis patient cost instrument for a longitudinal study in Africa. *Global Health Action*, *14*(1). https://doi.org/10.1080/16549716.2020.1865625
- Harrison, J. A. K., Thomson, R., Banda, H. T., Mbera, G. B., Gregorius, S., Stenberg, B., & Marshall, T. (2020). Access to health care for people with disabilities in rural Malawi: What are the barriers? *BMC Public Health*, 20(1), 1–17. https://doi.org/10.1186/S12889-020-08691-9/TABLES/3
- Meghji, J., Lesosky, M., Joekes, E., Banda, P., Rylance, J., Gordon, S., Jacob, J., Zonderland, H., MacPherson, P., Corbett, E. L., Mortimer, K., & Squire, S. B. (2020). Patient outcomes associated with post-tuberculosis lung damage in Malawi: A prospective cohort study. *Thorax*, *75*(3). https://doi.org/10.1136/thoraxjnl-2019-213808
- Migliori, G. B., Marx, F. M., Ambrosino, N., Zampogna, E., Schaaf, H. S., van der Zalm, M. M., Allwood, B., Byrne, A. L., Mortimer, K., Wallis, R. S., Fox, G. J., Leung, C. C., Chakaya, J. M., Seaworth, B., Rachow, A., Marais, B. J., Furin, J., Akkerman, O. W., Al Yaquobi, F., ... Visca, D. (2021). Clinical standards for the assessment, management and rehabilitation of post-TB lung disease. *The International Journal of Tuberculosis and Lung Disease*, 25(10), 797. https://doi.org/10.5588/IJTLD.21.0425

- Migliori, G. B., Wu, S. J., Matteelli, A., Zenner, D., Goletti, D., Ahmedov, S., Al-Abri, S., Allen, D. M., Balcells, M. E., Garcia-Basteiro, A. L., Cambau, E., Chaisson, R. E., Chee, C. B. E., Dalcolmo, M. P., Denholm, J. T., Erkens, C., Esposito, S., Farnia, P., Friedland, J. S., ... Ong, C. W. M. (2022). Clinical standards for the diagnosis, treatment and prevention of TB infection. *The International Journal of Tuberculosis and Lung Disease*, 26(3), 190. https://doi.org/10.5588/IJTLD.21.0753
- Mpagama, S. G., Msaji, K. S., Kaswaga, O., Zurba, L. J., Mbelele, P. M., Allwood, B. W., Ngungwa, B. S., Kisonga, R. M., Lesosky, M., Rylance, J., & Mortimer, K. (2021). The burden and determinants of post-TB lung disease. *International Journal of Tuberculosis and Lung Disease*, 25(10). https://doi.org/10.5588/ijtld.21.0278
- Ng'ambi, W. B. G. (2021). Post-Tuberculosis Disability Experiences of Healthcare Workers Treated of Tuberculosis in Malawi between 2016 and 2020.
- OECD. (2010). DAC Guidelines and Reference Series Quality Standards for Development Evaluation. https://read.oecd-ilibrary.org/development/dac-quality-standards-for-development-evaluation\_9789264083905-en#page1
- Patel, V., & Hanlon, C. (2018). Where There Is No Psychiatrist: A Mental Health Care Manual. 360. https://www.cambridge.org/core/books/where-there-is-no-psychiatrist/47578A845CAFC7E23A181749A4190B54
- Pontali, E., Silva, D. R., Marx, F. M., Caminero, J. A., Centis, R., D'Ambrosio, L., Garcia-Garcia, J. M., Muhwa, J. C., Tiberi, S., & Migliori, G. B. (2022). Breathing Back Better! A State of the Art on the Benefits of Functional Evaluation and Rehabilitation of Post-Tuberculosis and Post-COVID Lungs. *Archivos de Bronconeumología*, *58*(11), 754–763. https://doi.org/10.1016/J.ARBRES.2022.05.010
- Quaife, M., Allwood, B., Coussens, A. K., Harries, A. D., & Marx, F. (2020). Post-tuberculosis mortality and morbidity: Valuing the hidden epidemic. *The Lancet Respiratory Medicine*, 8(4), 332–333. https://scholar.google.com/citations?view\_op=view\_citation&hl=en&user=CYg0iJ0AAAAJ&citation for view=CYq0iJ0AAAAJ:hC7cP41nSMkC
- Shoib, S., Osman Elmahi, O. K., Siddiqui, M. F., Abdalrheem Altamih, R. A., Swed, S., & sharif Ahmed, E. M. (2022). Sudan's unmet mental health needs: A call for action. *Annals of Medicine and Surgery*, 78. https://doi.org/10.1016/J.AMSU.2022.103773
- Tanzania holds its first-ever national mental health dialogue | WHO | Regional Office for Africa. (2022). News. https://www.afro.who.int/countries/united-republic-oftanzania/news/tanzania-holds-its-first-ever-national-mental-health-dialogue
- TB Sequel Network. (n.d.). Retrieved April 9, 2023, from https://www.tbsequel.org/tb-sequel-network-countries/
- The World Health Organisation- Five Well-Being Index (WHO-5). (n.d.). Retrieved March 22, 2023, from https://www.corc.uk.net/outcome-experience-measures/the-world-health-organisation-five-well-being-index-who-5/
- Tomeny, E. M., Nightingale, R., Chinoko, B., Nikolaidis, G. F., Madan, J. J., Worrall, E., Ngwira, L. G., Banda, N. P., Lönnroth, K., Evans, D., Chakaya, J., Rylance, J., Mortimer, K., Squire, S. B., & Meghji, J. (2022). TB morbidity estimates overlook the contribution of post-TB disability: evidence from urban Malawi. *BMJ Global Health*, 7(5). https://doi.org/10.1136/bmjgh-2021-007643
- Topp, C. W., Østergaard, S. D., Søndergaard, S., & Bech, P. (2015). The WHO-5 well-being index: A systematic review of the literature. *Psychotherapy and Psychosomatics*, 84(3). https://doi.org/10.1159/000376585
- Udedi, M. (2016). Improving access to mental health services in Malawi. In *Policy Brief* (MOH). https://doi.org/10.13140/RG.2.1.3996.9524
- Vasantha, M., Muniyandi, M., Ponnuraja, C., Srinivasan, R., & Venkatesan, P. (2021). Bayesian structural equation modeling for post treatment health related quality of life among tuberculosis patients. *PLoS ONE*, *16*(5 May 2021). https://doi.org/10.1371/journal.pone.0252205
- Wanner, A., Edwards, M., Harries, A. D., Kirenga, B. J., Chakaya, J., Jones, R., & Van Kampen, S. C. (2018). International research and guidelines on post-tuberculosis chronic lung disorders: a systematic scoping review. *BMJ Global Health*, 3(4), e000745. https://doi.org/10.1136/BMJGH-2018-000745

- WHO. (2017). *Tuberculosis patient cost surveys: a handbook*. WHO Guideline. https://www.who.int/publications/i/item/9789241513524
- WHO. (2020a). *Mental Health Atlas 2020: Sudan*. https://datahelpdesk.worldbank.org/knowledgebase/topics/19280-country-classification
- WHO. (2020b). *Mental Health Atlas 2020: Tanzania*. https://datahelpdesk.worldbank.org/knowledgebase/topics/19280-country-classification
- WHO. (2022). Global Tuberculosis Report. http://apps.who.int/bookorders.
- World Health Organization. (2010). Measuring Health and Disability: Manual for WHO Disability Assessment Schedule WHODAS 2.0. In *World Health Organization*.

