Lymphatic filariasis - managing morbidity and preventing disability: An aide-mémoire for national programme managers, Second edition
Lymphatic filariasis - managing morbidity and preventing disability: An aide-mémoire for national programme managers, Second edition
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>v</td>
</tr>
<tr>
<td>New in this edition</td>
<td>vi</td>
</tr>
<tr>
<td>Glossary</td>
<td>vii</td>
</tr>
<tr>
<td>The Global Programme to Eliminate Lymphatic Filariasis (GPELF)</td>
<td>x</td>
</tr>
<tr>
<td>Aim of this document</td>
<td>xi</td>
</tr>
<tr>
<td>Target readers</td>
<td>xi</td>
</tr>
<tr>
<td>Organization</td>
<td>xi</td>
</tr>
</tbody>
</table>

### Section 1: Introduction

1. **Lymphatic Filariasis and Associated Morbidity**
   - 1.1.1 Background and epidemiology
   - 1.1.2 Signs and symptoms
   - 1.1.3 Socioeconomic burden of lymphatic filariasis
   - 1.1.4 Associated disability
   - 1.2 Eliminating lymphatic filariasis
     - 1.2.1 Background
     - 1.2.2 Integrating elimination of lymphatic filariasis into the control of other diseases

### Section 2: MMDP within the Global Programme to Eliminate Lymphatic Filariasis

2.1 Why manage morbidity and prevent disability?
2.2 What is MMDP?
2.3 Goals and aim of MMDP
2.4 Guiding principles
2.5 Elements of the essential package of care
   - 2.5.1 Treating acute attacks
   - 2.5.2 Managing lymphoedema
   - 2.5.3 Managing hydrocele
   - 2.5.4 Providing antifilarial medicines
2.6 Strategic planning

### Section 3: Planning MMDP in a national programme

3.1 Strategic planning and implementation
   - 3.1.1 Situation analysis
   - 3.1.2 Developing or updating an implementation policy and plan
   - 3.1.3 Providing the essential package of care
3.2 Monitoring and evaluation
   - 3.2.1 Reporting to the Global Programme to Eliminate Lymphatic Filariasis
   - 3.2.2 National monitoring and evaluation plan

### References

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*iii*
Annexes

Annex 1: Dreyer Seven-stage classification system for lymphoedema
Annex 2. Simplified staging of lymphoedema for community-level health workers
Annex 3. Management for seven stages of lymphoedema (or elephantiasis)
Annex 4. Algorithm for determining the management of acute attacks
Annex 5. Example of steps for home-based management of lymphoedema (or elephantiasis)
Annex 6. Community Morbidity Register
Annex 7: Examples of individual intake and follow-up forms for community health workers
  Example of Individual Intake Form for Community Health Worker
  Example of Individual Follow-up Form for Community Health Workers
Annex 8: Example Reporting Framework from Communities to the National Level and from the National Level to WHO
  Example reporting form from community health worker (CHW) to health centre (HC) (each reporting period)
  Example reporting form from health centres (HC) to implementation unit (IU) (each reporting period)
  Example reporting form from implementation unit (IU) to national level (each reporting period)
  Example reporting form from national level to GPELF (annually)

Web Annex A: Protocol for evaluating minimum package of care of morbidity management and disability prevention for lymphoedema management in designated health facilities
https://apps.who.int/iris/bitstream/handle/10665/339870/9789240017085-eng.pdf

Web Annex B: Lymphatic filariasis: Situation analysis tool for morbidity management and disability prevention
https://apps.who.int/iris/bitstream/handle/10665/339871/9789240017092-eng.pdf

Web Resource: Lymphatic Filariasis Morbidity Management and Disability Prevention Training Workshop Modules
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New in this edition

Since the first edition of Lymphatic Filariasis: Managing Morbidity and Preventing Disability: An Aide-Memoire for National Programme Managers was published by the World Health Organization in 2013, significant progress has been made in reducing filarial infection globally and there has been a groundswell of support for expanding availability to morbidity management and disability prevention (MMDP) services for individuals suffering from the chronic manifestations of lymphatic filariasis (LF). Morbidity management and disability prevention remains a critically important aspect of the Global Programme to Eliminate Lymphatic Filariasis, particularly as countries approach validation of elimination of LF as a public health problem.

The new edition has been developed to make widely available to programme managers, health care workers in endemic settings, academic researchers, and other key partners, a concise source of information on strategies for MMDP for LF. It is a product of efforts to elaborate and concepts and approaches introduced in the previous edition, with a focus on ensuring that countries have the tools necessary to provide the essential package of care for LF.

In an effort to assist member states in expanding and evaluating MMDP programs, WHO has developed a toolkit of materials to provide expanded clinical, operational, and managerial standard operating procedures for planning and implementing morbidity management and disability prevention activities.

This manual is the result of collaboration between the WHO Department of Control of Neglected Tropical Diseases and the WHO Department of Emergency and Essential Surgical Care. Updates reflect new published WHO guidance and evidence to further develop concepts and approaches for implementing and monitoring MMDP programmes in endemic settings, such as:

- Harmonized terminology and definitions related to morbidity management and disability prevention
- Updated practical information for clinical management, delivery, and evaluation of clinical services for filarial lymphoedema
- Outlined new and promising therapeutics for treatment of LF infection and lymphoedema management
- Aligned morbidity management and disability prevention standard operating procedures with other relevant initiatives (e.g. SDGs and UHC) and programs (e.g. global surgery, WASH, and case management for other NTDs and other conditions)
- Elaborated indicators and processes related to MMDP for requesting validation of the elimination of LF as a public health problem

Further, minor revisions, including clarification of wording and corrections (e.g. grammatical and typographical) have been made throughout the manual. Some new figures and tables were added to the manual based on feedback from reviewers and some have been modified for clarification. Additionally, three new tools are available as web annexes to help countries plan and extend availability of MMDP and document criteria for validation of LF as a public health problem.
Glossary

The definitions given below apply to the terms used in this manual. They may have different meanings in other contexts.

abscess: localized collection of pus surrounded by inflamed tissue
acute attack: acute onset of swelling, warmth, redness, and pain with or without fever, chills, headache, and weakness caused by a bacterial infection; used commonly to refer to ADL
acute dermatolymphangioadenitis (ADLA): acute inflammation of the skin, lymph vessels, and lymph glands associated with secondary bacterial infections
adenolymphangitis (ADL): inflammation of the lymph vessels or glands often accompanied by pain, fever, and swelling; also termed acute attack (encompasses ADLA and AFL)
adenoapathy: any disease or enlargement of a lymph gland
acute filarial lymphangitis (AFL): inflammation caused by the death of adult worms, which usually produces a palpable ‘cord’ along the lymph vessel and progresses distally
analgesic: medicine used to relieve pain
antibacterial cream: a cream that kills bacteria or stops their growth; used to treat infected entry lesions and wounds and prevent infections in deep folds
antibiotic: medicine used to kill bacteria or stop their growth
antifilarial medicine: medicines used to kill filarial parasites; most primarily decrease microfilaria in the blood and may or may not kill adult worms in lymphatic vessels
antifungal cream: a cream that kills fungi or stops them from growing; used to treat fungal infections between the toes or in deep folds. For patients with advanced-stage lymphoedema (or elephantiasis), antifungal creams can help prevent fungal infections in deep folds and in the interdigital spaces.
antipyretic: medicine used to treat fever
antisepctic: any medicine that stops or delays bacteria from growing; used on the skin
chronic manifestation: clinical sign present over a long period
chyluria: presence of chyle in the urine as a result of organic disease (as of the kidney) or obstruction of lymph flow from ruptured lymph vessels
clinical case of LF: case in a resident of or a long-term visitor to an endemic area, with hydrocele, lymphoedema (or elephantiasis), chyluria, haematochyluria, haematuria, or tropical pulmonary eosinophilia syndrome for which other causes have been excluded
community home-based care: care to ensure that patients maintain the best possible quality of life in their activities with the help of community health workers in the community, health staff or volunteers.
disability: an umbrella term for impairments, activity limitations and participation restrictions; an interaction between individuals with a health condition (e.g. LF disease) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social support).
elephantiasis: severe or advanced lymphoedema
endemic area: area in which the average resident population or any subunit of population has a positivity rate of filarial antigenaemia or microfilaraemia equal to or greater than 1%

entry lesion: any break in the skin that allows bacteria to enter the body; often occurs between the toes or in deep skin folds, through wounds on the skin surface, such as cuts, scrapes or scratches; visible in almost all patients with ADL or acute attacks

evaluation unit: study area selected for assessing transmission; can comprise multiple implementation units or be part of an implementation unit

family home-based care: care to ensure that patients maintain the best possible quality of life by carrying out activities at home, with or without the help of a family member

filarial infection: presence of adult filarial worms in lymphatic vessels or of microfilaria in blood

gerographical coverage: proportion of administrative units in which morbidity management and disability prevention activities are being implemented out of all those that require such activities

haematoma: mass of usually clotted blood that forms in a tissue, organ or body space as a result of a broken blood vessel

haematuria: blood in urine

hydrocele: collection of excess fluid inside the scrotal sac that causes the scrotum to swell or enlarge

hygiene: conditions or practices conductive to maintaining health and preventing disability. In the context of managing morbidity from LF, hygiene involves washing the affected areas with soap and water until the rinse water is clear and then carefully drying.

implementation unit: administrative unit in a country that is used as the basis for making a decision about mass drug administration

community health worker: any person, such as a member of the family or community, who provides regular, continuous assistance to another person

interdigital lesion: lesion between the toes or fingers; a subset of entry lesions

long-term care and management: various services to ensure that patients who are not fully capable of long-term self-care can maintain the best possible quality of life

lymph scrotum: disease in which the scrotal sac is thick, usually enlarged and has vesicles on the surface filled with (and frequently leaking) lymph

lymphatic system: network of nodes and vessels that maintain the delicate balance of fluid between the tissues and blood; an essential component of the body’s immune defence system

lymphoedema: swelling caused by the collection of fluid in tissue; lymphoedema most frequently occurs in the legs, arms, breasts, scrotal skin, vulva and penis

mass drug administration: a modality of preventive chemotherapy in which anthelminthic medicines are administered to the entire population of an area (e.g. state, region, province, district, sub-district, village) at regular intervals, irrespective of the individual infection status

mass drug administration round: distribution of antifilarial medicines to a target population during a defined period.

microfilaria: microscopic larval stage of filarial parasites that circulate in the blood and are transmitted by mosquitoes

microfilaraemia: presence of microfilariae in blood

morbidity: clinical consequence of infections and diseases that adversely affect the health of individuals. LF causes chronic morbidity by damaging the lymphatic system in the arms, legs, breasts, genitals (including hydrocele in men), or kidneys.
neglected tropical diseases: primarily infectious diseases that thrive in impoverished settings, especially in the heat and humidity of tropical climates. They have been largely eliminated elsewhere and thus are often forgotten. They include: Buruli ulcer, Chagas disease, dengue and chikungunya, dracunculiasis, echinococcosis, foodborne trematode infections, human African trypanosomiasis, leishmaniases, leprosy, LF, mycetoma, onchocerciasis, rabies, scabies/ectoparasite, schistosomiasis, snakebite envenoming, soil-transmitted helminth infections, taeniasis and cysticercosis, trachoma and yaws (endemic treponematoses).

neurological disorder: disorder that affects the brain, spinal cord or nerves

preventive chemotherapy: the use of anthelminthic drugs, either alone or in combination, as a public health tool against helminth infections. Mass drug administration is one modality of preventive chemotherapy

primary prevention: prevention of disease; strategies applied to the general population to improve general well-being and provide specific protection against selected diseases

prophylactic antibiotic: antibiotic used to prevent bacterial infections

reporting unit: implementation unit or other administrative unit responsible for reporting morbidity management and disability prevention activities

secondary prevention: strategies and activities for the earliest possible identification of disease in at-risk populations to ensure prompt treatment and to prevent adverse sequelae

social mobilization: broad-scale movement to engage participation in achieving a specific development goal and effective behavioural and social change; involves reaching, influencing and involving all relevant segments of society

target population: population in an implementation unit that is targeted for treatment. In the context of LF, the target population for mass drug administration is the same as the population eligible to receive the medicines, according to the criteria for drug safety, which is usually 85–90% of the total population. The target population for morbidity management and disability prevention activities are those with acute attacks, lymphoedema (or elephantiasis), or hydrocele.

tertiary prevention: strategies and activities to promote independent function and prevent further disease-related deterioration
The Global Programme to Eliminate Lymphatic Filariasis (GPELF)

The Global Programme to Eliminate Lymphatic Filariasis (GPELF) was launched by the World Health Organization (WHO) in 2000. As of the end of 2018, LF was endemic in 72 countries and territories; an estimated 892 million people were at risk for infection (1). At the beginning of the programme, more than 40 million people were incapacitated and disfigured by LF-related disease, predominantly lymphoedema and its advanced form, elephantiasis, and hydrocele.

The Programme has two main aims:

- stopping the spread of LF infection through mass drug administration (MDA) and;
- alleviating suffering through morbidity management and disability prevention (MMDP).

Significant progress has been made with mass drug administration between 2000 and 2018 with over 7.7 billion doses delivered to more than 910 million people at least once. While GPELF interventions are estimated to have prevented more than 97 million cases (2), interventions to prevent and manage LF-related disability in endemic communities remain limited. Of the 72 endemic countries, limited data on LF morbidity has been reported from 60 countries. Based on reports, only 51.5% of implementation units with known LF patients are providing MMDP care (1).

Figure 1 illustrates the twin pillars of the GPELF: stopping the spread of LF infection and alleviating suffering among people who have the disease. Vector control, when appropriately used, can supplement activities to interrupt transmission (3). A strong monitoring and evaluation component is essential throughout the programme life cycle to ensure the programme is meeting outlined aims (see Section 3.2).
Aim of this document

In 2018, only 37 countries were reporting MMDP by the implementation unit, indicating active morbidity management and disability prevention activities (1). The GPELF strategic plan stipulates that, by 2021, all endemic countries should be collecting and reporting data on MMDP to WHO (4). Despite an overall expansion of MMDP service globally, a rapid scale-up of MMDP services is necessary in order to achieve 2030 targets.

