

# Key messages

- In the context of universal health coverage, health systems need to ensure that health services meet the needs of the many people affected by neglected tropical diseases (NTDs), who are often the poorest and most vulnerable.
- Integrating the detection, management, recording and reporting of NTDs into primary healthcare needs be recognised as a cornerstone of efforts to ensure good quality service delivery for NTDs.
- Mainstreaming NTDs into routine healthcare should comprise developing harmonised case definitions; assigning appropriate roles and responsibilities to different levels of the health system; providing guidelines, tools and training to health workers; and ensuring that drugs, equipment and infrastructure are available.
- Based on Malaria Consortium's experiences of implementing and evaluating a small-scale
  pilot intervention in Ethiopia, the following are key in strengthening primary healthcare
  for NTDs: raising awareness of NTDs at the community level, taking into account local
  disease concepts and highlighting treatment options, responding to gender and stigma
  issues, and ensuring adequate health worker capacity building.

## Introduction

Neglected tropical diseases are a diverse group of 20 diseases (see Table 1) that affect more than a billion people in tropical and subtropical conditions. [1] NTDs are diseases of poverty and have historically received less global attention than high-profile "killer diseases" such as HIV/AIDS, tuberculosis or malaria. Nevertheless, they affect just as many lives, causing suffering, disability, disfigurement and sometimes death.

In recent years, the global development community has come together to tackle the burden of NTDs, agreeing on an ambitious NTD roadmap<sup>[2]</sup> which envisages the control and eradication of at least two NTDs by 2020. The Sustainable Development Goals, adopted by the 193 countries of the UN General Assembly, also call for an end to "the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases" by 2030.<sup>[3]</sup>

Global efforts to reduce the burden of NTDs have largely focused on developing and distributing safe and effective drugs to at-risk populations, often through mass drug administration (MDA), which takes place in many countries to prevent and control lymphatic filariasis, onchocerciasis, schistosomiasis, soil-transmitted helminth infections and trachoma. While MDA remains a costeffective prevention and control strategy, there is growing recognition that alternative and complementary tools

and approaches are needed to advance the NTD agenda, especially for the many NTDs that are not treatable through MDA. [4]

There is also an urgent need to address the acute and chronic suffering, including long-term disabilities, associated with many NTDs. A cornerstone of the post-2020 NTD agenda is therefore to ensure that health services meet the needs of those living with NTDs. To achieve this, countries will need to transition from providing vertical, dedicated NTD control to mainstreaming NTD care into the routine health system.

To strengthen service delivery for NTDs at the different levels of the primary healthcare system in Ethiopia (see Table 2), Malaria Consortium conducted an operational research study in collaboration with the Ethiopian Federal Ministry of Health and the Regional Health Bureau in the Southern Nations, Nationalities and Peoples' Region (SNNPR). The study aimed to systematically develop an intervention and to test its feasibility and acceptability. This brief describes the intervention and summarises research findings.

Table 1. Diseases currently recognised as neglected tropical diseases by the World Health Organization

Buruli ulcer	Mycetoma, chromoblastomycosis and other deep mycoses	
Chagas disease	Onchocerciasis (river blindness)	
Dengue and chikungunya	Rabies	
Dracunculiasis (guinea-worm disease)	Scabies and other ectoparasites	
Echinococcosis	Schistosomiasis	
Foodborne trematodiases	Soil-transmitted helminth infections	
Human African trypanosomiasis (sleeping sickness)	Snakebite envenoming	
Leishmaniasis	Taeniasis/cysticercosis	
Leprosy (Hansen's disease)	Trachoma	
Lymphatic filariasis	Yaws (endemic treponematoses)	

## **Methods**

## Study design

The study was designed as a small-scale pilot to develop and evaluate an intervention that aimed to integrate the detection, management, recording and reporting of five NTDs into primary healthcare: trachoma, schistosomiasis, soil-transmitted helminth infections, and morbidity related to podoconiosis and lymphatic filariasis. When developing the intervention, consideration was given to gender and stigma issues, as well as the need to embed the intervention within reference documents, guidelines, procedures and tools that are already in use in the primary healthcare system.