# Annex 1: Evaluation matrix

The matrix outlines how the six main project activities will be evaluated along the lines of the OECD-DAC criteria. We assess the issues as described in the various cells, the method to gather data / information and the target group from which the information /data is to be obtained.

	Interventions as	stated in the TOR				
OECD DAC evaluation criteria	1. Identification of people with post TB disabilities, including post disabilities, including post TB lung disease and mental health. Mapping the scope of health problems among former TB patients and how it affects their lives.	2. Collaboration between local health system and community-based organizations	3. Development and implementation of a local and volunteer-based lung rehabilitation	4. Social and medical support to people with post TB disabilities, e.g. follow-up/home visits, medical check-ups, nutritional support, transport, vocational training and income generating activities, in addition to the lung rehabilitation in some sites	5. Capacity building of health workers and volunteers on Inclusive health communication, post TB disabilities, and lung rehabilitation.	6. Share results and advocate to regional and national health authorities
1 «Relevance»: Considering the target group's needs and the Project's theory of change	et group's needs and tl	he Project's theory of cl	hange			
	Issue	Issue	Issue	Issue	Issue	Issue
	Method	Method	Method	Method	Method	Method
	(target group)	(target group)	(target group)	(target group)	(target group)	(target group)
1a. Does the Project have a relevant	1a.1. Health needs met of		1a.3. Existence and extent	1a.4. Extent of social and	1a.5. # of health workers	1a.6. # of advocacy events.
approach?	persons affected by TB?	CBOs taken into account by	of a volunteer-based lung	medical support other than	and # volunteers	Describe.
	Hiw did it affect their lives?	the local health system?	rehabilitation system. How	lung rehabilitation? Can you capacitated	capacitated	> reports
	> FGD	Was there any form of	did it come to this point?	give examples?	> reports	(implementation partner)
	(members of organizations	collaboration and how did	> interview &	> documentation / reports (implementation partner)	(implementation partner)	
	of persons affected by TB)	that look like?	documentation	(implementation partner)		
		> Interview	(local CBO & local health			
		(local CBO)	authority)			
	1a.1. Mapping documented	(1000)	action(y)		1a.5. Opinion of health	1a.6. Awareness about
	of scope of health problems				workersand of volunteers	PTLDand activities among
	> Review of documents				about capacitation	regional and national health
	(implementing partner)				> FGD	authorities. Describe what
					(health workers)	is known
						> interview
						(national and 1 regional
1h Does the Project have relevant	This is nepoling till the project		hiectives and expected outcomes are made available by I HI	Ξ		
objectives and outcomes?		)				
1c. What should we do more of, or in			1c.3. What should we do		1c.5. What should we do	1c.6.What should we do
addition to, existing initiatives?		ion to,	more of, or in addition to,	more of, or in addition to,	more of, or in addition to,	more of, or in addition to,
		existing initiatives?	existing initiatives?	existing initiatives?	existing initiatives?	existing initiatives?
		Suggestions by health	Suggestions by	Suggestions by	Suggestions by local health	Suggestions by
		center staff, local health	implementation partners	implementation partners	authorities, CBOs, and	implementation partners
		authorities, CBOs, and	> interviews	and organizations of people organizations of people	organizations of people	and national regional health
		organizations of people		affected by TB	affected by TB	authorities, and
		affected by TB		> interviews	> interviews	organizations of people
		> interviews				affected by TB
						> interviews

		stated in the TO	50000		- 1	
OECD DAC evaluation criteria	1. Identification of people with post TB disabilities, including post TB lung disease and mental health. Mapping the scope of health problems among former TB patients and how it affects their lives.	2. Collaboration between local health system and community-based organizations	3. Development and implementation of a local and volunteer-based lung rehabilitation	4. Social and medical support to people with post TB disabilities, e.g. follow-up/home visits, medical check-ups, nutritional support, transport, vocational training and income	5. Capacity building of health workers and volunteers on Inclusive health communication, post TB disabilities, and lung rehabilitation.	6. Share results and advocate to regional and national health authorities
2 Coherence»: How well does the intervention fit? Assess the initiative's added value. Look at both external and internal synergies	itervention fit? Assess	the initiative's added	I value. Look at both e	xternal and internal sy	nergies	
	lssue	lssue	lssue	lssue	lssue	lssue
	Method (terror group)	Method (respet group)	Method	Method (Parget group)	Method (teroot group)	Method
2. Enternal arternation from	Carl Javaliahananah	(death adies)	(dnoif) jafije))	2. 4 Evisional	(dnoth )aftigu)	Carget group)
Za. External coherence: from synergies/interlinkages with	Za. I. Interlinkages with other programs:			Za. 4. Existence and extent of social and		Za.b. Za. I. Interlinkages with other programs:
systems and potential other post-	NSP and grant			other channels than NTP		messages l'visits
TB interventions, to Norway's	applications			> document review		> documentation /
strategy on inclusion of persons  with disabilities in international development and recent evaluation on disability inclusion	> documentreview (NTP)			(via NTP)> interview (CSOs and organizations of persons affected by		reports (implementing partner)
	2a.1. 2a.1. Interlinkages	SIR .		, and		2a.6. 2a.1. Interlinkages
	with other programs:					with other programs:
	Existence of multispectoral link ages					Awareness of national
	(MAF)					authorities about the
	> document review					need of an intersectoral
	(via NTF)> interview (via COM TUC TE)					approach to Pillus> interview
						health authorities)
2b. Internal coherence: synergies and interlinkages of LHL International and partners' interventions in the same setting	2b. 1. Synergies: Extent of integration of issues for persons with PTLD and persons with other disabilities  -> interview & perhaps documentation implementation partner and CSO!	2b. 2. Synergies: Extent of collaboration between CSO and the local health system concerning issues of persons with disabilities other than PTLO —-> interview (CSO and local health	2b.3. Synergies: Do volunteer networks engage in other issues than only PTLD? —-> interview (implementation partner and CSO)	2b. 4. Synergies: Existence and extent of social and medical support through other channels than NTP > document review (via NTP) > interview (CSOs and organizations		

