

ENGAGE-TB

Empowering communities

to **END TB** with the **ENGAGE-TB** approach



“The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.” Declaration of Alma-Ata.



Community Volunteers
TB/HIV
Referral Paper

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FOREWORD

Community engagement is critical to improve the reach and sustainability of tuberculosis (TB) interventions, helping save lives from this top infectious killer.

In 2012, the World Health Organization (WHO) launched an innovative approach called ENGAGE-TB to better identify and treat people with TB, by involving previously unengaged non-governmental organizations (NGOs) and other civil society organizations (CSOs). This includes a wide spectrum of community-based organizations working in primary health care, HIV, maternal and child health, education, agriculture and livelihood initiatives.

There has been impressive progress from the implementation of the ENGAGE-TB approach in five focus countries. This document highlights how communities are advancing the response to TB with the support of WHO, NGOs and other CSOs, and the impact of these activities on reaching people with TB.

Looking forward, efforts are being made to integrate the ENGAGE-TB approach in national strategic plans and donor applications, including to the Global Fund, to ensure sustainability of activities beyond the duration of the project. Over US\$ 5 million in funding has already been leveraged from additional sources for future implementation in Democratic Republic of Congo, Ethiopia, Kenya, Malawi, United Republic of Tanzania and Zimbabwe.

The fight to end the TB epidemic by 2030 can only be won with communities at the heart of the TB response. The ENGAGE-TB approach lays out the path to make enhanced community engagement a reality, and expand the base for the global TB response.



Mario Raviglione
Director of the Global TB Programme

TB QUICK FACTS

- 9.6 million people fell ill with TB in 2014, including 1.2 million people living with HIV.
- In 2014, 1.5 million people died from TB, including 0.4 million among people who were HIV-positive.
- TB is one of the top five killers of adult women aged 20-59 years.
480 000 women died from TB in 2014, including 140 000 deaths among women who were HIV-positive.
- At least 1 million children became ill with TB and an estimated 140 000 children died of TB in 2014, including 55 000 who were HIV-positive.
- Globally in 2014, an estimated 480 000 people developed multidrug-resistant TB (MDR-TB) and there were an estimated 190 000 deaths from MDR-TB.
- In 2014, over 3 million people who developed TB in 2014 were missed by national systems.



Harnessing the power of **COMMUNITIES TO END TB**

THE POWER OF **COMMUNITIES**

“**COMMUNITY ENGAGEMENT** is defined as the process of working collaboratively with and through communities to address issues affecting their well-being”.

Despite the best efforts of health systems, about one third of people who develop TB globally are still either not diagnosed, or their cases are not reported. Difficulty in accessing health facilities is one of the reasons why people with TB may not be diagnosed, and can also have a negative impact on treatment adherence. Access to health care can be affected by social and political factors (such as stigma and discrimination, and the availability of cross-border services for migrants), and economic barriers (for example, the cost of transport). The role of community engagement in contributing to TB prevention, diagnosis and treatment, especially where people with TB have poor access to formal health services, is therefore well-recognized.

Community engagement for TB covers a wide range of activities that contribute to the detection, referral and treatment of people with drug-susceptible, drug-resistant and HIV-associated TB. They are conducted outside the premises of formal health facilities (e.g. hospitals, health centres and clinics) in community-based structures (e.g. schools, places of worship, congregate settings, markets) and homesteads.

COMMUNITY ENGAGEMENT FOR TB CARE

Community health workers and community volunteers carry out community-based TB activities, depending on the national and local context.

Screening

Screening for TB and TB-related morbidity (ex. HIV counselling and testing, diabetes), contact tracing, sputum collection and transport, including through home visits



Referral

Referring for diagnosis of TB and related diseases, linking with clinics, transport support and facilitation, accompaniment, use of referral forms



Treatment adherence support

Home visits, adherence counselling, stigma reduction, pill counting, home-based care



Social and livelihood support

Cash transfers, insurance schemes, nutrition support and supplementation, voluntary savings and loans, inclusive markets, income generation



Awareness creation and stigma reduction

Awareness-raising, behavior change communications, community mobilization and reduction of stigma and discrimination



ENGAGE-TB

Engaging NGOs/CSOs in community-based TB activities

WHO AND COMMUNITY ENGAGEMENT

- WHO supports community engagement by providing policy and programmatic guidance, promoting standardized monitoring and evaluation, brokering partnerships between national programmes and NGO/CSOs and offering training and technical assistance.
- Fostering community participation is one of the four principles underpinning the WHO End TB Strategy.
- WHO monitors the contributions of communities to the fight against TB, through a global monitoring and evaluation system. In 2014, 41 countries reported on community contribution to case notification and treatment support.
- In addition to improving the documentation and reporting of community-based TB activities, efforts to engage nongovernmental organizations that have previously not been involved in TB prevention, diagnosis and treatment are ongoing using the ENGAGE-TB approach.

