

Strategy to Sustain Leprosy Services Following Elimination in Asia and the Pacific



World Health Organization
South-East Asia Region Western Pacific Region

Strategy to Sustain Leprosy Services Following Elimination in Asia and the Pacific

2005



World Health Organization

South-East Asia Region

Western Pacific Region

WHO Library Cataloguing in Publication Data

Strategy to sustain leprosy services following elimination in Asia and the Pacific.

1. Leprosy -- prevention and control. 2. Asia. 3. Pacific Islands.

ISBN 92 9061 206 1 (NLM Classification: WC 335)

© World Health Organization 2005

All rights reserved.

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by the World Health Organization in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

The World Health Organization does not warrant that the information contained in this publication is complete and correct and shall not be liable for any damages incurred as a result of its use.

Publications of the World Health Organization can be obtained from Marketing and Dissemination, World Health Organization, 20 Avenue Appia, 1211 Geneva 27, Switzerland (tel: +41 22 791 2476; fax: +41 22 791 4857; email: bookorders@who.int). Requests for permission to reproduce WHO publications, in part or in whole, or to translate them - whether for sale or for noncommercial distribution - should be addressed to Publications, at the above address (fax: +41 22 791 4806; email: permissions@who.int). For WHO Western Pacific Regional Publications, request for permission to reproduce should be addressed to Publications Office, World Health Organization, Regional Office for the Western Pacific, P.O. Box 2932, 1000, Manila, Philippines, Fax. No. (632) 521-1036, email: publications@wpro.who.int

Acknowledgements:

The contribution and the valuable comments of the following writing committee members on the drafts of the document are gratefully acknowledged:

Pieter Feenstra, Tran Hau Khang, Lai Ky, Krisada Mahotarn, S.K. Noordeen, P.S. Rao, Sunil Settinayake, Shen Jianping, W.C.S. Smith, and Yo Yuasa.

The Leprosy Units of WHO South-East Asia Regional Office (SEARO) and WHO Western Pacific Regional Office (WPRO) jointly published this publication, in collaboration with WHO Headquarters.

For correspondence:

SEARO: Dr Jai P. Narain, Director–CDS [narainj@whosea.org]; and Dr Derek Lobo, Regional Adviser–Leprosy [lobod@whosea.org]

WPRO: Dr Dong Il Ahn, Regional Adviser–Stop TB and Leprosy Elimination [ahnd@wpro.who.int]; and Dr Sumana Barua, Medical Officer, Leprosy Elimination [baruas@wpro.who.int]

Contents

Preface.....	7
1. Background: Leprosy Situation.....	9
1.1 South-East Asia Region	9
1.2 Western Pacific Region	9
1.3 Justification for a new strategy for leprosy	10
1.4 Informal consultative meeting in Western Pacific Regional Office in 2003	11
2. Strategy to Sustain Leprosy Services following Elimination in Asia and the Pacific	13
2.1 Strategy	13
2.2 Objective	13
2.3 Key elements of the strategy	13
2.3.1 Integration of leprosy services into general health services	13
2.3.1.1 Detection of leprosy cases under low endemic conditions	14
2.3.1.2 Management of cases, including rehabilitation	15
2.3.1.3 Referral services and capacity building	15
2.3.1.4 Logistics and supply of MDT	16
2.3.2 Sub-national approaches.....	16
2.3.3 Monitoring, supervision, surveillance and evaluation	17
2.3.4 Political commitment and partnerships	18
2.3.4.1 Advocacy for political commitment.....	18
2.3.4.2 Partnerships	19
2.3.4.3 The role of WHO	20

Preface

The elimination of leprosy is one of the success stories in public health. With the advent of multidrug therapy (MDT), which WHO has promoted since the early 1980s, cases of leprosy have decreased remarkably worldwide. The global goal of eliminating leprosy as a public health problem (prevalence of less than 1/10 000 population) by the year 2000 has been achieved in time. In 113 out of the 122 countries where leprosy was endemic in 1985, the goal has been achieved as well at the national level. More than 14 million around the world have been cured of the disease.