	Interventions as	stated in the TOR	~			
OECD DAC evaluation criteria	1. Identification of people with post TB disabilities, including post TB lung disease and mental health. Mapping the scope of health problems among former TB patients and how it affects their lives.	2. Collaboration between local health system and community-based organizations	3. Development and implementation of a local and volunteer-based lung rehabilitation	4. Social and medical support to people with post TB disabilities, e.g. follow-up/home visits, medical check-ups, nutritional support, transport, vocational training and income	5. Capacity building of health workers and volunteers on Inclusive health communication, post TB disabilities, and lung rehabilitation.	6. Share results and advocate to regional and national health authorities
3 «Effectiveness»:						
	Issue Method Itaraet group)	Issue Method (target group)	Issue Method (target group)	Issue Method Itaraet group	Issue Method (target group)	Issue Method (target group)
ı	3-1 Tondin	32.2 Trandin	San Transfir # of	3.4 Tronders # 06	32 C Trond in # books	3x B. Okanand nalising
3a. Is the Project reaching its objective, outcomes and results? Describe key reasons whyllwhy not the Project will reach its planned objectives, outcomes and results.	3a.1. Trend in identification of persons with PTLD and mental health issues: what are underlying reasons? > reports (implementation partner)> interview about reasons (implementation partner) (implementation partner)	3a.2. Trend in collaborative activities: what are underlying reasons?> reports (implementation partner)> interview about reasons (implementation partner and local health authorities)	3a.3. Trend in # of volunteers engaged in LR initiatives: what are underlying reasons?> reports (implementation partner)> interview about reasons (implementation partner)	3a.4. Trends in # of social and medical support rendered: what are underlying reasons?> reports (implementation partner)> interview about reasons (implementation partner)	3a,5. Trend in # health workers capacitated: what are underlying reasons?> reports (implementation partner)> interview about reasons (implementation partner)	3a.6. Changed policies / activities to the benefit of persons with PTLD and/or mental health problems: what are underlying reasons? > reports (implementation partner)> interview about reasons (implementation partner) health authorities)
	3a.1. Documented scope of health problems among former TB patients:> reports (implementation partner)> interview about reasons			3a.4. Trends in # of persons taking part in and benefitting from LR activities: what are underlying reasons?> reports (implementation partner)		
3b. How has the pandemic and the following financial crisis affected the effectiveness of the Project?	3b.1. Trend in identification of persons with PTLD and mental health issues before, during and after the pandemic. What are underlying reasons? > reports (implementation partner)> interview about reasons (implementation partner) (implementation partner)	3b.2. Trend in collaborative activities before, during and after the pandemic —> reports (implementation partner reasons (implementation partner and local health authorities)	3b.3. Trend in # of volunteers engaged in LR initiatives before, during and after the pandemic> reports (implementation partner) reasons (implementation partner)	3b.4. Trends in # of social and medical support rendered before, during and after the pandemic> reports (implementation partner)> interview about reasons (implementation partner)	3b.5. Trend in # health workers capacitated before, during and after the pandemic> reports (implementation partner) reasons (implementation partner)	3b. 6. Attention of health authorities for PTLD and mental issues before, during and after the pandemic: describe and what are underlying reasons? > interview (implementation partner, health authorities)

	Interventions as	Interventions as stated in the TOR	28		- 6		
OECD DAC evaluation criteria	1. Identification of people with post TB disabilities, including post TB lung disease and mental health. Mapping the scope of health problems among former TB patients and how it affects their lives.	2. Collaboration between local health system and community-based organizations	3. Development and implementation of a local and volunteer-based lung rehabilitation	3. Development 4. Social and and and implementation medical support to of a local and people with post TB volunteer-based disabilities, e.g. follow-up/thome visits, medical check-ups, nutritional support, transport, transport, transport, and income	5. Capacity building of health workers and volunteers on Inclusive health communication, post TB disabilities, and lung rehabilitation.	6. Share results and advocate to regional and national health authorities	
4 "Efficiency":							
	lssue	Issue	Issue	lssue	lssue	lssue	
	Method	Method	Method	Method	Method	Method	
	(target group)	(target group)	(target group)	(target group)	(target group)	(target group)	
4a. How well is the Project using its resources, especially	0.81 -0.01 -0.01		5000 - 1200 - 10	4a.4. Trendin cost per person taking part in LR	4a.5. Trendin cost per health worker		
with regards to delivering lung				activities: try to explain	capacitated; try to		
renabilitation to former 15 patients?				me trend > performance and	explain the trend > training and financial		

	Interventions as	interventions as stated in the TOR				
OECD DAC evaluation criteria	1. Identification of people with post TB dis abilities, including post TB lung disease and mental health. Mapping the scope of health problems among former TB patients and how it affects their lives	2. Collaboration between local health sistem and community-based organizations	3. Development and implementation of a local and volunteer-based lung rehabilitation	4. Social and medical support to people with post TB disabilities, e.g. follow-up/home visits, medical check-ups, nutritional support, transport, vocational training and income generating activities, in addition to the lung rehabilitation in some	5. Capacity building of health workers and volunteers on Inclusive health communication, post TB disabilities, and lung rehabilitation.	6. Share results and advocate to regional and national health authorities
5 "Impact":	Issue Method (target group)	Issue Method (target group)	Issue Method (target group)	Issue Method (target group)	Issue Method (target group)	Issue Method (target group)
5a. What difference does the project make for the target group and possibly in a sociosconomic perspective?				5a.4. Experiences of persons affected by TB in terms of fung rehabilitation, social, and medical support and its impact on socio-economic status  -> FGD (per sons affected by TB) -> interview (CBO and organizations of persons affected by TB) -> reports (implementation partner)		
5b. What are the best practices from the Project?	5b.1. What are the best practices from the Project in terms of dentitying the right people with PTLD and mental health issues? Harves ting stories of good practices — interview (implementation partner and CSO)	5b.2. What are the best practices from the Project in terms of collaboration between local health system and community based organizations? Harvesting stories of good practices rinterview (health authorities and CSO)	5b.3. What are the best practices from the Project in terms of development and implement ation of a loo al and volunteer. Dased lung rehabilitation? Best dung rehabilitation? Good practices -> Interview (implementation partner and CSO)	5b.f. What are the best practices from the Project in terms of social and medical support to people with post-TB lung disease? Harvesting stories of good practices> interview (implementation partner, CSO, and organizations of persons affected by TB)	5b.5. What are the best practices from the Project in terms capacity building of health workers and volunteers? Harvesting stories of good practices (**) interview (**) interview and health authorities)	5b.6. Extent of good practices shared with health authorities, please describe what was shared with them -> documentation partner) -> interview -> interview -> interview -> interview -> authorities)
5c. Does the Project have any unintended negative offects?	50.1. Does the Project have any unintended negative effects in returns of identifying the right people with PTLD and mental health is sue 29. Harvesting stories of unintended negative effects -> interview (implementation partner and CSD)	50.2. Does the Project have any unintended negative effects in terms of collaboration between local health system and community based organizations? Harve sting stories of unintended negative offects > interview (health authorities and CSD)	56.3. Does the Project have any unintended negative effects in terms of development and implementation of a local and volunteer-bared lung. Harvesting stories of unintended negative effects.   -> interview (implementation partner and CSO)	50.4. Does the Project have any unintended negative effects in terms of social and medical support to people with post-TB turn disease? Harvesting stories of unintended negative effects> interview (implementation partner, CSO, and organizations of persons affected by TB)	56.5. Does the Project have any unintended regative effects in reducial support to people with post-TB lung disease? Harvesting stories of unintended negative effects	50.6. Does the Project have any unintended negative effects? Describe unintended Describe unintended negative effects as observed by the health authorities  -> interview (implementation partners and health authorities)

