Global Leprosy Strategy 2016–2020

Accelerating towards a leprosy-free world

Operational Manual

World Health Organization

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Abbreviations

A-MDT	accompanied multidrug therapy
BCG	*bacille Calmette-Guérin*
CBO	community-based organization
CBR	community-based rehabilitation
ENAPAL	Ethiopia National Association of People Affected by Leprosy
ENL	*erythema nodosum leprosum*
GLP	Global Leprosy Programme
G1D	grade-1 disability
G2D	grade-2 disability
IDP	internally displaced person
IEC	information, education, communication
ILEP	International Federation of Anti-Leprosy Associations
KAP	knowledge, attitude and practices
MB	multibacillary
MDT	multidrug therapy
MoH	Ministry of Health
M&E	monitoring and evaluation
NCD	noncommunicable disease
NFI	nerve function impairment
NGO	nongovernmental organization
NTD	neglected tropical disease
PB	paucibacillary
PHC	primary health care
SMHF	Sasakawa Memorial Health Foundation
TB	tuberculosis
TLMTI	The Leprosy Mission Trust India
TNF	The Nippon Foundation
UHC	Universal Health Coverage
US$	United States dollar
WHO	World Health Organization

Executive summary

The Global Leprosy Strategy 2016–2020 “Accelerating towards a leprosy-free world” was officially launched on 20 April 2016. The overall goal is to further reduce the burden of leprosy while providing more comprehensive and timely care following the principles of equity and social justice. The purpose of this Operational Manual is to provide guidance for managers of national leprosy programmes (or equivalent entities) to adapt and implement the Global Leprosy Strategy in their own countries.

Leprosy services have been integrated into the general health services in most leprosy-endemic countries; much greater emphasis is given here to the need for an effective referral system, as part of an integrated programme. Good communication between all involved in the case-management of a person affected by leprosy and those disabled due to leprosy is essential. This manual should help managers to choose which activities can be carried out at the primary healthcare level and for which aspects of care for patients will have to be referred. This will depend on the nature of the complication as well as on the capacity of the health services to provide appropriate care at different levels of the health system. The strategy encourages integrated approaches to implement active screening for higher risk groups and to seek wider partnerships with all stakeholders, including with the private-for-profit sector.

It is important to identify and remove barriers that may prevent new cases from coming forward, including stigma and outdate discriminatory legislations. In line with the Global Leprosy Strategy 2016–2020, this manual suggests interventions specifically aimed at reducing stigma and discrimination and promoting the inclusion of persons affected by leprosy.

The provision of multidrug treatment (MDT) has been a continuing success; neither relapse nor drug-resistance is a significant problem, and the regimens are well tolerated. More emphasis, however, is now put on ensuring a global surveillance network to monitor the occurrence of resistance, especially in a context in which many countries have started projects for the use of chemoprophylaxis with rifampicin.

Prevention of disability, self-care practices and rehabilitation have a strong emphasis in this manual as well as an approach with a strong focus on data compilation, monitoring and evidence-based practices supported by research.

The complete monitoring tools to measure progress towards the global targets (including elimination as a public health problem at subnational levels) and quality of leprosy elimination activities will be defined into a dedicated stand-alone monitoring guide.

Overall, this document calls for more action in bringing down the burden of leprosy under the umbrella of a wider partnership involving all actors of the health and social sectors, the private sector, persons affected by leprosy, their families and organizations working on human rights and gender equality.

Global Leprosy Strategy at a glance

2016-2020
GLOBAL LEPROSY STRATEGY

- Zero disease
- Zero transmission of leprosy infection
- Zero disability due to leprosy
- Zero stigma and discrimination

Further reduce the global and local leprosy burden

INDICATORS	2020 target
Number of children diagnosed with leprosy and visible deformities	0
Rate of newly diagnosed leprosy patients with visible deformities	<1 per million
Number of countries with legislation allowing discrimination on basis of leprosy	0

PILLARS AND COMPONENTS

1. Strengthen government ownership, coordination and partnership

- Ensuring political commitment and adequate resources for leprosy programmes.
- Contributing to universal health coverage with a special focus on children, women and underserved populations including migrants and displaced people.
- Promoting partnerships with state and non-state actors and promote intersectoral collaboration and partnerships at the international level and within countries.
- Facilitating and conducting basic and operational research in all aspects of leprosy and maximize the evidence base to inform policies, strategies and activities.
- Strengthening surveillance and health information systems for programme monitoring and evaluation (including geographical information systems)

2. Stop leprosy and its complications

- Strengthening patient and community awareness on leprosy.
- Promoting early case detection through active case-finding (e.g. campaigns) in areas of higher endemicity and contact management.
- Ensuring prompt start and adherence to treatment, including working towards improved treatment regimens.
- Improving prevention and management of disabilities.
- Strengthening surveillance for antimicrobial resistance including laboratory network.
- Promoting innovative approaches for training, referrals and sustaining expertise in leprosy such eHealth.
- Promoting interventions for the prevention of infection and disease.

3. Stop discrimination and promote inclusion

- Promoting societal inclusion through addressing all forms of discrimination and stigma.
- Empowering persons affected by leprosy and strengthen their capacity to participate actively in leprosy services.
- Involving communities in actions for improvement of leprosy services.
- Promoting coalition-building among persons affected by leprosy and encourage the integration of these coalitions and or their members with other community-based organizations.
- Promoting access to social and financial support services, e.g. to facilitate income generation, for persons affected by leprosy and their families.
- Supporting community-based rehabilitation for people with leprosy-related disabilities.
- Working towards abolishing discriminatory laws and promote policies facilitating inclusion of persons affected by leprosy.

Introduction 1

1.1 Purpose of the Operational Manual

The Operational Manual is a companion document to the "Global Leprosy Strategy 2016–2020, Accelerating towards a leprosy free-world", which went through an extensive process of review and revisions based on suggestions from a wide range of experts, national programme managers and partners. While the strategy presents an overview of the ethics and guiding principles, the Operational Manual provides suggestions for the implementation of activities adapted to local settings.

Following the publication of this manual, a stand-alone guide on how to monitor the strategy's implementation and, in general, leprosy programmes activities will be produced.

This Operational Manual has two important functions:

- To define and explain targets, terms, concepts and activities mentioned in the Global Leprosy Strategy; and
- To provide guidance on how the Global Leprosy Strategy can be implemented in the context of a national programme.

The manual also indicates the scope for global and regional interventions.

Because of its global scope, the Operational Manual remains a generic guidance document and may not necessarily give country-tailored direction and guidance on every aspect of leprosy elimination. However, it is intended that national programme managers should be able to adapt suggested actions to their countries' realities.

1.2 Target audience

The target audience consists of managers of health services at national and intermediate levels responsible for leprosy elimination activities in their countries or areas, who will be required to implement the Global Leprosy Strategy 2016–2020. The Operational Manual is also useful for public health officers and experts providing technical assistance or involved in monitoring and programme evaluation to better understand the Global Leprosy Strategy 2016–2020 and to more effectively support countries in its implementation. The Operational Manual is also intended for use by national and external monitors and for supervisors of leprosy services.

1.3 Implementation in different health systems and epidemiological contexts

For each pillar of the Global Leprosy Strategy 2016–2020 guidance will be provided on how the key areas of interventions could be implemented according to the local priorities. Approaches used in each country to implement them might vary. Examples on good practices are provided, as suggestions only, since each country needs to base its actions upon the availability of local resources and to the prevailing situation.

In previous strategies countries were classified based on absolute disease burden (absolute number of new cases) only in three groups: group A (>10 000 cases), group B (1000–10 000 cases) and group C (<1000 cases). With the renewed focus on cutting the transmission and realizing the wide epidemiological variety within high-burden countries, it was felt that other criteria should also be considered for classifying countries. Therefore, the following indicators were used to rate countries globally: prevalence, case detection, case detection rate, percentage of children among newly diagnosed cases (as proxy for ongoing transmission), percentage of G2D among newly diagnosed cases (as proxy for late case finding and thus ongoing transmission) and G2D rate per million cases. A composite score has therefore been determined in the following way: for each co-indicator, a score from 0–5 was given to each country and a weightage was given to each co-indicator in the final score. Latest available data were used (2014 for most countries). Countries were then ranked according to composite score. Based on this, the 22 countries shown in Table 1 (in alphabetical order) are considered as having a higher absolute or relative leprosy burden and, therefore, are further prioritized.

Table 1: *Global list of 22 high-burden countries for leprosy*

Angola	Kiribati
Bangladesh	Madagascar
Brazil	Mozambique
Comoros	Myanmar
Côte d'Ivoire	Nepal
Democratic Republic of Congo	Nigeria
Egypt	Philippines
Ethiopia	South Sudan
Federated States of Micronesia	Sri Lanka
India	Sudan
Indonesia	United Republic of Tanzania

WHO regions can identify additional countries to be prioritized within their region in order to ensure adequate support. For this, additional epidemiological and socioeconomical parameters relevant for the Region can be used.

Each country would require epidemiological assessments to be done since leprosy tends to be more endemic in specific geographical areas in each country. Additionally, programmes might observe high proportion of cases with G2D disabilities in areas where the health system is weak and the access to services is limited. Some aspects, such as quality of care reflected, for example, in treatment completion rate can also be considered to prioritize and target activities in specific areas/regions/districts/subdistricts.

Some of the key areas of intervention will have more or less relevance according to the epidemiological context, and this will be specified in the correspondent section of these guidelines. For instance, in areas where the number of persons with leprosy-related disabilities is high, more service will need to be provided for disability management. Analysis of hard-to-reach areas and/or identification of vulnerable groups, for example migrants, would guide national planning since cultural and geographical challenges might require specific approaches, such as active screening campaigns in order to ensure that leprosy patients are detected and treated.

This baseline analysis of epidemiological data versus available services shall form the basis for each country and state/regional managers will decide which actions are more relevant among the ones listed under the three pillars of the strategy. Partners and stakeholders are encouraged to support countries to carry out this exercise as a first step to prepare national operational plans and to look for funding support.

Actions meant to be carried out with the intention to lead to global impact or with impact on entire regions of the world are proposed as "global and regional actions" in the following sessions of this manual. All the other actions proposed are meant to be implemented in countries at national or sub-national levels, according to epidemiological and health system-related considerations.

1.4 What does it mean to "reduce the burden due to leprosy"?

The goal of the Global Leprosy Strategy 2016–2020 is to reduce the burden of leprosy by 2020. However, the "burden of leprosy" can be viewed from at least two perspectives.

First, the most relevant epidemiological measure of the burden of leprosy is the number of new cases detected, defined as the number of people diagnosed with leprosy during a defined period of time, usually one year, in a specific population. Because incidence of leprosy is difficult to measure, new case detection rate is used as a proxy indicator for incidence rate.

The global case detection rate, defined as the notification rate per 100 000 population, seems to be declining slowly. In many areas it remains static and in a few places this rate seems to even increase. Changes in detection rate happen slowly, over decades, due to the long incubation period of the disease. They are related to factors such as BCG vaccination coverage, socioeconomic development and good leprosy programmes' practices, especially early diagnosis. New cases will continue to appear for many years, emanating from the pool of already infected people who are in incubation. Thus, diagnostic and treatment services as well as disability prevention and rehabilitation services need to be maintained.

The burden may also be measured as prevalence of the disease, which is defined as the number of people on treatment at a given point in time (point prevalence). The registered prevalence is much affected by the number of new cases diagnosed and treated as well as by the duration of treatment.

Second, the burden may be considered from the viewpoint of people affected by leprosy, especially those affected by disabilities, who may suffer the problems arising from social rejection. Leprosy can lead to disability of the hands, feet and eyes and sometimes also to blindness. It is estimated that more than 3 million people are living with disabilities due to leprosy. Much of these disabilities could have been prevented. The Global Leprosy Strategy 2016–2020 calls for increased efforts to address this "burden" by reducing the number of new cases presenting with disabilities through early detection and by improving the management of acute and chronic complications due to leprosy reactions, promoting self-care support activities and rehabilitation and reconstructive surgery.

Along with physical consequences, leprosy tends to generate enormous psychological and social suffering, which is also a "burden" often resulting from stigma and discrimination. This Operational Manual advocates for a person-centred holistic approach, which takes into account the social and psychological suffering of each affected person and indicates examples of activities that could be implemented to fight stigma and discrimination wherever they exists.

1.5 Quality leprosy services

The Global Leprosy Strategy 2016–2020 emphasizes the quality of leprosy services as an essential and integral component of an effective health programme. Quality is based on appropriate training of staff at every level, regular technical supervision and knowledge/installed capacity to report and monitor key indicators. The pursuit of quality assumes the willingness of staff to make changes aimed at improving their skills and the functioning of the health services in which they work.

Quality leprosy services are as follows.

- **Accessible** to all who need diagnosis and treatment without geographical, economic or gender barriers.
- **Prompt in identifying and managing reactions** and other complications.
- **Patient-centred** and observant of patient's rights, including the rights to timely and appropriate treatment and to privacy and confidentiality. The system needs to be

flexible to patient's needs and also able to provide "accompanied MDT" (A-MDT), when indicated, to facilitate adherence.

- **Aimed at empowering patients and their families** through appropriate dissemination of information about the disease and its consequences, the patient's role in care and the service provision, including for rehabilitation.
- **Ensuring information provision** to patients and their family on disease and present them various treatment options, inform about possible reactions and rehabilitation services and emphasize the need for contact examination.
- **Addressing each aspect of case management**, based on solid scientific evidence:
  - **Diagnosis** is timely and accurate, with supportive counselling;
  - **Treatment** with MDT is timely, free-of-charge and user-friendly;
  - **Prevention of disability** interventions are carried out appropriately and timely;
  - Services for complications and **rehabilitation,** including reconstructive surgery, are provided as needed;
  - Facilitate access to patients and their families to **psychological and socioeconomical support,** in order to guarantee the regularity of treatment and cure and to facilitate social inclusion.
- **Consider patients, cured patients and their families as resources** for the health system.
- **Stigma-free** with regard to attitude of health-care workers towards persons with signs and symptoms of leprosy or persons diagnosed with leprosy.

1.6 Health system considerations

Effective leprosy control requires an integrated approach, which provides wider equity and accessibility, improved cost-effectiveness and long-term sustainability. This implies that leprosy elimination activities should be implemented by the general health services, including integrated referral facilities. Integration not only improves accessibility to treatment, but also reduces the stigma and discrimination faced by persons affected by leprosy.

In defining leprosy programme needs, the context of their integration should not be forgotten. Integration means that day-to-day patient management and recording and reporting become the responsibility of general health staff. However, under an integrated system, specialized services need to be guaranteed. A system should be in place for the referral of difficult or complicated cases to hospitals or specialists (e.g. general medical officers with some additional training in leprosy, dermatologists or surgeons) and referral by specialists back to the peripheral health facilities for continuation of treatment. The specialized referral services for leprosy are part of the general health services, just like a surgeon in a district hospital is part of the general health services.

Depending on local conditions (e.g. availability and level of training of various categories of health staff and the burden of the disease), each country or area must decide at which level of the health system such specialist expertise should be made available. In settings where leprosy is endemic, peripheral general health workers should be capable of diagnosing and treating uncomplicated leprosy cases that represent the majority of the cases and know where to find specialized health services. They should also develop linkages with nongovernmental organizations (NGOs) and other partners (social movement, e.g. patients' representative, other government sector, e.g. education, medical specialist societies, religious leaders) for medical and/or socioeconomical interventions.

All peripheral health staff should know the clinics and health staff to whom they will refer patients so that they can advise their patients accordingly in order to minimize their difficulties. A directory of specialized services/sites and specialist service shall be available. Staff at all levels shall be able to seek specialized advice via telemedicine or through a centre of excellence to ensure that patients are provided needed care. Good communication between peripheral level and referral centre health-care workers should be maintained to allow discussion of patients' progress and as an opportunity for further training. The convenience of mobile phones and text messaging can make this easy and timely.

Among the most urgent events requiring prompt referral are severe reactions, the most frequent of which are listed below:

- Severe reversal reactions, especially if overlying a major nerve trunk;
- Neuritis, including silent neuritis;
- Erythema nodosum leprosum (ENL) reactions;
- Severe infection of the hand or foot (usually related to an ulcer with foul-smelling discharge); the hand or foot will be hot, red, swollen and painful;
- Eye involvement in leprosy. Four specific problems that need urgent referral are (1) recent loss of visual acuity; (2) painful red eye; (3) recent inability to close the eye (lagophthalmos); and (4) reaction in a leprosy skin patch on the face.

Other cases that might require urgent referral are patients with severe adverse drug reactions or with discharging ulcers/burns. Sometimes the peripheral health-care worker might need to refer patients to confirm an uncertain diagnosis. This is also considered an urgent referral since treatment of leprosy need to be started as soon as possible to stop transmission and avoid complications. Where leprosy is relatively less common, the ability to suspect leprosy and refer the patient to a referral unit is the most important skill required for peripheral general health workers. Confirmation of diagnosis can be done by specialized referral centres that must also have drugs available for treatment initiation and have the capacity for initial follow-up. Care should be taken for proper referral back and forth, so as not to lose track of leprosy suspects and cases.

Continuation of treatment could be delegated to the peripheral health facility serving the community in which the patient resides, after adequate orientation has been provided by the referral centre on possible side effects and to ensure timely identification of reactions. Referral centres will treat the difficult complications of leprosy. Provision of rehabilitative surgical services will be even more centralized. Some referral services may also be provided through mobile units.

