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METHODS AND TOOLS TO STRENGTHEN LYMPHATIC FILARIASIS (LF) MORBIDITY MANAGEMENT AND DISABILITY PREVENTION (MMDP) SERVICES

Multi-country experiences in implementing a direct inspection protocol, a situation analysis, and collecting hydrocele and lymphedema patient estimates

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Photo: Helen Keller International / USAID MMDP Project

BACKGROUND

The World Health Organization (WHO) estimates there are 40 million people globally who suffer from the debilitating morbidity and disability caused by lymphatic filariasis (LF). This includes swelling of the limbs and breast, termed lymphedema (elephantiasis in its most severe form), and swelling of the scrotum, termed hydrocele.¹ Those with lymphedema and hydrocele often face great stigma and isolation due to their condition. Without care and treatment, the disease can further progress and ultimately diminish the health and productivity of individuals, families, communities, and nations. In all LF-endemic areas where there are known hydrocele and lymphedema patients, national LF elimination programs aim to provide treatment and care through morbidity management and disability prevention (MMDP). MMDP services consist of limb hygiene, elevation, and exercise for lymphedema, and corrective surgery for hydrocele. These activities are delivered through the health system and are a key tenet of the strategy for the WHO Global Programme to Eliminate Lymphatic Filariasis (GPELF).

To help countries quantify the estimated number of patients and gather information to help plan for and assess LF MMDP services, the following methods and tools have been developed by the WHO, in collaboration with partners. They are published in the 2nd Edition Lymphatic Filariasis MMDP Aide-Memoire for National Programme Managers: 1) Methods for Estimating the Number of Hydrocele and Lymphedema Patients (Web Annex B), 2) Situation Analysis (Web Annex B), and 3) Direct Inspection Protocol (Web Annex A).¹ Use of these methods and tools by LF-endemic countries generates information needed for WHO’s validation of the elimination of LF as a public health problem.²

TABLE I. DESCRIPTION OF METHODS AND TOOLS AVAILABLE TO HELP PLAN FOR AND ASSESS LF MMDP SERVICES

| Patient Estimates Methods | Situation Analysis Tool | Direct Inspection Protocol |
|--|---|--|
| <ul style="list-style-type: none"> Describes strengths and weaknesses of methods for collecting hydrocele and lymphedema patient estimates Data indicate where LF MMDP services are needed and are generated at the implementation unit (IU) level | <ul style="list-style-type: none"> Assesses factors that influence LF MMDP services (e.g., facility designation, equipment, supplies, training needs, and available epidemiological data) Serves as a method to compile existing patient estimate data Data are generated at various levels (e.g., national, regional, implementation unit) depending on context | <ul style="list-style-type: none"> Measures the readiness and quality of facility-based lymphedema care Identifies strengths and gaps around: health care staff knowledge / skills, patient tracking, and infrastructure Data are generated at the facility level, but based on geographic scope can serve as a regional or national assessment |

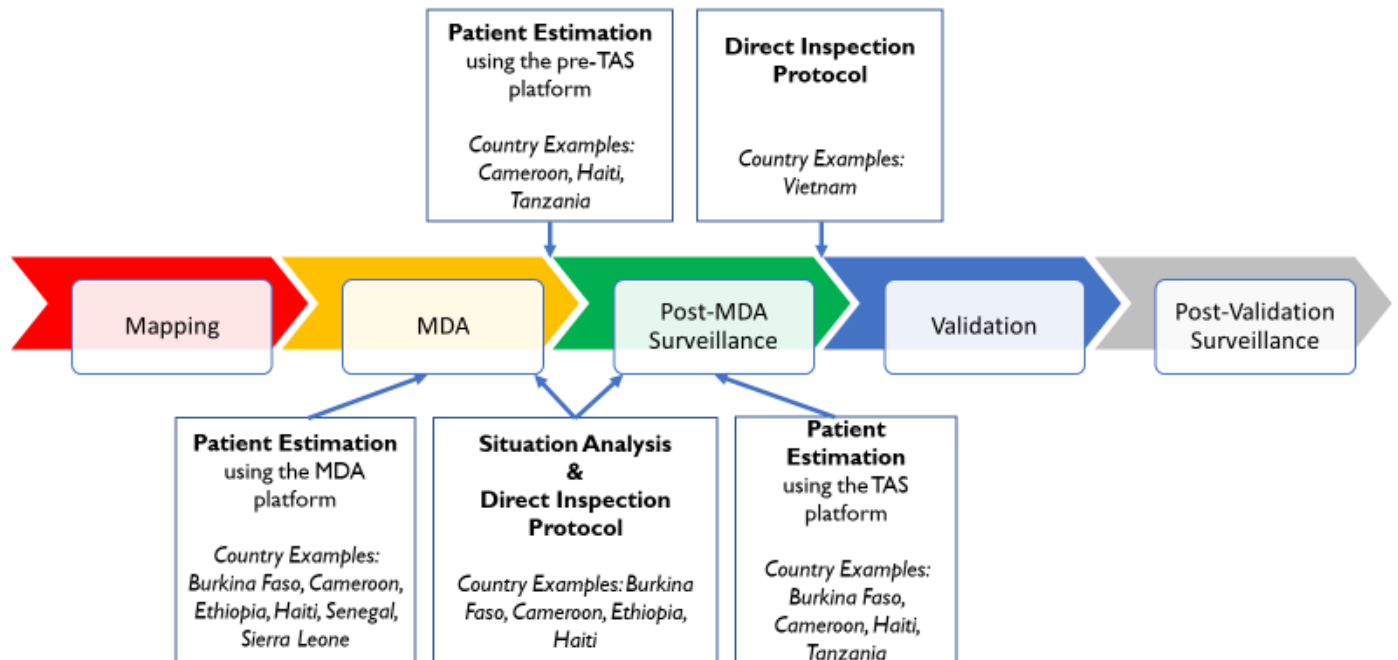
¹ LYMPHATIC FILARIASIS - MANAGING MORBIDITY AND PREVENTING DISABILITY: AN AIDE-MÉMOIRE FOR NATIONAL PROGRAMME MANAGERS, SECOND EDITION. GENEVA: WORLD HEALTH ORGANIZATION; 2021. LICENCE: CC BY-NCSA 3.0 IGO.