	Interventions as	ated in the TOR				
OECD DAC evaluation criteria	1. Identification of people with post TB disabilities, including post TB lung disease and mental health. Mapping the scope of health problems among former TB patients and how it affects their lives	2. Collaboration between local health system and community-based organizations	3. Development and implementation of a local and volunteer-based lung rehabilitation	4. Social and medical support to people with post TB disabilities, e.g. follow-up/home visits, medical check-ups, nutritional support, transport, vocational training and income generating activities, in addition to the lung	5. Capacity building of health workers and nolusive health communication, post TB disabilities, and lung rehabilitation.	6. Share results and advocate to regional and national health authorities
6 "Sustainability":	1		2000	-	Comme	- Inchina
	Mothod (target group)	Method (target group)	Mothod (target group)	Method (target group)	Method (target group)	Method (target group)
6a. Vill the benefits last for the target group (persons with post-TB disabilities)?		6a.2. Perspectives of continued collaboration in terms collaboration in terms collaboration persons with post TB disabilities) if funding would decrease / stop interview (implementation partner, health authorities)	6a.3. Perspectives of continued volunteer. based lung rehabilitation activities rehabilitation activities decrease / stop> interview (implementation partner, health authorities, CSO)	6a4 Expectations of persons affected by TB concerning lasting medical people with PTLD if funding would decrease / stop > FGD (organizations of persons affected by TB)	6a.5. Trend in turn-over of hosith staff > reports (health authorities)	6a.6. Expectations of and adoption of policies by health policies by health authorities towards the 4th "90" (90% of persons with PTLD receive social nad medical support) s interview (health authorities)
6b. How can implementing partners and LHL International work to increase sustainability of initiatives for this target group?	6b.t. How can sustainability be increased in terms of increased in terms of increased in terms of PTLD and mental health? Suggestions by implementation partners, CSOs, and or gamizations of people affected by TB > interviews	up ybe tems of	6b.3. How can sustainability be increased in terms of developing and under the colonial and volunteer-based lung rehabilitation? Suggestions by implementation implementation.	6b.4. How can sustainability be increased concerning social and medical support for people with PTLG and mental health issues? Suggestions by implementation partners, health authorities, organizations of people affected by TB, and any interviews	6b.5. How can sustainability be increased in terms of capacity building for health staff and volunteers? Suggestions by local health authorities, implementation partners, and CBOs	6b.6. How can sustainability be increased in terms of advocacy for support to persons with PTLD and mental health is sues? Suggestions by implementation partners and national fregional health authorities, and organizations of people affected by TB
6c For future projects, which financial sources could be relevant?	6c.1 For future projects, which financial sources could be relevant for identifying perons with PTLD and mental health issues? Suggestions by implementation partners, CSDs, and partners, CSDs, and coganizations of people affected by TB> Interviews	be Z. For future projects, which financial sources could be relevant to maintain or increase collaboration between the health system and community based organizations? Suggestions by health each authorities, CBOs, and organizations of people affected by TB> interviews	66.3. For ruture projects, which financial sources could be relevant for the implementation of a local volunteer lung rehabilitation scheme? Suggestions by implementation partners and CSOs> Interviews	66.4. For future projects, which financial sources oould be relevant for social and medical support for persons with PTLD and mental health (Seues? Suggestions by implementation partners, health authorities, organizations of people affected by TB, and any intersectoral forum	6c.5. For future projects, which financial sources could be relevant for capacity building of health staff and volunteers? Suggestions by local health authorities, implementation partners, and CBOs	60.6. For future projects, which financial sources could be relevant to maintain communication between implementers and health authorities? Suggestions by implementation partners and national? regional health authorities, and organizations of people affected by TB

#### Annex 2: Data collection tools

A lot of information can be found in reports of the project. As time is limited, evaluators in first instance will focus on the yellow and orange topics listed below, followed by the green ones.

#### Documentation Topics (quantifications)

- 1a.3. Existence and extent of a volunteer-based lung rehabilitation system. How did it come to this point?
- --> interview & documentation (local CBO & local health authority)
- 1a.4. Extent of social and medical support other than lung rehabilitation? Can you give examples?
- --> documentation / reports (implementation partner)
- 1a.5. # of health workers and # volunteers capacitated
- --> reports (implementation partner)
- 1a.6. # of advocacy events. Describe.
- --> reports (implementation partner)
- 1a.1. Mapping documented of scope of health problems
- --> Review of documents (implementing partner)
- 2a.1. Interlinkages with other programs: attention for PTLD in NSP and grant applications
- --> document review (NTP)
- 2a.4. Existence and extent of social and medical support through other channels than NTP
- --> document review (via NTP)
- --> interview (CSOs and organizations of persons affected by TB)
- 2a.6. Interlinkages with other programs: Content of advocacy messages / visits --> documentation / reports (implementing partner)
- 2a.1. 2a.1. Interlinkages with other programs: Existence of multisectoral linkages (MAF)
- --> document review (via NTP)
- --> interview (via CCM TWG-TB)
- 2b.1. Synergies: Extent of integration of issues for persons with PTLD and persons with other disabilities
- --> interview & perhaps documentation (implementation partner and CSO)
- 2b.2. Synergies: Extent of collaboration between CSO and the local health system concerning issues of persons with disabilities other than PTLD
- --> interview & perhaps documentation (CSO and local health authority)
- 2b.3. Synergies: Do volunteer networks engage in other issues than only PTLD? --> interview & perhaps documentation (implementation partner and CSO)
- 2b.4. Synergies: Existence and extent of social and medical support through other channels than NTP
- --> document review (via NTP)
- --> interview (CSOs and organizations of persons affected by TB)