There are several community-based organizations (CBOs), NGOs and private institutions providing a range of leprosy services close to the community. Networking with those institutions along with referral centres, medical colleges and dermatologists is key to ensure a comprehensive, patient-tailored care. These nongovernmental institutes can be highly effective focal centres for basic as well as specialized services and interventions. Their activities can be well coordinated within national programmes, thereby saving resources while ensuring service provision.

It is important to develop linkages with other sectors, public and private, and within the community, including with organizations and self-help groups of persons affected by leprosy to facilitate access to care and to ensure high-quality leprosy services. For countries with relative high burden of the disease, national coalitions of stakeholders contributing to leprosy services could help to raise funds, ensuring awareness and creating demand for quality services.

In some countries, there is still a "vertical" structure to manage leprosy programmes either per se or within joint tuberculosis/leprosy programmes or under Neglected Tropical Diseases (NTD) programmes. Usually those programmes have administrative/managerial focal points at the various administrative levels of the health services, while the first point of entry to care remains with the primary healthcare network that provides integrated service for communicable and noncommunicable diseases. In such context, coordination between the levels of care must ensure proper management of MDT and ancillary drugs to manage reactions, provide refresher training and supportive supervision of field workers, enhance the quality of referral services and monitor the availability of quality data to assess the progress of programme implementation. In areas where such resources are not available, at least a single central level unit shall be made responsible for leprosy control and shall take charge in order to ensure capacity to detect, treat and report leprosy accurately in at least one centre in the country and to facilitate access to care for all cases.

I. Strengthen government ownership, coordination and partnership

2

Ultimately the responsibility to control and eliminate leprosy lies with the national authorities of each country. Partners and other stakeholders can play a supportive role to sustain and enhance political commitment. Following the declaration of leprosy elimination, almost all countries have experienced reduced resources for carrying out leprosy activities. The lack of funding might also have contributed to late detection, resulting in the globally observed increasing rate of patients already disabled at the time of the diagnosis. One of the reasons for delay is the loss of expertise but also the lack of structured involvement of the private sector, including private-for-profit and informal private sectors that are very important in Asia and Africa.

The Bangkok Declaration signed in 2013 by the ministers of health of the countries with the highest burden of leprosy with the support of The Nippon Foundation has to some extent again raised the momentum. In a context where leprosy becomes a rare disease (especially compared with previous decades) and with competing priorities due to other communicable diseases and noncommunicable diseases programmes, tackling leprosy is becoming more challenging.

There are also opportunities to revitalize action for leprosy elimination, such as the possibility to effectively work under the NTD umbrella and/or integrated service delivery with better funded programmes (e.g. tuberculosis [TB]). To work beyond the traditional partnerships for leprosy might also bring new opportunities looking at organizations involved in the areas of disabilities and social development. Even within traditional leprosy partnerships (including leprosy NGOs and research institutions), coordination can be further improved to avoid duplication of efforts and deliver services more effectively. Funds for coordination and partnerships are low, while in the modern world there is an increasing need for specific competencies to develop tools and online platforms for coordination. This pillar of the strategy focuses on political commitment, including for sustaining efforts for effective national plans keeping in mind the importance of universal health coverage (UHC) and involvement of the private sector and pushes for a wider partnership, especially for research and monitoring and evaluation (M&E). Surveillance and supervision need to be sustained, including in regions with very few cases (e.g. Eastern Mediterranean and European Regions) and in all the countries reporting very few cases. Adequate resources and strong political will, along with partnerships and better coordination in key areas (including research), represent the foundation to enable effective activities listed under pillars two and three of the strategy. For this reason, this first pillar is a cross-cutting pillar. It is, therefore, corresponding to the frame of bicycle in the strategy logo.

2.1 Political commitment and adequate resources

Ministries of health should continue leading the overall national leprosy response, as elaborated in a national leprosy plan or part of a wider national NTD plan or TB/leprosy plan, depending on the structure of the national leprosy programme. Under this government ownership, more regulatory approaches should be employed to support elimination efforts, including mandatory disease notification, while ensuring privacy of single patients' data, strong and harmonized drug regulatory policies and standards of care, including through public–private approaches.

Scaling up and sustaining interventions for detection, care and prevention requires high-level political commitment indicated by good planning and adequate financial and human resources. A National Plan, embedded in or linked to a national health sector plan, is a key instrument for managing programmes effectively. It is crucial that stakeholders and partners are fully engaged in the development of such plan, that national efforts are supported, and that any assistance is in harmony with national and global objectives and targets.

The Global Leprosy Strategy 2016–2020 includes a call for action beyond the health sector and pushes for research, innovation and operationalization of new interventions. These changes will be possible only if adequate funding is secured. Therefore, national plans must be costed and budget sources (and gaps) identified. Such costed plans will facilitate resource mobilization from international and national sources, including private sector ones.

Engaging patients, families and communities in programme planning and service delivery will not only increase community awareness, but also nurture an enabling environment for patients and families, and potentially lead to a bold community-supported response.

In-depth epidemiological analysis, internal field monitoring and evaluation, external programme reviews, and stakeholder consultations significantly helped countries to assess the epidemiological and programmatic situation, determine gaps, identify new goals and objectives, and define strategic directions and interventions.

In a context in which domestic investment for leprosy is dwindling, innovative approaches liaising/piggy-backing on other programmes' funding and/or in liaising with external partners could be used to promote more effective implementation of the action plans. This is already happening in several countries, but it requires a more structured approach through the development of strategic and operational plans with the support of old and new stakeholders and with the aim to deliver quality services and improve the overall national/local health systems.

Proposed actions in high-burden settings

(1) Review and update national leprosy plans through (a) sound epidemiological external reviews; (b) optimal use of regular internal monitoring and evaluation; (c) wider stakeholder consultations, including key affected communities; and (d) strengthening the routine monitoring and the information systems.

(2) Aim for maximum efficiency gains through (a) alignment of planning with the overall health sector planning framework; (b) collaboration across public health programmes to promote joint planning and share programmatic policies and strategies; and (c) improve coordination of external technical assistance.

(3) Secure adequate funds through resource mobilization from diverse international and national sources by using a well-budgeted national comprehensive plan.

Proposed actions in low-burden settings

(1) Ensure that leprosy is included in national communicable diseases/NTD plans and that activities are based upon (a) sound epidemiological review with a focus on high-risk groups; (b) collaboration across public health programmes and involving the social sector to promote joint planning and share programmatic policies and strategies; (c) coordination with national or other institutions that provide technical assistance at national and/or regional levels to ensure continuity of care/referral services.

In Liberia, the Ministry of Health has developed in June 2016, with technical support from Effect: Hope and others as well as nongovernmental country stakeholders, its first national strategic plan for integrated case management NTDs, focusing on Buruli ulcer, leprosy, yaws and complications of lymphatic filariasis. The inclusion of a strategy focusing on integration within NTD programmes will contribute to retain staff with expertise in this area, while garnering a higher commitment in this area, than the one achieved by each programme individually. It will result in a better inclusion at all levels of service (primary, secondary and tertiary care levels).

Afghanistan is a low-burden country; in 2015, only 42 new cases of leprosy were detected. As cases occur sporadically, leprosy planning and case finding activities rely on partnerships established with other public health programmes, with the aim of strengthening the “leprosy network”, that includes all the health personnel who are able to suspect, diagnose and manage or refer leprosy cases. In this way, the efficiency of the programme is maintained high, by keeping only a few dedicated leprosy clinics open while widening accessibility to these “specialized” clinics. In 2009, a collaboration with the TB programme started through extensive capacity-building of TB staff, counting on a wide network of over 1400 TB service centres throughout the country. Refresher courses and capacity-building activities are regularly held and, in addition to dermatologists, they also target physicians, nurses, leishmania programme staff, and other health workers, with a focus on the areas where most cases of leprosy are reported from. As a result, in the last 6 years the leprosy programme has observed a consistent reduction of paediatric cases and a decrease in the proportion of new cases with G2D. In the most affected areas, active case-finding activities are also embedded into other public-health services, thus allowing detection of hidden leprosy cases in an early stage of the disease.

2.2 Contributing to Universal Health Coverage with a special focus on children, women and underserved populations

The goal of UHC is to ensure that all people obtain the health services they need without suffering financial hardship. This requires a strong, efficient, well-run health system with a system for financing health services, access to essential medicines and technologies and sufficient capacity of well-trained motivated health workers. Universal coverage is firmly based on the WHO constitution of 1948 declaring health a fundamental human right and on the Health for All agenda set by the Alma-Ata Declaration in 1978. Equity is paramount to ensure UHC; for this reason, countries need to track progress not just across the national population but within different groups (e.g. by income level, gender, age, place of residence, migrant status and ethnic origin). UHC can only be achieved through adequate, fair and sustainable financing for quality-assured health services with progressive and equitable population coverage. The global thrust towards UHC presents great opportunities to advance on leprosy control and reduction of transmission since it envisions all people having access to quality health services without any obstacle considering that leprosy patients very often belong to vulnerable/marginalized groups and/or to underserved populations.

The underserved populations refer to groups of people who live in specific geographic areas (forests, riverbanks, deserts, mountains) or have special characteristic that denies them opportunity for access (e.g. tribal, nomadic population, immigrants, internally displaced due to war, civil disturbance, social unrest, economic or climatic crisis) or live in special facilities (e.g. prisons) or marginalized population within big urban areas (e.g. slum dwellers). These groups may face difficulties in obtaining adequate health care because of poor health infrastructure, lack of information or because of discrimination they experience due to their social, political, cultural and economic background or because of limited transportation facilities.

Other groups that might have restricted access to care are women and children, especially in areas where leprosy-associated stigma and discrimination are high. With the focus of the Global Leprosy Strategy 2016–2020 on children, more detailed collection of data and information on paediatric cases has become even of greater importance. The strategy also calls for collection of indicators disaggregated by sex in order to allow analysis of access by women and also of quality of care provided to women.

Proposed actions in high-burden settings

(1) Analyse the current national leprosy control structure and systems in terms of functions for control, service providers, funding flows and payment mechanisms in order to identify policy options for sustainable financing for leprosy control and care.

(2) Identify core essential functions for leprosy control that should be retained in the public sector as "non-negotiable" functions to secure leprosy control as a public good for health.

(3) Identify nationally appropriate methodologies and periodically measure patient financial burden due to leprosy and ensure that treatment is provided for free to all patients.

(4) Modify the health information system in order to capture information on vulnerable groups and to have data by age and sex.

(5) Coordinate with programmes working to provide health care to such groups to ensure access to diagnosis, treatment and prevention/management of disabilities.

(6) Involve community leaders and persons affected by leprosy belonging to vulnerable groups in planning and decision-making.

(7) Introduce convenient service hours to increase accessibility to services and be sensitive to local cultures, use of interpreters and translators and, where possible, encourage recruitment of staff from local area to ensure access for vulnerable groups.

(8) Ensure adequate supply of MDT and ancillary drugs and materials.

Proposed actions in low-burden settings

(1) Assess if the few cases of leprosy reported belong to vulnerable groups.

(2) Design projects to target active screening for leprosy among high-risk groups/population and to implement preventive measures.

(3) Coordinate with programmes/institutions working to provide health care to such groups to ensure access to diagnosis, treatment and prevention/management of disabilities.

(4) Ensure adequate supply of MDT and supportive drugs and materials.

Somalia has been afflicted by conflicts for more than 20 years, resulting in limited access to some regions and significant displacement and relocation of population within its borders, notably from southern and central Somalia; the areas where most leprosy patients usually come from are Banadir and greater Mogadishu.

In 2015, in spite of major financial constraints and with support from WHO, the Ministry of Health's NTD programme has intensified its actions to ensure a restart of leprosy elimination activities in eight priority regions in southern and central Somalia that have recently become accessible. This was done by strengthening the leprosy network through refresher courses for local nurses and community health workers. The aim was to ensure that they are able to suspect, diagnose and treat leprosy, provide counselling to patients, compile reports and sensitize communities, including underserved groups such as nomadic populations. In dealing with communities, tackling stigma is crucial to avoid social exclusion of old cases and encourage self-reporting of new cases.

In addition, attention has been dedicated to internally displaced persons (IDPs), by organizing community awareness activities and free dermatological screening and counselling ("skin camps") in 17 IDP camps located around Mogadishu and elsewhere. Widening community health screening to all skin conditions not only offers a better service to the population, but also reduces the emotional focus on leprosy thus facilitating self-reporting.

Thanks to these renewed efforts, 107 new cases of leprosy were detected in Somalia in 2015, compared to only 14 in 2014.

2.3 Partnerships and intersectoral collaboration

Partnerships have always played an important role in leprosy control. The World Health Organization (WHO) and national and international NGOs and institutions, such as TNF and the Sasakawa Memorial Health Foundation (SMHF), provide a significant supportive function in partnership with national governments. Among the current NGOs involved, the members of the International Federation of Anti-Leprosy Associations (ILEP) play a prominent role while other institutions, such as the Novartis Foundation for Sustainable Development and other non-ILEP NGOs (e.g. ANESVAD, Effect:Hope, Pacific Leprosy Foundation) also provide support in various regions of the world. Novartis has been donating medicines free-of-charge and is committed to do so till at least 2020.

A partnership can be defined as 'Inter-organizational relationship involving activities aimed at achieving shared goals based upon close working relationships'. There are more definitions of partnership but they usually include these common themes: commitment to shared objectives; mutuality, equality and open dialogue; a sense of trust and respect between the partners; and reciprocal obligations and accountability. Partnership does not mean that partners should agree on all aspects, but implies that there is a willingness on both sides to 'give and take' so as to reach consensus. Hence, partnerships will be most effective when the objectives are clearly expressed and agreed by all partners, the role of each partner is agreed and acknowledged and activities and challenges are widely discussed and negotiated.

Globally but especially in the WHO South-East Asia Regions (which bears the biggest part of the leprosy burden worldwide), people seek health care in the growing private health sector. Evidence suggests that despite the availability of free-of-charge treatment within primary health care, a significant number of patients report leprosy signs and symptoms at first to private providers or tertiary level hospitals. Therefore to aim reaching the strategy targets on early detection, an assessment of patients' access to care must be performed and alliances shall be set up with the private sector. Additionally, leprosy diagnosis sometimes requires specialist consultations and so does the management of reactions; therefore, coordination in the form of partnership shall be sought with specialized centres, whether public or private, outside the primary healthcare government network. Last but not least, persons affected by leprosy with grades 1 and 2 disabilities often require lifelong protective tools to prevent further disability to occur and for reconstructive surgery and in order to ensure access to those services also partnerships with private for profit and not-for-profit shall be explored.

Beside partnerships built to ensure access to services, partnerships with organizations facilitating access to social care for patients and for community rehabilitation services shall be developed at national level as well as the building of national coalitions to ensure coordination, to raise awareness and to contribute advocating for more resources for leprosy control, per se or under other national coalition/umbrellas for NTD, TB or disabilities. The government, particularly the Ministry of Health (MoH), is the owner of the programme, and should coordinate national and international donor support to the country. Effective donor coordination is an important requirement for a consistent and uniform implementation of the programme activities throughout the country. All partners should know how their resources are utilized, and should therefore be involved in the planning and evaluation process. It is necessary that the MoH and its partners, including WHO and ILEP members, reach consensus on the implementation of the Strategy, long-term planning and annual plans of action and budgets. This will be greatly helped by organizing joint programme reviews by the MoH and all partners. A robust response to end leprosy and act on the current cases' stagnation will require establishing lasting partnerships across the health and social sectors and between the health sector and communities.

Proposed actions at global and regional level

(1) Sustain and enhance current partnerships at global level for leprosy promoting actions and set up mechanisms to improve coordination between partners like global platforms and/or global alliances.

(2) Set up regional partnerships with regional or interregional institutions to provide support to countries with low burden, which are still in need of managing cases (i.e. regional training centres, remote help desks, research medical and laboratory institutions, regional rehabilitations hubs).

(3) Generate evidence on involvement of the private providers in leprosy care and promote implementation research to encourage their involvement through structure partnerships and collaboration.

Proposed actions in high-burden settings

(1) Set up coalitions against leprosy with all stakeholders to raise awareness and to improve coordination.

(2) Engage civil society organizations, community representatives, patients and families in planning, service delivery and monitoring, as well as in information and education activities, support to patients and their families, research and advocacy.

(3) Ensure that affected populations are meaningfully represented in the venues to discuss national response and relevant bodies at national and local levels.

Proposed actions in low-burden settings

(1) Create formal links with national and regional institutions that provide high-quality care for leprosy to ensure diagnosis and management of patients during and after treatment.

(2) Include leprosy into existing national health coalitions for communicable disease control or on noncommunicable diseases/ disabilities to raise awareness and ensure some funding for coordination, surveillance and care.

2.4 Research maximizing the evidence base to inform policies, strategies and activities

Considering that the agent causative of leprosy has been discovered in the year 1873 by Dr Armauer Hansen (hence leprosy is also known as Hansen's Disease), still a great amount of information with regard to transmission and pathogenesis remains unknown. To date it has not been possible to cultivate the organism in the laboratory.

Disabilities that often mark the life of the patients in spite of the medical treatment are consequences of immunological mechanisms that are only marginally understood. Even if the access to antibiotic treatment is wide and free of charge, access to treatment for reactions is partial and the effect of those drugs is not a full halt of the reactions.

The implementation of effective preventive measures for leprosy still need more evidence and the implementation of research in the field of the social aspects of leprosy is still limited.

In **Nepal,** a national platform for leprosy was formed since 1990. It is chaired by the NLP Manager with the aim of coordinating activities carried out by different stakeholders and to ensure alignment with the national programme policies and scopes. The national programme calls for periodical regular meetings, which have ensured a coordinated and more effective approach while providing leprosy services.