This document provides relevant information to guide national programmes on planning, implementing and monitoring morbidity management and disability prevention activities at the national level in alignment with the GPELF essential package of care for LF. It summarizes the best available information on morbidity management and disability prevention associated with acute attacks, lymphoedema, and hydrocele. It also provides general operational and managerial guidance for reducing the number of cases of LF and providing care for those affected.

Target readers

This document is intended for managers of national LF programmes, national staff members involved in morbidity management and disability prevention, district public health managers and medical or non-medical staff responsible for not only the design and implementation of such activities, but also sustaining and integrating LF activities with other activities.

Organization

Section 1 provides background information, including a general description of the GPELF and the concepts of interruption of transmission, morbidity management and disability prevention associated with LF within the wider framework of neglected tropical diseases. It also gives a scientific overview of the associated morbidity, including epidemiology, signs and symptoms, and associated disability associated with filarial-morbidity. Section 2 describes the morbidity management and disability prevention component within the GPELF framework, with its goals, aims, and guiding principles. Also, it also describes the strategies available for morbidity management and disability prevention with the essential package of care described by GPELF. Section 3 provides guidance for national programmes building a morbidity management and disability prevention programme aligned with GPELF, but with consideration to local factors. The annexes give additional tools and resources for activities not only for national NTD programmes, but also in hospitals, health facilities and communities.
Section 1: Introduction

1.1. Lymphatic Filariasis and Associated Morbidity

1.1.1 Background and epidemiology

LF is a vector-borne infection caused by three species of thread-like parasitic worms, called filariae. The species *Wuchereria bancrofti* is the most prevalent worldwide, *Brugia malayi* and *B. timori* are found mostly in Southeast Asia. Filarial parasites in their adult stage live in the lymphatic system. The worms have an estimated active reproductive span of 4–6 years, producing millions of small immature larvae, microfilariae, which circulate in the peripheral blood. They are transmitted from person to person by several species of mosquito (Figure 2).

**Figure 2. Life-cycle of Wuchereria bancrofti**

Source: US Centers for Disease Control and Prevention, 2019

Before widespread control efforts, it was estimated that 120 million people globally were infected with filarial parasites. A new geostatistical modelling analysis of LF prevalence indicates that 54.1 million people were infected in 2018 (5). Currently, 72 countries are considered endemic for LF and 856 million people live in areas requiring MDA (1). More than 80% of the people affected with the disease live in India and endemic countries in Africa, while the remainder live in Southeast Asia, the Eastern Mediterranean and the Pacific. Approximately 17 million people globally are affected by LF-related lymphoedema (or elephantiasis), which includes swelling of the limbs, breasts or genitals, and almost 19 million men are affected by urogenital swelling, primarily hydrocele (6). Although these clinical manifestations are not often fatal, they lead to the ranking of LF as one of the world’s leading causes of permanent and long-term disability (7).
LF infection can occur early in life. In some areas, about 30% of children are infected before the age of 4 years (8; 2) and, while the clinical disease usually appears later in life, subclinical damage starts at an early age (2). LF is unlikely to cause lymphoedema or hydrocele in children under 10–15 years of age (9; 10).

In the context of the GPELF, the term ‘lymphatic filariasis’ refers both to infection with human filarial parasites and to clinical disease, including adenolymphangitis (ADL), lymphoedema (or elephantiasis) and hydrocele.

### 1.1.2 Signs and symptoms

LF is characterized by a wide range of acute and chronic clinical features. The acute form of the disease is called ADL and encompasses acute dermatolymphangioadenitis (ADLA) and acute filarial lymphangitis (AFL). ADLA, defined as acute inflammation of the skin, lymph vessels, and lymph glands associated with secondary bacterial infection, is more commonly termed acute attack and requires antibiotic therapy. Acute filarial lymphangitis involves inflammation caused by the death of adult worms and is generally self-limited. In some circumstances, it may be difficult for health workers to distinguish between ADLA and AFL. Therefore, for the purposes for this document, ADL is the technical term that will be used to describe acute attacks. Chronic manifestations include lymphoedema (or elephantiasis), hydrocele, chyluria, and tropical pulmonary eosinophilia. Section 2.5 describes the management of these clinical manifestations in detail.

### Acute attacks

The adult filarial worms cause inflammation of the lymphatic system, resulting in lymphangitis and lymphadenitis. These conditions lead to lymphatic vessel damage, even in asymptomatic people, and lymphatic dysfunction, which predispose the lower limbs in particular to recurrent bacterial infection. These secondary infections provoke ADLA, commonly called ‘acute attacks’ or ADL, which are the most common symptom of LF and play an important role in the progression of lymphoedema (11). It has been suggested that bacteria commonly gain access to damaged lymphatic vessels through ‘entry lesions’, often between the toes or within skin folds. Acute attacks present as an acute onset of swelling, warmth, redness, and pain in the affected area with or without fever, chills, headache, and weakness. Acute attacks often resemble erysipelas or cellulitis.

### Lymphoedema (or elephantiasis)

Lymphoedema and its more advanced form, elephantiasis, occurs primarily in the lower limbs and are more common in women, but can also occur in the arms, breasts, or genitals (12; 13; 14). Lymphoedema secondary to LF, or filarial lymphoedema, presents as a gradual onset of limb swelling, which can be unilateral or bilateral, and can be associated with skin changes such as thickened skin, knobs, folds and mossy lesions. In its most advanced form, elephantiasis may prevent people from carrying out their normal daily activities. Individuals with filarial lymphoedema may or may not have evidence of microfilaria, filarial antigen, or anti-filarial antibodies (15), and therefore laboratory studies cannot be used as confirmatory testing for filarial lymphoedema.

There is currently no agreement on lymphoedema classification, however Annex 1 provides a widely used classification scheme. A seven-stage classification system may be appropriate for use in clinical settings.
(Annex 1), while a three-stage classification system may be more appropriate for use by community health workers (Annex 2). Further, Annex 3 presents a summary of how lymphoedema management should be modified based on disease stage.

Several factors have been implicated in the progression of filarial lymphoedema. Repeated episodes of ADL have been found to have a strong epidemiological association with the progression of lymphoedema and are thought to be a major factor associated with disease advancement; however, the roles of other factors remain largely unexplored. Certain traditional practices, such as scarification of the skin, has been found to be a risk factor for disease progression due to its association with increased risk of ADL (16).

Lymphoedema due to LF should be distinguished from conditions that present with edema or lymphoedema that require other management strategies, such as heart failure, renal disease, cancer, hepatic disease, malnutrition, and HIV/AIDS-associated Kaposi sarcoma, amongst other etiologies.

### Hydrocele

Hydrocele is due to accumulation of fluid in the cavity of the tunica vaginalis. Hydrocele secondary to LF presents as post-pubertal progressive scrotal swelling that is generally not painful or red. It has been suggested that true filarial hydrocele occurs after the death of adult filarial worms, while a chylocele is due to accumulation of fluid after the rupture of lymphatic vessels in the scrotal cavity (11). A system for classifying hydrocele has been proposed (17) and adopted by an expert Consultation panel on hydrocele management as the classification system that will be used for defining standard operating procedures for hydrocele management and for making international comparisons (18).

### Other Manifestations

Many asymptomatic individuals living in endemic settings suffer from subclinical lymphatic abnormalities, particularly dilation of the vessels, which can be seen on ultrasonography or lymphoscintigraphy. Further, microscopic haematuria, associated with microfilariae, can be observed in otherwise asymptomatic infected people.

Other clinical manifestations associated with LF include chyluria, haematoclyuria, and tropical pulmonary eosinophilia. Chyluria is characterized by the presence of chyle in the urine, leading to urine that is milky in appearance. This occurs following a rupture of dilated vessels into the urinary system. Blood may also be present, which is known as haematoclyuria.

Tropical pulmonary eosinophilia (TPE) is a syndrome that occurs due to immunologic hyperresponsiveness to microfilariae in the lungs. This syndrome is characterized by cough, fever, marked eosinophilia, high serum immunoglobulin E concentrations, and positive antifilarial antibodies.

The management of other clinical manifestations is not addressed in this document due to the lack of coordinated public health approaches to address these conditions.

### 1.1.3 Socioeconomic burden of lymphatic filariasis

Lymphoedema and hydrocele lead to permanent, long-term disability; they also often cause disfigurement, with serious psychosocial and economic consequences. The direct economic costs of managing
acute and chronic manifestations are a burden on patients and health systems alike. The cost to patients of treating ADL episodes ranges from US$ 0.25–1.62, almost two days’ wages in some countries, while the cost to patients for hydrocele surgery, depending on the country and source of care, is US$ 5–60 (11). In the third WHO report on NTDs, a review of the cost of NTD interventions estimated surgical management of hydrocele to cost US$ 80–360 (19).

Indirect losses due to diminished productivity are also a severe drain on local and national economies. ADL was estimated to be responsible for losses of US$ 60–85 million per year in India (20; 21) and US$ 38 million per year in the Philippines (22). Furthermore, disability and disfigurement due to chronic manifestations often mean that patients have to stop working or change to less productive jobs (2; 8; 9; 10; 20; 21; 22; 17; 23; 24). LF also exerts a heavy social burden on patients, as chronic complications are often considered shameful and prevent patients from playing their role in society and from leading a fulfilling emotional life (25; 26; 11; 27; 28; 29; 30). For men, genital damage is a severe disability, leading to physical limitations and social stigmatisation (25; 31). For women, shame and taboo are associated with lymphoedema, especially elephantiasis. When their lower limbs and genitals are enlarged, they are severely stigmatized; marriage, in many situations an essential source of security, is often impossible. These individuals may be prone to depression and poor mental health (32). LF often affects not only the patient but also the family, especially if the patient is the major income earner.

1.1.4 Associated disability

The WHO International Classification of Functioning, Disability and Health (33) provides a coherent view of the intersections of the biological, individual and social perspectives of health, balancing both the medical and social perspectives of disability. In the context of LF, the following terms are relevant (see Box 1):

- Functioning includes body functions, body structures, activities and participation. It denotes the positive aspects of the interaction between an individual with a health condition and the individual’s environmental and personal factors.
- Impairment is loss or abnormality of psychological, physiological or anatomical structure or function.
- Disability refers to impairment, activity limitation and restriction on participation. It denotes the negative aspects of the interaction between an individual with a health condition and the individual’s environmental and personal factors. Disability can be altered by changes in environmental and personal factors.

Box 1. How the International Classification of Functioning, Disability and Health (34) relates to patients with LF

People with clinical manifestations related to LF have a disability when the manifestations interfere with their daily life or professional activities, such as walking normal distances or regular attendance at work or school.

For example, men with small hydroceles may have no difficulty in riding a bicycle, but large hydroceles may impede such activities.

Depending on existing services and social stigmatisation, people with lymphoedema (or elephantiasis) may have difficulty in having an acceptable social life, such as getting married or finding suitable employment.

Anyone infected with adult worms or microfilariae may be considered to have impairment, as they have lymphatic damage and their skin defenses may be impaired.
The development of disability and restrictions on participation that result from impairment as well as how program prevention strategies aim to reduce the impact of these elements are illustrated in Figure 3. Infection is directly linked to living in an endemic area, poverty, social habits, ecological and other environmental variables. Infections lead to morbidity and may generate impairments and restrictions.

The activities for MMDP described in this document address restrictions on participation through primary, secondary and tertiary prevention. Primary prevention involves mass drug administration to the population at risk in order to reduce transmission of LF and the development of new infections. Secondary and tertiary prevention involve providing care for people who are infected, with or without disabilities, in all areas with known patients, regardless of whether LF transmission is present.

Figure 3. Programme prevention strategies to reduce the impact of LF disease, impairment, and restrictions
1.2 Eliminating lymphatic filariasis

1.2.1 Background

In 1997, the World Health Assembly resolved to eliminate LF as a public health problem (35). The World Health Organization (WHO) subsequently launched the Global Programme to Eliminate Lymphatic Filariasis (GPELF) and proposed a comprehensive strategy based on two main components: (i) stopping the spread of LF infection through mass drug administration and (ii) alleviating suffering through morbidity management and disability prevention.

Mass drug administration

The approach to interrupting transmission comprises annual mass administration of a combination of antifilarial drugs to entire populations at risk. The treatment consists of a combination of the following antihelminthic medications: albendazole (400 mg), diethylcarbamazine (6 mg/kg) in areas without onchocerciasis or loiasis, and ivermectin (150–200 µg/kg) (36). Recently, alternative MDA regimens have been proposed to accelerate progress towards 2020 goals as outlined in Table 1 (37).

Table 1: WHO recommendations on alternative MDA regimens to eliminate LF*

<table>
<thead>
<tr>
<th>In countries using diethylcarbamazine plus albendazole (DA) to eliminate LF</th>
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<tr>
<td>(in countries endemic for LF but without either onchocerciasis or loiasis)</td>
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<tr>
<td><strong>Recommendations:</strong></td>
</tr>
<tr>
<td>WHO recommends annual DA rather than biannual DA.</td>
</tr>
<tr>
<td>WHO recommends annual ivermectin + diethylcarbamazine + albendazole (IDA) rather than annual DA in the following special settings:</td>
</tr>
<tr>
<td>• For IUs that have not started or have fewer than four effective rounds of DA;</td>
</tr>
<tr>
<td>• For IUs that have not met the epidemiological thresholds in sentinel and spot-check site surveys or in transmission assessment surveys; and</td>
</tr>
<tr>
<td>• For communities where post-MDA or post-validation surveillance identified infection suggesting local transmission</td>
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<thead>
<tr>
<th>In countries using ivermectin plus albendazole (IA) to eliminate LF</th>
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</thead>
<tbody>
<tr>
<td>(in countries endemic for LF and either having onchocerciasis or being co-endemic for loiasis)</td>
</tr>
<tr>
<td><strong>Recommendations:</strong></td>
</tr>
<tr>
<td>Where onchocerciasis is endemic in any part of the country, WHO recommends annual IA rather than annual IDA.</td>
</tr>
<tr>
<td>Where onchocerciasis is endemic in any part of the country, WHO recommends annual IA rather than biannual IA, except in areas where biannual distribution of ivermectin is already being delivered for onchocerciasis.</td>
</tr>
<tr>
<td>Where LF is co-endemic with loiasis and ivermectin has not already been distributed for either onchocerciasis or LF, WHO recommends biannual albendazole rather than annual albendazole in IUs.</td>
</tr>
</tbody>
</table>
Drugs are usually given by mass administration for at least 5 years, until adult worms have reached the end of their reproductive lifespan. In programmes where coverage is poor or where transmission is particularly intense, annual campaigns may have to be longer in order to ensure interruption of transmission (38). Details of the use of mass drug administration to interrupt LF transmission can be found in national programme managers’ guidelines (39; 40; 37).