Leprosy was eliminated as a public health problem in the Western Pacific Region in 1991 and in 35 of the 37 countries and areas in the Region by the end of 2003, leaving only two island countries yet to achieve the goal. The South-East Asia Region, though yet to achieve elimination, has drastically reduced its disease burden, which used to be the world's highest. Eight of the 11 countries in the Region had achieved the goal of elimination by the end of 2003.

But the elimination of leprosy as a public health problem was only an interim goal. The ultimate goal is to reduce the disease burden until leprosy is eliminated throughout Asia and the Pacific and the rest of the world. Because of the long incubation period and low levels of transmission, new cases will continue to occur for many years. In low endemic situations, new approaches will be required to detect and treat cases, manage complications, and integrate cured persons into the community.

Vertical or specialized services that existed in many countries where leprosy was endemic will not be cost-effective. Moreover, when the disease no longer poses a public health problem, there is danger of complacency, less skilful diagnosis and management, low priority accorded to the disease, as well as low political commitment and inadequate resources. Sustaining leprosy services after the elimination of the disease calls for a new strategy.

A biregional consultation between the WHO South-East Asia and Western Pacific regions was therefore held from 30 November to 3 December 2004 in Manila, the Philippines, with participants from 16 Member States, nongovernmental organizations (NGOs), and WHO. This biregional strategy document was developed during the consultation, to sustain quality leprosy services in Asia and the Pacific beyond 2005, and to further reduce the leprosy burden. The main strategy involves timely detection of new cases, multidrug treatment, and the key element of integration of leprosy services into general health services.

It is hoped that this strategy document will be useful to policy-makers, programme managers, national and international NGOs, bilateral and multilateral development partners, and all other stakeholders supporting leprosy work.


Dr Samlee Plianbangchang
Regional Director
South-East Asia Region


Dr Shigeru Omi
Regional Director
Western Pacific Region

1. Background: Leprosy Situation

1.1 South-East Asia Region

Between 1998 and 2003, the prevalence of leprosy in the South-East Asia Region was reduced from 4.1 per 10 000 to 1.90 per 10 000 population, and new cases detected went down from 47.8 per 100 000 to 25.5 per 100 000 population. However, leprosy has yet to be eliminated in South-East Asia, the only WHO Region that still has to achieve this goal, and in three of its countries—India, Nepal, and Timor Leste. In 2003, South-East Asia had 68.5% of the globally registered cases and 81% of the new cases detected that year. India alone accounted for 88% of the prevalence and 91% of the new cases detected in 2003.

Leprosy prevalence and new case detection declined in all countries in 2003 compared with 2002. Of the nearly 14 million cases worldwide that were cured with multidrug therapy (MDT), 11.8 million were from South-East Asia and more than 10 million were from India.

Bangladesh, Bhutan, Indonesia, the Democratic People's Republic of Korea, Maldives, Myanmar, Sri Lanka, and Thailand have all eliminated leprosy at the national level and are working to eliminate it at the subnational level as well.

South-East Asia, including India, Nepal, and Timor Leste, expects to eliminate the disease by December 2005. Political commitment has been sustained in all countries, which are implementing critical and focused activities and have integrated leprosy services into general health services. However, the integration must be further strengthened to ensure the quality of leprosy services after elimination.

1.2 Western Pacific Region

Leprosy as a public health problem was eliminated in the Region in 1991 (prevalence rate of less than 1/10 000 population), and by the end of 2000 had been eliminated in 35 of 37 countries (with more than 99.9% of the population of the Region). Only the Federated States of Micronesia and Marshall Islands,

both with small populations, had yet to eliminate leprosy as a public health problem by the end of 2003.

At the end of 2003, the Western Pacific Region had 10 449 registered cases (versus 67 593 in 1991) and a prevalence rate of 0.06/10 000. New cases reported that year numbered 6165 (14 674 in 1991); the case detection rate was 0.36/100 000. Around 90% of the registered and new cases were in areas with prevalence rates of less than 0.5/10 000 population. A considerable number of cured patients with disabilities still need rehabilitation.

The prevalence rate in the Region has continued to decline following elimination and has also declined in most of the highly populated countries in the Region. New case detection declined by 56.7% in the Region between 1998 and 2003 and declined as well in countries with large populations following elimination. In countries with small populations, both prevalence and new case detection rates have fluctuated following elimination.