² VALIDATION OF ELIMINATION OF LYMPHATIC FILARIASIS AS A PUBLIC HEALTH PROBLEM. GENEVA: WORLD HEALTH ORGANIZATION; 2017. LICENSE: CC BY-NC-SA 3.0 IGO.

MULTI-COUNTRY SURVEY RESULTS ON THE USE OF LF MMDP METHODS AND TOOLS

In 2019, an Excel-based survey was issued to 15 LF-endemic countries to learn more about their experiences (e.g., scale of implementation, cost, and time) and key learnings (e.g., utility) from use of LF MMDP patient estimation methods, the situation analysis tool, and the direct inspection protocol. Responses were received from National Neglected Tropical Disease (NTD) Programs in 12 countries: Burkina Faso, Cameroon, Ethiopia, Ghana, Haiti, Indonesia, Laos, Senegal, Sierra Leone, Tanzania, Uganda, and Vietnam. This technical brief summarizes the findings from the implementation of these methods and tools in the field across a broad range of settings, at various stages in each country's LF program as characterized by the GPELF framework stages: mapping, MDA, post-MDA surveillance, validation, and post-validation surveillance (Figure 1).

FIGURE 1. COUNTRY EXAMPLES OF USE OF THE LF MMDP METHODS AND TOOLS AT VARIOUS PROGRAM STAGES IN THE GPELF FRAMEWORK



PATIENT ESTIMATES

Twelve countries collected patient estimates for hydrocele and lymphedema across 983 IUs. Most countries utilized existing platforms such as mass drug administration (MDA), the transmission assessment survey (TAS), and other NTD surveys, such as the pre-TAS, trachoma impact survey and post-MDA coverage evaluation survey to collect patient estimates. Some countries used stand-alone methods such as key informant questionnaires and active case finding.

TABLE 2. DATA ON METHODS, SCALE, TIME, AND COST ASSOCIATED WITH COLLECTING PATIENT ESTIMATES

| | |
|---|--|
| <p>12 countries collected patient estimates using:</p> <ul style="list-style-type: none"> • MDA platform • TAS platform • Other survey platform (pre-TAS, trachoma impact survey, post-MDA coverage survey) • Key informant questionnaire • Active case finding | <p>Patient estimates collected in 983 IUs:</p> <ul style="list-style-type: none"> • MDA: 376 IUs • TAS: 87 IUs • Other survey: 363 IUs • Key informant questionnaire: 121 IUs • Active case finding: 36 IUs |
| <p>Time range*:</p> <ul style="list-style-type: none"> • MDA: 4-10 days/IU • TAS: length of TAS (varied) • Other survey: 6-14 days/IU • Key informant questionnaire: no data • Active case finding: 5-10 days/IU | <p>Cost range:</p> <ul style="list-style-type: none"> • MDA**: \$0-\$54/IU*** • TAS: \$0-\$76/IU*** • Other survey: 0-\$242/IU*** • Key informant questionnaire: no data • Active case finding: \$1,200-\$9,095/IU |

* For the MDA, TAS, and other survey platforms, time reported is not incremental time for just the patient estimation component, but total activity time for the broader activity platform.

** Outlier: highest range value was \$3,560/IU in one country since costs included 1 full day of training on LF MMDP so that those collecting the data could provide detailed education on clinical management to any patients found.