THE ENGAGE-TB APPROACH

The **ENGAGE-TB approach** aims to integrate community-based TB activities into the work of the health and other development programmes of previously unengaged NGOs and other CSOs. It provides practical guidance to NTPs and NGOs and other CSOs on how to:

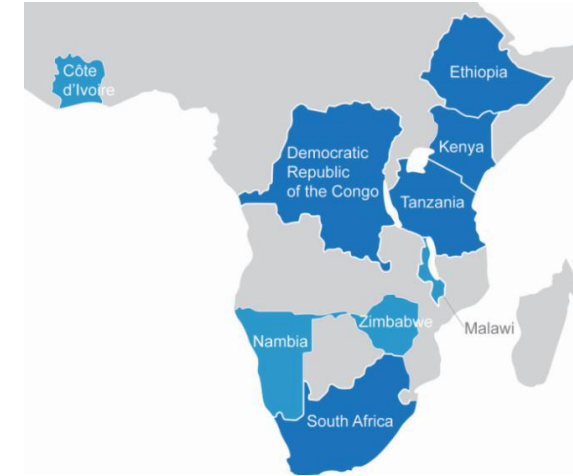
- Integrate TB activities into ongoing community-based activities of NGOs and other CSOs, in sectors such as reproductive, maternal, newborn and child health, HIV care, primary health care, education, agriculture and livelihoods development programs.
- Foster collaboration between NTPs or their equivalents and NGOs and other CSOs.
- Ensure close alignment with national systems, particularly in TB reporting and monitoring, so that community contributions are captured in national TB data.

The approach was initially implemented in **Democratic Republic of Congo, Ethiopia, Kenya, South Africa and United Republic of Tanzania**. Five additional countries, Burkina Faso, Côte d'Ivoire, Malawi, Namibia and Zimbabwe adopted ENGAGE-TB principles in national strategies and policies in 2013.

A strong coalition with CSOs and communities is one of the four principles of WHO's Global End TB Strategy after 2015.

Key achievements

ENGAGE-TB initial projects



■ ENGAGE-TB focus countries
■ new ENGAGE-TB countries

8 MILLION
Population covered with community-led access to TB services in project areas



4000 TB patients newly identified and treated in 2013-2014



Up to 90% TB patients provided treatment adherence support in the community



INTEGRATION

of TB through innovative community based models into:



Maternal and child health
in Ethiopia, Kenya



Cervical and breast cancer screening in Ethiopia



Livelihood initiatives in Kenya



HIV in DR Congo, South Africa, United Republic of Tanzania

“Before, people would go to the health centres at the last minute because they didn’t have the money to pay for the consultation, or didn’t have a referral. They would wait until their condition was serious. Now those people are treated sooner.

*Community Volunteer,
Fondation Femme Plus, Kikwit, DRC.*



DEMOCRATIC REPUBLIC OF CONGO

Key successes

PARTNER ON THE GROUND

Fondation Femme Plus

ACTIVITIES IMPLEMENTED

Working with the urban poor and high risk groups in Kinshasa and Kikwit districts in the Democratic Republic of Congo (DRC) on:

- Community mobilization and advocacy targeted at community leaders;
- Integrating TB into existing HIV programmes.

SUCSESSES

- Fondation Femme Plus reported 2831 new notifications by their community volunteers between January 2013 and June 2014 in the two districts. This equals a contribution of **41% of total case notifications** in its coverage area;
- 53% of new cases notified thanks to Fondation Femme Plus community volunteers were found through contact tracing;
- Among the patient cohort referred and subsequently supported by Fondation Femme Plus, the **treatment success rate was 93%** over a five-quarter period. This exceeds the national cure rate of 88%;
- Health centres that were rarely visited by local communities for TB services, were revitalized when Fondation Femme Plus CVs began referring people presumed to have TB to them.

NATIONAL SCALE-UP

- DRC's national strategic plan, incorporates principles and practices emphasizing the importance of engaging NGOs/CSOs and communities in the national TB response, and the integration of TB into other programmes;
- Community-level indicators were integrated into the national TB and HIV monitoring and evaluation system;
- NGO/CSO and community engagement were integrated into guidelines for provision of TB care in DRC;
- Contact tracing was integrated into DRC's national TB guidelines, based on the ENGAGE-TB experiences.