When countries like Cambodia, Lao People's Democratic Republic, Papua New Guinea, Philippines, and Viet Nam achieved the goal of elimination, many areas at the first subnational level still have prevalence rates of more than 1/10 000, but the number of such areas is gradually decreasing.

A post-elimination surveillance system has been in place in selected provinces of Cambodia since 2000 as a pilot project. Leprosy elimination monitoring exercises were also conducted in Cambodia, Papua New Guinea, and Viet Nam as part of the evaluation.

Four countries and areas in the Region—Mongolia, Niue, Pitcairn Islands, and Wallis and Futuna—have never reported any cases of leprosy.

1.3 Justification for a new strategy for leprosy

Since the elimination of leprosy as a public health problem was only an interim goal to reduce the disease burden, it is expected that new cases of leprosy will continue to occur at low levels of transmission. The disease is not uniformly distributed; there are still pockets of endemicity at the sub-national level. At the same time, because elimination has left very few cases in the community, diagnostic expertise and general awareness of the disease are likely to decline. New cases may therefore occur without being detected and treated in time. But even after the disease has been eliminated at both national and sub-national levels, a considerable number of cured patients with disabilities will still need physical, socio-economic, and psychological rehabilitation. Vertical service structures that may exist will not be cost-effective if prevalence is low. If the disease is no longer a public health problem, complacency and low priority

accorded the disease could weaken political commitment and constrict resources. A revised strategy is therefore needed to ensure that new cases are detected and treated in time.

To build on the achievements so far, identify the remaining challenges, and develop appropriate approaches for the future, it was considered necessary to review the leprosy situation in the Western Pacific and South-East Asia regions and to formulate an overall post-elimination strategy for the two regions. The aim is to propose sustainable activities at the various levels of health care in the member countries and areas.

1.4 Informal consultative meeting on the strategy for sustaining leprosy services in 2003

An informal consultative meeting at the Western Pacific Regional Office in Manila on 28 and 29 November 2003 was attended by national and international experts in leprosy. The objectives of the meeting were:

- (1) to review the leprosy situation and the progress of regional leprosy elimination;
- (2) to discuss and outline the key elements in regional post-elimination strategies; and
- (3) to discuss future steps needed to further develop and finalize a comprehensive regional post-elimination strategy.

The report of the consultative meeting was presented to the WHO Technical Advisory Group (TAG) at its meeting in February 2004. At this meeting, the South-East Asia Regional Office expressed its willingness to collaborate with the Western Pacific Regional Office in developing a biregional post-elimination strategy for leprosy.

A biregional meeting in Manila from 30 November to 3 December 2004 resulted in this draft strategy.

2. Strategy to Sustain Leprosy Services following Elimination in Asia and the Pacific

2.1 Strategy:

Timely new case detection and treatment with multidrug therapy (MDT).

2.2 Objective:

To further reduce cases of leprosy and sustain good-quality leprosy services including rehabilitation.

2.3 Key elements of the strategy

- Integration of leprosy services into general health services
 - Detection of leprosy cases under low endemic conditions
 - Management of cases including rehabilitation
 - Referral services and capacity building
 - Logistics and supply of MDT
- Sub-national approaches
- Monitoring, supervision, surveillance and evaluation
- Political commitment and partnerships
 - Advocacy for political commitment
 - Partnerships
 - The role of WHO

A brief description of each of the key element is given below:

2.3.1 Integration of leprosy services into general health services

Leprosy services, to be sustained, must be integrated into general health services. Integration involves many elements including training for general health staff and equipment of health facilities to detect and manage cases, supervision,

information systems, and good drug management. But the level of integration may vary from country to country depending on the infrastructure. Since integration is important in all countries, it should be supported and promoted. Existing health care facilities and personnel should be used to make the programme sustainable during the post-elimination period and to ensure good coverage, better accessibility, and cost effectiveness. Countries should document how leprosy services are organized within general health services and give specific details for the various levels at which leprosy should be suspected, *diagnosed*, *confirmed*, and *treated*.