The first pillar of the GPELF strategy plays a role in primary prevention, by decreasing and reducing transmission rates in populations at risk. In addition, mass drug administration can prevent progression from subclinical to clinical disease and worsening morbidity. The benefit can also be quantified in terms of the number of people protected, as well as economic savings to health systems and to individuals through increased productivity (Table 2).

Table 2. Estimated health and economic impacts of the Global Programme to Eliminate LF, 2000–2014

<table>
<thead>
<tr>
<th>Impact on health</th>
<th>No. of people protected (millions)</th>
<th>Cost savings (billion US$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protection from acquiring infection</td>
<td>21</td>
<td>55.7</td>
</tr>
<tr>
<td>Subclinical morbidity prevented from progression</td>
<td>12.5</td>
<td>33.2</td>
</tr>
<tr>
<td>Alleviated clinical disease</td>
<td>12.8</td>
<td>11.6</td>
</tr>
<tr>
<td>Total</td>
<td>46</td>
<td>100.5</td>
</tr>
</tbody>
</table>


Morbidity management and disability prevention

A significant proportion of the public health problem represented by LF is due to impairment and disability related to lymphoedema (or elephantiasis) and hydrocele. Therefore, national programmes must focus on morbidity management and disability prevention. These activities will not only help LF patients but can improve MDA compliance (41).

Morbidity management and disability prevention (MMDP) in LF requires a broad strategy involving both secondary and tertiary prevention (Figure 3). Secondary prevention includes basic measures, such as hygiene and skin and wound care, to prevent acute attacks and progression of lymphoedema to elephantiasis (32; 25). For management of hydrocele, surgery is appropriate (18). Tertiary prevention includes psychological and socioeconomic support for people with disabling conditions to ensure that they have equal access to rehabilitation services and opportunities for health, education and income. Activities beyond medical care and rehabilitation include promoting positive attitudes towards people with disabilities, combatting stigma, preventing the causes of disabilities, providing education and training, supporting local initiatives, and supporting micro- and macro-income-generating schemes (42). The activities can also include education of families and communities, to help persons with LF to fulfil their roles in society. Thus, vocational training and appropriate psychological support may be necessary for overcoming the depression and economic loss associated with the disease (11).
MMDP must be continued in all areas with known patients, irrespective of original endemicity status, and after surveillance and validation of the elimination of LF as a public health problem, as chronically affected patients are likely to remain in these communities.

1.2.2 Integrating elimination of lymphatic filariasis into the control of other diseases

The GPELF is now part of integrated efforts to prevent and treat neglected tropical diseases (Figure 4). Transmission is being interrupted by mass drug administration, other forms of preventive chemotherapy and vector control, in collaboration with programmes for other neglected tropical and vector-borne diseases. For example, national LF programmes are increasingly being integrated with preventive chemotherapy programmes to control or eliminate onchocerciasis, trachoma, soil-transmitted helminthiases, and schistosomiasis. Strategic planning, training, drug distribution and monitoring are often common across these programmes. Integrated preventive chemotherapy and transmission control results in savings, due to optimal use of the resources of several programmes.

Figure 4. Opportunities for integrating LF activities into programmes for other diseases

WHO recommends an essential package of care to alleviate suffering in persons with lymphoedema and hydrocele. The measures for managing lymphoedema described in this document can be used to manage not only LF but other types of lymphoedema detected in areas endemic for LF. Therefore, management of lymphoedema could be integrated with that of other chronic diseases that require long-term care, such as podoconiosis and diabetes. Essential care for persons with LF fits well into an integrated skin NTD strategy that includes leprosy, Buruli ulcer, podoconiosis, mycetoma, and other chronic skin diseases. The same essential care
also fits well with the care of diabetes, consequences of trauma or burns, obesity, venous insufficiency, and chronic conditions associated with neurological diseases (poliomyelitis, encephalitis, cerebral haemorrhage or stroke). These programmes also involve training of health care workers and community and family members to care for people with chronic disabling diseases.

Integration of activities for hydrocele would complement ongoing initiatives to strengthen emergency and essential surgical care and anesthesia as a component of universal health coverage (UHC). This initiative includes strengthening surgical services capacity at the district hospital level to deliver adequate surgical and anesthesia care when and to whom it is necessary, as well as developing a sufficient health workforce able to deliver this care.
Section 2: MMDP within the Global Programme to Eliminate Lymphatic Filariasis

2.1 Why manage morbidity and prevent disability?

LF is a public health problem because the infection damages the lymphatic system, increasing the risk for secondary infections and complications. An estimated 36 million people globally have clinically significant manifestations of LF—predominantly lymphoedema and hydrocele—accounting for 5.9 million disability-adjusted life years (2), with a concomitant loss of productivity and social stigmatization. As the goal of the GPELF is to eliminate the disease, managing morbidity and preventing disability are integral to achieving elimination of LF as a public health problem (43).

Access to management of lymphoedema and surgery for hydrocele may increase community cooperation in mass drug administration (41) and thereby contribute to interrupting transmission of the parasite and preventing new infections. The main reason for managing morbidity, however, is to relieve suffering. This component of the programme is therefore rooted in compassion. All national programmes must manage morbidity and prevent disability in order to eliminate LF, including care for those affected, even after interruption of transmission. Persons with clinical and social consequences have a right to health care, and this is the responsibility of national elimination programmes (44).

UHC, a Sustainable Development Goal (SDG), means that all individuals and communities receive the health services they need without suffering financial hardship. This can only be achieved if people at risk of or affected by NTDs have equitable access to high-quality health services. Providing care for persons with lymphoedema or hydrocele alleviates unnecessary suffering due to LF and supports meeting SDG target 3.8.

The GPELF target of 100% geographical coverage of the essential package of care for persons with LF defined as lymphoedema management, treatment of acute attacks, and hydrocelectomy is fully aligned with UHC. Delivery of these services is through the primary health care system at the appropriate level and should be integrated with other quality health services and initiatives as appropriate. These services should be provided under the framework of UHC, with the aim of ‘leaving no one behind.’

The GPELF is part of integrated efforts to prevent and treat a number of neglected tropical diseases, and collaboration is already established with other programmes in terms of preventive chemotherapy and integrated vector management to interrupt transmission. Combined approaches to MMDP should also be explored with other programmes, such as those for chronic diseases; such as podoconiosis, leprosy, diabetes, and Buruli ulcer (see section 1.2.2).

2.2 What is MMDP?

The public health priorities are the management of ADL, lymphoedema and hydrocele, the main manifestations of the disease. Management of other clinical forms of filarial disease, such as chyluria, haematochyluria, or tropical pulmonary eosinophilia, should follow standard clinical and referral practices, as public health approaches have not yet been established.

Almost 17 million people have lymphoedema or its more advanced form, elephantiasis, primarily of a lower limb (1; 2). Lymphoedema (or elephantiasis) can be managed by basic measures that include hygiene, skin and wound care, elevation, exercises, and wearing comfortable shoes. These basic measures are effective in reducing episodes of acute attacks, improving the quality of life of persons with LF and can be maintained by
home-based self-care. Approximately 19 million men have urogenital disease related to LF, most commonly hydrocele (1; 2). Hydrocele is effectively treated by surgery, and this has been shown to improve men’s economic situation, community participation and quality of life.

To prevent disability, people with disease related to LF should also have access to psychological and social support to assist their reintegration into society and economic life (see section 3.1.3) (44).

2.3 Goals and aim of MMDP

The goals of this component of the GPELF are to alleviate suffering in people with acute attacks, lymphoedema and hydrocele and to improve their quality of life (44). The aim is to provide access to the recommended essential package of care for every person with these manifestations in all areas with known patients (lymphoedema/hydrocele).

The recommended essential package of care includes:

- Treating acute attacks: Treating episodes of ADL among people with lymphoedema or elephantiasis;
- Managing lymphoedema: Preventing debilitating, painful episodes of acute attack and progression of lymphoedema;
- Managing hydrocele: Providing access to hydrocele surgery; and
- Providing antifilarial medicines: to destroy any remaining worms and microfilariae by mass drug administration or individual treatment for LF infection.

People with lymphoedema must have access to continuing care throughout their lives, both to manage the disease and to prevent progression to more advanced stages. Thus, MMDP should be part of the primary health care system to ensure sustainability (43).

2.4 Guiding principles

The aim of MMDP is to give every person with LF a better, more productive life and allow them to participate equally in the community, both socially and economically. By 2030, every national programme should have achieved full geographical coverage of access to basic recommended care in all areas with known patients.

The guiding principles for MMDP are:

- Access: Provide access to basic care for all persons with acute attacks, lymphoedema (or elephantiasis) and hydrocele as part of the programme to eliminate LF.
- Flexibility: Allow flexible approaches to strategies for preventing and alleviating disabilities associated with LF.
- Integration: Whenever possible, integrate the activities into other disease control programmes.

2.5 Elements of the essential package of care

Various strategies exist to address morbidity and disability associated with LF. An essential package of care has been defined to address the main clinical manifestations of LF with established public health
approaches. The following sections describe the implementation of the components of the essential package of care. Table 3 summarizes the signs and symptoms and management of the three most common chronic manifestations of LF: acute attacks, lymphoedema (or elephantiasis), and hydrocele.

<table>
<thead>
<tr>
<th>Clinical manifestation</th>
<th>Symptoms</th>
<th>Management</th>
</tr>
</thead>
</table>
| **Acute Attack**       | Acute onset of limb swelling, redness, warmth, and pain with or without fever, chills, headache, and weakness | • Antibiotic treatment  
• Symptomatic management:  
  • Analgesics  
  • Anti-inflammatory medication  
  • Antipyretics  
• Supportive measures  
  o Rest  
  o Elevation  
  o Hydration  
  o Cooling the affected area  
• Hygiene as tolerated |
| **Lymphoedema** (or elephantiasis) | Gradual onset of swelling, usually of the legs, but also arms, breasts, and genitals  
Can be associated with skin changes, such as thickened skin, skin knobs, skin folds, and mossy lesions | • Hygiene  
• Skin and wound care  
• Elevation  
• Exercises  
• Wearing comfortable shoes |
| **Hydrocele**           | Post-pubertal progressive scrotal swelling, generally not painful or red | • Surgery |


2.5.1 Treating acute attacks

The clinical presentation and management of an acute attack is similar to that of cellulitis. Therefore, the primary treatment involves antibiotic therapy using antibiotics which cover common skin bacteria, including Streptococcus spp. and Staphylococcus spp. (11). National authorities should modify the antibiotic in accordance with the accepted norms for the use of antibiotics.

In addition to antibiotic treatment, symptomatic management is an important component of treating an acute attack. Symptomatic management includes: use of analgesic, anti-inflammatory, and antipyretic medications, as needed, in addition to supportive measures such as rest, elevation, hydration, and cooling of the affected area. It is important to continue with hygiene measures as tolerated by the patient.

Antifilarial medications, such as DEC, should not be given as treatment for acute attacks. In addition, other harmful practices such as popping, opening or cutting blisters or otherwise damaging the skin; bandaging; exercise; actively peeling the skin from the affected area; and harmful traditional practices should be avoided during an acute attack. An algorithm for determining patient treatment needs during an acute attack is described in Annex 4.

2.5.2 Managing lymphoedema

Hygiene represents the cornerstone of lymphoedema management, and hygiene in conjunction with the other components of lymphoedema management are associated with a reduction in the incidence of ADL episodes (45; 46; 47; 20). When applied diligently, the expected outcomes of lymphoedema management include improving lymphatic flow and skin integrity; decreasing the frequency and severity of ADL episodes; preventing lymphoedema progression; improving patient function; and improving patient quality of life.

The basic measures for lymphoedema (or elephantiasis) management include, hygiene, skin and wound care, elevation, exercises, and wearing comfortable shoes (Figure 5) (48; 49; 32; 25).

- **Hygiene**: The affected area should be washed at least once daily with soap and clean water at room temperature and dried carefully with a clean towel or gauze. The importance of hygiene in the management of lymphoedema cannot be overstated; diligent washing may reduce acute attacks and prevent progression of lymphoedema.

- **Skin & wound care**: Intact skin provides an effective barrier against infection. Care should be taken to protect the skin from injury and treat wounds. Topical medications (e.g. antiseptics, and antibiotic creams) should be used to treat small wounds or abrasions. Antifungal creams can help prevent fungal infections in deep skin folds and in interdigital spaces. Nails should be kept clean. Clip the nails carefully avoiding injury.

- **Elevation**: The affected area should be raised at night and when possible during the day to promote lymphatic flow.

- **Exercises**: The affected area should be exercised regularly with low-intensity movement of the joints to promote lymphatic flow.

- **Wearing comfortable shoes**: Comfortable shoes adapted to the size and shape of the foot should be worn to protect the feet against injury.
Figure 5. Basic measures for managing lymphoedema

To support patient uptake of basic lymphoedema management practices, the programme or supporting agency could provide patients with a hygiene kit, or provide the list of necessary materials to patients if a kit is not provided. While the items in the hygiene kit can vary by country context and available budget, the following hygiene kit components could be considered: unscented soap, towels/gauze, antibacterial cream, antifungal cream, antiseptics, basin, bucket, cup, suitable shoes, and patient education materials.

