Report of the Seventh Meeting of the WHO Technical Advisory Group on the Elimination of Leprosy

Geneva, 4-5 April 2005
Annex 3

List of participants

Members

Professeur Henri Assé
Président de l'Association des Léprologues de Langue Française
BP 229, Adzope
Côte d'Ivoire
Tel. office - 00225 23 540461
Fax. 00225 23 540072
E-mail: ginef@aviso.ci

Dr (Mrs) Khin Than Oo
Director
Central Health Education Bureau
Department of Health Planning
Ministry of Health
Myanmar
E-mail: doh@bagamail.net.mm

Dr Paul Saunderson
Leprosy Consultant
American Leprosy Missions (and Executive Officer, International Leprosy Association)
1 AMW Way, Greenville
SC 29601, USA
Tel. 001 864 241 1750
Fax. 001 864 271 7062
E-mail: psaunderson@leprosy.org

Dr Jianping Shen
Institute of Dermatology
Chinese Academy of Medical Sciences
National Centre for STD and Leprosy Control
12 Jingshuxiangiao Road
Nanjing
210042 Jiangsu
People's Democratic Republic of China
Tel. 0086 25 547 8031
Fax. 0086 25 542 1123
E-mail: jianping_shen2@yahoo.com.cn

*Professor W. C. S. Smith
Head
Department of Public Health
Medical School, Palmer Building
University of Aberdeen, Foresterhill
Aberdeen AB9 2ZD, UK
Tel. 0044 224 553802
Fax. 0044 224 662994
E-mail: w.c.smith@abdn.ac.uk

Dr (Mrs) Kiran Katoch
Deputy Director
Central JALMA Institute for Leprosy (ICMR)
P. O. Box 101
Mayo R. Ramanathan Road
Taj Ganj
Agra 282001, India
Tel. 0091 562 331755-4
Fax. 0091 562 331755
E-mail: jalma@zyberway.com

Special Invitees

Dr K.V. Desikan
Chairman
Candhi Memorial Leprosy Foundation
Wardha 442 001, Maharashtra State, India
Tel. 0091 0752 242627
Fax. 0752 232602
E-mail: desikan_wda@sanchamnet.in or gmslur_wda@sanchamnet.in
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Tuesday, 5 April 2005

09:00 – 09:30 Report on the bi-regional meeting on strategy to sustain leprosy services in Asia and the Pacific (Dr S. Barua)
Discussion

09:30 – 10:30 Discussion on the draft Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities: Plan Period 2006-2010
Moderator: Dr P. Feenstra
Introduction: Dr V. Pannikar
Discussion

11:00 – 12:30 Discussion on the draft Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities (cont’d.)

14:00 – 16:30 Discussion on the draft Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities (cont’d.)

17:00 – 17:30 Conclusions and recommendations
Annex 2

Programme

Monday, 4 April 2005

09:00 – 09:15 Welcome (Dr H. Endo)
   Introduction of new members (Dr M. Cunha)
   Opening remarks (Chairperson: Professor W. Cairns Smith)
   Approval of report of 6th TAG meeting (Geneva, February 2004)
   Discussions
09:15 – 09:45 Current global leprosy situation (Dr V. Pannikar)
   Discussions
09:45 – 10:10 Long-term follow-up of highly bacillated patients (Dr K. V. Desikan)
   Discussions
10:10 – 10:35 Social stigma and integration of leprosy services (Dr P. Saunderson)
   Discussions
11:00 – 11:30 Effectiveness of BCG against leprosy among contacts of leprosy patients
   (Dr M. Cunha)
   Discussions
11:30 – 12:00 Validation of diagnosis of newly detected cases in India
   (Dr GPS Dhillon)
   Discussions
   Ensuring the accuracy of the diagnosis of leprosy in routine control programmes
   (Dr P. Saunderson)
12:00 – 12:30 Brief report on the African Leprosy Congress (Professor H. Assé)
   Discussions
14:00 – 15:30 Remaining challenges: Sustaining Leprosy Services beyond 2005
   Brazil (Dr Rosa Castália França Ribeiro Soares)
   India (Dr GPS Dhillon)
   Madagascar (Dr M. Vokoloarinosinjatovo)
   Philippines (Dr BW Rivera)
   Sudan (Dr El Fatih El-Badawi)
   Progress with ongoing multicentre clinical trial for treatment of PB leprosy patients
   with single dose ROM (Professor M. D. Gupte)
   Discussions
15:30 – 16:00 Uniform-MDT regimen for all leprosy patients: progress report
   (Professor M. D. Gupte)
   Discussions
16:30 – 17:30 Uniform-MDT regimen for all leprosy patients: progress report
   (Professor M. D. Gupte)
   Discussions