“Before the project came, the majority of patients thought that TB was not curable. Now the community thinks that TB is curable. Now everyone can say: I have TB, and the public knows that it is curable.” Health Extension Worker, Awash Fentalle district, Ethiopia.



ETHIOPIA

Key successes

PARTNERS ON THE GROUND

AMREF

CUAMM

Save the Children

ACTIVITIES IMPLEMENTED

Working with **remote pastoralist communities** in the Afar region on:

- Building capacity of local health facilities;
- Increasing awareness and access to TB care services;
- Integrating TB and HIV into existing malaria and maternal, newborn and child health programmes.

- Integrating TB and HIV into existing cancer-screening projects;
- Building awareness and providing community-based treatment support;
- Training health extension workers;
- Improving facility-based HIV and TB care.

Working with **remote pastoralist communities** in the Somali region on:

- Increasing community awareness and enhancing demand for services;
- Integrating TB and HIV into existing into ongoing expanded immunization and livelihoods programme.

SUCSESSES

AMREF reported a contribution of 28% of total case notifications in its coverage area.

CUAMM reported a contribution of 7% of total case notifications in its coverage area.

Save the Children reported a contribution of 58% of total case notifications in its coverage area.

NATIONAL SCALE-UP

- National Community TB Working Group established in Ethiopia;
- Ethiopia's national strategic plan, incorporates the ENGAGE-TB approach for addressing gaps in community systems strengthening and the integration of TB into other programmes;
- Community-level indicators were integrated into the national TB and HIV monitoring and evaluation system;
- Community-based TB Care guidelines and training of community health workers/volunteers were strengthened, using elements and experiences from the implementation of the ENGAGE-TB approach.

"The stigma and discrimination associated with TB has been reduced due to ENGAGE-TB, and more women are now accessing care."

Community Volunteer, CHAP, Isiolo County, Kenya.



KENYA



"The role of the WHO country office is critical to broker positive relationships between NGOs and the Ministry of Health, and help with capacity building for TB service delivery."

Joel Kangangi, WHO NPO, Kenya

Key successes

PARTNERS ON THE GROUND

Community Health Access Program (CHAP)

Grassroots Alleviation of Poverty Programme (GAPP)

Talaku

ACTIVITIES IMPLEMENTED

- Working in rural Kenya on:
- Integrating TB services into Health, immunization, sanitation and breastfeeding;
 - Increasing awareness and access to TB care services;
 - Household screening, contact tracing, treatment and social support.

- Working with rural, fishermen along the shores of Lake Victoria
- Integrating TB services into HIV, agriculture and livelihoods, social justice and human rights programmes;
 - Increasing awareness and access to TB care services;
 - Household screening and contact tracing;
 - Case holding- community follow-up and support till the patient completes treatment.

Working with underserved nomadic Maasai communities in Kajiado County.

- Increasing awareness and access to TB testing services;
- Providing TB treatment support;
- Reducing stigma and discrimination.

SUCCESSSES

CHAP reported a contribution of 12% of total case notifications in its coverage area.

GAPP reported a contribution of 9% of total case notifications in its coverage area.

Talaku reported a contribution of 31% of total case notifications in its coverage area.

NATIONAL SCALE-UP

- National CSO/community coordinating committee established in Kenya;
- Kenya's national strategic plan, includes previously unengaged NGOs and other CSOs in the national TB response and promotes the integration of TB into other programmes;
- Community-level indicators were integrated into the national TB and HIV monitoring and evaluation system;
- WHO ENGAGE-TB operational guidance has been adapted, published and disseminated to partners.



“Community mobilization and outreach is the best strategy for managing and supporting communities in the treatment and care of tuberculosis”

Phangisile Mtshali, BMSF,
Secure The Future.

SOUTH AFRICA

Key successes

PARTNER ON THE GROUND

BAMBISANANI

ACTIVITIES IMPLEMENTED

Working in the Eastern Cape Province of South Africa on:

- Promoting, strengthening and integrating HIV and TB education and awareness in three rural communities in the Eastern Cape Training of community health workers and home based carers;
- Engaging community leaders on advocacy and awareness on TB and HIV;
- Providing training on TB and health education to community volunteers and health professionals;
- Undertaking door-to-door HIV and TB education in the communities and promoting TB testing programs in schools;
- Preparing materials from National Health Laboratory Services for sputum collection;
- Organizing technical workshops to train on the HIV and TB national guidelines and implement data tools for HIV and TB to health care volunteers.

SUCCESSES

In 2014, Bambisanani reported a contribution of 27% in of total case notifications in its coverage area.