After initial training, basic measures can usually be carried out by the person with lymphoedema in the home-setting, sometimes with the assistance of a family member. When possible, community health workers should be involved in these activities to support patients and families in maintaining lymphoedema management practices and referring patients for further care, such as the treatment of ADL episodes, when necessary.

Persons with lymphoedema should use these measures more vigilantly during the rainy season where relevant because of the increased risk for developing interdigital lesions and ADL. In areas where Brugia spp. are present, patients should be taught to dress abscesses properly, as patients infected with these species are at higher risk for abscesses on the proximal limbs.

The application of these measures is described in detail in WHO guides on community home-based prevention of disability due to LF (48; 49; 32) and as part of the new WHO MMDP Workshop Modules, which together with this document and the associated web annexes form the WHO MMDP Toolkit.

Adjunct measures for managing lymphoedema (or elephantiasis), such as compressive bandaging, lymphatic massage, and decongestive therapy may be difficult to implement in many resource-poor settings,
and therefore are not included as part of the essential package of care. In settings with a comprehensive health system, health workers could promote the use of adjunct measures, in addition to basic measures where possible. However, these measures should only be applied by skilled staff and may not be appropriate for all settings.

2.5.3 Managing hydrocele

Hydroceles can be cured in a health facility with access to capacity to perform hydrocelectomy surgery. Expected outcomes of surgery are: return to normal or reduction in the size of the scrotum; improvement of patient quality of life; and improvement in patient function. In 2002, a WHO informal consultation on surgical approaches to urogenital manifestations of LF discussed the management of hydroceles from a public health perspective (32; 18; 29). A subsequent informal consultation was undertaken in 2017 to revise these standard operating procedures based on review of new evidence on surgical practice and in an effort to harmonize the management of hydrocele with other ongoing surgical initiatives (18). The following section summarizes the results of the 2017 surgical consultation.

Surgery is recommended for all stages of hydrocele, even small hydroceles, to prevent progression to more severe and therefore more difficult to treat stages of hydrocele. Notably, hydrocelectomy has been identified by the Disease Control Priorities (DCP-3), as one of the 28 essential surgical procedures that should be available at first level health facilities worldwide (50).

There are different recommended methods for hydrocelectomy and the choice of method will largely depend on the practice adopted by the surgical service in the district. The surgical technique and surgical facility requirements may vary based on several factors including: capacity of local facilities to perform hydrocelectomy, patient risk factors, as well as the stage/grade of hydrocele. The Capuano and Capuano hydrocele grading system (17) was adopted to standardize indicators across settings and to allow for the development of stratified standard operating procedures to guide the management of hydrocele. In general, the management of hydrocele can be stratified by hydrocele stage:

- **Uncomplicated hydrocele (Stage I, II, III / Grade 0, 1):**
  - Uncomplicated hydrocectomies, particularly Stages I and II, can typically be performed in Level I or Level II facilities. In some settings, with experienced surgeons, Stage III may also be managed at Level I or II facilities. Ultimately, the surgical team will determine when referral to a higher level of care is warranted.
  - The expert committee from the recent consultation preferred the excision technique, performed with electrocautery and conducted by experienced surgeons.
  - Single dose of pre-operative antibiotics is frequently sufficient for control of surgical site infection in uncomplicated hydroceles.

- **Complicated hydrocele (Stages III, IV, V, VI / Grades 2, 3, 4):**
  - Complicated hydrocele in most cases require a Level III facility with a specialized surgical team. Frequently, scrotal reconstruction is required for complicated hydroceles.
  - Excision, performed with electrocautery and conducted by experienced surgeons, is the recommended surgical technique for complicated hydroceles.
  - The antibiotic course should be based on pre-operative skin cultures, scrotal skin thickness, and other conditions such as patient nutritional status and environmental conditions (18).

To align with current recommendations for essential surgery, hydrocele surgery, like all surgical procedures, should be conducted in a proper operating room rather than a minor procedure room, and that
room should be fitted with oxygen, sufficient lighting, suction, an electrocautery machine (if available), patient monitoring equipment, and resuscitation medications and equipment. Surgical teams are also strongly encouraged to use the WHO Surgical Safety Checklist to improve safety in surgery by reducing deaths and complications (51).

Care should always be taken to ensure that patients have adequate pre- and post-operative preparation and support, as these significantly improve the success of this intervention. Pre-operatively, a comprehensive physical exam, including the use of ultrasound, should be performed to confirm the diagnosis of hydrocele and identify any complicating features. An algorithm, proposed by the Consultation, should be used to determine if the facility is capable of conducting the surgery based on the findings of the initial studies (18); patients should be referred to a higher level of care if circumstances dictate.

The Consultation noted that strong efforts should be made to prevent surgical site infection (SSI), including appropriate sterilization techniques, hygiene procedures, and standardized procedures for the administration of antibiotics. Antibiotic use should be dictated by local antibiotic protocols and patient-level factors, such as hydrocele stage/grade. Chlorohexidine in alcohol is the preferred compound for skin preparation prior to surgery, however povidone iodine is acceptable if chlorohexidine is not available.

As inguinal/groin hernia is a common differential diagnosis and is frequently a co-morbidity seen with hydrocele, surgeons should be prepared to deal with hernia repairs in the same surgical procedure, using a tension-free technique such as mesh.

Post-operatively, facilities providing hydrocelectomies should have the ability to observe patients on-site for at least 72 hours after surgery, at which time the dressing should be changed, in order to reduce risk of post-operative infection.

The Consultation also noted that hydrocelectomy “camps” can play an important role in strengthening local care for patients with hydrocele and can result in the treatment of a large number of hydrocele patients relatively quickly. These camps may also reduce the backlog of patients, provide an infusion of medications and consumables, which are often in limited supply in many settings, and can serve as a platform for experts to strengthen the capacity of local surgical teams to manage hydrocele. However, there are some limitations to hydrocele camps including prolonged wait times for patients, the potential of overwhelming local hospital staff, and the potential of diversion of resources that could otherwise be used for local capacity strengthening; therefore, camps should not be seen as a substitute for strengthening local access to surgical care.

2.5.4 Providing antifilarial medicines

All people who are positive in filarial test strip (FTS) or have evidence of microfilaraemia should receive anti-filarial drug treatment to eliminate microfilariae. They can be treated with the dose recommended for MDA (based on the settings) or with diethylcarbamazine 6 mg/kg alone for 12 days (40; 52; 33; 37).

It should be noted that many patients with filarial lymphoedema are frequently negative for microfilariae or filarial antigen (53). This can also be true for men suffering from filarial hydrocele. Lymphoedema or hydrocele patients who are negative for filarial antigen or microfilaria need not be treated with anti-filarial medicines.

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1 This recommendation is based on expert opinion formulated at a meeting of the Monitoring and Evaluation Subgroup on Disease-specific Indicators of the Strategic and Technical Advisory Group for Neglected Tropical Diseases, Task Force for Global Health, Atlanta, Georgia, USA, 1 October 2012, and not on a systematic review or a synthesis of the evidence.
There is limited evidence to suggest that a 4-6 weeks course of doxycycline (200 mg per day) may reverse or stabilize the progression of disease in individuals with lymphoedema (54; 55). Further clinical trials are ongoing to evaluate the effectiveness of doxycycline as a novel management strategy for lymphoedema. WHO will update recommendations if a full review of the evidence from ongoing studies supports the adoption of doxycycline as a management strategy for filarial lymphoedema.

2.6 Strategic planning

In 2010, WHO published a strategic plan for 2010–2020 in which it defined the strategic aim and goals for managing morbidity and preventing disability². These targets have been refined given the progress to date and to align with the Sustainable Development Goals and included in the NTD Roadmap 2021-2030 (56). During the next few years, such programmes will be a priority in all countries endemic for LF, with the aim of providing access to care for all people with manifestations of the disease. Starting programmes and scaling them up to achieve full coverage both geographically and in terms of the clinical conditions managed will be a challenge if approached vertically. The new emphasis on Universal Health Coverage, Primary Health Care strengthening, and integrated management of skin neglected tropical diseases provide opportunities to facilitate inclusion of care for lymphoedema with care for related conditions and inclusion of hydrocele surgery into other surgical programmes. The ultimate aim is to integrate quality services for the morbidity management and disability prevention due to LF fully into national health systems by training health staff to care for these patients, strengthening referral mechanisms from community to health worker to specialist and back.

There are multiple opportunities to expand and sustain morbidity management and disability prevention for LF, including integration with the global disability action plan and service availability and readiness assessment (SARA); promoting UHC (57); and supporting SDG 2030 as they relate to LF and other NTDs (58).

Global goal:

The WHO Expert Committee Meeting on Filarial Infections established the post-2020 global goal of 100% geographic coverage with the recommended LF minimum package of care, defined as lymphedema management, ADL treatment, and hydrocelectomy (59). The goal is also for delivery of these services to be through the health system at the appropriate level, integrated with other quality health services and initiatives as appropriate. These services should be provided under the framework of UHC, with the aim of “leaving no one behind.”

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² Note: Potential methods for estimating the numbers of lymphedema and hydrocele patients are outlined in the LF MMDP Situation Analysis tool and MMDP training modules and include door-to-door surveys, population-based prevalence surveys, MDA registers, and health facility surveys. There is currently no ‘gold standard’ methodology for estimating number of patients. While step 1 is to report all currently available data by 2025, countries are expected to have collected data from all IU’s. For numbers of lymphedema and hydrocele patients, these data could be collected by any of the methods outlined in the WHO guidance documents.
Global targets:

The following global targets are part of the GPELF Strategic Plan 2021-2020, and support the global NTD targets found in the WHO Roadmap for NTDs 2021-2030 (4; 56).

To meet the above global goal, the following targets have been established:

- By 2023, 100% of endemic countries will report all currently available data on LF morbidity to WHO
- By 2027, 100% of endemic countries will have data for every IU on numbers of lymphedema and hydrocele patients and on the number of health facilities providing the essential package of care ³
- By 2025, 100% of endemic countries will have included LF interventions in their UHC essential services package policy
- By 2030, 100% of endemic countries will have recommended data on the quality of the provision of the minimum package of care ⁴
- By 2030, 100% of endemic countries will have 100% geographic coverage of the LF MMDP minimum package of care
- By 2030, 100% of endemic countries will be providing LF interventions without out-of-pocket expense for patients

Success will be achieved by reducing the human suffering associated with LF through the application of the essential package of care for people with lymphoedema (or elephantiasis), and hydrocele in areas with known patients (60). The benefits from these activities will help to alleviate poverty by having a positive impact on the health, social, and economic statue of the world’s most underserved populations.

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³ Note: Potential methods for estimating the numbers of lymphedema and hydrocele patients are outlined in the LF MMDP Situation Analysis tool and MMDP training modules and include door-to-door surveys, population-based prevalence surveys, MDA registers, and

⁴ Note: Quality of provision of care for lymphedema and ADL management is defined in the WHO Direct Inspection Protocol. Quality of provision of care for hydrocelectomy is currently being defined as part of essential surgical services by the WHO Global Initiative for Emergency and Essential Surgical Care (GIEESC).
Section 3: Planning MMDP in a national programme

Each endemic country is encouraged to prepare a plan for the MMDP component of the national programme to eliminate LF. Countries should ensure that their plan is aligned with the goals and aims of the global plan (and regional plans if any), even if they adopt innovative approaches and use opportunities to integrate their programme with those that provide similar care.

3.1 Strategic planning and implementation

The steps involved in setting up an effective national MMDP programme are:

(i) conducting a situation analysis
(ii) developing or updating an implementation policy and plan, and
(iii) providing the essential package of care (Figure 6).

Figure 6. Setting up effective morbidity management and disability prevention (MMDP) programme

3.1.1 Situation analysis

A national situation analysis can be helpful to aid in the implementation of national MMDP strategies as part of NTD control and elimination plans by assessing the estimated numbers of lymphoedema and hydrocele patients, the efficiency of the health care and information system, the policy environment, the role of advocacy, the capacity of health staff and possibilities for integrating activities with those for other chronic diseases. Web Annex B provides a tool to aid countries in conducting a national situation analysis, including sample tools and frameworks for organizing and reporting collected data.
Ideally, a situation analysis would be conducted prior to initiating MMDP services, however countries may conduct such analyses at various stages of the programme. This information makes it possible to identify the best service delivery platforms and models for improving access to surgery and lymphoedema management training. While NTD programmes are often operated by the public health system, MMDP activities are often under the authority of both clinical health care system and the social welfare system, therefore a situation analysis serves to bridge these systems and responsibilities. Further, some data collected during this process will be relevant for annual reporting to WHO and preparation of the LF elimination dossier (see Section 3.2.1).

The comprehensiveness of the analysis will depend on the disease burden, the number of stakeholders, and the available resources. The steps briefly outlined below represent an approach to the collection of data but can be modified by national programmes. This information can be collected at the level of the implementation unit, which often requires detailed information in order to adapt activities to local conditions and resources. A national situation analysis usually covers epidemiology, the health and social environment and a strategic framework for MMDP.

**Epidemiology**

The first step is to assess the number of lymphoedema (or elephantiasis) and hydrocele cases by implementation unit in all historically endemic areas, regardless of whether MDA was implemented. Estimates of the number of patients with lymphoedema (or elephantiasis) and hydrocele are needed to help plan and set priorities for activities within implementation units. This information may already be available in the health information system, or it may have to be collected through various patient estimation surveys. While no gold standard exists for collecting patient estimation data, Web Annex B includes various methodologies that countries could consider for estimating lymphoedema and hydrocele cases and their relative advantages and disadvantages. This information is useful for designing activities and training packages that can be implemented to teach patients how to practice lymphoedema management or for patients to seek surgical care for hydrocele.

**Health and social environment**

The basic characteristics of endemic communities in the country, e.g. culture, language, literacy and socioeconomic characteristics, should be noted as well as, environmental barriers and facilitators that might influence services delivery or patient access to care should be investigated, such as:

- the availability of basic supplies and materials for care, e.g. clean water, soap, cloths, basins, antifungal cream or ointment;
- decision-making structures in households;
- access to transportation and distance to health facilities;
- the availability of appropriate footwear for lymphoedema patients; and
- access to assistive technology and devices.