However, for a disease that targets elimination at national and subnational levels and ultimately eradication, far more investments are needed into the following research areas: (1) transmission; (2) diagnosis (of infection and of disease); (3) identification and treatment of reactions; (4) social integration; (5) prevention; and (6) alternative chemotherapies. Unfortunately, health research is often underfunded, which poses a significant bottleneck in increasing health research activities and strengthening capacity. All of the mentioned actions, especially with a comprehensive research strategic plan, including an effective collaborative mechanism, unified research priorities and a strategic capacity-building plan, would attract funding from both domestic and international sources. While allocating an appropriate proportion of funding to operational research continues to be important, the focus should be on mobilizing more resources for research activities by governments or by partners.

At the global level, leprosy has in the past benefitted of large scale research studies thanks to the support of Tropical Diseases Research[1]/WHO. However, this support has become negligible in terms of funding in the last

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[1] TDR: the Special Programme for Research and Training in Tropical Diseases is a global programme of scientific collaboration that helps facilitate, support and influence efforts to combat diseases of poverty. It is hosted at the World Health Organization (WHO), and is sponsored by the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the World Bank and WHO.

10 years. On the other hand, the Leprosy Research Initiative, which was launched in 2013, has provided to date US$ 4 million. There is a need to disseminate results of those studies widely. There is also a need to generate more funding for basic biological research. Different institutes conduct leprosy research in different parts of the world but coordination with national programmes or between them is limited. Therefore, there is the need for a global platform to set up priorities and to act as venue of scientists interested in doing research in this area.

Setting national research priorities is important to align all partners' efforts, avoid duplication and mobilize resources for research. The national research priorities should be developed in collaboration with all partners in the national research network, while maintaining the appropriate balance between types and broad topics of research. They should be periodically updated as a living document and fed into the update of the national, regional and global research plans.

An area of interest in research is definitely the area of preventive tools like post-exposure prophylaxis with rifampicin and/or BCG vaccine. While the efficacy of provision of rifampicin to contacts of leprosy patients has been proven, feasibility studies and implementation research results are currently being carried out by multi-country studies. Those results might be able to guide programmes on how to use the available tools and on how to monitor the impact of such activities.

Proposed actions at global and regional level

(1) Increase resources for research through diversified funding sources.

(2) Coordinate leprosy research through a global platform, which can also be used as a global forum for dissemination of information.

(3) Identify global and regional research centres to ensure that the leprosy research priorities are translated into studies to improve its control.

(4) Analyse the results and contributions of the research conducted aiming at incorporation of new technologies and strategies in services, when appropriate.

Proposed actions in all settings

(1) Establish national research priorities (national research agenda).

(2) Plan and implement strategic capacity-building activities to increase human resources for leprosy health research.

Proposed actions in low-burden settings

(1) Establish a link with regional and global centres to ensure the carry out of regional studies.

(2) Facilitate availability of access to latest international evidence in relation to leprosy.

The **Leprosy Research Initiative** was launched at the International Leprosy Congress in 2013 to promote, fund and facilitate high-quality leprosy research, to strengthen research capacity in endemic countries and to facilitate translation of research results into policy and practice. The LRI has five priorities for research: early detection of leprosy; prevention, early detection and effective treatment of nerve function impairment (NFI) and reactions; inclusion of persons affected by leprosy in society; prevention of disability activities and their integration in national programmes and integrated wound and limb care programmes; and test methods and tools to interrupt the transmission and incidence of leprosy, including increasing the coverage of effective contact management and chemoprophylaxis. Over 20 projects have been supported to the sum of around €5 million. More information can be found on the LRI website: http://www.leprosyresearch.org/

2.5 Surveillance, health information systems and programme monitoring

The basis of good surveillance relies on good quality data – hence the focus given into the Global Leprosy Strategy 2016–2020 on strengthening health information systems. The information system used shall allow analysis of data by geographical areas and vulnerable groups. This is fundamental to assess the epidemiology of the disease and to plan activities targeted to different areas/settings.

An ideal health information system shall be case-based and allow reporting by all service providers, including private providers involved in leprosy programmes and submit disaggregated data by geographical area, sex, age, country of origin, living city/rural and allow an analysis of risk factors/vulnerable groups for leprosy. Otherwise, aggregated data formats should ensure a recording and reporting of detection and of outcomes. Ideally it shall also facilitate drug management, contact screening and record leprosy-related disabilities. It shall be preferably on a central data repository accessed via web-interface by relevant service providers; otherwise, standalone field repository with national level aggregation and regular exchange. Data entry shall be done at the level where there is enough capacity, resources and motivation to ensure timely and effective data entry. Data quality systems shall be put in place to minimize mistakes and to ensure good data to inform policy-makers. Interoperability (interfaces/compatibility) between available data repository should be promoted to avoid duplication of efforts such as vital registration systems, electronic health records systems, social records systems and other as relevant.

Proposed actions at global level

(1) Strengthen the global surveillance and response monitoring system, by engaging regional offices in facilitating countries' data collection to a global repository (web-based data collection via country surveillance focal points).

(2) Support the development of a new or promote the adaptation of an existing generic sound health information system with interoperable functions for free use at country level and contribute to expand its use. Promote an integrated system within existing platforms for NTDs and communicable diseases.

(3) Support monitoring through training of monitors and support of countries' monitoring and evaluation activities.

Proposed actions in all settings

(1) Ensure quality reporting of leprosy cases by all providers.

(2) Develop a health information system either for leprosy or as integrated system for communicable diseases/other NTDs.

(3) Ensure availability of data to allow assessing groups at risk of leprosy and monitor imported cases and paediatric cases closely to monitor achievement of interruption of transmission.

(4) Monitor the programme through impact, outcomes and process core indicators and take action on the basis of the results of the monitoring.

The **WHO Regional Office for the Western Pacific** has utilized the open platform known as DHIS2 to collect and store regional country data since 2011. Each national programme manager is given a password and he/she can login with his/her email address. Annually data are submitted and are "stored" also for the country use as data repository for countries with no electronic data system. With the decrease of leprosy burden, potentially the system can be modified to include also subnational data and identify hot spots for the disease. The WHO Regional Office for Africa is promoting the use of the Country Integrated NTD Database to report periodically, (especially annually at National level) on four NTDs, for which preventive chemotherapy is used (Lymphatic filariasis, onchocerciasis, schistosomiasis and soil-transmitted helminthiasis), as well as on five case-management NTDs (leprosy, Buruli ulcer, human African trypanosomiasis, leishmaniasis and endemic treponematoses that include yaws). This CIND tool helps to provide report from national, subnational and district level on leprosy elimination indicators that includes prevalence and detection (crude numbers and rates), number and percentages of multibacillary, child cases, female cases and grade 2 disabled cases among new cases. Customized reports in terms of indicators, periodicity as well as additional administrative reporting levels could also be programmed and generated.

II. Stop leprosy and its complications

3

This pillar focuses on diagnosing and treating leprosy and on preventing and managing disabilities associated with the disease. Though this has been traditionally the area of work of the national programmes and of some NGOs involved in service delivery, the Global Leprosy Strategy 2016–2020 aims at enhancing aspects, such as early detection in high-burden areas or high-risk groups, surveillance of drug resistance and a much stronger focus on disability prevention and management, including for rehabilitation and reconstructive surgery. Children affected by leprosy-related disabilities at the time of diagnosis were placed at the centre of this strategy. Therefore, specific efforts for early detection and treatment of children are encouraged by this manual including a "critical incident investigation-like" approach for each child with G2D. The way to reach a leprosy-free world is through achieving zero transmission, which is monitored through watching trends in age-specific case detection over time as well as transmission among nationals against cases reported among foreign-born. No paediatric leprosy cases shall be seen/expected in very low-burden countries and high-burden ones shall observe, along with a reduction of the case detection, a marked reduction of patients belonging to young age groups. This shall reflect the impact on the disease epidemiology. In fact, it is not easy to quickly curb the burden in terms of absolute numbers and rates since, even if patients become very quickly non-infectious after few doses of MDT, due to the long incubation of the disease, secondary cases might occur long after the treatment of the "index" case. Efforts to interrupt transmission and development of disease among high-risk groups, including through research projects on post-exposure prophylaxis are also encouraged. Similarly implementation of new e-tools to sustain knowledge and facilitate access to a diagnosis, which often requires expertise and a differential diagnosis with other NTD and non-NTD skin diseases, is promoted. Awareness of leprosy and other NTD or communicable diseases shall be sustained and the manual aims to suggest activities in this area as well. This second pillar is represented in the strategy logo by the front wheel of the bicycle, the one leading the way moving forward towards the targets and the goals.

3.1 Strengthening patient and community awareness of leprosy

The purpose of health action aimed at generating community awareness is to improve understanding about the disease and the programme and encouraging an active role in the service. The outcome one expects is increase in self-referral and development of positive attitude towards persons affected by leprosy by the community.

Public information and education in the field of leprosy control is aimed at building awareness by the following:

- improving understanding about the disease and the programme;
- stimulating civic concern about quality and responsibility;
- increasing demand and support for quality health services;
- refuting myths and misconceptions;
- making stigma and discrimination unacceptable;
- developing a sense of community ownership;
- enabling development of positive attitude and behaviour for social action;
- providing support to people affected by leprosy in enabling them to overcome barriers that prevent them from discharging their social responsibilities; and
- increasing knowledge and awareness of human rights specially those more strongly related to leprosy.

Messages should be objective, positive, specific and sensitive to age, gender, location, language and culture. The messages should reach the population at risk as well as other stakeholders, decision-makers and communities. Reference should be on curability, availability of drugs free of cost, early signs, removing discrimination and stigma from the mindset, and providing support and encouragement to persons affected. Examples of core messages could be the ones below.

- **Curable**: Leprosy is a communicable disease that can be cured with drugs that are widely available and which are free of charge.
- **Signs** of leprosy like pale or reddish skin patches with loss of sensation; numbness or tingling of the hands or feet; weakness of the hands, feet or eyelids; painful or tender nerves; swellings or lumps in the face or earlobes; painless wounds or burns on the hands or feet.
- **Early detection** with appropriate treatment helps to prevent disability from leprosy, makes the treatment easier and stops disease's transmission.
- **No need to fear**: The disease can be managed just like any other disease; affected people should not suffer any discrimination. Treated persons are no longer infectious after few weeks of treatment. So they can work, study, marry and live life normally.
- **Support**: affected people need the support and encouragement of their family and community; first, to take MDT and any other treatment as prescribed, and second, to be able to live a normal life.

The development of standard and culturally sensitive education and awareness material for patients and for communities will be very important to ensure that those messages are effectively delivered and to facilitate the work of the health-care workers.

When someone is newly diagnosed with leprosy, he/she should receive help and counselling so that the disease can be treated quickly in the best possible manner. It is important that the person learns the following:

- that he/she should lead a normal life;
- where to get answers to any questions about leprosy;
- where to look for diagnosis and treatment;
- that leprosy is caused by a germ and is not hereditary; it is not due to a sin or curse;
- that leprosy is curable:
  - the treatment is for either 6 or 12 months;
  - common side-effects due to MDT include red urine (all cases) and darkening of the skin (MB only);
  - tablets must be taken every day at home;
  - a new blister-pack is needed every 28 days: discuss how often the person should attend: monthly or less often depending from issues in relation to access to the health;
- that consultations are free of charge in the public sector;
- that treatment is free of charge;
- that leprosy is no longer infectious once treatment has started:
  - however close, contacts are more likely to already have been infected, and hence, at higher risk of developing the disease; they should therefore be brought for examination at the next visit;
- that the skin patches take time to disappear;
- that leprosy reactions can occur, even during and after treatment and if so need to be treated;
- signs of leprosy reactions in order to timely report to the health services:
  - patches can suddenly become red and swollen again;
  - there may be pain or numbness in the limbs;
  - there may be weakness of hands or feet;
  - there may be eye problems: loss of vision, pain or redness;

- existing disability may or may not improve with treatment;
- that various skills will need to be learnt to help prevent and manage disabilities;
- location of disability prevention and management services, including for reconstructive surgery.

The awareness efforts need to be stronger among high-risk groups and among high-burden communities/hot spots. Awareness campaigns need to be tailored to the target audience and to the expected outcome of the campaigns. They could be supported by other sectors, including private or other governmental sectors such as ministries of education or social welfare. They might be already counting with private enterprises experts in communication.

When generating awareness, there is a need to ensure availability of services and mechanisms in place to cope with increased demand.

Besides awareness activities that target patients and their families and/or highly-endemic communities, they can also target wider audiences like politicians and other public figures, community leaders, including spiritual leaders, media and international organizations. Awareness could also target health-care workers outside the leprosy care network to sensitize the health system and enhance detection and facilitate proper care.

The first step to organize awareness activities would be to identify the target audience and then to test their present knowledge about leprosy. Then there shall be a planning phase to develop targeted materials to increase awareness. The impact of awareness activities shall also ideally be measured either directly by the programmes and/or by partners (scientific institutions, NGOs). The activity shall be repeated to ensure periodical recall of messages and to sustain the effect on leprosy control over time. Integrated awareness campaigns with other health programmes might be beneficial and cost-effective even if they might require a longer planning and the development of new material.

The impact/effect of awareness and health information activities shall be monitored and plans shall be based on those periodical assessments.

Proposed actions in all settings

(1) Identify target audience and current KAP (knowledge, attitude and practices) either for leprosy or for other communicable diseases (NTD, TB, others).

(2) Carry out periodical leprosy only or integrated awareness activities to ensure that basic level of knowledge on leprosy is sustained; make use of support of known/influential public persona and of community leaders, including religious leaders.

(3) Assess the impact of activities through repeating KAP surveys and plan awareness campaigns taking into account those assessment’s results.

India: Anti leprosy fortnight is observed in the last week of January until first 2 weeks of February throughout the country. During this period, rallies, road shows, media briefing, school quiz and wide range of awareness activities and campaigns are organized at central state up to primary health care (PHC) levels. These awareness campaigns are funded solely on Governmental funding. In 2016 the national leprosy programme has decided to spend considerable time and efforts to develop and launch a national Information, Education, Communication/Behavioural change and Communication strategy, which tackles comprehensively the issue of communication in leprosy. The strategy also includes the use of a practical excel-based tool to guide State leprosy coordinators with the use of communication means tailored to the context of each State of India. This is in recognition of the importance of communication for a disease as leprosy and with the intent to deliver better quality impacting BCC campaigns to be used also as tool to ensure successful active screening campaigns in highly-endemic districts.

3.2 Early case detection through active case-finding and contact management

There are two methods of case detection: active and passive. The promotion of voluntary self-reporting is now crucial to case detection. Active case finding methods, including large-scale campaigns are generally recommended only among areas with higher endemicity and/or for hard-to-reach areas. Additionally, active case finding may be recommended to target high-risk and vulnerable groups. The detection of a child case with disabilities justifies an active screening of his/her contacts and his/her community in all epidemiological contexts/settings to avoid such incident to occur again to another child. While in low burden the detection of each and every single paediatric case with or without disabilities shall trigger the same exercise.

While contacts of leprosy cases shall voluntarily report for screening, in high-burden pockets and/or countries with very low burden active screening at home could be considered, if the index case could provide his/her consent. Retrospective screening of contacts of registered cases might also represent a good effort to detect leprosy early targeting contacts of cases diagnosed within five years earlier. Same approach might be chosen in countries with very low numbers of leprosy cases in order to try to stop transmission. Any active screening effort must be paired with the availability of a system to check the quality of diagnosis (to avoid over-diagnosis) and to monitor its impact versus costs. Access to laboratory services shall be also ensured because some of the cases may require diagnostic confirmation either through referral of the patient or through transportation of a fixed smear and/or tissue that could be then stained at the laboratory and/or examined by the pathologist. Enhanced diagnostic efforts shall be made, when leprosy is diagnosed on solely clinical grounds, to ensure proper classification of leprosy as paucibacillary (PB) and multibacillary (MB) ensuring enough time is devoted to examine leprosy suspects and ensuring the availability of a trained female health-care worker for the clinical examination of women and girls, with services tailored to local customs and culture. Privacy/safe areas for clinical examination should be ensured whether screening is done through a passive or an active modality.

For saving costs and obtaining a stronger public health impact in most countries integrated screening campaigns among high-risk and hard-to-reach areas might be organized. Some programmes conduct integrated NTD campaigns or undertake active detection using transport and staff of the TB programme.

For passive case finding, actions shall be undertaken to remove barriers that prevent persons with signs and symptoms of the disease and their contacts from reporting for examination; the most common of such barriers are the following.

(1) Lack of awareness that leprosy is treatable and that treatment is free and available locally. This can be addressed most effectively by public information campaigns using a variety of media, including traditional means of communication.

(2) Fear is also a common barrier. This may be fear of the diagnosis, fear of future deformity, fear of being known as having leprosy or fear that one’s family will suffer. The latter two relate to negative attitudes or other forms of stigma and discrimination in society and, as consequence also on self-stigma and depression. Such fears may persist even long after general attitudes have become more tolerant and instances of overt discrimination have become rare. Fear and stigma are difficult to remove. They can only be addressed successfully through a combination of strategies that include factual information about leprosy and its treatment, context-specific media messages addressing misconceptions and traditional beliefs about leprosy, positive images of leprosy and testimonies of people successfully cured from leprosy.

(3) A third group of barriers include other disadvantages, some of which are culturally determined, such as gender, ethnic group and poverty. These require specific approaches, which include awareness raising and education, but also advocacy for supportive legislation and services, and general poverty alleviation measures.