2.3.1.1 *Detection of leprosy cases under low endemic conditions*

Case detection and diagnosis. Cases must be detected in time and diagnosed correctly to prevent transmission and reduce the risk of disability. However, cases are often detected very late after the onset of clinical symptoms and signs of the disease. There are many reasons for this, such as ignorance of the signs and symptoms of disease, lack of skill among general medical practitioners in diagnosing leprosy, the social stigma attached to the disease, low accessibility and affordability of health services, and certain cultural beliefs and practices.

Information, education, and communication (IEC) activities to increase awareness of leprosy in communities and schools, and the involvement of private practitioners and traditional healers, will heighten sensitivity to cases and facilitate timely and voluntary reporting of cases to health facilities. Household contacts of cases are considered to be at higher risk of infection and should be encouraged to report voluntarily. Similarly, orientation and in-service training for health staff will improve their awareness of leprosy and help them to detect cases at outpatient clinics and during field visits.

Leprosy is primarily diagnosed on the basis of clinical findings. As the number of cases continues to decrease, diagnostic expertise will decline, especially in peripheral health facilities, and so will awareness of the disease in the community and among health staff. Therefore, in some countries the peripheral facilities may need to have their diagnosis confirmed through referral. WHO-recommended standard definitions and examination procedures, a simple built-in system of routine validation of diagnosis (at least on a sample basis), and periodic on-the-job training of staff as part of routine supervision will be important in improving the quality of diagnosis. Since most leprosy cases present with skin lesions, specialized skin care facilities would be very useful and should therefore be strengthened.

2.3.1.2 Management of cases including rehabilitation

Clinical findings should be properly documented by the responsible staff on standard forms at the referral centres. Referral and peripheral health facilities should communicate to ensure that the treatment is completed in time and the details of the treatment are documented. Cases should start MDT at the centre where diagnosis is confirmed, and treatment should continue at the centre or at a health facility nearer to the patient's residence, at the patient's own discretion. Accompanied MDT may also be given where appropriate. Countries or areas with low rates of treatment completion and cure should promote the use of accompanied MDT as a policy for certain categories of patients—those from hard-to-reach or distant areas, migrant labourers, nomads, those with jobs which entail constant travel, etc. Complications such as reactions and plantar ulcers should be treated promptly in peripheral facilities or referred to referral centres, if required, and followed up. Reconstructive surgical facilities should be made available to leprosy patients in general hospitals.

Rehabilitation of patients: Some leprosy patients will need rehabilitation—physical, social, economic, and psychological—either while undergoing MDT or after treatment, because of disabilities and deformities caused by leprosy. The rehabilitative services available to persons with disabilities from other diseases should also be made available to leprosy patients. Community-based rehabilitation (CBR) should be encouraged. Misconceptions about the disease and the social stigma associated with leprosy may sometimes hamper rehabilitation. Improved IEC activities, coupled with social mobilization, may foster more favourable social attitudes and reduce the social stigma.

Some rehabilitation practices, such as having separate schools for children of those affected with leprosy, separate wards for leprosy cases, and separate operation theatres for reconstructive surgery on leprosy cases, must be strongly discouraged and discontinued.

2.3.1.3 Referral services and capacity building

When the number of cases goes down, the diagnostic and management expertise of staff is likely to decline, starting at the periphery, since they will see fewer cases each year. In some countries, the diagnosis and management of leprosy services may need to be shifted to the referral level.

Referral facilities at intermediate or higher levels of general health services, depending on the country, should be designated as referral facilities for leprosy. These referral facilities would (a) diagnose and classify new cases for MDT; (b) diagnose and treat reactions or nerve involvement in general; (c) diagnose and

treat drug reactions; (d) diagnose and treat post-MDT reactions and relapse; (e) care for plantar ulcer or any other physical problem associated with leprosy, if such care cannot be provided at the peripheral level; (f) supervise and monitor health workers treating leprosy; and (g) provide on-the-job training in leprosy to health workers.

These referral facilities should have at least one doctor with clinical expertise in leprosy diagnosis and treatment and one public health worker who can apply MDT. The assigned staff at the referral facilities should be adequately trained and equipped to perform their leprosy-related tasks effectively and efficiently. The referral facilities could be stationary units, or the staff could be provided with transport or use public transport to visit the peripheral health facilities that refer cases to them.