- 3a.1. Trend in identification of persons with PTLD and mental health issues: what are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 3a.2. Trend in collaborative activities: what are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner and local health authorities)
- 3a.3. Trend in # of volunteers engaged in LR initiatives: what are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 3a.4. Trends in # of social and medical support rendered: what are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 3a.5. Trend in # health workers capacitated: what are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 3a.6. Changed policies / activities to the benefit of persons with PTLD and/or mental health problems: what are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner, health authorities)
- 3a.1. Documented scope of health problems among former TB patients:
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 3b.1. Trend in identification of persons with PTLD and mental health issues before, during and after the pandemic. What are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 3b.2. Trend in collaborative activities before, during and after the pandemic
- --> reports (implementation partner)
- --> interview about reasons (implementation partner and local health authorities)
- 3b.3. Trend in # of volunteers engaged in LR initiatives before, during and after the pandemic
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 3b.4. Trends in # of social and medical support rendered before, during and after the pandemic
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)

- 3b.5. Trend in # health workers capacitated before, during and after the pandemic
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 4a.4. Trend in cost per person taking part in LR activities: try to explain the trend --> performance and financial reports (implementation partner)
- 4a.5. Trend in cost per health worker capacitated; try to explain the trend --> training and financial reports (implementation partner)
- 5a.4. Experiences of persons affected by TB in terms of lung rehabilitation, social, and medical support and its impact on socio-economic status
- --> FGD (persons affected by TB)
- --> interview (CBO and organizations of persons affected by TB)
- --> reports (implementation partner)
- 5b.1. What are the best practices from the Project in terms of identifying the right people with PTLD and mental health issues? Harvesting stories of good practices --> interview & perhaps documentation (implementation partner and CSO)
- 5b.2. What are the best practices from the Project in terms of collaboration between local health system and community-based organizations? Harvesting stories of good practices
- --> interview & perhaps documentation (health authorities and CSO)
- 5b.3. What are the best practices from the Project in terms of development and implementation of a local and volunteer-based lung rehabilitation? Harvesting stories of good practices
- --> interview & perhaps documentation (implementation partner and CSO)
- 5b.4. What are the best practices from the Project in terms of social and medical support to people with post-TB lung disease? Harvesting stories of good practices --> interview & perhaps documentation (implementation partner, CSO, and organizations of persons affected by TB)
- 5b.5.What are the best practices from the Project in terms of the capacity building of health workers and volunteers? Harvesting stories of good practices
- --> interview & perhaps documentation (implementation partner and health authorities)
- 5b.6. Extent of good practices shared with health authorities, please describe what was shared with them.
- --> documentation (implementation partner)
- --> interview (implementation partner and health authorities)
- 5c.1. Does the Project have any unintended negative effects in terms of identifying the right people with PTLD and mental health issues? Harvesting stories of unintended negative effects
- --> interview & perhaps documentation (implementation partner and CSO)

- 5c.2. Does the Project have any unintended negative effects in terms of collaboration between local health system and community-based organizations? Harvesting stories of unintended negative effects
- --> interview & perhaps documentation (health authorities and CSO)
- 5c.3. Does the Project have any unintended negative effects in terms of development and implementation of a local and volunteer-based lung rehabilitation? Harvesting stories of unintended negative effects
- --> interview & perhaps documentation (implementation partner and CSO)
- 5c.4. Does the Project have any unintended negative effects in terms of social and medical support to people with post-TB lung disease? Harvesting stories of unintended negative effects
- --> interview & perhaps documentation (implementation partner, CSO, and organizations of persons affected by TB)
- 5c.5. Does the Project have any unintended negative effects in terms of social and medical support to people with post-TB lung disease? Harvesting stories of unintended negative effects
- --> interview & perhaps documentation (implementation partner and health authorities)
- 5c.6. Does the Project have any unintended negative effects? Describe unintended negative effects as observed by the health authorities
- --> interview & perhaps documentation (implementation partner and health authorities)

6a.5. Trend in turn-over of health staff --> reports (health authorities)

Interview questions for implementation partners and CSOs

The questions below are extracted from the evaluation matrix.

#### Questions for Implementation partners & CSOs

- 1a.2. Are experiences of CBOs taken into account by the local health system? Was there any form of collaboration and how did that look like?
- --> Interview (local CBO)
- 1c.2. What should we do more of, or in addition to, existing initiatives? Suggestions by health center staff, local health authorities, CBOs, and organizations of people affected by TB --> interviews
- $1\mathrm{c.}3.$  What should we do more of, or in addition to, existing initiatives? Suggestions by implementation partners
- --> interviews
- 1c.4. What should we do more of, or in addition to, existing initiatives? Suggestions by implementation partners and organizations of people affected by TB --> interviews
- 1c.5. What should we do more of, or in addition to, existing initiatives? Suggestions by local health authorities, CBOs, and organizations of people affected by TB --> interviews
- 1c.6.What should we do more of, or in addition to, existing initiatives? Suggestions by implementation partners and national regional health authorities, and organizations of people affected by TB
- --> interviews
- 2a.4. Existence and extent of social and medical support through other channels than NTP --> document review (via NTP)
- --> interview (CSOs and organizations of persons affected by TB)
- 2b.1. Synergies: Extent of integration of issues for persons with PTLD and persons with other disabilities
- --> interview & perhaps documentation (implementation partner and CSO)
- 2b.2. Synergies: Extent of collaboration between CSO and the local health system concerning issues of persons with disabilities other than PTLD
- --> interview (CSO and local health authority)
- 2b.3. Synergies: Do volunteer networks engage in other issues than only PTLD? --> interview (implementation partner and CSO)

- 2b.4. Synergies: Existence and extent of social and medical support through other channels than NTP
- --> document review (via NTP)
- --> interview (CSOs and organizations of persons affected by TB)
- 3a.1. Trend in identification of persons with PTLD and mental health issues: what are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 3a.2. Trend in collaborative activities: what are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner and local health authorities)
- 3a.3. Trend in # of volunteers engaged in LR initiatives: what are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 3a.4. Trends in # of social and medical support rendered: what are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 3a.5. Trend in # health workers capacitated: what are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 3a.6. Changed policies / activities to the benefit of persons with PTLD and/or mental health problems: what are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner, health authorities)
- 3a.1. Documented scope of health problems among former TB patients:
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 3b.1. Trend in identification of persons with PTLD and mental health issues before, during and after the pandemic. What are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 3b.2. Trend in collaborative activities before, during and after the pandemic
- --> reports (implementation partner)
- --> interview about reasons (implementation partner and local health authorities)
- 3b.3. Trend in # of volunteers engaged in LR initiatives before, during and after the pandemic
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)