The intervention was implemented in the catchment area of Garariketa Health Centre in Hawassa City Administration, including Adare General Hospital as the referral hospital to which the health centre reports. The evaluation used a mixed methods approach to capture insights that could be used to further refine the intervention, as well as strengthen the delivery of high quality services for NTDs more generally.

## Intervention development

#### 1. Literature review

Malaria Consortium conducted a critical literature review to explore the published literature on three focus areas that were of interest to the study: community engagement, gender, and stigma. This helped the study team to situate the community-level components of the intervention in the context of other NTD-related community engagement interventions and informed a training module on gender and stigma.

### 2. Situation analysis

Existing guidelines, reference documents and tools relating to the detection, management, recording and reporting of NTDs at the primary healthcare level in Ethiopia were reviewed by an NTD specialist. This resulted in a comprehensive overview of currently used materials and the identification of gaps and issues that required clarification, harmonisation or updating.

## 3. Capacity assessment

All health facilities participating in the study were visited by the study team to assess their prior capacity to detect, manage, record and report NTDs, and to determine adequate levels of support. Structured checklists were used to collect data on health facilities' general profiles, availability of drugs, infrastructure and equipment,



A health extension worker with a register used to record health post data

previous training on NTDs, supervision, and recording and reporting procedures. The exercise was also used to identify health workers responsible to detect, manage and record NTDs in participating health facilities.

# 4. Engagement with technical experts, stakeholders and policy makers

Throughout the development phase, the study team consulted technical experts, NTD stakeholders and policy makers. This included a stakeholder workshop, which was attended by representatives from the Federal Ministry of Health's NTD Team, as well as civil society organisations with expertise in NTD prevention and control.

## Intervention

Malaria Consortium worked with the Federal Ministry of Health to introduce and embed harmonised case definitions for the five target NTDs, as well as define appropriate roles and responsibilities at the different levels of Ethiopia's primary healthcare system: hospital, health centre, health posts and the Health Development Army (HDA) — a network of female volunteers delivering health education and support to families in their communities.

Specifically, the intervention provided guidance on and defined procedures for the following:

- detection of NTDs based on signs, symptoms and/or laboratory tests
- clinical management of NTDs including treatment, referral between health system levels and follow-up
- recording NTDs at the point of care and reporting cases via the national Health Management Information System (HMIS), including distinguishing between suspected and confirmed cases.

A set of tools were developed to facilitate implementation:

- simple visual representations of key signs and symptoms of NTDs (Figure 1) to support the HDA in detecting suspected cases at the community level
- practical job aids for health personnel at hospitals, health centres and health posts, designed to guide health workers through the detection, management, recording and reporting of NTDs, linking to existing guidelines and reference documents where appropriate.

Table 2. Ethiopia's primary healthcare system

#### **PRIMARY HOSPITALS**

- Provide inpatient and outpatient services to an average population of 100,000
- Provide emergency surgical services

- Act as referral and training centres for health centres
- Supervision provided by Regional Health Bureaus and zonal health authorities

## **HEALTH CENTRES**

- Provide services to approximately 25,000 people
- Provide preventive and curative services as well as simple surgical procedures, typically as outpatient services
- Serve as referral centres and practical training institutions for the health posts
- Supervised by District Health Offices

#### **HEALTH POSTS**

- Provide services at kebele (village) level, serving approximately 5,000 people
- Typically staffed by two or three health extension workers — salaried health workers who provide preventive and basic curative health
- 17 work packages under four themes: family health, disease prevention, hygiene and environmental sanitation, and health education and communication
- Expected to spend considerable time at the kebele level to supervise and support the Health Development Army in community outreach activities
- Health extension workers are female residents of the kebele where the health post is located
- Supervision is provided by a health centre