The staff at the peripheral health facilities should refer all suspected cases of leprosy and cases with complications to referral health facilities and follow up these cases as advised by the referral facilities. General health staff at all levels must be trained to carry out their assigned tasks in leprosy care and management. The tasks and responsibilities of each category of health staff will vary depending on the level at which they work. The training period could be as short as one day for some staff.

2.3.1.4 Logistics and supply of MDT

Health facilities where leprosy cases are diagnosed and treated must have an assured supply of MDT drugs. Where necessary, the referral centre that first treats a case should provide the MDT drugs to the local unit that will continue the treatment. The drugs and materials for treating complications such as reactions and plantar ulcers should be made available from the pharmacies of general health facilities. Laboratory equipment such as microscopes and staining materials should be provided at referral facilities. Some leprosy patients prefer to get their treatment from private practitioners. Hence, depending on the local situation, private practitioners may also be supplied with MDT drugs through organized professional bodies like medical associations and dermatological societies.

2.3.2 Sub-national approaches

It is well known that leprosy is not uniformly distributed in any given area and that cases tend to cluster. The spatial distribution of cases at different administrative levels must therefore be studied to identify areas and groups of population where cases are more frequent. A geographic information system (GIS) would be useful in identifying pockets of high endemicity and clustered

cases and would aid in understanding the spatial distribution of cases. However, it is important to exclude operating factors as the reason for the clustering of cases, so control measures can be focused where they are most needed and resources can be used cost-effectively. Pockets of high endemicity are better identified through a flexible process that is not strictly limited to administrative areas. What constitutes such areas should be decided by the country programme managers on the basis of past endemicity in the area and the continued occurrence of cases. Particular attention should be paid to urban and peri-urban situations and under-served population groups and areas. Countries should then develop sustainable and effective interventions and use integrated approaches to tackle these highly endemic areas.

2.3.3 Monitoring, supervision, surveillance, and evaluation

Although new case detection will not reflect the true incidence and transmission of leprosy, it can still be a proxy indicator of incidence. The prevalence rate under very low endemic conditions will not be useful in understanding the dynamics of the disease in the community. The long-term trends of the disease must be studied, because of the long incubation period and the time needed for MDT to affect transmission. As such, short-term fluctuations in new case detection may not be of much epidemiological significance. It should be remembered that trends in new case detection would be influenced by operating factors such as case detection activities, IEC activities, and staff competence.

Information should be collected for monitoring at different levels. Information on new cases is most important under conditions of low prevalence. It is important to integrate simplified information, specifically on new cases, into general health information covering large areas. The basic information in the general information systems should include new case detection and, if possible, treatment completion rates.

At the same time, essential information must be available at the centres where cases are diagnosed and managed, and can be used in supervision and programme evaluation.

Records and reports should be kept to a minimum and simplified. Elaborate records and large numbers of reports, especially when the disease is becoming rare, would be burdensome to the general health staff and counterproductive.

A regular report—most likely an annual report from referral centres with more detailed data to provide other indicators of case detection and treatment completion—should be prepared. Central registration of cases will facilitate monitoring. Often, information collected and analysed is not properly stored

and maintained, resulting in information gaps in long-term evaluations. Materials must be actively archived for ready reference and for use in decision making.

The number of indicators should be kept to a minimum but should be enough for effective monitoring and evaluation of the programme. As the number of cases decreases, analysis by absolute numbers—rather than by rates—will be more meaningful and useful. The indicators considered essential are annual case detection, treatment completion rate, and proportion by grade 2 disability, by age and by type among new cases. MDT drug regimens are different for adults and children, and for multibacillary and pauci-bacillary types. Information on the number of cases cured will be useful in measuring the outcome of the programme.