- 3b.4. Trends in # of social and medical support rendered before, during and after the pandemic
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 3b.5. Trend in # health workers capacitated before, during and after the pandemic
- --> reports (implementation partner)
- --> interview about reasons (implementation partner)
- 3b.6. Attention of health authorities for PTLD and mental issues before, during and after the pandemic: describe and what are underlying reasons?
- --> interview (implementation partner, health authorities)
- 5a.4. Experiences of persons affected by TB in terms of lung rehabilitation, social, and medical support and its impact on socio-economic status
- --> FGD (persons affected by TB)
- --> interview (CBO and organizations of persons affected by TB)
- --> reports (implementation partner)
- 5b.1. What are the best practices from the Project in terms of identifying the right people with PTLD and mental health issues? Harvesting stories of good practices
- --> interview (implementation partner and CSO)
- 5b.2. What are the best practices from the Project in terms of collaboration between local health system and community-based organizations? Harvesting stories of good practices --> interview (health authorities and CSO)
- 5b.3. What are the best practices from the Project in terms of development and implementation of a local and volunteer-based lung rehabilitation? Harvesting stories of good practices
- --> interview (implementation partner and CSO)
- 5b.4. What are the best practices from the Project in terms of social and medical support to people with post-TB lung disease? Harvesting stories of good practices
- --> interview (implementation partner, CSO, and organizations of persons affected by TB)
- 5b.5.What are the best practices from the Project in terms of the capacity building of health workers and volunteers? Harvesting stories of good practices
- --> interview (implementation partner and health authorities)
- 5b.6. Extent of good practices shared with health authorities, please describe what was shared with them.
- --> documentation (implementation partner)
- --> interview (implementation partner and health authorities)
- 5c.1. Does the Project have any unintended negative effects in terms of identifying the right people with PTLD and mental health issues? Harvesting stories of unintended negative effects --> interview (implementation partner and CSO)

- 5c.2. Does the Project have any unintended negative effects in terms of collaboration between local health system and community-based organizations? Harvesting stories of unintended negative effects
- --> interview (health authorities and CSO)
- 5c.3. Does the Project have any unintended negative effects in terms of development and implementation of a local and volunteer-based lung rehabilitation? Harvesting stories of unintended negative effects
- --> interview (implementation partner and CSO)
- 5c.4. Does the Project have any unintended negative effects in terms of social and medical support to people with post-TB lung disease? Harvesting stories of unintended negative effects
- --> interview (implementation partner, CSO, and organizations of persons affected by TB)
- 5c.5. Does the Project have any unintended negative effects in terms of social and medical support to people with post-TB lung disease? Harvesting stories of unintended negative effects
- --> interview (implementation partner and health authorities)
- 5c.6. Does the Project have any unintended negative effects? Describe unintended negative effects as observed by the health authorities
- --> interview (implementation partner and health authorities)
- 6a.2. Perspectives of continued collaboration in terms of benefits for the target group (persons with post-TB disabilities) if funding would decrease / stop
- --> interview (implementation partner, health authorities)
- 6a.3. Perspectives of continued volunteer-based lung rehabilitation activities if funding would decrease / stop
- --> interview (implementation partner, health authorities, CSO)
- 6b.1. How can sustainability be increased in terms of identifying persons with PTLD and mental health? Suggestions by implementation partners, CSOs, and organizations of people affected by TB
- --> interviews
- 6b.2. How can sustainability be increased in terms of collaboration between the health system and community-based organizations? Suggestions by health center staff, local health authorities, CBOs, and organizations of people affected by TB
- --> interviews
- 6b.3. How can sustainability be increased in terms of developing and implementation of local and volunteer-based lung rehabilitation? Suggestions by implementation partners and CSOs --> interviews
- 6b.4. How can sustainability be increased concerning social and medical support for people with PTLG and mental health issues? Suggestions by implementation partners, health authorities, organizations of people affected by TB, and any intersectoral forum --> interviews

- 6b.5. How can sustainability be increased in terms of capacity building for health staff and volunteers? Suggestions by local health authorities, implementation partners, and CBOs --> interviews
- 6b.6. How can sustainability be increased in terms of advocacy for support to persons with PTLD and mental health issues? Suggestions by implementation partners and national / regional health authorities, and organizations of people affected by TB --> interviews
- 6c.1. For future projects, which financial sources could be relevant for identifying perons with PTLD and mental health issues? Suggestions by implementation partners, CSOs, and organizations of people affected by TB
- --> interviews
- 6c.2. For future projects, which financial sources could be relevant to maintain or increase collaboration between the health system and community-based organizations? Suggestions by health center staff, local health authorities, CBOs, and organizations of people affected by TB --> interviews
- 6c.3. For future projects, which financial sources could be relevant for the development and implementation of a local volunteer lung rehabilitation scheme? Suggestions by implementation partners and CSOs
- --> interviews
- 6c.4. For future projects, which financial sources could be relevant for social and medical support for persons with PTLD and mental health issues? Suggestions by implementation partners, health authorities, organizations of people affected by TB, and any intersectoral forum
- --> interviews
- 6c.5. For future projects, which financial sources could be relevant for capacity building of health staff and volunteers? Suggestions by local health authorities, implementation partners, and CBOs
- --> interviews
- 6c.6. For future projects, which financial sources could be relevant to maintain communication between implementers and health authorities? Suggestions by implementation partners and national / regional health authorities, and organizations of people affected by TB --> interviews

#### Questions for health staff in health facilities

1a.2. Are experiences of CBOs taken into account by the local health system? Was there any form of collaboration and how did that look like?

--> Interview

(local CBO and health staff and local health authority)

1c.2. What should we do more of, or in addition to, existing initiatives? Suggestions by health center staff, local health authorities, CBOs, and organizations of people affected by TB

--> interviews

2b.2. Synergies: Extent of collaboration between CSO and the local health system concerning issues of persons with disabilities other than PTLD

--> interview

(CSO and local health authority and health staff)

5b.2. What are the best practices from the Project in terms of collaboration between local health system and community-based organizations? Harvesting stories of good practices

--> interview

(health authorities, health staff and CSO)

5b.5.What are the best practices from the Project in terms of the capacity building of health workers and volunteers? Harvesting stories of good practices

--> interview

(implementation partner and health authorities and health staff)

5c.2. Does the Project have any unintended negative effects in terms of collaboration between local health system and community-based organizations? Harvesting stories of unintended negative effects

--> interview

(health authorities, health staff, and CSO)

- 6b.2. How can sustainability be increased in terms of collaboration between the health system and community-based organizations? Suggestions by health center staff, local health authorities, CBOs, and organizations of people affected by TB --> interviews
- 6c.2. For future projects, which financial sources could be relevant to maintain or increase collaboration between the health system and community-based organizations? Suggestions by health center staff, local health authorities, CBOs, and organizations of people affected by TB

--> interviews

Questions for health authorities (district and/or national level)