#### **HEALTH DEVELOPMENT ARMY**

- Teams comprise up to 30 households residing in the same neighbourhood and are further divided into smaller groups of six households, commonly referred as one-to-five networks
- Health Development Army leaders are female and act as unpaid volunteers
- Assist in implementing the health extension programme, including helping during immunisation campaigns, keeping track of pregnancies and illnesses, and relaying messages between households and health extension workers
- Supervised by health extension workers

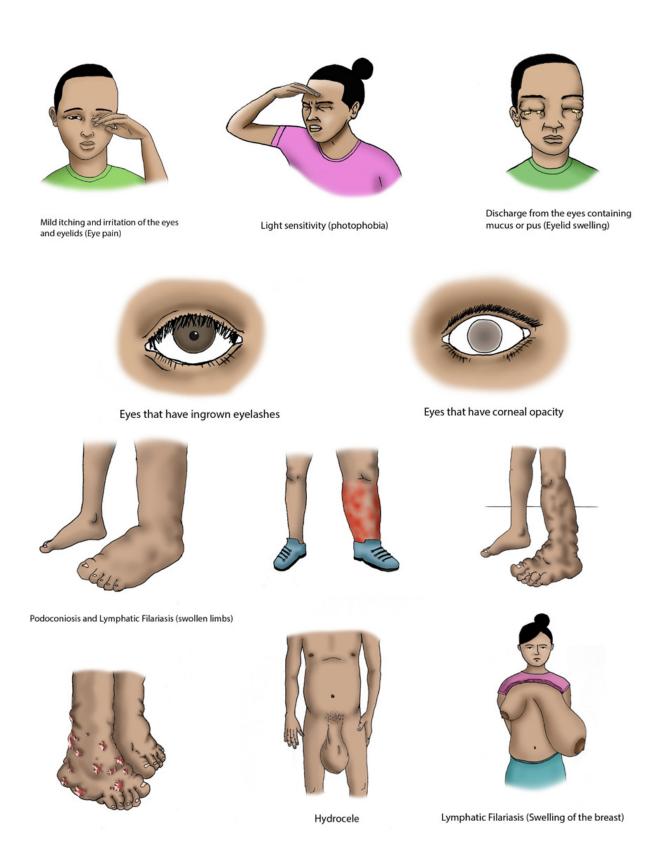


Figure 1. Examples of drawings used in the visual tool developed for use by the Health Development Army and health extension workers to detect suspected NTD cases at the community level

In May 2018, as part of the intervention, health personnel at all levels of the primary healthcare system received training to familiarise them with the guidance, procedures and tools that the intervention introduced. The training followed a cascade approach, whereby the study team and central-level master trainers trained a cohort of regional and zonal-level trainers. This cohort, in turn, trained approximately 50 percent of relevant health personnel at health centre and hospital levels, as well as all health extension workers (HEWs) at health post level. Attendees were asked to share information with colleagues who could not attend and HEWs were tasked with training the HDA as part of their routine interactions. Drugs and equipment that were not routinely available, but were required to perform the new roles and responsibilities were provided to the health facilities in the study area.

Figure 2 illustrates the theory of change that underpins the intervention. In the medium term, the intervention is expected to result in increased case detection, improved case management and more reliable facility-level data. If successful, it is expected to result in improved capacity of the primary healthcare system to identify NTD cases, better quality of care and improved health outcomes for NTD patients, and strengthened capacity of health authorities to respond to local disease trends in the long term.