1. Introduction

The seventh meeting of the WHO Technical Advisory Group on the Elimination of Leprosy (TAG) was held in Geneva, Switzerland, on 4 and 5 April 2005. Professor M.D. Gupte kindly agreed to Chair the meeting since Professor WCS Smith was unable to attend. National Leprosy Programme managers from Brazil, India, Madagascar, Nepal and the United Republic of Tanzania also participated in the meeting. The Technical Commission of the International Federation of Anti-leprosy Associations (ILEP) was represented by its chairperson, Dr Pieter Feenstra.

The meeting’s main objective was to review and finalise the draft Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities: 2006-2010. This succeeds the WHO Strategic Plan for Leprosy Elimination 2000–2005. The large-scale implementation of the Strategic Plan increased the coverage of leprosy control activities and brought many previously undetected cases to health facilities for treatment. The draft Global Strategy 2006-2010, submitted to the TAG, represents the natural evolution of the Strategic Plan 2000-2005, to address the remaining challenges and further reduce the global leprosy disease burden.

2. Report on the sixth meeting of TAG

The report of the sixth meeting of the TAG - held in Geneva on 9 and 10 February 2004, was approved.

3. Current global situation

According to reports from 114 countries, 407 791 new cases of leprosy were detected during 2004 and the global registered prevalence of leprosy was 286 063 cases at the beginning of 2005 (Table 1). The number of new cases detected globally appears to have fallen by around 107 000 cases (21%) during 2004 compared to 2003 (Table 2). This decline was mainly due to a 29% reduction in new case detection in India over the previous year.
Table 1: Leprosy situation in WHO regions at the beginning of 2005 (excluding European Region)

<table>
<thead>
<tr>
<th>WHO Region</th>
<th>Registered prevalence at the beginning of 2005</th>
<th>New cases detected during the year 2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>African</td>
<td>47,596 (0.66)*</td>
<td>46,918 (6.5)**</td>
</tr>
<tr>
<td>Americas</td>
<td>36,877 (0.42)</td>
<td>52,662 (6.0)</td>
</tr>
<tr>
<td>South-East Asia</td>
<td>186,182 (1.14)</td>
<td>298,603 (18.3)</td>
</tr>
<tr>
<td>East Mediterranean</td>
<td>5398 (0.12)</td>
<td>3392 (0.7)</td>
</tr>
<tr>
<td>Western Pacific</td>
<td>10,010 (0.06)</td>
<td>6216 (0.4)</td>
</tr>
<tr>
<td>Total</td>
<td>286,063</td>
<td>407,791</td>
</tr>
</tbody>
</table>

* Prevalence rate is shown in parenthesis as the number of cases per 10,000 population.
** Case-detection rate is shown in parenthesis as the number of cases per 100,000 population.

As demonstrated in Table 2, the reported global annual case detection has declined greatly since 2001. The decline is evident in the Eastern Mediterranean, South-East Asia and Western Pacific Regions, but in the African and Americas Regions the numbers have remained constant.

Table 2: New case detection trend during the years 2001 – 2004 in WHO regions

<table>
<thead>
<tr>
<th>WHO Region</th>
<th>Number of new cases detected</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2001</td>
</tr>
<tr>
<td>African</td>
<td>39,612</td>
</tr>
<tr>
<td>Americas</td>
<td>42,830</td>
</tr>
<tr>
<td>South-East Asia</td>
<td>668,658</td>
</tr>
<tr>
<td>Eastern Mediterranean</td>
<td>4,758</td>
</tr>
<tr>
<td>Western Pacific</td>
<td>7,404</td>
</tr>
<tr>
<td>Total</td>
<td>763,262</td>
</tr>
</tbody>
</table>

Table 3 shows reported new case detection for the past three years in 20 countries that detected 1000 or more new cases during the year 2004. Currently, these 20 countries contribute 96% of global new case detections.

Annex 1

WHO Technical Advisory Group on Leprosy Control

Terms of reference

The WHO Technical Advisory Group on Leprosy Control is composed of experts who are independent of WHO. Members are chosen for their expertise in leprosy and programme management with particular reference to public health, epidemiology, community mobilization and advocacy, operational research and disability prevention. They form a strong team with a good technical balance and geographical representation.