(4) Physical barriers, such as mountains, rivers or distance pose particular challenges. These need flexible arrangements of diagnostic and treatment services, such as mobile clinics.

(5) The final group, issues of security in areas of war or civil unrest, is the most difficult to address, but is nevertheless a reality in several leprosy-endemic countries.

Proposed actions in high-burden settings

(1) Active screening (active case finding activities/leprosy elimination campaigns) should be considered in the following:

- Areas with higher burden compared to national rates (use to identify areas at risk primarily the new case detection rate but also percentage of cases with disabilities and percentage of paediatric cases as indicators of transmission) – these are the so-called "hot spots";
- Hard-to-reach areas/areas with no health services.

The following groups should be targeted for active screening:

- Contacts of leprosy cases – this can be advocated everywhere;
- School children as part of integrated public health effort Investigations/screening.

(2) Awareness campaigns targeting high-burden communities, health-care workers and the general public at least once per year.

(3) Ensure availability of trained human resources at peripheral and referral level, including adequate number of female staff and make available a room with adequate privacy for proper examination/classification of patients.

(4) Provide incentives to community health-care workers to facilitate early suspicion of the disease and put a mechanism in place to either transport a smear and/or ensure referral of the patient for diagnosis confirmation.

(5) Ensure that leprosy is part of the training curriculum of the clinical nurses and the medical officers and of the community health-care workers; training and cooperation with university hospitals to ensure that training material is up to date and in line with the MoH programme.

(6) Ensure availability of expertise on how to detect and treat paediatric cases of leprosy, at least in referral centres, and consider developing special models of "intensive" care for children with leprosy to avoid development of disabilities and/or to surgically treat disabled children.

The above activities can be organized for leprosy or within coordinated/integrated activities for NTD and/or TB, depending on the funding and human resources availability. Supervision of the leprosy "component", in case of integrated activities, shall be done at least once per year by central/regional staff working solely on leprosy.

Proposed actions in low-burden settings

(1) Target the following groups for active screening:

- Contacts and extended communities of leprosy cases (every year for a period of 5 years);
- Communities living in hard-to-reach/underserved areas: once per year;

  - Investigations/screening of families and wider community as response to the detection of leprosy (with or without G2D) in a child;
  - "Silent" communities living geographically near other endemic and/or with similar social and infrastructure condition or having had leprosy cases reported in previous years.

(2) Ensure availability of trained health-care workers at regional/central level, including adequate number of female staff and make available a room for proper examination/classification of patients. Ensure availability of laboratory and/or pathology capacity in at least one central centre for confirmation of leprosy diagnosis (either testing directly or through a regional excellency centre where to send the samples).

(3) Ensure that leprosy is part of the curricula of the clinical nurses and/or the medical doctors, including for specialized branches like dermatology.

Countries might have areas of high endemicity. They might also have areas with high G2D due to lack of strong health system. Some countries have "silent zones" that have stopped notifying leprosy cases and the programmes need to ensure if leprosy has reached zero transmission in those areas or if, on the contrary, the lack of notifications simply reflect lack of competent detection and/or recording and reporting. Each country shall therefore "map" their situation and plan activities accordingly. The table below aims to guide interventions once the mapping of the burden and the correspondent level of services has been performed at national level.

In **Brazil** the Ministry of Health, in partnership with states and municipalities, promotes actions that are based on active case finding for the diagnosis of leprosy in the early stages, timely treatment, cure and surveillance of contacts, providing knowledge and alerting the population about the signs and symptoms. The main recommended strategies are the National Campaign leprosy, worms, trachoma and schistosomiasis in schoolchildren aged 5–14 years who are enrolled in public schools in municipalities with greater social vulnerability and increased risk of disease; the Contingency Surveillance Actions, Prevention and Control, which aims to strengthen the active search "house to house" of new cases of the disease in the general population and specific groups, such as household and social contacts, living in 40 municipalities that are distributed in 14 states in the North, Northeast and Midwest, considered more endemic and areas of major maintenance of disease transmission; and the World Day Against Leprosy, which aims to alert the population about the signs and symptoms of the disease, mobilizing health professionals to perform the active search for new cases and examination of contacts; and promote health education activities that promote the reduction of stigma and prejudice. It is emphasized that the federal government held "complementary" financial transfer to priority municipalities.

The **Democratic Republic of the Congo** has submitted in 2015 a project for funding to the Nippon Foundation as part of the support to fulfil the Bangkok Declaration "towards a leprosy-free world" signed in 2013 by ministries of health, the highest burden countries for the disease. The multi-year projects aimed at increasing by 50% detection in the targeted areas through active screening and to 100% of treatment completion. During the first year, awareness campaigns followed by active case finding were carried out in eight provinces resulting in the detection of 1488 new leprosy cases, to which MDT treatment has been provided. The cases detected represent an increase by 75% compared to the previous year notifications. Treatment results on cohort of patients with PB-leprosy will be available soon to monitor improvements also in quality of case holding. In 2016 DRC is planning to expand the active screening activities to other geographical areas as part of the multi-year project.

Table 2: *Summary of intervention to increase detection of leprosy cases according to the epidemiological setting*

Intervention	High burden	Moderate burden	Low burden	Underserved areas/hard-to-reach
"Incident" investigation of extended contacts of a child with leprosy		×	×	×
Incident investigation of extended contacts of a child with leprosy-related G2D	×	×	×	×
Screening of contacts	×	×	×	×
Active screening of contacts every year			×	×
School children screening	×	× (integrated)	× (integrated)	×
High-burden districts communities active screening		×	×	×
Awareness campaigns	×	×	× (integrated)	×
Ensure laboratory/pathology capacity and/or referral of samples centrally or abroad	×	×	×	×
Ensure refresher training	×	×	×	×
Ensure availability of both male and female health-care workers	×	×	×	×
Update curricula of health service providers	×	×		
Ensure availability of referral centres to confirm diagnosis and ensure correct patient's classification and staging (also through online consultation and/or sample/biopsies shipping)	×	×	×	×

In **Cambodia,** the leprosy programme, through a collaboration with Novartis Foundation and CIOMAL, conducted contacts “surveys” in 2015 in high-burden areas covering household and neighbour contacts (defined as living within 300 meters radius from index case house) of cases registered in the previous 10 years. The screening is conducted with the support of community health workers who identify suspects that are later on confirmed by the health-care workers in health facilities. The screening has led to a consistent increase in the case detection rate with the aim of earlier detection and reduction of transmission within high-risk groups (contacts) and in high-burden areas.

Egypt achieved the WHO leprosy elimination target in 1994 at national level and in 2004 at governorate and district levels. The elimination target has also been reached in most of the 4800 villages/sub-districts across the country. Nevertheless, 18 villages/sub-districts in 6 Governorates, mainly located in the southern part of the country, still have not reached that goal.

Approximately 60% of the new cases of leprosy detected each year in Egypt originate from the 6 Governorates, of which the majority from the 18 villages. The Ministry of Health and Population is engaged in intensifying efforts in such hot spots, consolidating achievements and accelerating progress towards a leprosy-free country. Activities coordinated by the National Leprosy Programme include:

- Strengthening capacities of health-care workers based in primary health clinics in the 18 villages, with the aim of ensuring early detection.
- Implementing active screening among residents of the 18 villages at regular intervals, not to miss any cases, with a focus on contact screening.
- Increasing community awareness of leprosy, to encourage self-reporting.
- Engaging community leaders and civil society to reduce stigma and social exclusion and to promote rehabilitation of patients.

Close supervision from central-level and governorate-level teams, including on-the-job training, monitoring and evaluation. Implemented activities aim at reaching the elimination target in the 18 villages and progressively curb transmission of leprosy.

In **Paraguay,** there is a nongovernmental hospital named Hospital Mennonita Km 81, located in the rural area (81 kilometer away from the capital Asunción) that works as referral centre for treatment of patients with leprosy and for training for doctors, nurses and students from medical and nursing schools from the national and private sector. Through an agreement between this Hospital and the most important school of nursing, they have established that all students from the third year of the course have to participate at practical lessons at this hospital for two days (for leprosy and tuberculosis). After that, they have to go to all the high schools in their districts of residence, provide short sessions on health education in leprosy and tuberculosis, and perform active screening house to house to ask for people with patches on skin and cough for more than two weeks. Once they detect some persons with suspect of these diseases, they bring them to the local health unit". Thanks to this activity that started in 2009 the programme has increased case detection and ensured more awareness on leprosy practically at zero financial cost.

3.3 Ensuring prompt start and adherence to treatment, including working towards improved treatment regimens

Multidrug therapy is a combination of drugs that is very safe and effective in treating leprosy to prevent the emergence of drug resistance; **under no circumstance should leprosy disease be treated by a single drug.** MDT is distributed free-of-charge to all who need it upon recommendation of the prescribing physician through a donation from Novartis (and earlier from SMHF) with the distribution to countries coordinated globally by the World Health Organization. The distribution nationwide is managed by the ministries of health according to their own distribution regulations and practices. Whatever the internal distribution methodology in the country, it shall be ensured that there would be no shortage of MDT at health facilities so that treatment can be started as quickly as possible to stop the transmission of the disease. The lack of drugs can be an important factor of no adherence to treatment and irregular treatment could provoke resistance. The drugs donation shall also involve private providers under agreements with the National programmes since no leprosy affected person shall be paying for his/her treatment.

In many countries there are agreements between the governments and private service providers like NGOs to also supply MDT free-of-charge.

MDT consists of drugs to be taken orally. The drugs are dispensed in convenient blister packs, which provide four weeks of treatment (in these guidelines the four week period is referred to as a “month”). Specific blister packs are available for multibacillary (MB) and paucibacillary (PB) leprosy as well as adult and children. MDT is safe during pregnancy and breast-feeding. MDT can be given to HIV-positive patients, including the ones under anti-retroviral treatment and to patients on treatment for TB. If a leprosy patient is treated for TB, the MDT regimen should omit rifampicin as long as the TB regimen contains rifampicin. For PB patients the treatment duration is 6 months, for MB patients it is 12 months.

Every effort must be made to ensure compliance to treatment, so that PB cases complete their 6-month treatment within a period of maximum 9 months and MB cases take their 12 months treatment within a period of 18 months. Rarely, it may be considered advisable to treat a patient according to medical evaluation for more than 12 months. Specialists at referral units may only take this decision after careful consideration of the clinical and bacteriological evidence of the need for an extension of treatment.

Some studies suggest that it might be possible to shorten the duration of treatment of MB cases to 6 months. This opens the door for introducing a uniform treatment regimen for both PB and MB cases with three drugs; hence, a single regimen for both forms of the disease, also known as Uniform-MDT. In this regard new guidelines will be issued by WHO once the amount of supportive evidence would justify the change of recommendations in the regimen compared to the ones released by the Expert Committee in its meeting in 2008.

When it is determined that a patient needs to be treated with MDT, the following steps must be taken:

- Fill in the Patient Record Card and the Leprosy Treatment Register Determine which type of MDT is required: PB or MB;
- Determine which dose level is required: adult or child;
- Counsel the person (and the parents, if it is a child) to indicate:
    - the need for regular treatment;
    - the possibility of complications of leprosy, which may need other treatment;
    - that the clinic is always ready to see them if they have any problems like intolerances and/or side effects.

- Give the first dose of treatment and explain how to take treatment at home.

As long as accessibility is not a problem, the drugs given once a month ("pulse dose") should be supervised – in other words, the health worker should make sure that the drugs have actually been taken. The other drugs are taken at home. The supervised dose is most conveniently arranged by having the patient attending the clinic each month. This monthly visit is also useful for monitoring the regularity of treatment and to identify complications (such as neuritis, reaction, etc.) at an early stage. Supervision of the monthly dose is important to ensure regularity of treatment, ensure cure and prevent relapse.

MDT treatment is provided in blister packs, each containing four weeks' treatment.

For **children weighing 20–40 kg:** the MDT paediatric blister pack can still be used using with the following adaptations:

- half of dapsone 50 mg tablet (thus 25 mg);
- clofazimine twice weekly (instead of every other day);
- single formulation rifampin 300 mg (instead of 450 pill included into the blister pack).

For **children weighing below 20 kg:** the appropriate dose for children under 10 years of age can be decided on the basis of body weight following the below recommended doses prokilogram:

- rifampicin: 10 mg per kilogram body weight (once per month);
- clofazimine: 1 mg per kilogram per body weight daily and 6 mg per kilogram once per month;
- dapsone: 2 mg per kilogram body weight daily.

Table 3: *Doses of medications in the MTD regimens*

The standard adult treatment regimen for MB leprosy is as follows:
Rifampicin: **600 mg once a month**
Clofazimine: **300 mg once a month, and 50 mg daily**
Dapsone: **100 mg daily**
Duration: *12 months (12 blister packs)*

The standard adult treatment regimen for PB leprosy is as follows:
Rifampicin: **600 mg once a month**
Dapsone: **100 mg daily**
Duration: *6 months (six blister packs)*

Standard child (ages 10 – 14) treatment regimen for MB leprosy is as follows:
Rifampicin: **450 mg once a month**
Clofazimine: **150 mg once a month, and 50 mg every other day**
Dapsone: **50 mg daily**
Duration: *12 months (12 blister packs)*

The standard child (ages 10 – 14) treatment regimen for PB leprosy is as follows:
Rifampicin: **450 mg once a month**
Dapsone: **50 mg daily**
Duration: *6 months (six blister packs)*

MDT is a very effective treatment for leprosy. If a full course of treatment has been taken properly, relapse is rare, although continued vigilance is important as sporadic reports of relapses due to drug resistance have been recently reported. Fortunately, the use of a combination of drugs has limited the development of drug resistance in leprosy, so generally relapse cases can be treated effectively with the same drug regimen – MDT. If it is decided to treat someone as a PB relapse, they are given a normal 6-month course of PB-MDT. The MB relapses are generally treated with 12 months MB MDT.

MDT is remarkably safe and serious adverse effects are very rare. The most common are summarized in the table below. The severe ones require stopping of the treatment and management in referral centres.

Substitutive/alternative treatment regimens should be used only in cases with severe intolerance or contra-indication to one or more drugs of the standard MDT regimens or in the evidence of resistance. These drugs should be available in specialized services, outpatient and/or hospital to form alternative regimens for such patients. WHO Guidelines in this regard are expected to be published in 2017.

Every effort should be made to persuade newly diagnosed patients to complete their treatment as prescribed and programmes' performances in terms of case holding shall be evaluated on the basis of their treatment completion rate, which shall be considered a core programmatic indicator. Programmes shall ensure that health-care workers have resources for tracing patients (mobile phone, home visits, through volunteers) that abandon the treatment and shall have a patient-centred approach to facilitate adherence. Annual refresher training on recording and reporting for leprosy shall be performed to ensure that this indicator, which implies a cohort analysis of treatment completion, is calculated correctly. Research studies on adherence to treatment (assessment and to improve it) shall be encouraged to be carried out. Supervision and monitoring, including patients' interviews, shall be periodically conducted to ensure that treatment is provided regularly and free of charge to patients and that medications' side effects are correctly and promptly identified. A good leprosy control programme shall ensure a treatment completion rate above 95%. Programmes could consider directly-observed treatment (DOT), daily or weekly, by a health-care worker or by a community member for

Table 4: *Side effects to MDT drugs*

Minor	Drug	Management
Red urine	Rifampicin	Reassurance
Brown discoloration of the skin	Clofazimine	Counselling
Gastro-intestinal upset	All three	Give drugs with food
Anaemia	Dapsone	Give iron and folic acid

More serious	Drug	Management
Itchy skin rash	Dapsone	Stop dapsone, refer
Allergy, urticarial	Dapsone or rifampicin	Stop both, refer
Jaundice	Rifampicin	Stop rifampicin, refer
Shock, purpura, renal failure	Rifampicin	Stop rifampicin, refer

In the **Marshall Islands,** paediatric leprosy patients are given MDT daily by a nurse performing home visits to the patient house in Majuro and Ebeye, where the majority of the Marshall Islanders live. A similar arrangement is organized to ensure adherence of elderly and living-alone patients or patients with concomitant mental illnesses.

paediatric cases and/or for all cases considered at high risk to interrupt treatment.

MDT represents an effective treatment for leprosy and an effective measure to stop transmission. However, care for patients that will present reactions and will need medications to control the pain and prevent the development of disabilities shall also be ensured either at primary healthcare level or the referral centres and their access to those services shall be facilitated. Patients with grade-1 disability (G1D) and G2D will need a lifelong care to prevent and/or reduce the impact of disabilities as will be discussed in the following chapter. MDT is the cornerstone of leprosy elimination but it shall not be the only tool to treat leprosy and ensure patients' well-being, including the psychological one, which will be discussed in the sessions related to Pillar III of the strategy.

Proposed actions in high-burden settings

(1) Ensure availability of free-of-charge WHO distributed MDT for all leprosy patients, including those cared for by the private sector, and implement A-MDT, when required.

(2) Train and supervise health-care workers to ensure proper care and good recoding and reporting in relation to treatment completion rate.

(3) Ensure stock of MDT related to numbers of cases observed in each district in the last 3 years mapping cases against available stock.

(4) Promote a patient-centred model of care adapting balancing between the need to facilitate patients adherence to the need to ensure that drugs are taken.

(5) Ensure availability of health education material to ensure proper counselling of patients.

(6) Consider the introduction of DOT or A-MDT for paediatric cases and start a similar approach for patients considered at risk of non-adherence/defaulting.

(7) Encourage and/or carry out operational research studies on treatment adherence.