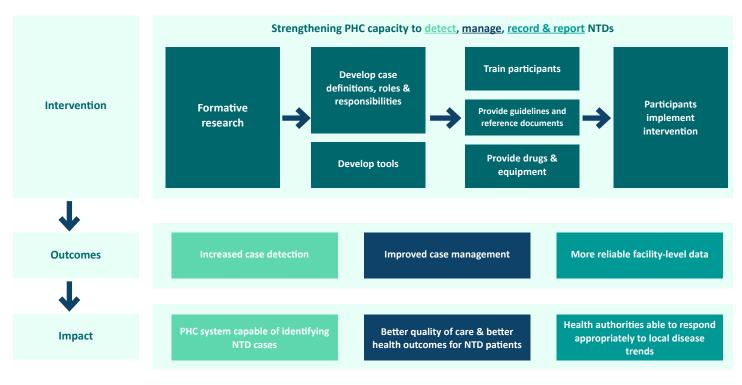


Figure 2. Theory of change

## **Evaluation**

# 1. Pre- and post-training health worker knowledge assessment

A paper-based, self-administered multiple-choice questionnaire was designed with 12 questions to assess health workers' pre- and post-training knowledge across three themes: detection (four questions), management (five questions), and recording/reporting (three questions). Each question had either four or five answer options, each of which could be true or false.

Total scores for each question were calculated as a percentage based on the number of statements correctly identified as true or false. For example, if a respondent correctly identified three out of four statements as true or false, they would receive 75 percent for that question. Weighted total scores and percentages were then calculated for each theme. Overall test scores were stratified by sub-group. A paired sample t-test was done to compare the pre- and post-training results.

### 2. Health worker skills assessment

Health workers' skills in applying intervention guidance, procedures and tools were assessed in October 2018, approximately three months after the training. The skills assessment was adapted from the objective structured clinical examination (OSCE) approach, which involves participants going through a series of stations in which they are presented with, and have to respond to, practical problems that might occur in their day-to-day work. Participants' performance at each station is assessed against standardised scoring criteria.

For this study, all relevant health workers at the participating health centre were invited to take part. Ten stations relating to the detection, management and recording of the five target NTDs were developed by a capacity building specialist, who also trained 12 research assistants to supervise the stations and assign a pass or fail score for each criterion. Total scores were calculated as proportions of pass scores and total number of scoring criteria, i.e. a total score of 75 percent indicates that a participant received pass scores for three quarters of all scoring criteria. Simple descriptive statistics were used to compare results between sub-groups.

# 3. Key-informant interviews and focus group discussions

Key-informant interviews (KIIs) were conducted in August and September 2018 with the following target groups:

- two HEWs
- twelve health workers responsible for detecting and manging NTDs at health centre and hospital levels
- two health workers responsible for recording and reporting NTDs at health centre and hospital levels
- four laboratory staff at health centre and hospital levels.

In addition, two focus group discussions (FGDs) were conducted with HDA members and two with community members who were seen as opinion leaders. Each FGD comprised 10 participants.

Semi-structured topic guides for each target group were developed by an expert in qualitative research, who also trained and supervised six field researchers to collect the data. KIIs and FGDs explored participants' perceptions of NTDs and different intervention components, as well as challenges to providing good quality services for NTDs, in particular those relating to gender and stigma. All KIIs and FGDs were audio-recorded, translated and transcribed directly into English. Data were analysed using a modified thematic content analysis approach, whereby inductive analysis identified themes through open coding by a close line-by-line interrogation.

### 4. Observation visits

All participating health facilities were visited by the local project manager and a representative from the SNNPR Regional Health Bureau in October 2018, using structured checklists to observe and document interactions between health workers and patients, ideally those with signs and symptoms of NTDs. Unstructured topic guides were provided to guide informal discussions with health personnel, patients and community members. A report was prepared summarising each observation visit. Summaries of informal discussions were analysed qualitatively as described for KIIs and FGDs above. Observers' reflections were compiled into a summary report.

## Results

## Health worker knowledge

Ninety-three health workers completed the knowledge assessment, representing 94 percent of all health workers who attended the NTD classroom training. See Table 3 for participants' socio-demographic characteristics.

Table 3. Health worker knowledge assessment: participants' sociodemographic characteristics (N=93)

	n (%)
Sex	
Female	51 (54.8%)
Male	39 (41.9%)
Unknown	3 (3.2%)
Cadre	
Doctor	6 (6.5%)
Nurse	65 (69.9%)
Health officer	10 (10.8%)
Laboratory technician	8 (8.6%)
Unknown	4 (4.3%)
Health facility type	
Hospital	67 (72.0%)
Health centre	24 (25.8%)
Health post	2 (2.2%)

N: total sample size; n: number of participants in sub-sample.