With regard to health facilities and services, the information should include which unit(s) or department(s) are primarily responsible for the provision of MMDP services. Further, the technical and operational facilities that are available and appropriate for conducting hydrocelectomies and managing lymphoedema and treating acute attack episodes should be explored. Inter- or intra-sectoral platforms that could serve has points of integration for MMDP care could be explored. Further, whether appropriate referral systems are in place for complicated
cases of lymphoedema and hydrocele and whether appropriate rehabilitation services are available, either institutional or home-based should be noted.

A review could be made of the presence of appropriate health care workers, such as surgeons, doctors, nurses and public health staff, at regional, district, hospital and health centre levels and referral mechanisms. Ascertaining current knowledge, attitudes and prescribing practices of health providers will help in preparing appropriate training materials.

**Strategic framework**

A strategic framework should be developed or revised based on the analysis and identification of problems in relation to the policy environment, i.e. policies with an adverse or beneficial effect on managing morbidity and preventing disability due to LF, and identifying gaps in existing policy frameworks.

The activities include capacity-building, conducting applied research, ensuring within-sector coordination and intersectoral collaboration, decentralization, community empowerment and clinical treatment. Support is required at national level to enable the government, programme manager and the community to make decisions on these issues.

The feasibility of integrating lymphoedema management with that of other chronic disease frameworks that require long-term care should be investigated. Activities such as hygiene, skin and wound care, elevation, exercises, and wearing comfortable shoes are often similar in the programmes shown in Figure 4. Assessing the feasibility of integration with other chronic disease programmes may involve:

- determining whether there is a national policy for integrating chronic diseases;
- discussing the feasibility of integration with the departments responsible for these chronic diseases;
- sharing epidemiological data, the strategy and planned activities with focal persons for such diseases;
- collecting any missing epidemiological data through surveys and from community informants;
- establishing common activities for patients with lymphoedema and those with other chronic diseases;
- making decisions jointly with the departments involved in the integrated disease programme;
- adapting process indicators for each disease programme, e.g. programme coverage, frequency of referral to a health facility for monitoring integration; and
- training health staff and community health workers in hygiene, exercises and technical follow-up of patients in the same way for all the diseases.

**3.1.2 Developing or updating an implementation policy and plan**

The implementation plan for MMDP should be part of the national LF plan. The situation analysis will identify the policies that govern management of LF, including the criteria for diagnosis, treatment policies and rehabilitation methods. If there is no policy, it should be defined before the MMDP component is launched. However, in some situations a plan may already exist, in which case the plan should be updated to reflect information learned during the situation analysis activity.

Box 2 provides an example of the content of such a plan. It should be discussed with all stakeholders, and roles and responsibilities should be clearly established. Advocacy and social mobilization should be included, and the plan should be adapted to local circumstances. In all plans, the ultimate goal should be to
provide 100% geographic coverage for all known patients. At least one health facility per implementation unit should provide the essentials of lymphoedema (or elephantiasis) and ADL management for patients, with the capacity to refer to higher levels of care when necessary. It is recognized that not all districts or IUs have surgical services. Therefore, at least one surgical facility should serve all IUs that have hydrocele patients. If surgical services are not available at the district/IU levels, then hydrocele surgery should be provided at the next highest level that has consistent surgical services (e.g., regional hospital).

Nevertheless, the various morbidity management systems should be adapted to each community, even in the same country. For example, if a family home-based care system is chosen, staff at the health centre could supervise community health workers, if operationally feasible. If access to a health facility is easy, lymphoedema patients could be monitored at the primary health care centre. For patients who are unable to walk, staff from the health centre or community health workers could make home visits or the family could provide care in consultation with health centre staff. Alternatively, patients might care for themselves at home or go daily to the health facility.

Box 2. Example content of a MMDP implementation plan

1. **Country profile**
   - Geography and climate
   - Political situation and administration
   - Demographic and socioeconomic information
   - Health status
   - Health system

2. **Endemic situation and mass drug administration programme**
   - Mapping
   - Microfilariae or antigenaemia baseline prevalence by implementation unit
   - Mass drug administration coverage
   - Clinical cases

3. **Operational activities & responsibilities**
   - Management and organization
   - Advocacy and social mobilization
   - Capacity building and training
   - Minimum packages of care for acute attack, lymphoedema and hydrocele surgery
   - Psychological support and socioeconomic rehabilitation

4. **Monitoring & evaluation**
   - Data collection and analysis
   - Reporting

5. **Time frame**

6. **Budget**
3.1.3 Providing the essential package of care

National level

Management

As a first step, the national LF programme must decide how it will organize its activities. The national programme and district authorities are responsible for ensuring that MMDP services are available within the health care system and should decide which of the activities described in this document are to be included in the national LF elimination programme. The roles of the programme manager therefore include:

- harmonizing the institutional arrangements for mass drug administration and for MMDP at national, subnational and peripheral levels (e.g. determining whether the implementation units are the same); and
- integrating the MMDP component with that of other chronic diseases in order to optimize use of resources and improve programme efficiency.

It is suggested that one staff member be appointed as the focal point for MMDP in LF. If an integrated approach is chosen, the focal point could also be responsible for this aspect of other disabling diseases. The focal point could outline the responsibilities of the national programme, the primary health care system, non-governmental organizations, faith-based organizations and the private sector in these activities.

Health care staff in implementation units are often routinely involved in MMDP for LF patients. District health facilities serve as technical referral centres, provide treatment for complicated cases and provide expertise to communities. Even where most lymphoedema patients are cared for by their families or the community at home, the implementation unit often trains and supervises caregivers and conducts monitoring and evaluation. In areas with a high burden of disease or many stakeholders, a ‘LF team’ of health staff could be formed, as they may work in different parts of the health sector, e.g. surgeons, public health officers and nurses in health clinics.

In countries with a large burden of LF-related disease or where many stakeholders are involved in MMDP, a national committee might be established. The responsibilities of this committee could include sharing information, identifying common goals and objectives and assigning responsibilities for meeting programme objectives. As these activities include medical, psychological, social, economic and managerial issues, the committee should represent various sectors, including government ministries (health, education, social development), industry, donors, non-governmental organizations and United Nations agencies. The national committees for mass drug administration and for morbidity management may be combined or separate entities, as the expertise and input are not necessarily the same. The two committees should, however, communicate to ensure coordination of elimination efforts. An example of team organization for MMDP in national programmes to eliminate LF is shown in Section 3.2.2, Figure 7.

A LF committee might also be formed at peripheral level to help government staff involve the community and implement activities. This would be particularly appropriate in areas where the management system is community-based home care.

The stakeholders involved in implementing and supervising MMDP could include:

- community-based care organizations such as health workers, women’s groups and youth groups, whose involvement should be supervised;
• non-governmental organizations, whose involvement should be coordinated and supervised;
• individuals with or without expertise in community-based care to ensure organization and coordination;
• religious and community leaders; and
• traditional healers and members of faith-based organizations.

Programmes could also establish a team consisting of people interested in improving the status of LF patients in their community. It could include representatives of local non-governmental organizations, community-based care organizations or volunteers from women’s groups, support groups, self-help groups, youth groups or corporative groups. The membership should broadly represent the community.

Advocacy and social mobilization

Advocacy and social mobilization to encourage MMDP activities should be implemented at different levels in order to ensure smooth running as well as the involvement of all different actors. An example of advocacy and communication activities by target audience is presented in Table 4.

Table 4. Planning, advocacy and social mobilization activities for managing morbidity and preventing disability due to LF

<table>
<thead>
<tr>
<th>Level</th>
<th>Target audience</th>
<th>Method</th>
<th>Expected outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Policy</td>
<td>Health sector decision-makers, donors, policy-makers, community leaders, religious leaders, opinion leaders, teachers</td>
<td>Policy briefs, messages, success stories</td>
<td>Increase knowledge and awareness and change attitudes to become advocates for prevention activities, budget allocation, coordination</td>
</tr>
<tr>
<td>Programme</td>
<td>Managers of disease-specific programmes, doctors, nurses, public health workers</td>
<td>Messages, success stories</td>
<td>Collaboration in operation, monitoring and evaluation</td>
</tr>
<tr>
<td>Research</td>
<td>Medical laboratories, research scientists</td>
<td>Forum discussion</td>
<td>Research</td>
</tr>
<tr>
<td>Community</td>
<td>Community health workers and volunteers</td>
<td>Training sessions</td>
<td>Awareness, commitment</td>
</tr>
<tr>
<td>Community</td>
<td>Community at large, including young people (schoolchildren)</td>
<td>Information, education and communication materials and activities</td>
<td>Awareness, behavioural change</td>
</tr>
</tbody>
</table>

Educating patients and their families as well as schoolchildren about health is of primary importance in morbidity management and disability prevention. National programmes might also conduct broader social mobilization campaigns, depending on, for instance, the disease burden in communities, hygiene practices, levels of stigma and available resources.
Social mobilization for disability prevention can be incorporated into a mass drug administration campaign or with similar activities for other disabling diseases. Social mobilization is used to inform the population about the disease and its consequences; modify their attitudes, particularly when the persons with LF experience stigmatization; sensitize people to the importance of early screening, and encourage active participation in case identification. Social mobilization can also encourage modification of hygiene practices to prevent initial acute attack episodes, particularly in people who have sub-clinical lymphatic damage, and also to increase compliance and participation in mass drug administration.

Developing a social mobilization strategy requires special skills, and it is recommended that the programme work with specialists in this domain. Campaigns and advocacy targeted at stakeholders such as local leaders should create a sense of ownership and empowerment in the community in order to ensure that MMDP activities are sustainable, with limited input from the health system.

Capacity-building and training

Reinforcing the capacities of health staff at various levels and of communities will ensure the success of MMDP. Table 5 gives examples of capacity-building activities by target group and the various resources and tools necessary to build required competencies.

Table 5. Competencies and resources necessary to support MMDP capacity-building activities for various target groups

<table>
<thead>
<tr>
<th>Target group</th>
<th>Required competencies</th>
<th>Tools/Resources to Build Capacity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Programme managers &amp; staff</td>
<td>• Advocacy&lt;br&gt;• Inter-sectorial communication&lt;br&gt;• Programme planning&lt;br&gt;• Clinical management techniques&lt;br&gt;• Monitoring and evaluation</td>
<td>• WHO manuals and tools&lt;br&gt;• Regional and country-level training&lt;br&gt;• Databanks and reporting systems</td>
</tr>
<tr>
<td>Health facility staff</td>
<td>• Clinical management techniques&lt;br&gt;• Health promotion&lt;br&gt;• Monitoring and evaluation</td>
<td>• WHO tools&lt;br&gt;• Training&lt;br&gt;• Case management guidelines&lt;br&gt;• Patient health education materials&lt;br&gt;• Water infrastructure&lt;br&gt;• Medications and commodities&lt;br&gt;• Patient tracking systems</td>
</tr>
<tr>
<td>Community health workers and volunteers</td>
<td>• Basic management techniques&lt;br&gt;• Health promotion&lt;br&gt;• Social mobilization</td>
<td>• WHO tools&lt;br&gt;• Training&lt;br&gt;• Patient education materials</td>
</tr>
<tr>
<td>Patients</td>
<td>• Self-care techniques</td>
<td>• WHO tools&lt;br&gt;• Training&lt;br&gt;• Medications and commodities</td>
</tr>
</tbody>
</table>
In general, standard operating procedures and training procedures for treatment of acute attacks, management of lymphoedema (or elephantiasis) and hydrocele surgery should be established at the national level. National programme staff can adapt training materials for management of lymphoedema from general guidance, web annexes included with this document and included in the LF MMDP toolkit (48; 49; 32). Training materials also might have to be adapted for implementation units, depending on the available knowledge, language and literacy. Health care staff and caregivers should be trained to give persons with lymphoedema or hydrocele correct information on whom to contact, what to do and not do for self-care, and indications for hydrocelectomy (Box 3).

The steps in preparing a training programme for the management of acute attacks and lymphoedema (or elephantiasis) are:

- Define case management guidelines for identifying and managing acute attacks and lymphoedema (or elephantiasis) for physicians in primary health care, health workers and lay workers.
- Prepare training curricula on the basis of the situational analysis of the competencies and needs of health staff for managing morbidity and preventing disability due to LF and identify how the training will be structured, perhaps by identifying training facilities at national and subnational levels.
- Include modules on morbidity and disability due to LF in medical and nursing school curricula.

**Box 3. Training procedures for community home-based care** (48; 49)

The aim of training or capacity-building of targeted groups (health care workers, community health workers, individuals and families) should be to develop four competences:

- recognize the disease and its complications,
- understand home-based and long-term care,
- provide adequate management of lymphoedema and elephantiasis and
- establish appropriate follow-up, monitoring and referral systems.

The materials available to prepare a training curriculum include:

- a two-part training module: a tutor’s guide and a learner’s guide for training-trainers workshops,
- a flipchart for use by health care workers and
- a poster for patients with lymphoedema (or elephantiasis).
- WHO MMDP workshop modules included as a web resource.


Trained staff should be used to organize training courses for health staff at implementation units and for community health workers. Programmes should strengthen the capacity of the health system to provide hydrocelectomy surgery. Assessing the availability of surgery by level is a first step. Training programmes may then be organized for surgeons at all levels where warranted. Trainings should be led by master surgeons with experience in the procedure who work in endemic areas or surgeons attached to teaching or training institutions with continued experience in hydrocelectomy surgery. Surgeons should be trained in diagnostic procedures and differential diagnoses, evaluating hydrocele patients for surgery or referral, surgical techniques (excision and eversion), safe surgical practices, such as surgical site infection protocols, as well as post-operative care and follow-up procedures. Case demonstration and actual surgery is useful when possible.