*** Incremental cost range presented.

SITUATION ANALYSIS

Four countries implemented the situation analysis across 53 IUs, with the ability to use the data at the regional level and/or national level. In all four countries, the implementation of the Situation Analysis was conducted in combination with the Direct Inspection Protocol.

TABLE 3. DATA ON SCALE, TIME, AND COST ASSOCIATED WITH IMPLEMENTING THE SITUATION ANALYSIS

| | | |
|--|--|--|
| <p>4 countries implemented a situation analysis</p> | <p>Situation analysis conducted in 53 IUs</p> <ul style="list-style-type: none"> • 1 country conducted a national assessment • 3 countries conducted regional assessments | |
| <p>Time range: 1-7 days/IU</p> | <p>Cost range:</p> <ul style="list-style-type: none"> • \$19,200/national level* • \$3,150-\$4,334/regional level • \$724-\$1,319/IU level | <p>Average cost:</p> <ul style="list-style-type: none"> • \$19,200/national level* • \$3,398/regional level • \$973/IU level |

*Cost data from only 1 country.

DIRECT INSPECTION PROTOCOL

Five countries implemented the direct inspection protocol at the facility level, yet given the design, the assessment was equivalent to either a national or regional assessment. Several countries implemented a modified direct inspection protocol at the same time as the situation analysis, whereby the two tools were combined to optimize human and monetary resources.

TABLE 4. DATA ON SCALE, TIME, AND COST ASSOCIATED WITH IMPLEMENTING THE DIRECT INSPECTION PROTOCOL

| | | |
|--|---|---|
| 5 countries implemented the direct inspection protocol | Direct inspection protocol conducted in 502 facilities: <ul style="list-style-type: none">• 2 countries conducted national assessments• 3 countries conducted regional assessments | |
| Time range: 1-3 hours/facility | Cost range: <ul style="list-style-type: none">• \$10,000-\$19,200/national level• \$3,150-\$4,334/regional level• \$27-\$1,050/facility level | Average cost: <ul style="list-style-type: none">• \$14,600/national level• \$3,398/regional level• \$453/facility level |

KEY LEARNINGS FROM COUNTRIES

FEEDBACK ON USE OF METHODS FOR PATIENT ESTIMATES

- **Discuss the pros and cons of the different platforms up-front to determine which approach is best for your country context:** there is not a gold standard patient estimation method, and countries are encouraged to determine which ongoing platform (e.g., MDA, surveys) or stand-alone platforms (e.g., active case finding) would be most acceptable and cost-effective. Figure 2 and Table 5 were designed to help aid in the discussion.
- **Start collecting data now:** it is cost-effective to collect data on lymphedema and hydrocele patients by adding these questions to ongoing platforms, but countries must act quickly as many of the existing platforms are time-bound. These efforts will not only benefit LF patients by making their location known so that the essential package of care can be provided to them, but every IU with known hydrocele and lymphedema patients requires estimates for the validation process.
- **Develop a job aide for use during data collection, using local photos and vocabulary to describe lymphedema and hydrocele:** job aides help orient non-healthcare professionals (e.g., drug distributors, community members) to hydrocele and lymphedema and aid in identification of patients. The job aide should include photos of all stages of disease progression, not just the most severe states. In some settings, the ministry of health (MOH) may wish to have a health worker validate the patient estimates if there are concerns about reliability, but this is not required.
- **Discuss the availability of services, or plans for future availability of services with community members at the time of data collection:** Communities and patients do not respond well to the collection of data on lymphedema and hydrocele patients without being

followed-up with service provision; if services are not being provided to patients, they may not declare themselves during patient estimation activities.