Overall, the mean percentage score increased from 60 percent before the training to 65 percent after, with increases across each of the three themes (Table 4), though the increase within the recording/reporting theme was marginal. The overall increase in mean percentage scores was statistically significant (p<0.01).

When stratified by sex, cadre and health facility type, all sub-groups saw an increase in mean scores. Fifty-six percent of individuals increased their overall scores by more than five percent, while 16 percent saw their scores decrease by more than five percent.

While the training was successful in increasing knowledge among participating health workers, the increase was not as large as expected, and overall knowledge levels not as strong.

Table 4. Health worker knowledge assessment: mean percentage scores by theme, pre- and post-training

Theme	Pre-training score	Post-training score
Detection	65.66	72.51
Management	52.95	60.99
Recording/reporting	62.72	62.81
Total	59.63	65.29

## Health worker skills

Forty-nine out of 51 (96 percent) relevant health workers from Garariketa Health Centre participated in the skills assessment. See Table 5 for participants' sociodemographic characteristics.

Table 5. Health worker skills assessment: participants' sociodemographic characteristics (N=49)

	n (%)
Sex	
Female	27 (55.1%)
Male	22 (44.9%)
Cadre	
Nurse	39 (79.6%)
Health officer	4 (8.2%)
Laboratory technician	4 (8.2%)
Pharmacy technician	2 (4.1%)
Attended classroom training	
Yes	22 (44.9%)
No	27 (55.1%)

N: total sample size; n: number of participants in sub-sample

The mean percentage score across all participants was 29.17. Only three participants (six percent) scored 50 and above; 10 participants (20 percent) scored 40 percent and above; 20 (41 percent) scored 25 and below. There was no significant difference between participants who had attended the training and those who had not. A significant difference was found between female and male participants, with male participants achieving a mean percentage score of 36.36, while females achieved a mean percentage score of 23.36.

Overall, the skills assessment scores were disappointing, suggesting the need to better support health workers in integrating the detection, management, recording and reporting into their day-to-day jobs.

# Key-informant interviews and focus group discussions

A total of 20 individuals were interviewed and 39 individuals participated in four FGDs, including a mix of females and males, different cadres and health workers who had and had not attended the classroom training. The themes discussed below emerged from the data.

### Local health beliefs

Discussions with both community members and community level health workers revealed poor awareness of NTDs as they are conceptualised in biomedicine and categorised in public health. Many participants discussed local disease concepts with similar symptoms, often revealing misconceptions with regard to disease causes and transmission. This affects the HDA's and health workers' ability to communicate with community members about NTDs, and their causes and symptoms.

# Perceived burden of NTDs and treatment seeking behaviours

Several NTDs, including worm infections, trachoma, lymphatic filariasis and podoconiosis were reported as being common. However, community members tended to conceptualise disease as 'acute disease' and reported that the chronic disabilities caused by NTDs are traditionally seen as low-priority. They also tended to believe that there was no cure or treatment for chronic diseases, prompting people not to seek care or to delay treatment seeking. Many participants reported that a key realisation at the community level as a result of this intervention was that care for those conditions is available and that early treatment seeking is essential. However, both direct and indirect costs were seen as major barriers to treatment seeking.

#### Gender

Many participants pointed out that there are cultural barriers to discussing sensitive health issues, especially between men and women. A distinction was often made between body parts that are 'visible' and those that are 'hidden', with participants explaining that it would not be acceptable to discuss problems affecting 'hidden' body parts with members of the other sex. This is problematic as many of the symptoms of NTDs affect the urogenital area (for example hydrocele) and both the HDA and HEWs are exclusively female. It was also suggested that women, including HDA members, would be seen as vulgar or illmannered if they approached such sensitive issues within the community. Respondents reported that women are less likely than men to seek care for sensitive health issues and many highlighted the importance of receiving care in a safe space and from a health worker of the same sex.