- 1a.3. Existence and extent of a volunteer-based lung rehabilitation system. How did it come to this point?
- --> interview & documentation (local CBO & local health authority)
- 1a.6. Awareness about PTLDand activities among regional and national health authorities. Describe what is known
- --> interview (national and 1 regional health authority)
- 1c.2. What should we do more of, or in addition to, existing initiatives? Suggestions by health center staff, local health authorities, CBOs, and organizations of people affected by TB --> interviews
- 1c.5. What should we do more of, or in addition to, existing initiatives? Suggestions by local health authorities, CBOs, and organizations of people affected by TB
- --> interviews
- 1c.6.What should we do more of, or in addition to, existing initiatives? Suggestions by implementation partners and national regional health authorities, and organizations of people affected by TB
- --> interviews
- 2a.1. Interlinkages with other programs: Existence of multisectoral linkages (MAF)
- --> document review (via NTP)
- --> interview (via CCM TWG-TB)
- 2a.6. Interlinkages with other programs: Awareness of national and regional health authorities about the need of an intersectoral approach to PTLD
- --> interview (national and regional health authorities)
- 2b.2. Synergies: Extent of collaboration between CSO and the local health system concerning issues of persons with disabilities other than PTLD
- --> interview (CSO and local health authority)
- 2b.4. Synergies: Existence and extent of social and medical support through other channels than NTP
- --> document review (via NTP)
- --> interview (CSOs and organizations of persons affected by TB)
- 3a.2. Trend in collaborative activities: what are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner and local health authorities)

- 3a.6. Changed policies / activities to the benefit of persons with PTLD and/or mental health problems: what are underlying reasons?
- --> reports (implementation partner)
- --> interview about reasons (implementation partner, health authorities)
- 3b.2. Trend in collaborative activities before, during and after the pandemic
- --> reports (implementation partner)
- --> interview about reasons (implementation partner and local health authorities)
- 3b.6. Attention of health authorities for PTLD and mental issues before, during and after the pandemic: describe and what are underlying reasons?
- --> interview (implementation partner, health authorities)
- 5b.2. What are the best practices from the Project in terms of collaboration between local health system and community-based organizations? Harvesting stories of good practices --> interview (health authorities and CSO)
- 5b.5.What are the best practices from the Project in terms of the capacity building of health workers and volunteers? Harvesting stories of good practices
- --> interview (implementation partner and health authorities)
- 5b.6. Extent of good practices shared with health authorities, please describe what was shared with them.
- --> documentation (implementation partner)
- --> interview (implementation partner and health authorities)
- 5c.2. Does the Project have any unintended negative effects in terms of collaboration between local health system and community-based organizations? Harvesting stories of unintended negative effects
- --> interview (health authorities and CSO)
- 5c.5. Does the Project have any unintended negative effects in terms of social and medical support to people with post-TB lung disease? Harvesting stories of unintended negative effects
- --> interview (implementation partner and health authorities)
- 5c.6. Does the Project have any unintended negative effects? Describe unintended negative effects as observed by the health authorities
- --> interview (implementation partner and health authorities)
- 6a.2. Perspectives of continued collaboration in terms of benefits for the target group (persons with post-TB disabilities) if funding would decrease / stop
- --> interview (implementation partner, health authorities)
- 6a.3. Perspectives of continued volunteer-based lung rehabilitation activities if funding would decrease / stop
- --> interview (implementation partner, health authorities, CSO)

- 6a.6. Expectations of and adoption of policies by health authorities towards the 4th "90" (90% of persons with PTLD receive social nad medical support)
- --> interview (health authorities)
- 6b.2. How can sustainability be increased in terms of collaboration between the health system and community-based organizations? Suggestions by health center staff, local health authorities, CBOs, and organizations of people affected by TB --> interviews
- 6b.4. How can sustainability be increased concerning social and medical support for people with PTLG and mental health issues? Suggestions by implementation partners, health authorities, organizations of people affected by TB, and any intersectoral forum --> interviews
- 6b.5. How can sustainability be increased in terms of capacity building for health staff and volunteers? Suggestions by local health authorities, implementation partners, and CBOs --> interviews
- 6b.6. How can sustainability be increased in terms of advocacy for support to persons with PTLD and mental health issues? Suggestions by implementation partners and national / regional health authorities, and organizations of people affected by TB --> interviews
- 6c.2. For future projects, which financial sources could be relevant to maintain or increase collaboration between the health system and community-based organizations? Suggestions by health center staff, local health authorities, CBOs, and organizations of people affected by TB
- --> interviews
- 6c.3. For future projects, which financial sources could be relevant for the development and implementation of a local volunteer lung rehabilitation scheme? Suggestions by implementation partners and CSOs and health authorities
  --> interviews
- 6c.4. For future projects, which financial sources could be relevant for social and medical support for persons with PTLD and mental health issues? Suggestions by implementation partners, health authorities, organizations of people affected by TB, and any intersectoral forum
- --> interviews
- 6c.5. For future projects, which financial sources could be relevant for capacity building of health staff and volunteers? Suggestions by local health authorities, implementation partners, and CBOs
- --> interviews
- 6c.6. For future projects, which financial sources could be relevant to maintain communication between implementers and health authorities? Suggestions by implementation partners and national / regional health authorities, and organizations of people affected by TB
- --> interviews

rad guiding questions for persons with PTLD / Mental health issues.
FGD guiding questions for persons with PTLD / mental health issues
1a.1. Health needs met of persons affected by TB? Hiw did it affect their lives?
> FGD
(members of organizations of persons affected by TB)
5a.4. Experiences of persons affected by TB in terms of lung rehabilitation, social,
and medical support and its impact on socio-economic status> FGD
(persons affected by TB)
> interview (CBO and organizations of persons affected by TB)
> reports
(implementation partner)
6a.4. Expectations of persons affected by TB concerning lasting medical and social benefits for people with PTLD if funding would decrease / stop
> FGD
(organizations of persons affected by TB)

red guiding questions for volunteers in the Eding Rehabilitation enorts.
FGD guiding questions for volunteers in the Lung Rehabilitation efforts
1a.1. Health needs met of persons affected by TB? Hiw did it affect their lives?
> FGD (members of organizations of persons affected by TB)
(members of organizations of persons affected by 1b)
5a.4. Experiences of persons affected by TB in terms of lung rehabilitation, social, and
medical support and its impact on socio-economic status
> FGD
(persons affected by TB)> interview
(CBO and organizations of persons affected by TB)
> reports
(implementation partner)
6a.4. Expectations of persons affected by TB concerning lasting medical and social
benefits for people with PTLD if funding would decrease / stop> FGD
(organizations of persons affected by TB)

FGD guiding questions for health staff in health facilities

FGD guiding questions for health staff in health facilities

1a.5. Opinion of health workers and of volunteers about capacitation
--> FGD
(health workers)

6a.4. Expectations of persons affected by TB concerning lasting medical and social benefits for people with PTLD if funding would decrease / stop
--> FGD
(organizations of persons affected by TB)

## Annex 3: List of persons and places visited

# Malawi

We had a planning session with Paradiso and NONM on the sites to be selected and visited taking into consideration the accessibility of earth roads during this time of rainy season. One district was selected from each region/province (Central and Southern region) and one facility in each district was visited and these facilities are Matawale and Kaigwazanga health centres. In these sites, the evaluators paid a courtesy call to the Directors of Health and Social Services (DHSS) for the districts at district level and health in charges at health Centre level. We met and discussed with the following officials and persons:

- 1. District level Director of Health and Social Services (DHSS) or a representative and TB focal persons
  - Zomba Dr. Alexander Chijuwa (DHSS); Madalitso Chundira (District TB focal person).
  - Mchinji Dr. Benard Chiwomba (DHSS representative); Steven Nyika (District TB focal person).
- 2. Health Centre level Health facility in charge, health Centre staff, persons affected by TB & PTBLD volunteers.
  - Zomba Alex Nakhaonga (health centre in-charge) including nine health centre staff; and 14 volunteers.
  - Mchinji Getrude Kauma (health centre in-charge) including seven health staff and 15 volunteers.
- 3. National level 2 NTLEP officials (Mr. Madalitso Mmanga communication focal person and Mr. Noel Mphasa NTP manager representative)
- 4. Implementing partners Mr. Bruce Matawere, Executive Director, Paradiso and Harriet Chiomba, Project Officer, NONM.

Day/Date	Activity	comments
7 <sup>th</sup> Feb 2023	Consultant traveling to Lilongwe for a meeting with implementing partners – Paradiso and NONM	
8 <sup>th</sup> Feb 2023	Courtesy call at Paradiso and NONM in Lilongwe and developing the activity itinerary	
9 <sup>th</sup> Feb 2023	Making communication to all respondents – national, district, persons affected by TB and volunteers for LR	
10 <sup>th</sup> - 11 <sup>th</sup> Feb 2023	Desk review on reports from Paradiso and NONM	The whole day
12 Feb 2023	Travelling to Zomba	
13 <sup>th</sup> Feb 2023	Interviews with <b>Zomba</b> district authorities (1), FGD with volunteers for LR, persons affected by TB and health care workers	<ul> <li>The whole day activity</li> <li>Courtesy call DHO in Zomba</li> <li>Interview with DHO/representative</li> <li>Visit one facility to collect data through FDGs</li> </ul>
14 <sup>th</sup> Feb 2023	Travelling back to Lilongwe	
15 <sup>th</sup> Feb 2023	Interviews with <b>Mchinji</b> district authorities, FGD with volunteers for LR, persons affected by TB and health care workers	<ul><li>The whole day activity</li><li>Will pay courtesy call to the DHO in Mchinji</li></ul>

16 <sup>th</sup> Feb	Interviews with implementing partner and	Interview with     DHO/representative     Visit one facility to     collect data through     FDGs  Whole day activity
20023	Paradiso and other health authorities	
17 <sup>th</sup> Feb 2023	Interviews with NTP authorities	Program may change depending on their availability.

## **Tanzania**

Planning for the evaluation was done with the KIDH and MKUTA project coordinators. It was decided to visit the two districts of Siha in Kilimanjaro Region and Simanjiro in Manyara Region. There were visits to the facilities that were involved in the evaluation, the KIDH and the Mirerani Health Centre. Interviews were conducted with the district TB authorities, the project leadership, the volunteers and individuals with PTLD. The following people were met:

- 1. National level: the acting NTLP Manager was interviewed.
- 2. District level: District TB and Leprosy Coordinator at each of the two districts, MKUTA leadership, and volunteers at each of the districts.
- 3. Facility level: the person in-charge of the facility, the principal investigator, LHL coordinator, the two project coordinators for KIDH and MKUTA, the project staff, and other health care workers providing care to TB patients.
- 4. Community level: volunteers from MKUTA, persons with PTLD, patients with TB.

### Monday, 20 February 2023

- KIDH Project Centre
  - 1. Prof Stellah Mpagama Principal Investigator
  - 2. Dr Alexander William Mbuya LHL Coordinator
  - 3. Dr Florence Jared PTLD Project Coordinator, KIDH
  - 4. Dr Frank Thobias PTLD Project Coordinator, MKUTA
  - 5. Angela Kimaro Physiotherapist
  - 6. Leocardia Mteme Project Nurse
  - 7. Oliver Kimario Field Nurse
  - 8. Regina Amaa Project Nurse
- Dr Michael Mushi District TB and Leprosy Coordinator, Siha District

#### Tuesday, 21 February 2023

- MKUTA Offices Siha
- Rhoda Kifumu (Chair of MKUTA Siha) and her colleagues.
- PTLD persons
  - 1. Aletaulwa
  - 2. Heriel
  - 3. Eliza

### Wednesday, 22 February 2023

- Mirerani Health Centre
  - 1. Dr Frank Thobias MKUTA Project Coordinator
  - 2. Dr Patrick TB Clinic
- Dr Celestina Losaru District TB and Leprosy Coordinator, Simanjiro District

### Thursday, 23 February 2023

Exercise field

- Performed lung rehabilitation exercises together with various volunteers and patients
- MKUTA Offices Mirerani
  - 1. Mr Thobias Magati MKUTA Coordinator Northern Zone
  - 2. Rehema Ismail MKUTA Secretary Mirerani
- Many other MKUTA volunteer community health workers.
- PTLD patients
  - 1. Silas
  - 2. Juma

## Friday, 24 February 2023

- Mirerani Tanzanite Mines
- Visited four mines and inspected the conditions while having conversations with the supervisors.
- Mohamed (patient)

# Sudan

In Sudan the following persons and sites were visited by the evaluator.

Implementing partner interview (7-2-2023)

Name	Place	Local number
Hanadi Hussein Taj Al-Sir	HDP office	0912331398

FMOH interview (Health Authorities) (8-2-2023)

Name	Place	Local number
Khaled Bakhit Sheikh Assistant	FMoH	0113540414

Volunteer FGD (9-2-2023)

Name	Place	Local number
Muhammad Salahuddin	HDP office	0912225537
Nabil Shamseddine		0902848563
Osman Abo Baker		0922208007
Aisha Abdul-Jabbar		0919662140
Imad Idris		0912660239
Umm Doreen Mohamed Abdel		0919711434
Rahim		

**Health Workers (11-2-2023)** 

Name	Place	Local number
Zahraa Abdel Rahim	Eid Hussaib TBMUs	0124532977
Amira Fadel Idris		0912259828
Fatima Mustafa		0121130756
Ahmed Hussein		0960826067
Mirghani Abdel Hamid		0911168439
Abdullah Mohammed Al Kamel		0965479133

Post TB Disability group (12-2-2023)

Fost 1D Disability group (12-2-2025)		
Name	Place	Local number
Samia Ishaag	Jeraf Sharg TBMUs	0927122294
Ramisa Abdel Moneim Mohamed		0918665744
Jadallah Muhammad Ali		0965171818
Muhammad Ammar		0922983233
Aisha Ibrahim Mohamed		0124297491
Al Mojammer Hassan		0965479133