NATIONAL SCALE-UP

- South Africa has plans to integrate community-level indicators into the national TB and HIV monitoring and evaluation system.

“ENGAGE-TB has had a positive impact. It helped to increase case notification. The community is aware about TB and seek more services in TB and HIV. They know more, so they don't need as much time for counselling. It has reduced the workload on the health facility side. This has been a result of integrating TB and HIV services at the **community level.**” Dr Maliwanza, DTLC, Mwananyamala Regional Hospital, Dar es Salaam, United Republic of Tanzania.



UNITED REPUBLIC OF TANZANIA

Key successes



"The national TB programme plays a vital role in welcoming and engaging NGOs in TB efforts."

Beatrice Mutayoba, NTP Manager, United Republic of Tanzania

PARTNER ON THE GROUND

PATHFINDER INTERNATIONAL

ACTIVITIES IMPLEMENTED

- Working in peri-urban areas around Dar es Salaam on:
- Training of community health workers and home based carers;
 - Use of mobile phones to provide SMS services supporting TB screening and awareness through community volunteers;
 - Integrating TB into home-based HIV care programmes.

SUCSESSES

- Beyond increasing technical knowledge of health care workers working on TB, ENGAGE-TB has contributed to reducing the workload of TB nurses and District TB and Leprosy Coordinators in Kinondoni municipality in the United Republic of Tanzania thanks to the work of community volunteers. With the increase in community awareness and knowledge of TB, health care workers report spending less time than before when counselling and caring for presumptive and confirmed TB patients, given that clients now come with a better understanding of both illnesses;
- Pathfinder International reported a contribution of 8% of total case notifications in its coverage area.

NATIONAL SCALE-UP

- The United Republic of Tanzania's national strategic plan, incorporates the ENGAGE-TB approach for addressing gaps in community systems strengthening and the integration of TB into other programmes;
- Community-level indicators were integrated into the national TB and HIV monitoring and evaluation system;
- Community-based TB Care guidelines and training of community health workers/volunteers were strengthened, using elements and experiences from the implementation of the ENGAGE-TB approach;
- NGO/CSO and community engagement were integrated into national guidelines for provision of TB care;
- WHO ENGAGE-TB operational guidance has been adapted, published and disseminated to partners.



ENGAGE-TB



World Health Organization



LOOKING FORWARD

Sustaining ENGAGE-TB activities

EXPANSION



Beyond the focus countries, the **ENGAGE-TB approach** has been **adopted by six additional countries**: Burkina Faso, Côte d'Ivoire, Malawi, Morocco, Namibia and Zimbabwe.

CAPACITY



ENGAGE-TB modules are now included in two African yearly trainings for TB managers—one Anglophone (in Kenya) and one Francophone (in Benin). **Consultants from 12 countries** have been **trained on the ENGAGE-TB approach**. The engagement of the trained consultants in TB programme reviews and Global Fund processes has been critical for the expansion of the ENGAGE-TB approach beyond the five countries.

FINANCING



USD 5 million has been raised for the implementation and scale up of ENGAGE-TB activities in four of the focus countries (DR Congo, Ethiopia, Kenya and United Republic of Tanzania) and two additional countries (Malawi and Zimbabwe) through the Global Fund new funding model.

FUTURE DIRECTIONS



The success and positive experiences of the ENGAGE-TB approach need to be replicated and adopted across all high-TB burden countries to strengthen community engagement and reach all those in need with effective TB care.



STORY OF HOPE

Isabella, a TB patient from Isiolo County, Kenya.

Isabella is a TB patient in Isiolo county, Kenya. She is a mother of three children. She had been frequently sick but, despite getting medicines from the health centre, was never able to recover. At one point, it got so bad that she stopped working. She was so tired, she would lie under the tree all day. She felt she was going to die.

One day, Hellah, a community volunteer, came on a routine visit to check the immunization status of her daughter. Fortunately, the NGO she was associated with – CHAP – had recently decided to integrate TB into its health work and so Hellah had been trained on how to screen for TB and refer patients. This time, when Hellah saw Isabella lying under the tree and spoke to her, she suspected TB and asked Isabella to immediately go to the TB clinic in Isiolo town. The TB clinic diagnosed her active TB and put her on treatment. Isabella had no doubt that her life had been saved by the wise action of CHAP and Hellah and the drugs she took correctly with the support of Hellah.

WHO/HTM/TB/2015.27

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Printed by the WHO Document Production Services, Geneva, Switzerland

The ENGAGE-TB approach is supported by the Bristol-Myers Squibb Foundation SECURE THE FUTURE® program