## Stigma

Many NTDs are associated with stigma due to the disabilities and disfigurements caused by the diseases. Many participants speculated that those who are affected by NTDs might not seek care or delay treatment seeking out of shame and fear of rejection.

# Relationship between community and Health Development Army

Community members generally appreciated the services of the HDA, considering them a 'bridge' between the community and the health system. Their main role was generally seen as 'educating' the community about health issues and treatment options. The HDA's proximity to the community was seen as a double-edged sword: on the one hand, it increased access to and trust in the health system, but on the other hand, there were reservations around disclosing health issues to someone they knew socially. HEWs were generally seen as more educated and trustworthy than the HDA.

#### Health Development Army members' motivation

HDA members and HEWs generally agreed that they would be happy to take responsibility for NTDs in addition to their current responsibilities. They were often motivated by the opportunity to see positive change in the community, especially where patients are seen to be cured.

## **Training**

The NTD training was appreciated by all health workers who attended. The few that had not been invited to the training expressed disappointment with missing out on the opportunity and frustration that their colleagues

had not shared what they had learnt. This seemed to be a common occurrence. Several participants reported that the training had helped them to identify previous misdiagnoses. However, the extent of health workers' abilities to correctly recall training content varied widely. HEWs felt strongly that tasking them with cascading training information to the HDA was beyond their usual job remit and had added substantially to their workload.

### Intervention tools and job aids

HDA members and HEWs liked the visual tools depicting signs and symptoms of NTDs and reported using the tools on a regular basis, mostly to educate community members rather than detect potential cases. Health workers also generally stated that they appreciated the job aids developed for the different primary healthcare levels. However, their use seemed to depend on their level of expertise, whereby HEWs reported frequent use, but hospital-level health workers did not appear to use the job aids. Many respondents described the job aids as reference or training documents rather than practical aids to support clinical decision making.

## Health workers' capacity and motivation

Health workers overwhelmingly reported that they felt they had the capacity to take responsibility for the detection, management and reporting of NTDs. At health centre level, most did not think that these activities would substantially increase their workloads as the NTD case load was seen as low. However, both HEWs and health workers at hospital level expressed reservations given their generally high workload.

#### **Laboratory tests**

Several challenges were identified relating to laboratory testing. Most of the laboratory staff interviewed reported that they had not used the laboratory techniques recommended in the training, even though the necessary materials and infrastructure were available. The main reasons given were laboratory staff's high workload and the additional time those tests required compared with the more commonly used laboratory tests. It was also reported that patients would be unwilling to wait for test results and that health workers did not request those tests. Health workers, in turn, reported that they did not request the tests as they thought laboratory staff would be unwilling or unable to perform them. It was also pointed out that the request forms do not specify the exact laboratory techniques recommended by the clinician.

#### Treatment

Several health workers expressed concerns over some of the treatment options recommended in the training, especially where presumptive treatment is suggested and health workers had concerns over potential severe side effects.

## **Recording and reporting**

The introduction of a new computer-based reporting and recording system in Ethiopia coincided with the intervention and most of the tools and procedures suggested no longer applied. When discussing reporting and recording of NTDs in the past, there was a perception that cases tended to be underreported.

#### **Observation visits**

Interactions between health workers and 22 patients were observed. The observers reflected that there were few patients seeking care with signs and symptoms of NTDs. At health post and health centre levels, patient numbers were generally low, whereas the hospital was very busy. From the observed interactions, it appeared that health workers continued to detect and manage NTDs as they had previously, and that they did not adopt the new procedures and tests that the intervention had sought to introduce.

"The training focused on neglected diseases, but those diseases affect the community a lot. However, we did not pay much attention because those diseases attack slowly. But now we give attention to those diseases. We create awareness among the community through the Health Development Army that there is treatment for those and that people need to seek medical treatment."