WHO has developed a Lymphatic Filariasis Morbidity Management and Disability Prevention training package to assist regions and countries to plan, implement, and evaluation MMDP activities. The training package is intended to facilitate the training process of national LF and/or MMDP focal points, health professionals, and care providers from LF endemic countries. The training package includes a guide for facilitators, training presentations, and group work and knowledge assessment exercises, and instructions for performing MMDP demonstrations and role-play exercises.

Provision of the essential package of care

In order to ensure the provision of the essential package of care (see Sections 2.3 & 2.5), a variety of actors may be involved, including doctors and nurses, health care staff and community health workers, persons with LF disease and their families. The actors that will be involved in provision of care may vary based on the program delivery strategy and other context-specific factors. The potential actors involved, their responsibilities, the action, and skills required to provide the essential package of care are summarized in Table 6.

Table 6. Activities and responsibilities in an essential package of care for patients with LF

<table>
<thead>
<tr>
<th>Disease manifestation</th>
<th>Actors involved</th>
<th>Responsibility</th>
<th>Action</th>
<th>Skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute attacks (ADL)</td>
<td>Doctors and nurses</td>
<td>Treat acute attacks and its complications</td>
<td>Treat ADL and its complications with appropriate antibiotics and symptomatic management</td>
<td>Knowledge of basic principles of treatment and management of acute attack and complications, as well as referral criteria</td>
</tr>
<tr>
<td></td>
<td>Health care staff and community health workers</td>
<td>Identify patients, treat acute attacks, and report activities</td>
<td>Visit patients regularly to identify acute attacks, treat acute attacks with appropriate antibiotics, follow-up patients</td>
<td>Knowledge of basic principles of treatment and management of acute attacks and complications, as well as referral criteria</td>
</tr>
<tr>
<td>Condition</td>
<td>Professionals</td>
<td>Activities Description</td>
<td>Knowledge Areas</td>
<td></td>
</tr>
<tr>
<td>--------------------------------</td>
<td>------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Lymphoedema (or elephantiasis)</td>
<td>Doctors and nurses</td>
<td>Manage lymphoedema and its complications; consultation with patients</td>
<td>Knowledge of basic principles for management of lymphoedema and complications</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Health care staff and community health workers</td>
<td>Identify patients, manage lymphoedema and report activities; visit patients regularly to identify lymphoedema, demonstrate basic principles of lymphoedema management, and supervise and follow-up patients</td>
<td>Knowledge of basic principles of prevention of progression of lymphoedema, communication skills</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Patients with lymphoedema</td>
<td>Apply principals of basic lymphoedema management; ensure availability of hygiene supplies; Hygiene, skin and wound care, elevation, exercises, and wearing comfortable shoes</td>
<td>Knowledge of basic principles of prevention of progression of lymphoedema</td>
<td></td>
</tr>
<tr>
<td>Hydrocele</td>
<td>Surgeons, doctors, and nurses</td>
<td>Perform safe hydrocelectomy; Diagnose hydrocele, perform hydrocelectomy as appropriate, refer complicated cases</td>
<td>Knowledge of basic principles of hydrocelectomy, infection control, pre- and post-operative care, management of complications and referral system</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Health care staff</td>
<td>Identify patients who require surgery, refer to hospital and report activities; Visit patients to counsel on availability of surgery, follow-up after surgery</td>
<td>Knowledge of basic features of the disease, benefits of surgery, facilities available, when and how to refer post-operative complications</td>
<td></td>
</tr>
</tbody>
</table>
Community health workers

- Identify patients with scrotal swelling and refer them to hospital
- Visit patients to counsel on the availability of surgery and follow-up after surgery
- Communicate features of the disease, benefits of surgery, and facilities available

Hydrocele patients

- Understand the risks and benefits of hydrocelectomy
- Visit the hospital and receive surgery as needed
- Awareness of signs and symptoms of hydrocele, benefits and risks of surgery, facilities available for treatment, understand appropriate post-operative care

Three types of delivery strategies can be used to manage acute attacks and lymphoedema: hospital or primary health-based care, hospital or primary health-based care with community health worker involvement, and community home-based care. While the basic principles remain the same, the actors involved and the location of the service delivery may change based on the delivery strategy. An example of a community home-based care delivery system for the management of lymphoedema is given in Annex 5. Hydrocele surgery can be performed only in a hospital.

**Psychological support and socioeconomic rehabilitation**

Psychological support and socioeconomic rehabilitation are necessary to complement the medical and surgical care of patients so that they can achieve full integration into their community by overcoming the psychological consequences of stigma and shame. Actions can be taken to prevent stigma. Guides on Stigma and Mental Wellbeing have been developed and made available through collaboration with International Federation of Anti-Leprosy Associations and the Neglected Tropical Disease NGO Network.\(^5\)

As the impairments and disability associated with lymphoedema and hydrocele often lead to inability to work, these persons need assistance in finding suitable jobs. These activities are, however, often outside the remit of the staff of LF programmes both nationally and in implementation units. Programmes are encouraged to develop inter-departmental and intersectoral partnerships to ensure the holistic, total community-based rehabilitation of persons and their families with disabilities due to lymphedema and hydrocele.\(^6\)

Setting up a psychological support and socioeconomic rehabilitation system also depends on the human and financial resources available. Even if such support is not available, other MMDP activities should not be delayed.

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\(^5\) For further information, consult the Guides on Stigma and Mental Wellbeing from the International Federation of Anti-Leprosy Associations, Neglected Tropical Disease NGO Network, 2020. Online toolbox available at: https://www.infontd.org/toolkits/stigma-guides/stigma guides

For psychological support, the following activities might be considered:

- Discuss the relevance of psychological support for patients with lymphoedema or hydrocele and delivery strategies with health counsellors.
- Establish a referral system for patients to psychological support services.
- Decide which training materials are required for health care staff, community health workers and/or patients, and ensure that sufficient supplies are available.
- Organize training of health care staff and community health workers on screening for the need for psychological support and providing appropriate psychological support, including how to refer patients to appropriate support services.
- Monitor and supervise health care staff and community health workers who are giving support.
- Create psychosocial support groups for individuals with LF to share their experiences and support one another. These support groups can be integrated across disease conditions.
- Organize social mobilization on the potential psychological impact of the chronic complications of LF.

For socioeconomic rehabilitation:

- Organize a social mobilization campaign to reduce the social stigma attached to LF. Discuss social inclusion and income-generating activities with welfare or finance services.
- Assess the socioeconomic needs of persons with LF.
- Provide preliminary social support to patients through the welfare service by integrating persons with LF into existing income-generating activities.

**District and community levels**

**Management**

District health facilities could serve as technical referral centres, provide access to treatment of complicated cases and provide expertise to communities; they may also give medical training and supervision to community health workers and conduct monitoring and evaluation activities. Specific LF teams of health staff could be formed in areas with a high burden of disease or many stakeholders.

A LF committee could also be formed at the implementation unit or at peripheral level to strengthen the capacity of government staff to involve the community and implement activities. This would be particularly appropriate in areas where community home-based care is chosen as the service delivery strategy. Programmes could also establish community teams with varied professional profiles interested in improving the status of LF patients in their community. The stakeholders in the community involved in implementing and supervising MMDP activities are the same as those at national level.

If necessary, a situation analysis similar to that at national level could be completed at the implementation unit. The following steps could be taken:
• At the start of the programme, use the numbers of lymphoedema patients and patients with suspected hydrocele estimated using various patient estimation approaches, such as pre-MDA census.

• Refer men with hydrocele to health workers for accurate diagnosis of hydrocele or lymphoedema of the scrotum. Hydrocele patients should be offered surgery.

• Determine the geographical distribution of patients.

• Collect information on potential community health workers in order to form a managerial team, delivery strategy and referral system for lymphoedema.

• Investigate the possibility of integrating some activities for the long-term management of lymphoedema with other home-based care activities.

Training

In many implementation units, health care staff have been trained at national or subnational level and can organize training for other health staff and community health workers. The training cascade could be organized as follows:

• for trainers: training of district health and other government workers by professional trainers from national or subnational level;

• for community health workers: training of community health workers by recently trained trainers; and

• for lymphoedema patients and their families: training by community health workers in the homes of patients.

For management of hydrocele, national-level trainers can train regional and district level physicians and surgeons identified by national and local health systems. Medical officers must be trained in diagnosis, evaluation of fitness for surgery and all aspects of surgery including local anaesthesia, post-operative care and follow-up.

Implementation

This step involves setting up a follow-up system and other activities, such as social mobilization, lymphoedema management, hydrocele surgery, psychological support and socioeconomic rehabilitation. The target populations for social mobilization are selected in the implementation unit, which may use national materials and resources. The activities could be coordinated with similar activities of other programmes targeting behavioural change.

The choice of how lymphoedema management is to be delivered depends in part on the number and geographical spread of cases. The optimal number of cases that can be followed by a community health worker in a community home-based care programme has not been established. It can therefore be decided locally and reviewed later.

The steps in designing lymphoedema management by the LF team are:

• Determine the number of patients with lymphoedema and their location in the community, and sensitize the community before preparing the work plan, taking care to estimate the required human resources, monitoring of medications and commodities.
• Organize training in lymphoedema management, with emphasis on acute attack, for several
government health and non-health workers at district level.
• Set up a referral system for managing clinical manifestations of different severity.
• Once training has been completed, people involved in follow-up will begin making regular visits to
lymphoedema patients based on the national follow-up schedule or the patients will begin coming to
the health facilities for routine care.
• Organize regular supervision until the health workers or community health workers can record data
correctly in the patient tracking system.
• Track patient progress over time.
• Manage the supply of medications for treatment of acute attacks at the most peripheral health facilities.
These include antibiotics, antiseptics, antibacterial and antifungal creams, analgesics and anti-
inflammatory medications.
• Collect reports from the community health workers and health centres, and summarize them. Examples
of reports can be found in Annex 6-8
• Organize annual refresher training at least every two years for people involved in follow-up of
lymphoedema management for optimal sustainability of activities.

Hydrocelectomy should be made available as close to cases as possible to ensure it is easily accessible to the
population. If surgical services are not available the district or IU level, then hydrocele surgery should be
provided at the next highest level that has consistent surgical services. The following steps should be
implemented in order to provide hydrocelectomy:

• Determine the estimated numbers of hydrocele cases from patient estimation activities. The LF team
could work with community leaders and community health workers to inform individuals about the
availability of hydrocelectomy. Liaise with health authorities at the implementation unit to ascertain the
most suitable treatment approach.
• Organize training of the hospital medical staff who will be in charge of hydrocelectomy, with a surgeon
trainer and head of surgery.
• Organize monitoring and reporting to the national programme manager according to national
programme guidance.

Follow-up of hydrocelectomy can be included in follow-up of all surgical activities at the health facility.

3.2 Monitoring and evaluation

Monitoring and evaluation (M&E) of a MMDP programme is essential. The M&E framework serves not
only to guide countries to collect the necessary data for preparation of their elimination dossier, but also to
monitor progress and evaluate the impact of the national MMDP programme over time. There are specific
indicators that should be reported to WHO for submission of the country dossier for elimination of LF as a public
health problem and for annual reporting to the GPELF; however, countries should develop further indicators to
objectively measure the success of the MMDP component of national programmes based on the programme
design.
3.2.1 Reporting to the Global Programme to Eliminate Lymphatic Filariasis

Validation of elimination of LF as a public health problem

For preparation of the country’s elimination dossier, national programmes should follow the procedures outlined in the handbook Validation of elimination of lymphatic filariasis as a public health problem (61). For MMDP, a country claiming to have achieved elimination of LF as a public health problem is requested to document:

a. **Patient estimation:** The number of patients with lymphoedema or hydrocele (reported or estimated) by implementation unit or similar health administrative unit (regardless of whether the IU required MDA).

   - Number of lymphoedema patients (reported or estimated) by IU
   - Number of hydrocele patients (reported or estimated) by IU (in W. bancrofti areas)

Countries should list the number of known/estimated patients by IU. Various methodologies may be used by countries to obtain the estimated number of lymphoedema and hydrocele patients (Web Annex B). The priority for patient estimation should occur in all historically endemic areas regardless of whether MDA was implemented. Areas with known patients include not only areas that were classified as endemic during mapping exercises, but also areas that were considered to be non-endemic during mapping (i.e. <1% antigenaemia or microfilaraemia), but where there is evidence of individuals with hydrocele or lymphoedema. Annex 6 provides an example of a community morbidity register that could be used to capture data on lymphoedema (or elephantiasis) patients during a patient estimation activity.

b. **Availability of the recommended essential package of care:** In all areas of known patients, the availability of the recommended essential package of care.

   - Number of designated health facilities providing services for lymphoedema and ADL
   - Number of reference hospitals providing hydrocelectomies (in W. bancrofti areas)

The ultimate goal is to provide 100% geographic coverage of the essential package of care (see Sections 2.3 and 2.5) for all known patients with lymphoedema and hydrocele. At least one facility per IU with known patients should provide services for lymphoedema and hydrocele. In areas endemic for *W. bancrofti*, at least one surgical facility should serve all IUs that have known hydrocele patients. It is recognized that not all districts or IUs provide surgical services for any condition. If surgical services are not available at the district/IU level, then hydrocele surgery should be provided at the next health level that has consistent surgical services (e.g., regional hospital).

c. **Readiness and quality of available services:** In select designated facilities, document the readiness and quality of available services.

   - Number of facilities surveyed to assess quality of care for lymphoedema and ADL management and/or hydrocelectomy

The national programme is encouraged to conduct an evaluation of the readiness and quality of health services for treatment of ADL, lymphoedema and hydrocele. WHO proposes a direct inspection protocol for assessing quality of health services for lymphoedema and ADL (Web Annex A); however, countries may use other strategies to assess quality. The national programme, in coordination with staff in implementation units, is encouraged to sample at least 10% of the facilities nationwide providing each service (lymphoedema...
management or hydrocelectomy) to assess the quality of health services for these conditions in all IUs with known patients.