Information must be systematically collected, analysed, and disseminated for better control of all diseases including leprosy. Surveillance acts as an alert mechanism prompting timely action. It also helps us to understand the disease trends and the impact of a programme—its successes and failures. Besides referral centres for the diagnosis of leprosy under general health services, dermatologists and other doctors in both the public and private sectors should be involved in the surveillance of leprosy and should provide information on leprosy cases. Reports on individual new cases and leprosy statistics should be carefully analysed at appropriate levels, and the findings should be forwarded to higher authorities with feedback to the lower levels suggesting appropriate action when necessary.

Programme performance should be regularly evaluated at the central level, with a meeting of subnational staff, to understand problems in the field and find solutions. Performance at the sub-national level could be reviewed periodically along with other health programmes. Research on operations can help improve the quality of the programme. A standard protocol should be developed for programme evaluation.

2.3.4 Political commitment and partnerships

2.3.4.1 Advocacy for political commitment

Specific treatment for leprosy has been available since the early 1950s and several countries in Asia and the Pacific introduced leprosy control programmes in the 1950s and 1960s with Dapsone monotherapy, but these efforts lacked focus on a countrywide scale and suffered from insufficient political commitment and resources. The situation dramatically changed when WHO recommended MDT in the early 1980s, cutting short the treatment and ensuring definite cure of all cases. The adoption of the World Health Assembly Resolution in 1991 calling on Member Countries to eliminate leprosy as a public health problem by

the year 2000, further boosted the programme and resulted in intensified efforts, greater policy support, and increased political commitment and resources. The achievements have been spectacular: by the end of 2003, 113 of the 122 countries that were endemic for leprosy in 1985 had eliminated leprosy at the national level.

However, it must be emphasized that elimination is not eradication. Low levels of transmission are expected to continue for many years after elimination. Once the disease is eliminated, political commitment could gradually disappear and resources could be reduced, not just because cases of leprosy are much fewer but also because other new diseases and health problems demand higher priority.

The political commitment of national governments must be maintained to ensure an adequate flow of resources for a reasonably long period. Therefore, to sustain the gains and make progress towards a leprosy-free society, advocacy campaigns should be planned for key groups such as policy-makers, politicians, senior government officials, media, NGOs, and local leaders.

2.3.4.2 Partnerships

Partnerships should be promoted on the basis of shared objectives, mutual trust, and respect. Nongovernmental, voluntary organizations—national and international—all over the world have entered into partnerships with national governments in support of the fight against the disease and its elimination as a public health problem. Their continued support will be required to sustain effective integrated leprosy services.

A large number of people go to private practitioners of different systems of medicine when they fall sick. In most situations, these private practitioners are the first point of contact. They should therefore be trained to suspect or diagnose leprosy, informed about the availability of MDT free of charge, and motivated to refer suspects or cases to the nearest health facility. Private practitioners can refer cases with complications to the appropriate referral centres under general health services for proper management, where necessary. Public-private partnerships will improve MDT services to patients by offering timely expertise, more accessible treatment, and a wider choice of service provider. Similarly, work places and other services should be involved in identifying cases and assisting leprosy patients.

Nongovernmental organizations often express interest in supporting certain components of these programmes, for example, the rehabilitation of leprosy patients and IEC activities. Much collaboration and coordination between government departments and nongovernmental organizations is required to

optimize the benefits to patients from such activities and support. The ministries of health should take the lead in coordinating the partners. Besides nongovernmental organizations, a number of government departments, like education (for training of doctors and paramedical staff), social welfare, finance, communications and publicity, and transport, can help sustain leprosy activities.

All stakeholders would like to know how their resources are being used and what results have been obtained. Administrators and programme managers should make every effort to share information about their activities at least once a year—how the support from various partners was used, and the outcome of the activities. Partners should have a role in planning, implementing, and evaluating the programme. This will facilitate the continuation of partnerships and, thus, of sustainable gains in the long run.

2.3.4.3 The Role of WHO

WHO will continue to play an important role in sustaining effective leprosy services, particularly in the following:

- (1) Ensuring free MDT supplies with support from partners;
- (2) Carrying out advocacy to sustain political commitment and mobilize the required resources;
- (3) Assisting national governments and their partners in developing country-specific action plans and implementing strategies for sustained leprosy control within general health services;
- (4) Providing technical and operational guidelines for implementing the programme; and
- (5) Maintaining global and regional surveillance.