The members of this advisory body are selected and appointed by WHO and meet at least once a year. The period of membership is two years, with the possibility of extension.

The Technical Advisory Group’s deliberations are open to representatives of national and international partners as observers to encourage open debate.

In addition, the Group may invite, as necessary, representatives from selected leprosy endemic countries and other experts to its meetings.

The terms of reference are:

- To review and monitor the implementation of the Global Strategy to further reduce the leprosy burden and sustain leprosy control activities.
- To advise WHO on new strategies and approaches if necessary.
- To monitor progress in further reducing the leprosy burden.
- To give technical advice and guidance on sustaining leprosy control activities.
- To identify and facilitate implementation of a research agenda in order to improve the quality of leprosy control activities, including prevention of disabilities and rehabilitation.
- To support efforts related to reducing stigma and discrimination against individuals and families affected by leprosy.
This strategy will require endorsement and commitment from all those who are working towards the common goal of controlling leprosy to ensure that the physical and social burden of this disease continues to decline everywhere.

Expected outcome

- Further reduction of the disease burden to very low levels.
- Improved quality of diagnosis, case management and registration practices and a good management information system.
- Sustainable leprosy services in all endemic countries.
- Easy and equitable access to quality service through the general health services, including an efficient integrated referral network.
- Adequate tools and resources for POD and rehabilitation.
- Strengthened partnerships and collaborative working arrangements with all partners.

15. Conclusions and recommendations

(1) The TAG encourages examination of the operational and epidemiological factors underlying the increasing and decreasing trends for new case detection observed in various countries.

(2) The TAG encourages continued monitoring of the 12-month MDT regimen for MB leprosy patients.

(3) The TAG recognizes the importance of accurately diagnosing leprosy although it acknowledges the fact that a certain degree of misdiagnosis is unavoidable. It recommends that WHO and its partners develop guidelines which will be appropriate under routine settings to monitor the accuracy of diagnosis and the registering of new cases. This may be carried on a sample basis or through routine supervision.

(4) Legislation discriminating people affected by leprosy in matter of employment, marriage, travel, etc should be reviewed and amended.

(5) The TAG continues to recommend the integration of leprosy control activities into the general health service.

(6) The TAG recommends that the draft Global Strategy for 2006-2010 be reviewed taking into consideration comments from all participants and that an editorial group be formed to carry out the necessary revisions.

The TAG evaluating the data noted that the figures reported were difficult to interpret, since they were heavily influenced by operational factors which vary between countries, and have changed in recent years in response to the elimination target.

### Table 3: Reporting of new case (1000 or more) detection in 20 countries for 2002-2004

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of new cases detected</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angola</td>
<td></td>
<td>4272</td>
<td>2933</td>
<td>2319</td>
</tr>
<tr>
<td>Bangladesh</td>
<td></td>
<td>9644</td>
<td>8712</td>
<td>8242</td>
</tr>
<tr>
<td>Brazil</td>
<td></td>
<td>38365</td>
<td>49206</td>
<td>49384</td>
</tr>
<tr>
<td>Burkina Faso</td>
<td>NA</td>
<td></td>
<td>843</td>
<td>1100</td>
</tr>
<tr>
<td>China</td>
<td></td>
<td>1646</td>
<td>1404</td>
<td>1499</td>
</tr>
<tr>
<td>Cote d’Ivoire</td>
<td></td>
<td>1358</td>
<td>1205</td>
<td>1066</td>
</tr>
<tr>
<td>DR Congo</td>
<td></td>
<td>5037</td>
<td>765</td>
<td>11781</td>
</tr>
<tr>
<td>Egypt</td>
<td></td>
<td>1318</td>
<td>1412</td>
<td>1216</td>
</tr>
<tr>
<td>Ethiopia</td>
<td></td>
<td>4632</td>
<td>5193</td>
<td>4787</td>
</tr>
<tr>
<td>Guinea</td>
<td></td>
<td>1234</td>
<td>929</td>
<td>1097</td>
</tr>
<tr>
<td>India</td>
<td></td>
<td>473658</td>
<td>367143</td>
<td>260063</td>
</tr>
<tr>
<td>Indonesia</td>
<td></td>
<td>12377</td>
<td>14641</td>
<td>16549</td>
</tr>
<tr>
<td>Madagascar</td>
<td></td>
<td>5482</td>
<td>5104</td>
<td>3710</td>
</tr>
<tr>
<td>Mozambique</td>
<td></td>
<td>5830</td>
<td>5907</td>
<td>4266</td>
</tr>
<tr>
<td>Myanmar</td>
<td></td>
<td>7386</td>
<td>3808</td>
<td>3748</td>
</tr>
<tr>
<td>Nepal</td>
<td></td>
<td>11830</td>
<td>8046</td>
<td>6958</td>
</tr>
<tr>
<td>Nigeria</td>
<td></td>
<td>5078</td>
<td>4799</td>
<td>5276</td>
</tr>
<tr>
<td>Philippines</td>
<td></td>
<td>2479</td>
<td>2397</td>
<td>2254</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td></td>
<td>2214</td>
<td>1925</td>
<td>1995</td>
</tr>
<tr>
<td>United Republic of Tanzania</td>
<td></td>
<td>6497</td>
<td>5279</td>
<td>5190</td>
</tr>
<tr>
<td>Total (%)</td>
<td></td>
<td>602537</td>
<td>490051</td>
<td>392290</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(97%)</td>
<td>(97%)</td>
<td>(96%)</td>
</tr>
<tr>
<td>Total Global</td>
<td></td>
<td>620638</td>
<td>514718</td>
<td>407791</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NA: Not available</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4. **Long-term follow-up of highly bacillary leprosy patients**