Annual reporting to GPELF

National programmes should collect data on morbidity management and disability prevention regularly, at least once a year, depending on the local disease burden and the available human resources. National programmes should provide GPELF with morbidity data annually to WHO through the Epidemiological Data Reporting Form (EPIRF). Currently, the programme captures the following information in the report and submits it to WHO through the regional programme review groups.

The following data should be captured at the national level:

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Lymphoedema/ADL</th>
<th>Hydrocele</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of IUs with known patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of IUs with no known patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of IUs with patient estimation pending</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of IUs with at least 1 facility designated to providing care*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total number of health facilities providing services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New patients identified in reporting year</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cumulative number of patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of patients who received care* in the reporting year</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Care for lymphoedema/ADL includes an initial consultation/training, a follow-up visit, a visit for ADL management, or a psychological services visit; care for hydrocele includes hydrocelectomy surgery.

The following data should be captured at the level of implementation units:

- total number of patients (reported or estimated) listed separately by condition
- method of patient estimation by condition
- number of health facilities providing service (lymphoedema)
- number of health facilities providing hydrocelectomies

3.2.2 National monitoring and evaluation plan

The national filariasis programme should ensure that reporting tools and systems are developed to collect the indicators that should be reported to WHO for the annual report and the elimination dossier. They are also encouraged to develop additional indicators and reporting tools specific to their programme designs and objectives. The national LF programme should ensure that activities for MMDP are included in the national
health monitoring and evaluation plan, including indicators, targets, reporting templates and systems and a plan for analysing and disseminating the results.

Data collection and reporting

The national programme manager is responsible for ensuring the collection of all relevant data that is aggregated at the IU and national level. Because the method of data collection varies by country, so does the flow of data to the national programme. In general, each implementation unit (IU) is responsible for collecting all relevant data from the health center level, prior to aggregating and transmitting these data. Figure 7 outlines the potential flow of data up to WHO through the National Programme manager starting at the community level. Example data collection and reporting tools which include morbidity registers, clinical intake and follow-up forms, and reports are provided by each level as an example for countries to adapt as needed (Annexes 6 – 8).

Figure 7. Reporting by public health centres (HC) through reporting units (RU) to the focal point for morbidity management and disability prevention (MMDP) in a national programme to eliminate LF

Monitoring

Monitoring involves routine collection of information on all aspects of a programme. The monitoring indicators for LF MMDP include programme coverage, training, and lymphoedema and hydrocele activities. The frequency of data collection is specific to the country’s reporting periods. The indicators may include process, output, clinical and impact indicators and may be collected at the individual, community, or health facility level, depending on the design of the programme. An example of select monitoring and evaluation indicators at the implementation unit level can be found in Annexes 6-8.
To monitor progress of the national programme towards elimination dossier, the following indicators can be used by countries:

- proportion of IUs with patient estimations complete
- proportion of IUs with known patients in which MMDP care is provided
- proportion of IUs with known lymphoedema patients where a survey to assess quality of care for lymphoedema and ADL management was conducted (10% recommended)
- proportion of IUs with known hydrocele patients where a survey to assess quality of care for hydrocele was conducted in W. bancrofti areas (10% recommended)

**Program level indicators**

National programmes should design monitoring of their LF MMDP programme around implementation and outputs of specific activities under the direction of the programme. Therefore, these indicators will differ based on the scope and design of MMDP programmes in each country. These indicators may include aspects of training (e.g. total number of health workers trained in lymphoedema management, number of health facilities with at least one trained health provider in the management of lymphoedema and acute attack, percentage of health facilities with surgeon trained in hydrocelectomy, etc.); development and distribution of IEC materials (e.g. number of IEC materials distributed to health facilities); percentage of health facilities who received IEC materials that are displayed in the health facility; distribution of supplies (e.g. number of hygiene kits distributed to lymphoedema patients); the number of referrals of patients to health facilities; the proportion of referrals that resulted in a consultation; the number of patients who received care for lymphoedema (i.e. an initial consultation or training visit, a follow-up visit, a visit for ADL management, a psychological services visit) or hydrocele (i.e. hydrocelectomy surgery); implementation of psychological support (e.g. number of LF support group sessions conducted); or community and social mobilization (e.g. number of health education materials displayed in communities educating patients on availability of LF services, etc.). A national programme may choose to measure the outcome of their MMDP programme activities, such as change in knowledge, attitudes, and behaviors of patients, surgeons, health facility workers and community members regarding LF.

**Patient level indicators**

Patient level indicators can include physical, psychosocial, functional and economic indicators. The occurrence of acute attacks is correlated with clinical progression of the disease, and has been shown to be a simple and useful proxy for quality of life (45; 46). Other benefits of the programme at the patient level may be physical improvements such as a reduction in the size of the affected area (e.g. stage/grade, circumference, or volume), improved patient function (e.g. change in mobility, standing, walking, etc.) and improved economic status (e.g. reported number of days of work lost in past month).

Additionally, the programme could be assessed on the basis of an improvement of the quality of life (QOL) of patients. Several scales have been piloted for use in lymphoedema patients such as the Dermatology Life Quality Index (DLQI), Lymphatic Filariasis Quality of Life Questionnaire (LFSQQ), and World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) (62). All three scales performed moderately well among lymphoedema patients and there was no clear gold standard among scales.

While research has shown that patients who comply with lymphoedema management have an improvement in various measures, some caution should be used when assessing patient-level indicators to assess program quality for lymphoedema. Clinical indicators at the patient level are not always a reflection of the quality of the programme, because improve clinical improvement for lymphoedema involves patient adherence
to recommended strategies. Therefore, programmes are encouraged to use indicators for which the programme has control. For hydrocele, several indicators could be used to track program quality such as: post-operative hematoma, post-operative hemorrhage, surgical site infection, and recurrence of hydrocele.

Evaluation

Evaluation involves episodic assessment of changes in results that requires technical and financial resources. One measure of the success of a programme is the availability and accessibility of facilities staffed with trained health and community workers for the management of patients with ADL, lymphoedema (or elephantiasis), and hydrocele. The availability of several facilities that can support patients with various forms of filariasis and various models of provision of care, with flexibility in the choice of facility and provider, would indicate that a programme has successfully expanded and been accepted. The extent to which programmes offer services based on the principles of management of lymphoedema to patients with other chronic diseases (e.g. diabetes, leprosy, podoconiosis and vascular insufficiency) in an integrated fashion would be another useful evaluation parameter for national programmes.
References


55. Mande et al. Doxycycline Improves Filarial Lymphedema Independent of Active Filarial Infection: A Randomized Controlled Trial. *Clinical Infectious Diseases*, 2012, 621-30, 55 (5):.

56. *Ending the neglect to attain the sustainable development goals: A road map for neglected tropical diseases 2021-2030*. World Health Organization.


Annexes

Annex 1: Dreyer Seven-stage classification system for lymphoedema

<table>
<thead>
<tr>
<th>Stage 1:</th>
<th>Stage 2:</th>
<th>Stage 3:</th>
<th>Stage 4:</th>
<th>Stage 5:</th>
<th>Stage 6:</th>
<th>Stage 7:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Swelling is reversible overnight</td>
<td>Swelling is not reversible</td>
<td>Shallow skin folds</td>
<td>Knobs</td>
<td>Deep skin folds</td>
<td>Mossy lesions</td>
<td>Unable to care for self or perform daily activities</td>
</tr>
</tbody>
</table>

**Definition:**
- **Stage 1:** The swelling increases during the day and goes away overnight as the patient lies flat in bed.
- **Stage 2:** The swelling does not go away without lymphoedema management.
- **Stage 3:** The presence of one or more shallow skin folds, in which the base of the fold can be seen when the patients moves the leg or foot.
- **Stage 4:** The presence of knobs: defined as bumps, lumps, or protrusions of the skin.
- **Stage 5:** The presence of one or more deep skin folds. Deep folds are those whose base cannot be seen when the patient moves the leg or foot.
- **Stage 6:** The presence of mossy lesions on the surface of the skin: very small elongated or rounded small growths that are usually clustered together.
- **Stage 7:** The most advanced stage of the condition when patients are unable to adequately or independently perform routine daily activities such as walking, bathing, or cooking, etc.
Annex 2. Simplified staging of lymphoedema for community-level health workers

<table>
<thead>
<tr>
<th>Simplified stage</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description</td>
<td>Lymphoedema without folds. Can or cannot be reversible at night.</td>
<td>Lymphoedema with shallow folds.</td>
<td>Lymphoedema with skin changes (mossy lesions, knobs, and/or deep folds)</td>
</tr>
<tr>
<td>Equivalent in 7 stage classification</td>
<td>1 and 2</td>
<td>3</td>
<td>4-7</td>
</tr>
</tbody>
</table>
Annex 3. Management for seven stages of lymphoedema (or elephantiasis)

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
<th>Stage 5</th>
<th>Stage 6</th>
<th>Stage 7</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hygiene</strong></td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td><strong>Look for entry lesions</strong></td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Common between toes</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Likely present between toes &amp; folds</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td><strong>Preventative antiseptic and antifungal creams</strong></td>
<td>When necessary</td>
<td>When necessary</td>
<td>When necessary</td>
<td>When necessary</td>
<td>Usually necessary</td>
<td>Necessary</td>
<td>Necessary</td>
</tr>
<tr>
<td><strong>Treatment of entry lesions antibacterial/antifungal creams</strong></td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td><strong>Elevation</strong></td>
<td>Usually not necessary</td>
<td>Day &amp; night</td>
<td>Day &amp; night</td>
<td>Day &amp; night</td>
<td>Day &amp; night if possible</td>
<td>Day &amp; night if possible</td>
<td>Day &amp; night if possible</td>
</tr>
<tr>
<td><strong>Exercises</strong></td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td><strong>If possible</strong></td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td><strong>Treatment of acute attacks with antibiotics</strong></td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td><strong>Wear comfortable shoes</strong></td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
</tbody>
</table>

Annex 4. Algorithm for determining the management of acute attacks

Symptoms suggestive of acute attack
- Pain, swelling, warmth and redness of limb
- Pain and swelling in groin
- Fever with chills and rigor, headache

Look for
- Local rise of temperature, tenderness
- Swelling and redness of limb
- Entry lesions (injury, cuts, wounds, fungal infection in between toes)
- Pain and swelling in groin

Acute attack

Are any of the following present?
- Vomiting, confusion, high fever
- Entry lesions with drainage or foul smell
- Advanced lymphedema with recurrent attacks
- Patient is pregnant

YES
Referral to hospital

- IV/IM antibiotics as appropriate
- Antiemetics, Analgesics
- Other supportive measures
- Monitoring

NO IMPROVEMENT

NO
Review after 24 hrs

- Rest, elevation of limb
- Oral antibiotics
- Analgesics/antipyretics
- Antibiotic/antifungal ointment for entry lesion
- Hygiene measures as much as possible
- Cooling of limb

IMPROVEMENT

Continue the same for 5 days

Acute attack resolved

Continue
- Limb hygiene
- Exercise
- Elevation of limb
- Skin and wound care
- Appropriate, comfortable footwear

Annex 5. Example of steps for home-based management of lymphoedema (or elephantiasis)

Three types of home-based management of lymphoedema and elephantiasis have been recognized. These include: (i) community or family home-based care, which involves a community or family member in training, follow-up and monitoring of the lymphoedema patient; (ii) health facility-based care with community health worker support, which can be integrated with services that include care of patients with other chronic diseases such as leprosy, diabetes and neurological disorders; and (iii) primary health care system, in which prevention of disability is an integral part of the primary health care system.

The choice of system for managing lymphoedema and elephantiasis must ensure effective, efficient programme implementation and sustainability and follow-up of patients. The type of system is determined by the number and distribution of patients in the area, their social grouping and the awareness and support of the community, which depend on the setting.

The optimal number of patients who can be followed up by a community health worker in a community home-based care programme has not been established. The number suggested in this document is five patients; however, this number can be adapted to the local situation and reviewed over time. Thus, when there are more than five cases of chronic lymphoedema or elephantiasis per community, it is advisable to adopt community home-based care, follow-up and monitoring. When there are fewer than five cases, family home-based, community home-based or primary health centre-based care can be considered.

The steps in planning home-based management of lymphoedema under the responsibility of the LF team are:

1. Determine the number of patients and their location in the community.
2. Sensitize the community and hold discussions with key figures to establish their tasks. While the LF team coordinates, monitors and supervises the programme, the medical staff in the implementation unit runs the programme.
3. Set up the follow-up system (family or community home-based), and select the workers to be involved.
4. Hold monthly coordination meetings with medical staff and other caregivers, establish a quarterly reporting system, supervise technical and managerial issues and monitor.
5. Register the patients to be included with the help of the community.
6. Estimate the human resources and drugs and supplies required on the basis of the estimated number of patients and their geographical distribution:
   - Ascertain the number of patients to be followed by each caregiver.
   - Ascertain the distribution of patients per health facility.
   - Calculate the number of monitoring forms required per month and year and the number of training manuals.
   - Ascertain the means of transport required for supervision and monitoring
7. Organize meetings with people involved in supervision to discuss the screening of new patients.
8. Organize a training cascade in lymphoedema and elephantiasis management, with emphasis on acute attack management for several government health and non-health workers in the district. Set up a referral
system for managing clinical manifestations of different severity. In areas where community-based management has been chosen, train community health workers in teaching the principles of home-based self-care to patients and their relatives, friends or neighbours. When management in primary health care centres has been chosen, government health and non-health workers will train the patients.

9. Once training has been completed, people involved in follow-up will begin monthly visits to patients to disseminate messages on the prevention and alleviation of disability, involve patients' relatives, friends and neighbours, and maintain patients' commitment for maximum sustainability.

10. Organize monthly supervision until the health workers or community health workers can record data correctly on the follow-up forms. From then on, supervision can be conducted every 2 or 3 months by the community team in the case of community-based management or by the LF team and health staff where family or primary health care management systems are used. This will ensure not only correct recording but also the commitment of those involved in follow-up for maximum sustainability.

11. Manage the supply of drugs for treating acute attacks at the most peripheral health facilities, e.g. paracetamol and antiseptic, antibacterial and antifungal creams.