Proposed actions in low-burden settings

(1) Ensure provision of MDT for all leprosy patients having availability in at least a main referral centre with the possibility to dispatch medications to the peripheral level, when needed.

(2) Consider the introduction of direct observation of treatment by the health-care workers (DOT) for all leprosy cases or at the very least for all paediatric cases.

(3) Use digital health technology to observe treatment and/or assist health-care workers in providing good quality of care close to the patient residence.

3.4 Improving prevention and management of disabilities

3.4.1 Prevention of disabilities

Examination of the nerves is an important part of the examination of a person affected by leprosy. It requires, however, training and experience to do this properly. Patients need to be examined regularly, if possible at every clinic visit, with special careful examination of MB leprosy patients, among which reactions are more frequent. Where this is not possible, patients need to be evaluated at the very least twice: at the time of diagnosis and at the end of the treatment. At the time of diagnosis, nerve function should be examined to detect pre-existing nerve damage and to grade disability. Under the Global Leprosy Strategy 2016-2020, the proportion of patients with G2D at the time of diagnosis and at the end of treatment will be monitored. While the management of the majority of the leprosy cases is simple and they improve under MDT, a small proportion will suffer from leprosy reactions and/or the effect of nerve damage along with psycho-social problems. When patients have advanced disease they may have visible deformities (hands, arms, feet, legs), they may suffer visual impairment from blindness and rarely internal medical conditions, especially in case of Type 2 reactions. Patients with advanced leprosy usually face more stigma and discrimination. However, psycho-social problems associated with leprosy are related to widely-held beliefs and prejudices concerning leprosy and its underlying causes, not just to the problem of disability.

The long-term consequences of leprosy (disfigurement of the face, deformities and disability resulting in stigma and suffering for the patient and their family) are mostly due to nerve damage resulting from leprosy reactions. Early recognition and effective management of reactions are thus very important.

A leprosy reaction is the sudden appearance of signs and symptoms of inflammation in the skin lesions of a person with leprosy. There is redness, swelling and sometimes tenderness of the skin lesions. New skin lesions may appear. There may also be swelling, pain and tenderness of peripheral nerves, often accompanied by loss of function; sometimes nerve function impairment occurs without other signs of inflammation, making it much less obvious – so-called ‘silent neuritis’.

The longer the delay between the appearance of the first symptoms of leprosy and the start of treatment, the more likely nerve damage will occur. For this reason, every effort should be made to inform the public that early diagnosis and treatment of leprosy prevents the occurrence of long-term consequences.

Recent loss of nerve function is defined as sensory or motor nerve function impairment in one or more peripheral nerves occurring within the last 6 months. Severe leprosy reactions and recent nerve function impairment are the main indications prescribing corticosteroids in leprosy. Nerve function should be monitored on a regular basis, using a standard checklist. This enables timely detection of new nerve damage and prompt treatment.

The following signs indicate that a reaction is severe and that the patient must be referred:

- Red, painful, single or multiple nodules in the skin with or without ulceration;
- Pain or tenderness in one or more nerves, with or without loss of nerve function;
- Silent neuritis – nerve function impairment, without skin inflammation;
- A red, swollen skin patch on the face, or overlying another major nerve trunk;
- A skin lesion that becomes ulcerated, or that is accompanied by a high fever;
- Marked edema of the hands, feet or face;
- Pain and/or redness of the eyes, with or without loss of visual acuity;
- Painful swelling of the joints or testis with fever.

Also mild reactions that do not respond to anti-inflammatory treatment after two weeks or more shall be considered severe.

Reactions that show none of the above signs can be considered mild reactions and maybe treated symptomatically (with aspirin) and managed at peripheral level of care.

MB patients are more at risk of reactions compared to PB patients. MB patients with nerve damage present at the time of diagnosis are at higher risk of further nerve damage and should be monitored very closely.

There are two types of reaction: reversal reaction (or Type 1) and ENL (or Type 2). Distinguishing between the two is usually not difficult: in a reversal reaction, the existing skin lesions become inflamed, red and swollen; in an ENL reaction, new red nodules (about 1–2 cm across) appear under the skin of the limbs or trunk, while the original leprosy skin patches remain as they were. In addition, ENL reactions cause a general feeling of fever and malaise, while reversal reactions cause fewer or no systemic signs and symptoms. Both types can occur before the start of treatment, during treatment or after treatment with MDT. This is the reason why post-treatment care and monitoring shall be put in place by leprosy services.

Signs of a severe reversal reaction are as follows:

- Loss of nerve function – that is, loss of sensation or muscle weakness;
- Pain or tenderness in one or more nerves;
- Silent neuritis;
- A red, swollen skin patch on the face, or overlying another major nerve trunk;
- A skin lesion anywhere that becomes ulcerated;
- Marked edema of the hands, feet or face.

Signs of a severe ENL reaction are as follows:

- Pain or tenderness in one or more nerves, with or without loss of nerve function;
- Ulceration of ENL nodules;
- Pain and/or redness of the eyes, with or without loss of visual acuity;
- Painful swelling of the testes (orchitis) or of the fingers (dactylitis);
- Marked arthritis or lymphadenitis.

ENL reactions are complex medical problems requiring careful management by experienced clinicians.

Severe reactions should be treated with a course of steroids, usually lasting 3–6 months. Steroids should be prescribed by someone properly trained in using these drugs. There are a number of important side-effects associated with steroids, so a careful assessment must be made of any patient requiring them. ENL reactions often recur in multiple episodes. Patients with recurrent reactions should be treated with high-dose clofazimine (300 mg daily for three months; then tapering to a monthly maintenance dose of 100 mg daily, until no further reaction episodes occur). Clofazimine is provided by WHO free of charge to countries according to an annual request sent to WHO headquarters. Drugs and human resources trained in reactions' management shall be made available at least at referral levels, and access to those centres shall be facilitated for patients. It is very important to provide timely treatment of reactions because they are the main cause of leprosy-related disabilities.

Recent nerve damage (present for less than six months) can often be reversed by steroids but in many cases, damage occurred longer ago. In that case no further recovery is expected. Therefore, the first tool to prevent disabilities is to diagnose leprosy early and the second is to detect and treat reactions quickly. A third measure is to identify patients with G1D, mostly sensory impaired. Persons with leprosy and G1D should be carefully educated on how to prevent damage in the anaesthetic limbs through self-care and, if necessary, physiotherapy and through the use of protective footwear and other measures/tools to avoid wounds and burns. All leprosy patients need to be given education on signs and symptom of reactions and the need to report promptly if these occur.

Proposed Actions at global level

(1) Ensure availability of online training material on disability assessment.

(2) Enhance access to "hand and foot monofilament sets" to facilitate assessment of sensory nerve functions.

(3) Facilitate access to single formulation clofazimine for treatment of ENL reactions.

(4) Adapt existing education material on prevention of disabilities to national/ regional contexts and field test them before reproduction and distribution.

(5) Disseminate and translate the manual for self-care for prevention and management of disabilities "I can do it myself" in cooperation with partners targeting health-care workers and patients.

Proposed actions in high-burden settings

(1) Ensure training of peripheral and referral centre staff on disability assessment through national training or via online training ensuring certification of completion by all health-care workers in endemic areas.

(2) Ensure availability of steroids and clofazimine in stock for the treatment of reactions at least in referral centres, both public and private.

(3) Ensure reporting on disabilities at the end of treatment through training and supervision and record the additional disabilities' occurrence.

(4) Ensure availability and support for patients' self-care through provision of tolls/equipment free of charge directly or through referral to private institutions with the capacity to provide such service.

(5) Ensure provision of patients' education on disability prevention through simple education material developed using as reference the manual "I can do it myself" or other similar guides.

(6) Ensure social support to patients to facilitate access to referral centres.

Proposed actions in low-burden settings

(1) Ensure training at referral centre staff on disability assessment through national training or via online training ensuring certification of completion by the health-care workers.

(2) Ensure reporting on disabilities at the end of treatment through training and supervision and record the additional disabilities occurrence.

(3) Ensure availability and support for patients' self-care through provision of tolls/equipment free of charge directly or through referral to private institutions with the capacity to provide such service.

(4) Ensure provision of patients' education on disability prevention through simple education material developed using as reference the manual "I can do it myself" or other similar guides for persons affected by disabilities.

(5) Ensure social support to patients to facilitate access to referral centres.

In **Paraguay,** since the year 2000 the leprosy programme has ensured that there is a focal person for disability assessment and management of leprosy reactions in all of the 18 health regions. These are public health workers getting salaries from the government but also counting on additional funds from the German Tuberculosis and Leprosy Relief Association (GLRA) for the field trips within their region. They also get technical advice, upon request, by the Hospital Mennonita Km 81 to manage particularly complicated cases. They ensure proper assessment of disability grate at the time of diagnosis and at the time of finishing the MDT treatment. They also promptly examine patients to detect reactions and they are competent with the management of anti-inflammatory treatment with corticosteroids. They also ensure that patients' insensitive feet and hand get needed tools to prevent further impairment.

3.4.2 Management of disabilities

Despite MDT of anti-leprosy treatment, treatment of reactions and self-care to avoid disabilities, they still occur among some patients, even before diagnosis. The impairment can affect different organs and/or sites:

- The eye: lagophthalmos, corneal anaesthesia, cornea ulcers, visual impairment, blindness;
- The hand: ulcerations/skin cracks, wounds, muscle weakness, stiffness up to contracture of fingers, loss of tissue, including fingers;
- The foot: skin cracks, wounds, chronic ulcerations that can also affect the bones (osteomyelitis), muscle weakness, foot-drop, contracture of toes, loss of tissue, including toes.

For patients with G2D, surgical care has a role for improving functioning, and if also affected by sensory impairment, self-care and preventive tools shall be used to develop further G2D defining disabilities.

The healthcare system needs to put in place actions focused on affected persons, including social and psychological support to their families and community. Since persons affected by leprosy with disabilities will require life-long care, partnership with affected persons' groups, with their community and with CBOs/NGOs, might be sought to provide the needed support.

In high-burden countries the healthcare system must ensure availability and access to referral centres to provide care, devices including protective foot-wear, physiotherapy and reconstructive surgery services. Loss of sensitivity on the sole of the foot and ulceration are very common in people affected by leprosy, so the use of appropriate footwear is very important to prevent disability. Most people do not require special footwear – the right shoes bought in the market can be just as effective. Sports shoes are often very appropriate. Alternatively, sandals or shoes with a firm under-sole and a soft in-sole may be used. They should fit comfortably; Velcro straps are easier to use than other types of fastenings and heel straps are needed for sandals. Some people need specially designed orthopaedic footwear, others may need prosthesis. If those services cannot be provided by governmental facilities/resources only then private sector could be involved through agreements to ensure effective coverage of those fundamental services for people with leprosy-related disabilities. Self-care has an important role but a good health education must be provided to patients and their relatives at the moment of leprosy diagnosis to ensure that disabilities are prevented and/or managed to reduce their progression and impact. The services needed are often not leprosy specific. Integrated wound care, physiotherapy and surgical services should be encouraged to be provided jointly with services provided to persons with other NTDs, with diabetes and with non-leprosy related disabilities. Reconstructive surgery could be provided in the form of "surgical camps", very effective to reach persons affected by leprosy in hard-to-reach areas or among vulnerable populations.

Leprosy management does not stop at the time of diagnosis and treatment but in some cases requires life-long care. Even if leprosy patients with G2D at the time of diagnosis are globally "only" 3%, new disabilities also occur during treatment or later in life because of additional reactions or already irreversible nerve damage. For this reason, it is fundamental to note who is at increased risk of developing further disabilities at the time of completion of MDT and to continue surveillance of their disability status. In addition, it is important to find out the number of persons with leprosy-related disabilities who are in need of self-care training, disability management or rehabilitation in order to be able to plan for care after MDT. A mechanism for this should be part of the national programmes since the current surveillance system does not capture this information.

Proposed actions in all settings

(1) National programmes should set up recording and reporting of persons with existing disabilities and one with persons at risk of leprosy-related disabilities after MDT. Persons at risk of further disability should be identified and offered 'semi-active' surveillance, since they are at risk of social exclusion if their impairments become more severe.

(2) Encourage all patients with sensory impairment to join self-care groups to prevent secondary impairments.

(3) Ensure care for persons with G2D either directly or through public-private partnerships in order to promote disability prevention, care for wounds, use of protective foot-ware, use of devises for self-management, in case of hand impairment, and reconstructive surgery.

Proposed actions in high-burden settings

(1) Ensure good coverage of referral centres for leprosy disability care and reconstructive surgery linked with the social and welfare services to ensure accessibility of those services.

(2) Ensure that self-care and community self-care groups are part of the national leprosy guidelines and support their activities.

(3) Set up public-private partnerships to ensure services' coverage and supervise nongovernmental facilities to ensure compliance with the national agreements and quality of care.

Proposed actions in low-burden settings

(1) Ensure access to at least one centre for specialized care for disabilities.

(2) Promote integrated services for leprosy, other NTDs and noncommunicable diseases (NCDs) related disabilities to ensure coverage of services like wound care and reconstructive surgery.

(3) Coordinate with the social and welfare schemes for persons with disabilities to ensure that persons affected by leprosy have access free of charge to specialized care.

(4) Ensure availability of reconstructive surgery linking up with centres offering services for NCD programmes like disabilities and car accidents/traumas.

In **India,** The Leprosy Mission Trust India (TLMTI), in collaboration with other ILEP members, coordinates with the government either directly or indirectly through other ILEP member organizations in helping people affected by leprosy undergo reconstructive surgery in leprosy. It has 13 hospitals in eight states that are recognized by the Government for reconstructive surgeries for leprosy cases. In these hospitals, each year over the past 10 years, 1100 to 1300 reconstructive surgeries related to leprosy have been performed for cases referred by the District Leprosy Officers of the concerned districts. In addition, the surgeons of TLMTI have been operating in various government hospitals at the request of the State and District Leprosy Officers in the states of Chhattisgarh, West Bengal and Sikkim in the past 5 years. In the state of Assam, through AIFO (another ILEP member), TLMTI surgeons have operated in Guwahati Medical College, orienting the surgeons of the Plastic Surgery Department in the medical college in reconstructive procedures related to leprosy in 2014 and 2015. TLMTI surgeons have also operated in other hospitals selected by AIFO in Assam and Meghalaya. These initiatives have strengthened public private collaboration to ensure service delivery and to build and sustain leprosy expertise.

3.5 Strengthening surveillance for antimicrobial resistance

The current treatment based on WHO-recommended MDT is unlikely to have any major changes, except for the possible introduction of U-MDT. Limited availability of mouse-foot pad inoculation technique means that there has been very little information till recently on rifampicin drug resistance in leprosy. However, with the development of DNA sequencing methods, several reports of rifampicin, dapsone and ofloxacin resistance have been published. For this reason, the Global Leprosy Programme in collaboration with TNF started in 2009 a global network of laboratories for the surveillance of drug resistance. Since 2011, this initiative has been supported by ILEP members. The problem of drug resistance may not be significant at this stage but it is important to have a good surveillance system to monitor the trend carefully so that effective measures to combat this problem can be developed in future. This requires improved reporting of relapses at the national level, enhanced testing among a proportion of new cases and need to standardize case ascertainment and definitions. The PCR can be performed only on samples from MB cases (positive skin smear or tissue from a biopsy sample). For this reason, some capacity, at least at national level, shall be kept in place for performing skin smears and to have a collection point for dispatching samples for testing in a specialized molecular centre or to an international reference laboratory.

While smear examination is not essential to diagnose leprosy, in some cases of only nerves-affecting leprosy a positive biopsy for leprosy bacilli may be the only conclusive sign of the disease. The majority of people with leprosy have a negative smear. If there is no loss of sensation in the skin lesions and no enlarged nerves, but there are suspicious signs, such as nodules or swellings on the face or earlobes, or infiltration of the skin, it is important to get a skin smear test done. In these circumstances, a positive skin smear confirms the diagnosis of leprosy, while a negative result (in the absence of other cardinal signs) would, in practice, rule out leprosy. An alternative diagnosis should then be considered.

Since 2008, the GLP has set up, in collaboration with ILEP, a surveillance network to ensure that information related to resistance to MDT is collected at the global level. Representatives of the network, composed by reference and national laboratories, meet bi-annually to review results and plan the work ahead. The GLP is planning to enhance and strengthen the capacity of the current network to enhance access to testing and surveillance coverage to ensure proper monitoring of trends of antimicrobial resistance to MDT and to second line medications like ofloxacine.

Proposed actions at global and regional level

(1) Promote and sustain national capacity to perform skin smears in at least one centre in all high-burden settings and identify reference regional centres to link up with countries with low-burden and to set up a system for quality assurance.

(2) Enhance and publish the surveillance for drug resistance networks and set up regional testing "hubs" in each region.

Proposed actions in high-burden settings

(1) Generate capacity to perform testing for drug resistance or ensure funding to perform testing in a regional centre.

(2) Promote and sustain national capacity to perform skin smears in, at least, one centre in the country in order to be able to confirm diagnosis in doubtful cases and to identify samples suitable for drug-resistance testing.

Proposed actions in low-burden settings

(1) Ensure access to a testing centre for performing drug-resistance testing.

(2) Ensure access to a centre where skin smears can be performed.

3.6 Promoting innovative approaches for training, referrals and sustaining expertise in leprosy, such as e-Health

Sustaining expertise in leprosy after integration of services at primary healthcare level has become a challenge even in high burden countries. Additionally, due to the reduction of prevalence, many countries have seen their resources for referral centres shrinking, threatening the quality of services. Also the core group of experts that have led to key advances in the fight against leprosy, such as the introduction of MDT is ageing and a new generation of experts willing to commit to leprosy control is hard to find due to the fact that leprosy is becoming a rare disease.