Health extension worker

## Conclusion and recommendations

While this study highlights the complexity of integrating the detection, management and reporting of NTDs into the primary healthcare system, it also demonstrates that the approach has general support among communities and health workers. The study has also been a starting point for developing the general principles on which case definitions, roles and responsibilities, and tools and procedures should be built. Evaluation results suggest that the below areas require further thought and consideration.

- At the community level, the intervention focused exclusively on detecting NTD cases through the HDA. However, the HDA's role is seen more as an information sharing one. As any comprehensive approach to NTDs will need to address prevention as well as primary healthcare, the focus of the HDA's role should shift to facilitating social and behaviour change (including adoption of protective behaviours such as improved hygiene, as well as increased uptake of health services), using suitable community engagement approaches and taking local concepts of disease into account.
- The HDA's role also needs to be considered in the context of gender and stigma issues. It may not be appropriate for female HDA members to identify and refer community members with sensitive health issues and it may be more effective to use community engagement to change social norms, destigmatise NTDs and encourage early treatment seeking. This is likely to require both female and male local 'champions'.
- Gender and stigma also need to be factored into primary healthcare. When patients seek care from a health facility, they should receive good quality care in a safe and non-judgemental environment, ideally from a health worker of their own sex. Gender and stigma are essential elements of health worker training and supervision.
- Given their status within the community, HEWs can play a vital role in the early detection of NTDs, providing treatment for simple cases and referring complicated ones to appropriate higher health system levels. They could also play a role in overseeing home management of disabilities caused by NTDs, such as swollen limbs caused by lymphatic filariasis or podoconiosis. However, there are concerns about HEWs' ever increasing workload. It may be necessary to realign the health extension package with national health priorities.
- Detection and management of NTDs can be complex and increasing health workers' capacity to perform this function will be essential. Ideally, a comprehensive, competency-based NTD module should be included in health workers' pre-service

- training, with periodical refresher trainings. Where this is not possible, in-service training could be strengthened by more consistently applying best practice in adult learning (for example applying principles of facilitated self-directed learning). While training cascades are likely to remain an essential component of in-service training, cascading information to those who do not get a chance to attend classroom trainings should be aided by the development of training plans and suitable training cascade materials. In addition, NTDs need to be integrated into routine supervision and continuing medical education initiatives.
- Harmonised case definitions, roles and responsibilities, and referral mechanisms are important. They will need to be refined in close consultation with health workers and policy makers, taking into account the sensitivity and specificity of clinical and laboratory procedures, time and workload, acceptability among health workers and patients, and risks and benefits. They also need to be tailored to the capacity and infrastructure available at the different levels of the healthcare system. Findings from this study suggests that the health centre level in particular could play a stronger role in detecting and managing NTDs.

"What made me happy about being involved in this project is that the diseases we learned about are not commonly talked about. Even though those diseases exist among us, we do not speak in public about them. But during the training, we learned that those diseases affect our society. So understanding about the diseases and getting attention from the public and the government made me happy."

Health Development Army member

- Collaboration between clinical and laboratory staff should be improved and both sides need to better understand each other's capacity and requirements. This will also need to involve improving referral mechanisms between clinical departments and laboratories, such as the referral forms that specify (and ask clinical staff to justify) the exact test procedure requested.
- Job aids need to be designed in close consultation with users and they need to be tailored to their target audiences. This is likely to involve simple, easy-touse desk guides, integrated into existing guidelines, especially for the lower levels of the primary healthcare system. For the higher levels, it is likely that comprehensive reference guides will be more appropriate.
- Following the introduction of a new reporting and recording system, NTD-related indicators should be reviewed. We suggest distinguishing between 'suspected' and 'confirmed' cases based on agreed case definitions. It will also be important to strengthen health authority staff's capacity to use facility-level NTD data, for example to triangulate with mapping data and react appropriately to data trends.

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For more information about the study, contact Christian Rassi, Project Coordinator: c.rassi@malariaconsortium.org.





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Cover image: A health extension worker in front of a health post