12. Collect reports from community health workers and health centres and summarize them on a form such as that in Annex 7. Submit reports regularly to the national programme manager, usually every 6 or 12 months, as defined by the national programme.

13. Organize a refresher course at least every two years for people involved in following up lymphoedema management for optimal sustainability of activities.
Annex 6: Community Morbidity Register

The following form serves as an example of a community morbidity register and should be modified to the local context in order to help health workers identify lymphoedema and hydrocele patients during patient estimation exercises or other MMDP activities. This form could be used in conjunction with lymphoedema job aid to help community health workers distinguish the severity of lymphoedema.

<table>
<thead>
<tr>
<th>Health Centre Name:</th>
<th>Community Health Worker Name:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Last Name</td>
<td>First Name</td>
</tr>
<tr>
<td>☐ F</td>
<td>☐ M</td>
</tr>
<tr>
<td>☐ F</td>
<td>☐ M</td>
</tr>
<tr>
<td>☐ F</td>
<td>☐ M</td>
</tr>
<tr>
<td>☐ F</td>
<td>☐ M</td>
</tr>
<tr>
<td>☐ F</td>
<td>☐ M</td>
</tr>
<tr>
<td>☐ F</td>
<td>☐ M</td>
</tr>
</tbody>
</table>

* Mild = Lymphoedema without folds. Can or cannot be reversible overnight, Moderate = Lymphoedema with shallow folds, Severe = Lymphoedema with skin changes (mossy lesions, knobs, and/or deep folds)
Annex 7: Examples of individual intake and follow-up forms for community health workers

Example of Individual Intake Form for Community Health Worker

The following form serves as an example and should be modified to the local context in order to help health workers assess the status of a new lymphoedema or suspected hydrocele patient. The health worker should document key demographic data about the patient. Based on the findings of patient interview and physical exam, the health worker should note the presence and location of swelling, the staging of lymphoedema (if applicable), the presence of entry lesions, and the history of acute attacks (ADL episodes).

If health workers are responsible for training lymphedema patients, they should train patients on the five components of lymphedema management: hygiene, skin and wound care, elevation, exercises, and wearing comfortable shoes. Training should be conducted or the patients should be referred for training at a separate location (e.g. health centre).

Some patients may require a referral to the hospital. Health workers should review the danger signs: chest pain, shortness of breath, fever with sweats (outside of an acute attack), unexplained weight loss, infrequent urination, yellowish skin or eyes (jaundice), or rapid onset of swelling (days to weeks). The presence of any danger sign, indicates that the swelling may not be related to filariasis, and should indicate immediate referral to the nearest health facility for further evaluation. Any presence of scrotal swelling should be referred to the hospital for further evaluation by a medical professional to confirm the diagnosis and if he may be a candidate for hydrocele surgery. Other reasons for referral include: an entry lesion or wound that has drainage, a foul odor, redness or swelling; an acute attack; or an individual in need of psychological services.
<table>
<thead>
<tr>
<th>Location of lymphoedema:</th>
<th>Leg</th>
<th>Arm</th>
<th>Breast</th>
<th>Scrotal Swelling</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>![Leg Image]</td>
<td>![Arm Image]</td>
<td>![Breast Image]</td>
<td>![Scrotal Swelling Image]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Presence of swelling?</th>
<th>Left</th>
<th>Right</th>
<th>Left</th>
<th>Right</th>
<th>Left</th>
<th>Right</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐ Yes</td>
</tr>
</tbody>
</table>

If yes, refer to health facility for further assessment.

<table>
<thead>
<tr>
<th>When did you first notice the swelling? (MM/YY):</th>
<th>Left</th>
<th>Right</th>
<th>Left</th>
<th>Right</th>
<th>Left</th>
<th>Right</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐ Yes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage*</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ None</td>
<td>☐ Mild</td>
<td>☐ Moderate</td>
<td>☐ Severe</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient known to the health system?</th>
<th>☐ Yes</th>
<th>☐ No</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Yes</td>
<td>☐ No</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Entry lesions/wounds present?</th>
<th>☐ Yes</th>
<th>☐ No</th>
<th>☐ Yes</th>
<th>☐ No</th>
<th>☐ Yes</th>
<th>☐ No</th>
<th>☐ Yes</th>
<th>☐ No</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐ Yes</td>
<td>☐ No</td>
<td></td>
</tr>
</tbody>
</table>

Has the patient had an acute attack in the last 30 days? ☐ Yes ☐ No

If yes, how many?

Was the patient trained in lymphedema management? ☐ Yes ☐ No

If no, why not?

Is a referral to the hospital needed? ☐ Yes ☐ No
If yes, reason for referral:  
- ☐ Danger signs** (immediate referral)
- ☐ Acute attack
- ☐ Wound
- ☐ Scrotal swelling
- ☐ Psychological services
- ☐ Other, specify: __________________________

Observations:

Advice Given:

* Mild = Lymphoedema without folds. Can or cannot be reversible overnight, Moderate = Lymphoedema with shallow folds, Severe = Lymphoedema with skin changes (mossy lesions, knobs, and/or deep folds)

**Danger signs include: chest pain, shortness of breath, fever with sweats (outside of an acute attack), unexplained weight loss, infrequent urination, yellowish skin or eyes (jaundice), and rapid onset of swelling.
Example of Individual Follow-up Form for Community Health Workers

The following form serves as an example and should be modified to the local context in order to help health workers track the progress of a lymphoedema patient overtime. At each visit, the health worker should note and document the date of the visit, the number of acute attacks in the past 30 days, and if the patient is appropriately implementing the various recommended measures for lymphoedema management. The worker should assess and note if a referral to the hospital is necessary due to an acute attack, a wound, scrotal swelling, need for psychological services, or for any other reason. Finally, the worker should note any other observations made during the visit or document any advice given to the patient to improve lymphoedema management.

While this form is presented longitudinally, it could be modified to display only one visit per page, such as in booklet or medical chart form. The interval between visits will be determined by the follow-up schedule determined by the standard operating procedures of the local MMDP programme. The data from these forms will allow the worker to track the progress of lymphoedema patients over time as well as count number of visits during the reporting period.

| Patient’s Name:_________________________________________________ | Community Health Worker Name:________________________________________ |
| Age:________ (years) | Health Centre Name:________________________________________________________________ |
| Village: ______________________________________________________ | Year:__________________ |

<table>
<thead>
<tr>
<th>Visit 1</th>
<th>Visit 2</th>
<th>Visit 3</th>
<th>Visit 4</th>
<th>Visit 5</th>
<th>Visit 6</th>
<th>Visit 7</th>
<th>Visit 8</th>
<th>Visit 9</th>
<th>Visit 10</th>
<th>Visit 11</th>
<th>Visit 12</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Follow-up Visit (DD/MM):</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has the patient had an acute attack in the last 30 days?</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
</tr>
<tr>
<td>If yes, how many?</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
</tr>
<tr>
<td>Are the necessary hygiene materials available?</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
</tr>
<tr>
<td>Is the affected area clean?</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
</tr>
<tr>
<td>Are there any wounds or lesions on affected area?</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
</tr>
<tr>
<td>Is the patient washing his/her limbs?</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
</tr>
<tr>
<td>Is the patient doing exercises?</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
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<tr>
<td>---------------------------------</td>
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<td>-------</td>
<td>-------</td>
<td>-------</td>
</tr>
<tr>
<td>Is the patient performing elevation?</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
</tr>
<tr>
<td>Is the patient wearing comfortable shoes?</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
</tr>
<tr>
<td>Referral to the hospital needed?</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
<td>☐ Yes</td>
</tr>
<tr>
<td><strong>If yes, reason for referral</strong></td>
<td>☐ 1=acute attack, 2=wound, 3=scrotal swelling, 4= psychological services, 5= other (specify)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Observations:

Advice Given:
Annex 8: Example Reporting Framework from Communities to the National Level and from the National Level to WHO

The following set of forms serve as an example of MMDP data flow from the community health worker (CHW) to the national programme, through the Health Centre (HC) and Implementation Unit (IU). The length of the reporting period depends on the country programme, however they should be conducted at least annually. Programs are encouraged to integrate reporting where feasible with existing reporting systems for other skin NTDs or health information systems.

Example reporting form from community health worker (CHW) to health centre (HC) (each reporting period)

This form would be completed by each community health worker (if applicable) and submitted to the appropriate health centre. To calculate the number of lymphoedema patients, it is necessary to add the total number of lymphoedema patients from the previous reporting period (Question 1) to the number of new lymphoedema patients identified during the reporting period (Question 2). Similarly, to calculate the number of known hydrocele patients, it is necessary to add the total number of hydrocele patients from the previous reporting period (Question 4) to the number of new hydrocele patients identified during the reporting period (Question 5).

<table>
<thead>
<tr>
<th>Reporting Period:</th>
<th>Name of community health worker:_________________________________</th>
</tr>
</thead>
<tbody>
<tr>
<td>_______ / _______ / ___________   ----    _______ / _______ / ___________</td>
<td>Name of communities where works: ____________________________</td>
</tr>
<tr>
<td>DD                MM                YYYY                                       DD             MM                 YYYY</td>
<td>Name of health centre: ______________________________________</td>
</tr>
</tbody>
</table>

**Lymphoedema**

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Number of lymphoedema patients for which the community health worker is responsible</td>
</tr>
<tr>
<td>2.</td>
<td>Number of new lymphoedema patients identified during reporting period</td>
</tr>
<tr>
<td>3.</td>
<td>Number of patients receiving any lymphoedema/ADL care*</td>
</tr>
</tbody>
</table>

**Scrotal swelling (Hydrocele)**

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.</td>
<td>Total number of known hydrocele patients</td>
</tr>
<tr>
<td>5.</td>
<td>Number of new patients with scrotal swelling (hydrocele) identified during reporting period</td>
</tr>
<tr>
<td>6.</td>
<td>Number of referrals for scrotal swelling (hydrocele)</td>
</tr>
</tbody>
</table>

* **Lymphoedema/ADL care includes**: initial consultation/training, a follow-up visit, a visit for ADL management, a psychological services visit
Example reporting form from health centres (HC) to implementation unit (IU) (each reporting period)

This form would be completed by each health centre that is designated to provide MMDP services and submitted to the appropriate implementation unit authority. This form would include a summary of the data that were submitted to the health facility by community health workers (if applicable). These results summarize the number patients and number of patients receiving care both at the community (if applicable) and at the health facility level. To calculate the number of known lymphoedema patients, it is necessary to add the total number of lymphoedema patients from the previous reporting period (Question 1) to the number of new lymphoedema patients identified during the reporting period from both the community and facility (Question 2). Similarly, to calculate the number of known hydrocele patients, it is necessary to add the total number of hydrocele patients from the previous reporting period (Question 4) to the number of new hydrocele patients identified during the reporting period (Question 5).

<table>
<thead>
<tr>
<th>Reporting Period:</th>
<th>Name of Health Centre:___________________________</th>
</tr>
</thead>
<tbody>
<tr>
<td>DD MM YYYY</td>
<td>Name of Implementation Unit:______________________</td>
</tr>
<tr>
<td>Services available at facility: ☐ Lymphoedema/ADL ☐ Hydrocele</td>
<td></td>
</tr>
</tbody>
</table>

**Lymphoedema**

1. **Total number of known lymphoedema patients**
2. **Number of new lymphoedema patients identified during reporting period**
   a. Community
   b. Facility
   c. Total (community + facility)
3. **Number of patients receiving lymphoedema/ADL care***
   a. Community
   b. Facility
   c. Total (community + facility)

**Hydrocele**

4. **Total number of known hydrocele patients**
5. **Number of new hydrocele patients identified during reporting period**
6. **Number of patients who received hydrocelectomy surgery**
7. **Number of hydrocele patients referred to another facility**

*Lymphoedema/ADL care includes: initial consultation/training, a follow-up visit, a visit for ADL management, a psychological services visit
Example reporting form from implementation unit (IU) to national level (each reporting period)

This form would be completed by each implementation with known lymphoedema or hydrocele patients and submitted to the appropriate national level directly or through a regional level. This form would include a summary of the data by each health centre providing MMDP care.

<table>
<thead>
<tr>
<th>Reporting Period:</th>
<th>Name of implementation unit: ____________________________</th>
</tr>
</thead>
<tbody>
<tr>
<td>DD / MM / YYYY</td>
<td>Total number of health facilities in IU: ___________________</td>
</tr>
<tr>
<td>DD / MM / YYYY</td>
<td>Number of health facilities providing lymphoedema/ADL services in IU: _______</td>
</tr>
<tr>
<td></td>
<td>Number of health facilities providing hydrocele services in IU: __________</td>
</tr>
</tbody>
</table>

**Lymphoedema**

<table>
<thead>
<tr>
<th>Health Centre A</th>
<th>Health Centre B</th>
<th>Health Centre C</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Total number of known lymphoedema patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Number of new lymphoedema patients identified during reporting period</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Number of patients receiving lymphoedema/ADL care*</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Hydrocele**

<table>
<thead>
<tr>
<th>Health Centre A</th>
<th>Health Centre B</th>
<th>Health Centre C</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Total number of known hydrocele patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Number of new hydrocele patients identified during reporting period</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Number of patients who received hydrocelectomy surgery</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Lymphoedema/ADL care includes: initial consultation/training, a follow-up visit, a visit for ADL management, a psychological services visit;*
Example reporting form from national level to GPELF (annually)

The form below is an extraction from the EPIRF form. National programmes should report on MMDP data on an annual basis. See the web annex for further information.

<table>
<thead>
<tr>
<th>Total number of implementation units (IUs)</th>
<th>Lymphoedema/ADL</th>
<th>Hydrocele</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indicator</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of IUs with known patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of IUs with no known patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of IUs with patient estimation pending</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of IUs with at least 1 facility designated to providing care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total number of health facilities providing care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New patients identified in reporting year</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cumulative number of patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of patients who received care* in the reporting year</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Care for lymphoedema includes: initial consultation/training, a follow-up visit, a visit for ADL management, psychological services visit
Care for hydrocele includes: hydrocele surgery