Together with these challenges there are also opportunities. Technological advances like mobile phones, social media, and wide access to the internet provide opportunities for long distance training and even for long-distance "clinical" examinations made through image-based teleconsultation. While online training is certainly a cost-effective option, its quality must be "certified" and the quality of the care provided shall be then monitored at service delivery level. Unfortunately, additionally to lack of skills to diagnose and manage leprosy, also lack of supervision and monitoring skills are observed, especially in regions and countries with low burden of the disease. The first step to be taken is to assess the training needs that have to be tailored to the country health system and burden situation. Globally and regionally, actions must be taken to promote and sustain knowledge and experience in leprosy. More donors' support to ensure that e-tools can be implemented to improve the referral system and to ensure early and more accurate diagnosis. E-health and e-learning shall be considered in the current times as key as developing training national curricula and as update medical schools, nursing schools and public health curricula for the "traditional" course of studies. E-tools might also be developed to ensure the quality of supervisors and monitors of leprosy programmes and projects.

Proposed actions at global and regional level

(1) Identify core training and centres of excellence (clinical, research and public health aspects) and advocate for resource for their functions as country and also regional resources.

(2) Support countries with the identification of training needs and with the development of training material and update of training curricula.

(3) Develop online training material for leprosy to include also certification and facilitate its translation and access online by countries also relying on initiatives, such as POLHN[2], established by the WHO Regional Office for the Western Pacific and others.

(4) Form a group of experts in each region to assist clinically and/or in terms of supervision and monitoring and ensure funding for sustaining of such core knowledge groups in partnership with key stakeholders.

(5) Facilitate access for funding with donors interested in neglected diseases and in funding field innovations also supporting the development of proposals.

Proposed actions in high-burden settings

(1) Map training needs of doctors, nurses and public health officers working at all levels, and ensure that training is carried out and its quality is monitored.

(2) Ensure update of the respective curricula along with refresher training through comprehensive and updated training material in line with leprosy programme guidelines.

(3) Ensure that training is mandatory as induction for all new staff, either developing within country or using WHO or other partners' online resources.

(4) Develop proposals for innovative e-approaches to diagnosis and referral.

(5) Contribute sustaining national and regional centres of excellence highlighting their contributions and involving them more closely into the programmes' activities.

Proposed actions in low-burden settings

(1) Map training needs of doctors, nurses and public health officers for a centre for leprosy at least at national level.

(2) Ensure availability of training course either at national level or through collaboration of a regional and/or of a global centre (including online courses).

(3) Develop proposals for innovative e-approaches to diagnosis and referral.

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[2] POLHN is a key programme of the WHO Western Pacific Regional Office carried out in partnership with Ministries of Health of Pacific Island countries. POLHN aims to improve the quality and standards of practice of health professionals by offering free, online and blended courses at www.polhn.org

In the **Philippines,** the Novartis Foundation with the national leprosy programme has implemented the Leprosy Alert Response Network and Surveillance System (LEARNS). This system utilizes teleconsultation to facilitate the flow of referral to the primary health centre. The patient consults the health worker in the field, who then sends the information i.e. photo of the patches and short description to the leprosy expert through SMS/MMS. In turn, the expert sends message to the frontline health worker and to the Municipal Health Officer, after which consultation follows. After confirmation of diagnosis, MDT treatment is initiated and the new case is recorded. As a result, surveillance is done rapidly, in a stratified and prioritized manner. Reports, maps are generated, hyperendemic areas are easily identified and contact tracing can be facilitated.

Through LEARNS, the local government provides support to the local health providers during training/capacity-building on leprosy and mHealth, leprosy elimination activities, monitoring and evaluation of the programme and local networking and multi-sectoral engagement between stakeholders, including persons affected by leprosy.

3.7 Promoting interventions for the prevention of leprosy infection and disease

Preventive tools of leprosy infection and of leprosy disease among persons already infected would have an enormous impact in leprosy elimination. While no vaccine has showed high efficacy, and current research on chemoprophylaxis with single-dose rifampicin (SDR) also shows partial and limited time protection, there is no doubt that their side effects and drug-resistance risks have been proven to be negligible. Additionally, combined immuno- and chemoprophylaxis seem to have higher efficacy among contacts of leprosy cases. However, availability of published evidence to date on the feasibility of the use of such tools at the country level is still limited. Diagnostic tests for detection of infection would be also key to allow better targeting of preventive measures while at present, none of the current experimental tests have been approved and released for routine use. Once the expected results of current studies in the field of detection of infection and for prevention are available as published evidence, WHO plans to perform a thorough assessment of the available evidence according to WHO procedures for issuance of new guidelines for leprosy. WHO would then see if any of the existing tools could be recommended for incorporation into routine national policies. Until then, research on prevention shall be encouraged to identify new regimens, new diagnostic tools and to define how to implement the new tools in the field.

Recommended actions at the global level:

(1) Review existing tools for prevention and disease according to WHO rules and regulations for guidelines issuance

(2) Encourage operational research in the areas of prevention and studies on diagnostic tests of infection and disease

Recommended actions in all settings:

(1) Prioritize as a key area for implementation research studies on the use of tools to prevent leprosy and promote studies on new diagnostic tests to detect infection and disease

(2) Use the outcome of published research studies to guide implementation research projects that shall allow effective monitoring of the impact of preventive activities

4

III. Stop discrimination and promote inclusion

Leprosy-related stigma and discrimination are pervasive in almost all cultures around the world. In many societies, leprosy-related stigma has received a historical "endorsement" through the legislation of compulsory segregation that has only been repealed in recent decades. Often, leprosy is seen as a punishment for sin, or misbehaviour or as the result of breaking a taboo. Despite being known as a disease caused by a germ since 1873, in many communities, these beliefs still persist today. As a heritage from the past, some countries still have discriminatory laws allowing for example divorce or deportation of migrant labourers on account of leprosy. These laws continue to fuel stigma and discrimination.

Since patients arise from the community, they are aware of the prevailing negative attitudes towards leprosy and stereotypes regarding persons affected by leprosy. Not infrequently, this causes affected persons to internalize such attitudes and separate or isolate themselves from the community. This is also known as internalized stigma or 'self-stigma', without any intention to blame the person affected for this phenomenon. Internalized stigma is often more widespread and pervasive, and no less disabling than other forms of stigma and may continue even after actual negative attitudes and discrimination have disappeared.

Stigma and discrimination do not only affect persons with the disease but also their family members and relatives. In this way, it may become a "family curse" with negative social consequences for the entire family. The impact of stigma is far-reaching as it may adversely affect a person's mental health. Increased levels of anxiety and depression and many accounts of (attempted) suicide have been reported in the literature. Self-esteem is often reduced. Stigma also affects many aspects of social participation. Most common are a negative impact on work performance, ability to find work, reduction in earnings, marital and other relationships, opportunities for education and access to medical care in general health services. Family members may be affected; for example, children and siblings may have reduced opportunities to get married and children of affected parents may be denied access to school. Stigma has also been reported to delay diagnosis, affect treatment compliance and implementation of prevention of disabilities activities, such as self-care.

The first step in promoting societal inclusion of persons affected by leprosy and their families and to stop stigma (including self-stigma) is to create awareness of the problem and include evidence-based strategies and interventions in the policies and plans of national leprosy programmes and NGO programmes and projects. The following sections give guidance on a number of key strategies to promote inclusion through tackling stigma and discrimination, promoting empowerment of affected persons, their involvement in leprosy services and coalition building among themselves and with other CBOs, involving communities, access to social and financial support systems and community-based rehabilitation. This pillar of the strategy is represented by the rear wheel in the strategy bicycle logo. For too long the leprosy fighting community has thought for going fast a single wheel was sufficient, in spite of the impact that aspects like stigma and discrimination have on patients and their communities. With two wheels and a light but solid frame, the bicycle can run more decisively towards the ultimate goal of a leprosy-free world.

4.1 Promoting societal inclusion through addressing all forms of discrimination and stigma

Exclusion and many forms of restrictions in social participation are often a direct result of negative attitudes towards leprosy and leprosy-affected persons, discrimination and internalized stigma.

When negative attitudes are acted upon – so-called enacted stigma – we speak of discrimination. This may be interpersonal or structural. Examples of interpersonal discrimination are when people lose their job or are excluded from the family on account of leprosy. Structural discrimination is when exclusionary measures or other disadvantages on account of leprosy are embedded in procedures, policies or legislation. Examples include policies to declare one's leprosy status on immigration forms or legislation allowing divorce of an affected spouse or denying voting rights to affected persons.

The motivation for a human rights approach to health, especially in the field of infectious diseases, is clear: poverty and inequality create conditions for infectious diseases to thrive, and the diseases, in turn, interact with social-ecological systems to promulgate poverty, inequity and indignity. Governments and intergovernmental organizations should be concerned with the control and elimination of these diseases, as widespread infections delay economic growth, contribute to higher healthcare costs and slow down achieving universal human rights.

The aspect related to human rights in the case of leprosy is so strong that had prompted in 2010 the United Nations General Assembly to issue a resolution on leprosy (A/RES/65/215) and more recently has prompted the Human Rights Council of the United Nations to promulgate on 2 July 2015 Resolution 29/5 "Elimination of discrimination against persons affected by leprosy and their family members". The resolution and the Guidelines that followed it call for an assessment on their implementation globally to ensure that persons affected by leprosy are everywhere treated with dignity and that are entitled to all human rights and fundamental freedoms.

Recognizing the role of stigma and discrimination as a core element that perpetuates disease transmission and with the sincere believe that stigma and discrimination related to leprosy is inacceptable in today's world, this aspect was elevated to a full pillar of the Global Leprosy Strategy 2016–2020.

A number of interventions have been highlighted to reduce stigma in its various forms, including discrimination.

- The first is information-based interventions. This includes education about leprosy and its treatment. It is crucial that local fears and beliefs are addressed. Messages need thus to be contextualised and culturally validated. Behaviour change communication is information aiming specifically to promote changes in behaviour. Changing behaviour without changing attitudes is very difficult, so any communication effort should address both attitudes and behaviour. Attitudes are based on local beliefs and stereotypes, so a thorough knowledge of these is essential to inform specific communication messages.
- The second intervention consists of facilitating contact between community members and affected persons. This can be done using a direct approach, for example, by arranging for an affected person to give a testimony during a community meeting and facilitating a dialogue between this person and the audience. An indirect approach is also effective, using a filmed testimony or comics that tell the story of the affected person. A recent stigma reduction trial in Indonesia combined both approaches. This approach was very successful in reducing stigma, not only among those attending the so-called 'contact events', but also among others living in the same villages who had heard the message second hand.
- An important source of stigma is the health and social services themselves. Staffs of these services are part of the same culture and are members of the same communities as persons affected by leprosy. It is therefore not surprising that they also have similar negative attitudes and demonstrate discriminatory behaviour. Sometimes health workers do this unwittingly through the terminology these use. Examples that have recently been highlighted in the field of TB control are common public health jargon, such as "suspect", "defaulter" or "control" used

when talking to affected people. In leprosy work, one could add disability-related terms, such as “deformity”, “claw hand” and even “leprosy patient”. Discrimination can also be structurally embedded through the way the health services are organized. For example, sometimes leprosy outpatient clinics are only organized on a particular day of the week, while all other patients can come any day. Comparatively little research has addressed the problem of stigma and discrimination in the health and social services and not only for leprosy. Tools are needed to assess stigma and discrimination in these settings. Development and/or validation of these, alongside studies to document discriminatory structures and practices and the attitudes of service providers, and research into effective interventions to abolish stigma and discrimination in the health and social services are urgently needed.

- Negative language and use of stereotypes can also be a source of stigma or can reinforce existing negative attitudes. This includes the use of the terms mentioned above, but especially denigrating terms that refer to persons affected by leprosy. The most notorious example is “leper”, which has been banned long ago, but is still used in some circles. Organizations of persons affected by leprosy have also argued against the use of the abbreviation “PAL” (person affected by leprosy) since this became a label in itself. Any terminology that identifies affected persons with their disease should be avoided in all languages. Use of positive and dignifying language should be encouraged, especially also in the media.
- Given their important role in their respective communities of believers, the leaders of all religions of leprosy programmes shall involve them so that their teachings, writings and speeches contribute to the elimination of discrimination against persons affected by leprosy by spreading awareness that leprosy is curable and stressing that there is no reason to discriminate against anyone affected by leprosy or members of their families. During an international symposium organized in Vatican city in June 2016 with leaders from five religions (Buddhism, Christianity, Hinduism, Islam and Judaism) stigma and discrimination in leprosy were discussed and clear recommendations to the religious communities were provided on how to ensure that persons affected by leprosy are given care and dignity.
- The impact of stigma experienced by affected people, including internalized stigma, can be mitigated through counselling, activities aimed at empowerment and by raising awareness of human rights and how to use human rights instruments; for example, activities implemented by the programme in Brazil. The latter is discussed in more detail below. While counselling can be effectively implemented through mental health professionals, such professionals may not be available and many people do not have access to any mental health services. Peer counselling is an effective alternative that has been used successfully in some countries, including Nepal and Indonesia. Affected persons with an affinity for counselling are trained in basic listening and counselling skills. They operate ideally embedded in a structure, such as the basic health services, a disabled people organization (DPO) or community-based rehabilitation (CBR) programme, or linked to community mental health services.
- Socioeconomic development (SED) activities have been shown to be effective in promoting empowerment and through this, reducing stigma and its effects on individuals. The ability to work and make a contribution to the family, community or wider society, is a very important element in people’s sense of self-worth and personal dignity. It often enables people to fulfil their role (again), which is expected in a given setting. Typically, SED activities include micro-credit loans, business training and, importantly, some form of coaching or mentoring, while a business

initiative is being set up. It is important to note that self-employment is not the right solution for everyone, so other strategies for empowerment through training in, for example, personal effectiveness and human rights are needed also.

Several other strategies to reduce stigma and discrimination are discussed in the next sections.

Proposed actions at global and regional level

(1) Promote awareness and compliance with the HRC resolution 29/4 2015.

(2) Identify global and regional partners, including donors to support the implementation of Pillar III of the Global Leprosy Strategy 2016–2020 and to raise awareness in ministries of health of the importance of including specific stigma-reduction strategies and interventions in national policies and plans.

(3) Collect and analyse information on stigma and discrimination related to leprosy and monitor impact of activities carried out to mitigate them. This may be done through sentinel surveillance based on periodic surveys.

Proposed actions in all settings

(1) Facilitate the implementation of the Principles and Guidelines for the implementation of the UN Human Right Council Resolution 29/5. This should include special guidelines for the use of dignifying language and avoidance of discriminatory terminology, especially in the media and in health and social services.

(2) Programmes shall have information in relation with stigma and discrimination. This information could be collected through a periodic "survey/data collection or through the routine use of an internationally validated stigma scale. If possible, in-depth interviews should also be done to provide a deeper understanding of any changes taking place. In countries with low burden of leprosy it could be done jointly with other stigmatizing diseases.

(3) Structural discrimination should be addressed through integration of services within existing ones (both and heath social services).

(4) Review national guidelines and publications to ensure removal of any discriminatory language and reaffirm principles of respect and human rights in any leprosy-related training for health-care workers.

(5) Ensure the availability of contextualized information, education, communication (IEC) materials and their use to provide correct information and address specific fears and beliefs related to leprosy.

(6) Include at least one other stigma reduction strategy besides provision of information, such as contact with affected persons, in all leprosy programme plans.

(7) Include interventions to promote empowerment and provide psycho-social support to persons affected by leprosy in all leprosy programme plans.

(8) Consider involvement of religious leaders to reduce stigma and discrimination in the community.

(9) Promote research into stigma and discrimination in the health and social services, including development of tools, inventories of discriminatory structures and practices, attitudes among staff and interventions to abolish stigma in service settings.

The Stigma Assessment and Reduction of Impact Project was carried out in Cirebon, West Java, **Indonesia,** starting in 2010. The aim was to assess the effectiveness of different sets of interventions to reduce leprosy-related stigma and its consequences, namely: 1) counselling and empowerment of persons affected by leprosy, 2) socioeconomic development and 3) contact between the community and persons affected by leprosy. The first two addressed stigma perceived and experienced by affected persons; the latter addressed stigma in the community. The contact intervention comprised testimonies, participatory videos and comics given or made by people affected by leprosy were used as methods to facilitate a dialogue during so-called 'contact events' that brought together affected persons and community members. The baseline survey showed a lack of knowledge about leprosy, a high level of stigma and contrasting examples of support to affected persons. In total, 91 contact events were organized in 62 villages, directly reaching 4443 community members (mean 49 per event). The interview data showed that knowledge about leprosy increased and that negative attitudes and behaviours reduced significantly in the intervention areas. The project concluded that the contact intervention was effective in increasing knowledge and improving public attitudes and behaviour regarding leprosy. It is relatively easy to replicate elsewhere and does not require expensive technology or specialist knowledge.

4.2 Empowering persons affected by leprosy

Persons affected by leprosy have a major role to play in leprosy services, especially in the areas of advocacy, awareness generation and inclusion. Organized efforts by persons affected by leprosy are needed to promote a positive perception and attitude regarding the disease among the public; to bring about essential changes in legal measures, policies and practices that are discriminatory in nature; and to ensure that leprosy continues to occupy an important place in the health policy framework of the country. There is a lack of awareness among policy makers and health managers of the importance of including individuals for whom the services are designed in service planning and evaluation. There is insufficient recognition of the significant contributions that people who have experienced leprosy have made to their communities.