FIGURE 2. DECISION TREE TO AID IN COUNTRY CHOICES ABOUT MOST APPROPRIATE PATIENT ESTIMATION METHODS

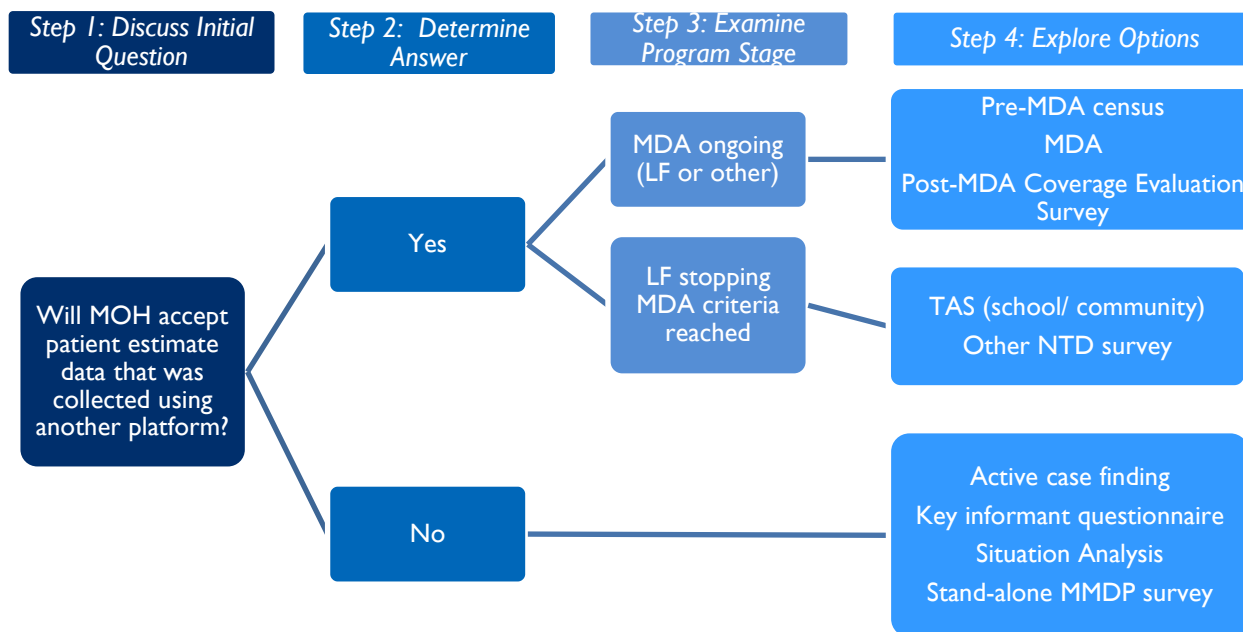


TABLE 5. COUNTRY FEEDBACK ON PROS VS. CONS OF DIFFERENT PATIENT ESTIMATION METHODS

| Pros | Cons |
|---|--|
| <ul style="list-style-type: none"> Pre-MDA/MDA Census and Active Case Finding offer a list of hydrocele and lymphedema patients by village, which can aid in service delivery and outreach For survey based platforms, those with cluster-based sampling and many clusters (e.g., TAS, post-MDA coverage survey) provide a more robust opportunity to collect patient estimates, as compared to other surveys such as the pre-TAS with often only two clusters per survey Collecting patient estimates on top of another platform can be much less expensive than a stand-alone activity to collect the same information | <ul style="list-style-type: none"> Survey-based platforms only provide information on those individuals (and their families) sampled Platforms that gather people together at a central location may not offer a setting that is discrete enough to ask sensitive questions about hydrocele and lymphedema, so special care must be taken to provide privacy when asking about clinical conditions |

FEEDBACK ON USE OF THE SITUATION ANALYSIS AND DIRECT INSPECTION PROTOCOL

- Use the Situation Analysis and Direct Inspection Protocol data to help shape the design (start) or evolution (mid-stream) of LF MMDP service provision: baseline data can help inform the design of new service delivery, while data collected in the middle of a program can help strengthen specific areas. Data collected immediately prior to submission of a validation dossier can define areas that need strengthening in the post-validation phase. Data collected at any point will ultimately

strengthen awareness about LF MMDP and gaps in service delivery among health staff working at the community level, as well as district, regional, and national levels.

- Integrate the Situation Analysis with the Direct Inspection Protocol or other assessment if it is practical to combine (e.g., WHO Services Availability and Readiness Assessment, DHS Services Provision Assessment): these two tools were designed to use separately, but based on when and how they are used, can be combined to provide more comprehensive data gathered in a cost-effective way when assessing facilities, compared to single-tool implementation.
- Share results from LF MMDP tools more broadly beyond NTDs: information gathered during the situation analysis about lymphedema services could benefit other skin diseases, and information on hydrocele surgery could benefit safe surgery initiatives.

CROSS-CUTTING FEEDBACK

- Consider the pros and cons of when the various methods and tools could be used early on in LF programs and discuss them openly with key stakeholders: the best approaches are country and context specific. Figures 1 and 2 were designed to aid these discussions.
- Use electronic data capture to implement the LF MMDP tools: use of smart phones or tablets to collect data in the field (compared to paper data collection) expedites both the receipt of data and the ability to act and provide or strengthen services based on those data.

CONCLUSIONS

These methods and tools were designed to enhance data collection and quality and promote the scale-up of service delivery, among other factors, of LF MMDP activities in the GPELF. The feedback provided from 12 countries demonstrates that these approaches generate useful data, are feasible to implement across the program lifespan from design to evaluation, and in many cases, are very cost-effective. Discussing the pros and cons early-on in the program to determine which method or tool is the best fit, and the timing of use, is recommended.

LF MMDP methods and tools:

- Are useful, feasible to implement, and cost-effective
- Data generated benefit those with LF, the health system, and the validation dossier
- Different approaches for implementation work best in different settings

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