Ensuring that persons affected by leprosy are the central focus of the programme will have profound implications for the way services are planned, delivered and evaluated. A central theme of these guidelines is the recognition of the expertise of individuals who have had the disease and, through partnership, enable them to support the delivery of leprosy services. Efforts should be made to promote opportunities for each individual to realize ways in which they can be involved in leprosy services. This will ultimately lead to individuals affected by leprosy having equal access to quality services and being respected in their roles as contributing members of society.

It will be important to show how participation of affected persons can be realized in practice and, particularly, how it can be structurally embedded in health services, social services and in other settings. For this purpose, promising initiatives should be developed into demonstration models through operational research. The scalability and sustainability of such models should be key criteria for success.

Since 1996, an association formed by persons affected by leprosy has been formed in **Ethiopia,** named Ethiopia National Association of People Affected by Leprosy (ENAPAL). ENAPAL is operating in seven regions of the country with about 66 local associations, which comprise more than 20 000 fee-paying members. The association has been formed to advocate for the rights of persons affected by leprosy, create awareness in the society about leprosy and its consequences, rehabilitate persons affected by leprosy to become productive citizens and to mobilize NGOs and other CBOs in the battle against leprosy. ENAPAL is a member of the Leprosy Expert Advisory Group. This advisory group is led by the Ministry of Health. New branch associations are established and capacitated to address the need of the members. Socioeconomic empowerment of members is an important activity that has had a great impact on individuals' lives and transformed them from begging to leading dignified lives. ENAPAL has been influential to draw attention to the needs of people affected by leprosy and the leprosy situation in Ethiopia.

Proposed actions at global and regional level

(1) Develop training and other materials to facilitate implementation of the global "guidelines on involvement of people affected by leprosy in service delivery".

(2) Facilitate operational research to build models that demonstrate how participation of affected persons can be structurally embedded in various contexts.

(3) Encourage and facilitate sharing of experiences between countries and programmes and within the scientific and public health community regarding involvement of leprosy-affected persons in leprosy services.

Proposed actions in all settings

(1) Include participation of persons affected by leprosy in service delivery in the main policy documents on leprosy management.

(2) Promote empowerment of former patients and build their capacity to contribute to the quality of leprosy services and to advocate for changes in legislation, policies and practices, where needed.

(3) Educate health and social service providers regarding stigmatizing attitudes, practices towards persons affected by leprosy and discriminatory policies and structures.

4.3 Involving communities in actions for improvement of leprosy services

Community members should be involved in disseminating health education messages, referral of persons with suspected leprosy, organizing health camps, promoting regular treatment and supporting persons with disabilities in managing self-care. It is important to work with certain specific subgroups of 'the community'. Family members are automatically involved in the sense of being affected, but are rarely targeted specifically to promote their support of the affected person or involvement in wider services. Models are needed of family-based approaches that can be used as strategies and interventions in leprosy services.

Other categories are (semi-)voluntary health workers, traditional healers and religious leaders. All of these groups are likely to have the same worldview and culture, and thus attitudes and beliefs regarding leprosy, as the rest of the community. It is important to work specifically with these groups to address their fears, attitudes and beliefs and try to mobilize them in efforts to reduce stigma and for involvement in other aspects of leprosy services. Very positive examples have been reported of the role of female health volunteers in India ("accredited social health activists" or ASHAs) and in Indonesia and Nepal (Kaders/Female Community Health Care Workers) and elsewhere in case detection, treatment monitoring and monitoring of self-care. Similarly, traditional healers have been successfully engaged in suspecting leprosy and supporting referral for diagnosis. Faith leaders are opinion makers in their communities; their active collaboration in reducing stigma and in promoting awareness of leprosy can be very effective. Operational research is needed to document and bring together successful examples of the above activities to make guidelines for scaling up such initiatives and to inform policies and practices elsewhere.

In underserved areas it is necessary to implement strategies that promote self-reliance and self-help, and which should involve community-based organizations so that the activities can be sustained.

Proposed actions at global and regional level

(1) Operational research into involvement of different community groups should be promoted and funded.

(2) Facilitate exchange of successful initiatives. Specific examples of good practice initiatives in community involvement should be collected and shared. They should be examined for scalability and sustainability and be promoted for replication if suitable.

Proposed actions in high-burden settings

(1) Policies and guidelines, especially at the national level, should include working with community volunteers, families, traditional healers and faith leaders.

(2) Build capacity of CBOs through partnership and regional support to facilitate and sustain set up of community support groups.

(3) Train partners within communities to facilitate access and improve services for leprosy.

Proposed actions in low-burden settings

(1) Policies and guidelines, especially at the national level, should include working with community volunteers, families, traditional healers and faith leaders.

(2) Build capacity of CBOs through partnership and regional support to facilitate and sustain set up of community support groups for NTD or jointly with other communicable diseases programmes.

(3) Train partners within communities to facilitate access and improve services for leprosy and other diseases.

International Association for Integration, Dignity and Economic Advancement (IDEA)

IDEA is an international advocacy organization whose leadership is primarily made up of individuals who have personally experienced leprosy. Established in 1994, IDEA has 20 000 members in more than 30 countries. It is dedicated to the principle that individuals, whose lives have been challenged by leprosy, have the right to full and equal participation in society, including the right to equal justice, equal opportunity, and equal dignity without discrimination.

IDEA's most valuable resource is the wisdom, achievements and inspiring words of individuals around the world, who have turned a diagnosis of leprosy into a personal challenge and ultimately a personal victory. Website: www.idealeprosydignity.org

4.4 Promoting coalition-building among persons affected by leprosy

There are multiple advantages of people organizing themselves in groups. Peer groups can support each other in many ways. They may offer moral, psychological, spiritual, social or practical support. An example of the latter are the many self-care groups, where the focus of the support is on practical level: helping each other to practise effective self-care to prevent (further) disabilities. These groups often offer each other types of support also and, not infrequently, they evolve into self-help groups in which socioeconomic developments become the main reason for operating as a group.

Groups are also able to achieve more together than individuals can on their own. This is particularly important in lobbying and/or standing up for one's rights in particular situations. Groups can elect leaders and representatives who can represent them during consultations or decision-making processes. Linking up with other persons affected by the disease might help in getting out from the isolation and open up opportunities to receive loans with a shared risk and related benefits. Government services and NGOs who want to collaborate with affected persons, often will need them to be organized so that a group leader or representative can be invited to speak on behalf of the group. Membership of a self-care or self-help group has been shown to be beneficial for reducing internalized stigma and its effects, such as low self-esteem and depression.

It is therefore an advantage if people organize themselves in self-help organizations. These can operate as organizations of persons affected by leprosy or join larger organizations or networks of DPOs. Together they often have much more power to advocate for realization of rights or improvements in services. To achieve this, people affected need to be empowered and guided on how to build local, regional and

Proposed actions at global and regional level

(1) Encourage national associations and coalitions of affected persons' organizations to exchange experiences and form larger networks.

Proposed actions in high-burden settings

(1) Organize or facilitate training of members, leaders and representatives of self-help organizations to develop leadership, organizational and governance skills.

(2) To offer opportunities to leaders and representatives of affected persons' organizations to gain experience in governance and decision-making processes through meeting attendance, participation in capacity-building workshops and providing opportunities to present in public national and international forums.

(3) Facilitate the formation of a national-level coalition of affected persons' organizations and/or a coalition of DPOs/CBOs in which these organizations participate.

Proposed actions in low-burden settings

(1) To offer opportunities to leaders and representatives of affected persons' organizations to gain experience in governance and decision-making processes by inviting them to meetings.

(2) Facilitate the formation of a national-level coalition of affected persons' organizations and/or a coalition of DPOs/CBOs in which these organizations participate in coordination with other programmes' initiatives.

Brazil enacted Law 11.520 of 18 September 2007, which provides special pension for persons affected by leprosy. The Ministry of Health in partnership with nongovernmental organizations and social movements also supports actions to promote dialogue on compensation for damage caused to patients affected by leprosy as well as the children of the victims of compulsory isolation.

In order to reduce the exclusion barriers, Brazil has advanced in implementing the necessary support to the full and effective exercise of legal capacity of all persons with disabilities to have committed to equality of opportunities through the National Rights of Persons Plan with Disabilities – Live without limit.

Some states have enhanced the actions of social reintegration through self-care groups to promote income generation, user empowerment and promotion of access to basic education.

national coalitions. They need to be trained in group organization, democratic processes, organizational skills, governance, human rights and approach and techniques for lobby and advocacy. NGOs or other CBOs may support such training and facilitate empowerment by allowing people to gain experience by attending their meetings, etc. CBOs formed by persons affected by leprosy may then link up with other associations of persons affected by other diseases/conditions, with DPOs and/or with CBOs/coalitions working on social aspects. The national leprosy programme, other services and also NGOs may draw up memoranda of understanding with such organizations to formalize their role and involvement.

4.5 Promoting access to social and financial support services

Leprosy-related stigma and discrimination, along with disease complications, such as reactions and disabilities have forced thousands of people deeper into poverty. In some cases, this resulted in homelessness and a life as street beggars. In some high-burden countries persons with leprosy-related disabilities are not yet eligible for support under existing social support schemes for disabled persons. Evidence shows that certain chronic complications, such as Type 2 reactions constitute a major economic burden for households of affected persons, while the majority already have a low socioeconomic status.

Continued advocacy and negotiations are needed to improve and expand social protection coverage in favour of leprosy-affected persons. This can be done through a close interaction between ministries of health and ministries for social welfare. Organizations of persons affected by leprosy can play an important role in lobbying as rights-holders for adequate social security. In most high-burden countries there are NGOs supporting income generating activities for persons affected by leprosy but their coverage is limited and thus can only be complementary to government social protection schemes. Disabilities, social rejection and exclusion last well beyond the medical treatment of leprosy. Therefore, the cumulative number of persons living with physical or psychosocial consequences of leprosy is likely to be several millions. Fortunately, not all are in need of support, since many have learned to cope and are managing well on their own. Leprosy services should be ready to assist those who cannot manage by themselves. Often this is increasingly true when people become elderly or may no longer have the traditional social support network.

Proposed actions proposed in all settings

(1) Periodically supervise services to ensure that treatment for leprosy is provided free-of-charge.

(2) Ensure that health insurance schemes cover post-treatment care for complications and disabilities.

(3) Ensure awareness of the availability of free services and their location/providers.

(4) Advocate for equal opportunities and access to social protection schemes for persons affected by leprosy.

(5) Establish a national focal point to facilitate access to social schemes by leprosy-affected persons. This could be a person, for example a representative of an affected person's organization, but it could also be a telephone helpline or internet helpdesk.

(6) Promote research of catastrophic costs related to care for leprosy to facilitate access for support for treatment completion and management and treatment of disabilities.

4.6 Supporting community-based rehabilitation for people with leprosy-related disabilities

Leprosy may lead to physical impairments, limitations in activities, and problems in social participation. The latter includes problems in relationships, employment and education. These in turn may lead to economic problems. Physical rehabilitation includes physiotherapy and occupational therapy, orthotics and prosthetics services, assistive and protective devices and sometimes corrective surgery. Social and economic rehabilitation aims at social inclusion, equal opportunities and improving livelihoods, thus, optimizing inclusion of the affected person and his/her family in their community and in society.

The World Health Organization introduced a strategy called community-based rehabilitation (CBR). CBR is defined as "a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities" (ref. to Joint Position Paper on CBR, 2004). In 2010, new WHO CBR Guidelines were published. Currently, CBR is viewed as a strategy for disability-inclusive development. It emphasises a rights-based approach in line with the UN Convention for the Rights of Persons with Disability, emphasising principles such as participation, empowerment and equal opportunities for all.

The CBR strategy uses a twin-track approach. The first track aims for the needs of persons with disabilities to be met by mainstream services and facilities. The second track is necessary to provide or facilitate specific actions or provisions to enable persons with disabilities to use mainstream services and facilities. In the case of leprosy, this may be a one-time intervention, such as advocacy by a DPO to change attitudes of teachers in a school to allow children affected by leprosy to join regular classes or to get someone who was fired because of leprosy reinstated in his job. At other times, an ongoing provision may be needed, such as a ramp to make health centres accessible, or an assistive device to facilitate mobility.

Poverty has been identified as a root problem causing and aggravating disability. Addressing poverty is therefore an essential part of CBR. Although most basic CBR activities can be carried out in the person's own community, a proportion of persons with disabilities have to be referred temporarily to specialized services. Close cooperation is needed between specialized services and CBR programmes. Networking among existing services is the essence of CBR and should be actively promoted. CBR is team work and requires full participation of the clients, their families and communities in the rehabilitation process. DPOs need to be involved actively in the planning and management of CBR services.

Persons affected by leprosy, who are in need of rehabilitation, should have access to any existing mainstream rehabilitation and CBR services. Similarly, where leprosy-specific rehabilitation services are available, people with other disabilities should be given access. This facilitates integration, helps to break down stigma and promotes sustainability of rehabilitation services.

Despite the recognition of the importance of CBR, the coverage of services that would ideally be available in a CBR network, and/or the networking between these services still leaves much to be desired. Governments struggle with limited funding and a limited expertise, while NGO efforts have often limited geographic coverage. Leprosy programmes should advocate for adequate policies and resources for CBR services for all persons with disabilities. The needs of persons with leprosy-related disabilities should be mainstreamed in these. It should be recognized, however, that this may require specific advocacy efforts.

The first step is to assess needs for physical, psychological and social rehabilitation services. A parallel activity would be to map available service providers and facilitate referral of those in need to the appropriate service providers. It is fundamental to promote intersectoral collaboration at various levels, since the services required involve several ministries. In addition, multiple nongovernmental stakeholders should be involved, including persons affected by leprosy and their families.

Proposed actions in high-burden settings

(1) Programme managers initiate or join the intersectoral committee or body that is concerned with CBR at ministerial level to advocate for inclusion of the needs of persons with leprosy-related disabilities per se or linked to a national committee on disabilities.

(2) National programmes ensure that national manuals of guidelines for leprosy services are up-to-date with regard to CBR.

(3) Development of networks, identifying services provided by local organizations or government – health, education, labour, social welfare/security, savings and credit programmes, skills training.

(4) National programmes should plan and conduct surveys to establish the number of persons with leprosy-related disabilities in need of various kinds of CBR services.

(5) National programmes should set up electronic mapping of such data, if possible integrated with other NTDs and preferably alongside information on where particular services are available. The latter should be integrated with any general CBR service mapping initiatives.

(6) Staff responsible for leprosy services at provincial and district level, and NGOs working in the leprosy field should promote identification and training community workers and/or social workers to facilitate local implementation of the CBR strategy.

(7) Link persons affected by leprosy with low scores at the participatory scale scores through referral chains with CBR and mental health services at national and subnational levels.

Proposed actions in low-burden settings

(1) Development of networks, identifying services provided by local organizations or government – health, education, labour, social welfare/security, savings and credit programmes, skills training.

(2) National programmes should plan and conduct surveys to establish the number of persons with leprosy-related disabilities in need of various kinds of CBR services.

(3) Link persons affected by leprosy with low scores at the participatory scale scores through referral chains with CBR and mental health services at national and subnational levels.

The Leprosy Mission **Myanmar** in coordination with the National leprosy programme in Myanmar has a strategy of double mainstreaming, which is mainstreaming people affected by leprosy into disability services/organization and mainstreaming people affected by disability into mainstream society. Core to this is the 17 Disability Resources Centres (DRCs) throughout the country. These DRCs provide physiotherapy support; livelihood training and microcredit; awareness of disability rights; help support self-help groups and disabled peoples' organizations; and assist people with disability access services and entitlements. As leprosy-affected people are scattered thinly across the country combining with other disabilities enables more comprehensive and sustainable programmes to be run, there is more scope for peer support with people affected by leprosy being in mixed self-help groups close to where they live. In addition, being in a mixed SHG reduces stigma as leprosy-related disability becomes just one more disability among many (and is not singled out). People with disabilities are facilitated to come together in advocacy in order to have a stronger voice and more influence over policy decisions.

4.7 Abolishing discriminatory laws and facilitating inclusion of persons affected by leprosy

Discrimination against persons affected by leprosy has historically been embedded in legislation and policies. In many endemic countries, persons affected were forcefully segregated from their families and communities for life. National laws enforcing or sanctioning compulsory segregation have all been repealed, but other laws and policies allowing discrimination on account of having leprosy are still in place in some countries. These include compulsory notification of one's leprosy status on immigration forms, laws allowing deportation of migrant workers affected by the disease, laws permitting divorce on account of leprosy and laws and policies restricting voting rights of affected persons. Any of these practices are completely unacceptable from a human rights perspective. The continuation of structural discrimination and other forms of stigma and discrimination discussed above prompted the Human Rights Council of the United Nations to issue Resolution 29/5. The resolution prompts governments to assess current legislation, policies and practices in order to end any legal basis for discrimination.

The Global Leprosy Strategy target of zero discriminatory laws by 2020 fits with the implementation of the above resolution. The first step in monitoring progress towards this is to make an inventory of laws and policies containing discriminatory elements in each leprosy endemic country. Such an inventory cannot be done solely by health programmes themselves. Ministries of health should seek help from ministries of justice, the national human rights councils, organizations of affected persons, and/or concerned NGOs to carry out the assessment. Cooperation with programmes dealing with similar discrimination and exclusion issues, such as gender, mental health and HIV, would be very helpful. While such assessment will need to be carried out at a national level, the inventory should be internationally promoted and coordinated. As rights holders, representatives from affected persons' organizations should be fully engaged in this process. International NGOs could play an important role in facilitating and supporting these inventories. A coordinated effort should be made to repeal all discriminatory laws and change any policies that allow discrimination on account of leprosy.

Proposed actions at global level

(1) Establish a taskforce or partnership to support countries with the assessment of legislation and to monitor progress towards the 2020 target.

(2) Collect information on discriminatory laws (including laws on deportation or limiting civil rights of patients and former patients), policies and practices and the progress towards repealing or modifying these.

(3) Collect and report progress towards the global target of zero discriminatory laws by 2020.

Proposed actions in high-burden settings

(1) National Programme Managers should set up a taskforce to promote and guide the inventory of discriminatory laws, policies and practices. This should include representatives from the Ministry of Justice, National Human Rights Council, affected persons' organization(s) and NGOs interested in supporting this process.

(2) Once any discriminatory laws, policies and practices have been identified, make detailed plans to get these repealed or changed in line with the resolution also through high-level advocacy.

(3) Promote legislation and advocate for policies that facilitate inclusion and create mechanisms to ensure that the rights of the persons affected by leprosy are respected, fulfilled and protected.

(4) Prepare a national guide on leprosy and human rights.

Proposed actions in low-burden settings

(1) National Programme Managers should set up a taskforce to promote and guide the inventory of discriminatory laws, policies and practices. This should include representatives from the Ministry of Justice, National Human Rights Council, affected persons' organization(s) and NGOs interested in supporting this process. This effort could be done jointly with programmes working on care for other stigmatizing diseases, especially in countries with low burden of the diseases and/or low resources.

(2) Once any discriminatory laws, policies and practices have been identified, make detailed plans to get these repealed or changed in line with the resolution of the UNHRC also through high-level advocacy.

(3) Prepare a national guide on human rights for NTD/Communicable Diseases.

Repeal of the Lepers Act in **India**.

Between 2010 and 2015, The Leprosy Mission Trust India's (TLMTI) project "Challenging Anti Leprosy Legislations" sensitized law makers, duty bearers and bureaucrats in relevant ministries and commissions to facilitate repeal of discriminatory legal provisions. In June 2014, the Minister of Law and Justice informed the media of the Government's decision to repeal obsolete laws on the instructions of Prime Minister Narendra Modi. TLMTI saw this as an opportunity to take forward the agenda of repealing The Lepers Act and other provisions. The Lepers Act (1898), which sanctioned the arrest and segregation of persons affected by leprosy into 'leper asylums', had lost both its relevance and was discriminatory. Even though 12 states and five union territories had repealed its application within their respective jurisdictions, The Lepers Act still continued to be in force in the remaining states and union territories. The Law Commission was in the process of drafting 'The Repealing and Amending (Fourth) Bill', 2015, a Bill to repeal 295 obsolete laws. Considering the nature of the law and the recommendations from ILEP members, The Lepers Act (1898) was included in the list of enactments that were sought to be repealed. At the time of passing these bills, the title was changed to the Repealing and Amending (Third) Bill (2015). The Bill was assented by the President of India and published in the Gazette of India in May 2016, which confirmed the repealing of The Lepers Act 1898 in its entirety.

5

Targets and core programmatic indicators

The tables below provide a more detailed definition of the targets of the Global Leprosy Strategy 2016–2020 along with the indicators defined as "core programmatic indicators". These are the sets of indicators that all leprosy programmes globally shall routinely collect, independently from the burden of the disease and the local context. Many more useful indicators shall be collected and used for assessing and monitoring over time the quality of services either routinely or as part of country programmatic reviews. Those will be indicated by the Monitoring and Evaluation Manual, due to be issued by the GLP before the end of 2016.

Targets

Target 1: *Zero G2D among paediatric leprosy patients*

Name	Zero G2D among paediatric leprosy patients
Description	No new registered child cases of leprosy to have G2D, i.e. visible deformities in eyes, hands and feet
Source of information	Patient records available at national/state/province/district/village/urban area/ health centre
Calculation	Enumerate paediatric cases with G2D on record at the end of the reporting year and report as absolute number
Reporting	Annual and in absolute numbers
Relevance	Indicates quality of detection of leprosy and awareness in the community about early symptoms and signs of leprosy

Target 2: *Reduction of new leprosy cases with G2D to less than one case per million population*

Name	Reduction of new leprosy cases with G2D to less than one case per million population
Description	Number of new leprosy cases with G2D case to be brought down to less than one case for every 1 million population (to be calculated at global and national/state level
Source of information	Patient records available at global and national level
Calculation	Numerator: Number of newly diagnosed leprosy cases with G2D at the time of diagnosis divided by (mid-year population) multiplied by 1 000 000 and presented as rate per million population
Reporting	Annual and as rate per million population only for global and national levels
Relevance	Indicates quality of detection, awareness in the community and availability of effective health services The target is applicable at global and at a national level with and for countries with more than 1 million population only

Target 3: *Zero countries with legislation allowing discrimination on basis of leprosy*

Name	Zero countries with legislation allowing discrimination on basis of leprosy
Description	Number of countries or jurisdictions where discrimination against persons affected by leprosy and their family members is allowed legally on the basis of existing legislations, laws and officially accepted practices and procedures
Source of information	National publications, Gazettes and Circulars on Legislations, publications and circulars on principles, rules and regulations, agreements between organizations, on licenses, visa permits, employment regulations of various organizations in countries reporting leprosy judgments on cases of discrimination against persons affected by leprosy and their family members
Compilation	Collect and compile information about laws, official procedures and practices followed prevailing in a country that allows discrimination of persons affected by leprosy and report on number of such legal provisions prevalent in a country
Reporting	Annual and to be reported as number of legislations or regulations or permissions that allow discrimination against persons affected by leprosy and their family members
Relevance	Indicates level of discrimination faced by persons affected by leprosy

Core programmatic indicators

1. Annual new case detection

Name	Number of new leprosy cases reported in a year
Description	Number of leprosy cases diagnosed and reported as new cases in a reporting year in a given area
Source of information	Patient records available at national/state/province/district/health centres
Calculation	Enumerate all new diagnosed leprosy cases during the year in a given area (global, national, state, province, district) from where the cases were detected and reports as absolute numbers
Reporting	Annual and reported as absolute numbers
Relevance	Indicates magnitude of leprosy burden in a given area

2. Annual new case detection rate (per 100 000)

Name	Annual New case detection rate (NCDR)
Description	Number of registered cases of leprosy at the end of the reporting year per 100 000 population
Source of information	Patient records available at national/state/province/ district/village/urban area/ health centre
Calculation	Enumerate all new leprosy cases on record at the end of the reporting year and divide by mid-year population of the area (global, national, state, province, district) from where the cases were reported and multiply with 100 000
Reporting	Annual and as rate per 100 000 population
Relevance	It is a proxy for leprosy incidence in a given area. To be calculated at national and subnational level up to population size of 100 000

3. Prevalence

Name	Prevalence
Description	Number of leprosy cases under treatment in a given area in a specific point of time of the year
Source of information	Patient records available at national/state/province/district
Calculation	Enumerate all diagnosed leprosy cases under treatment during the year in a given area (global, national, state, province, district) from where the cases were detected and reports as absolute numbers
Reporting	Annual and reported as absolute numbers
Relevance	Indicates magnitude of leprosy burden and it is used to calculate MDT requirements

4. *(Point) Prevalence rate (per 10 000)*

Name	Prevalence rate (PR)
Description	Number of registered cases of leprosy on multidrug therapy (MDT) at the end of the reporting year per 10 000 population
Source of information	Patient records available at national/state/province/district/village/urban area/health centre
Calculation	Enumerate all leprosy cases on record for multidrug therapy at the end of the reporting year and divide by mid-year population of the area (global, national, state, province, district) from where the cases were reported and multiply with 10 000
Reporting	Annual and as rate per 10 000 population
Relevance	It is a proxy for point prevalence in a given area; therefore, indicates magnitude of leprosy burden. It helps to calculate MDT requirement for the area (global, national, state, province, district, village, urban area or health centre). It shall be calculate only for areas with a population of at least 10 000 inhabitants

5. *Proportion of Grade 2 disability cases among new cases*

Name	Proportion of new grade 2 disability cases
Description	Proportion of new leprosy cases detected with grade 2 disability at registration for MDT among new cases detected during the reporting year
Source of information	Patient records available at national/state/province/district/health centres
Calculation	Enumerate all new leprosy cases detected with grade 2 disability at registration for MDT during the year and divide by new cases detected (global, national, state, province, district) from where the cases were detected and multiply with 100 Note: cases transferred in, cases continuing MDT after completing prescribed course of 6 or 12 pulses, relapse cases and cases registered as others should be excluded from the list of cases on record for calculation of proportion of new grade 2 disability cases among new cases
Reporting	Annual and reported as proportion in percentage
Relevance	Reflects the capacity to detect leprosy in a given area; high % are associated with delay in diagnosis

6. *Proportion of paediatric cases among new cases*

Name	Proportion of paediatric cases among new cases
Description	Proportion of new child leprosy cases among new cases detected during the reporting year and registered for MDT
Source of information	Patient records available at national/state/province/district /health centre
Calculation	Enumerate all paediatric leprosy cases (of age below 15 years), leprosy cases detected in a given area and registered for MDT during the year and divide by new cases detected in a given area (global, national, state, province, district) from where the cases were detected and multiply by 100
Reporting	Annual and reported as proportion in percentage
Relevance	Indicates transmission of leprosy in a given area (global, national, state, province, district, village, urban area or health centre). It is a sensitive indicator to measure transmission trends

7. *Proportion of MB cases among new cases*

Name	Proportion of multi-bacillary (MB) cases among new cases
Description	Proportion of leprosy cases grouped under multi-bacillary (MB) type at registration for MDT among new cases detected during the reporting year
Source of information	Patient records available at national/state/province/district
Calculation	Enumerate all leprosy cases grouped under multi-bacillary (MB) at registration for MDT during the year and divide by new cases detected (global, national, state, province, district) from where the cases were detected and multiply by 100
Reporting	Annual and reported as proportion in percentage
Relevance	Indicates magnitude of leprosy problem and its transmission in a given area (global, national, state, province, district, village, urban area or health centre). It also reflects the detection capacity since good health services shall be able to detect leprosy early when most cases are PB

8. *Proportion of female cases among new cases*

Name	Proportion of female cases among new cases
Description	Proportion of females diagnosed as leprosy and registered for MDT among new cases detected during the reporting year
Source of information	Patient records available at national/state/province/district /health centre
Calculation	Enumerate all new females diagnosed as leprosy and registered for MDT during the year and divide by new cases detected (global, national, state, province, district) from where the cases were detected and multiply by 100
Reporting	Annual and reported as proportion in percentage
Relevance	Indicates magnitude of leprosy problem among women in a given area (global, national, state, province, district, village, urban area or health centre). It also reflects the accessibility to leprosy services for women and indirectly informs about quality of services provided

9. *Proportion of foreign-born cases among new cases*

Name	Proportion of foreign-born cases among new cases
Description	Proportion of foreign-born diagnosed as leprosy and registered for MDT among the total new cases detected during the reporting year
Source of information	Patient records available at national/state/province/district
Calculation	Enumerate all new foreign-born diagnosed as leprosy cases and registered for MDT during the year and divide by new cases detected (global, national, state, province, district) from where the cases were detected and multiply by 100
Reporting	Annual and reported as proportion in percentage
Relevance	Indicates magnitude of leprosy local transmission in a given area (global, national, state, province, district, village, urban area or health centre). It also reflects the accessibility to leprosy services for foreign-born and indirectly informs about quality of services provided

10. *Number of relapses in a year*

Name	Number of relapses reported in a year
Description	Number of leprosy cases diagnosed as Relapse and reported as relapses in a reporting year in a given area
Source of information	Patient records available at national/state/province/district/health centres
Calculation	Enumerate all diagnosed leprosy relapse cases during the year in a given area (global, national, state, province, district) from where the cases were detected and reports as absolute numbers
Reporting	Annual and reported as absolute numbers
Relevance	Reflects the quality of treatment services provided. Indicates magnitude of transmission of leprosy. If the number raises, it might suggest circulation of drug resistant strains

11. Treatment completion/cure rate of MB cases

Name	Treatment completion/cure rate of MB cases
Description	Proportion of MB cases who have completed MDT within 18 months from the start date of treatment among those registered for MDT in a year
Source of information	Patient records available at health centre and leprosy registers available at districts
Calculation	The treatment completion/cure rate is calculated through cohort analysis. A cohort is a batch or a group of patients who started MDT in a year in a given area (global, national, state, province, district) Enumerate all MB cases registered for MDT two years before Year Y as a cohort (Y- 2 cohort) From this Y-2 cohort, count the number of MB cases who have completed treatment with 18 months from the start date of MDT and multiply by 100
Reporting	Annual and reported as proportion in percentage
Relevance	Treatment completion/cure rate of MB cases informs the proportion of patients who have completed their treatment on time. It is an indication of quality of services provided, supervised and how well the patients are served in a given area (global, national, state, province, district, village, urban area or health centre). It also reflects the accessibility to leprosy services

12. Treatment completion/cure rate of PB cases

Name	Treatment completion/cure rate of PB cases
Description	Proportion of MB cases who have completed MDT within 9 months from the start date of treatment among those registered for MDT in a year
Source of information	Patient records available at health centre and leprosy registers available at districts
Calculation	The treatment completion/cure rate is calculated through cohort analysis. A cohort is a batch or a group of patients who started MDT in a year in a given area (global, national, state, province, district) Enumerate all PB cases registered for MDT one year before Year Y as a cohort (Y- 1 cohort) From this Y- 1 cohort, count the number of PB cases who have completed treatment with 9 months from the start date of MDT and multiply by 100
Reporting	Annual and reported as proportion in percentage
Relevance	Treatment completion/cure rate of PB cases informs the proportion of patients who have completed their treatment on time. It is an indication of quality of services provided, supervised and how well the patients are served in a given area (global, national, state, province, district, village, urban area or health centre). It also reflects the accessibility to leprosy services and indirectly informs about quality of services provided

13. *Percentage of contacts screened among the household contacts registered*

Name	Percentage of contacts screened among the household contacts registered
Description	Proportion of household contacts screened among all household contacts of registered patients during the year
Source of information	Patient records available at health facility
Calculation	Enumerate all household contacts screened for leprosy during the year and divide by household contacts registered (global, national, state, province, district) from where the cases were detected and multiply with 100
Reporting	Annual and reported as proportion in percentage
Relevance	Indicates coverage of case detection among household contacts of registered patients in a given area (global, national, state, province, district, village, urban area or health centre). The higher the better since contacts are the highest risk group to contract leprosy in any country

6

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7

Glossary

- A-MDT: Accompanied-MDT a policy in which the patient is provided the entire supply of MDT at the time of diagnosis while asking someone close or important to the patient to assume the responsibility of helping him/her to complete treatment.
- Case of leprosy: a person with symptoms and/or signs of leprosy who requires chemotherapy.
- Corticosteroids: a group of drugs known for their ability to suppress inflammatory response.
- Defaulter: an individual who fails to complete treatment within an identified prescribed time-frame.
- Disability: a broad term covering any impairment, activity limitation or participation restriction affecting a person.
- DOT: means that a trained health-care worker or other designated individual (excluding a family member) provides the prescribed drug and watches the patient swallow every dose.
- EHF score: sum of the individual disability grades for each eye, hand and foot.
- Impairment: problem in body function or structure, such as a significant deviation or loss.
- Indicator: measurable aspect of a programme, which can indicate the level of performance and changes in performance.
- Multibacillary (MB): a leprosy patient with six or more skin patches.
- NGO: nongovernmental organization.
- Nerve function loss: loss of normal nerve functioning, demonstrated by loss of sensation (loss of feeling or numbness) in the skin served by the nerve and/or weakness of muscles supplied by the nerve.
- New case: a case of leprosy that has never been treated with anti-leprosy chemotherapy.
- Paucibacillary (PB): a leprosy patient with up to five skin patches.
- Programmatic indicator: numerical parameter related to the quality of the leprosy programme management reflecting the quality of the various aspects of leprosy elimination (diagnosis, treatment, disability management, prevention).
- Pulse dose: MDT is frequently referred to as being given on a ‘monthly’ basis; in fact, MDT blister packs provide 28-days, or 4 weeks, of treatment. Appointments must therefore be scheduled every 4 weeks, not strictly on a monthly basis.
- Reaction: sudden appearance of symptoms and signs of inflammation in the skin of a person with leprosy.
- Relapse: re-occurrence of the disease at any time after the completion of a full course of treatment (but typically after 2 years upon treatment completion).

The "Global Leprosy Strategy 2016–2020, Accelerating towards a leprosy-free world", was officially launched on 20 April 2016. Its overall goal is to further reduce the burden of leprosy while providing more comprehensive and timely care following the principles of equity and social justice. The purpose of this Operational Manual is to provide guidance for managers of national leprosy programmes (or equivalent entities) to adapt and implement the Global Leprosy Strategy in their own countries. It follows the structure of the global strategy, providing a list of suggested actions under each of the three strategic pillars: i) strengthen government ownership and partnerships; ii) stop leprosy and its complications; and iii) stop discrimination and promote inclusion. Adapting the suggested actions to national contexts will help countries to reach the global targets set for the year 2020. The Operational Manual has been developed by the World Health Organization with inputs from various core stakeholders such as national programme managers, technical agencies, funding agencies and nongovernmental organizations.

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