This long-term follow-up study was conducted by LEPRITA-India in two of its projects. Between 1991 and 1998, these projects registered more than 7000 multibacillary (MB) leprosy patients for treatment with multidrug therapy (MDT). The duration of the treatment was modified according to WHO recommendations. Of 660 MB patients in the study with initial skin smears 4+ or above 64 were treated for four to five years, 227 for three years, 310 for two years and 59 for one year. Most patients were observed for more than four years, and almost 60% of them for more than six years. Only 17 patients were skin smear positive at the time of the last examination in 2004 and none showed any clinical signs of activity. Of the 660 highly bacillary patients kept under surveillance, only 19 (3%) experienced one or more reactional episodes. The study did not report any relapse among these patients. The study adds to the evidence that the risk of relapse is low among highly bacillary patients who receive adequate and regular treatment with MDT.

5. **Social stigma and integration of leprosy services**

There were discussions on the complex relationship between social stigma and integration. Stigma may be an obstacle to integration when personnel in general health services are reluctant to deal with leprosy. On the other hand, integration may result in reducing stigma towards people affected by leprosy who will be treated at par with other members of the community reporting to the general health facility. In addition, integration may increase accessibility, ensure sustainability and promote equitable health care for all members of the community.

There is concern that the policy of integration may lead to a decline in the quality of services for persons affected by leprosy in areas where general health services are relatively less developed. The training of staff at various levels in the general health services must be an essential part of the process of integration to ensure that health care personnel are able to perform essential leprosy control activities.

6. **Effectiveness of BCG against leprosy among contacts of leprosy patients**

This retrospective cohort study was undertaken at the Oswaldo Cruz Foundation, Rio de Janeiro. The main objective of the study was to assess the effectiveness of BCG in preventing leprosy among contacts of leprosy patients. The study included household and non-household contacts of leprosy patients since June 1987 till April 2004.

The Brazilian Ministry of Health has since 1981 officially recommended BCG vaccination for contacts of leprosy patients. In addition, many of the contacts had BCG as and previously untreated leprosy patients (MB 711 and PB 1114) were recruited by March 2005. The intake continued until November 2005.

13. **Report of the bi-regional meeting on strategy to sustain leprosy services in Asia and the Pacific**

The bi-regional meeting to review and finalise the draft strategy to sustain leprosy services in Asia and Pacific was organized during November 2004. The key elements of the strategy included: Integration of leprosy services into general health services, monitoring new case detections, advocacy for political commitment and improved collaboration with partners. The final version of the strategy will be published in mid-2005.

14. **Global strategy for further reducing the leprosy burden and sustaining leprosy control activities: plan period 2006-2010**

The main principles of leprosy control, i.e. timely detection of new cases, their treatment with effective chemotherapy in the form of MDT and prevention of disabilities and rehabilitation, will not change over the coming years. Therefore, the strategy’s focus will remain on providing diagnostic and treatment services that are equitably distributed, affordable and easily accessible. At the moment there are no new technical tools or information that warrant any significant changes in the strategy. However, there is an urgent need to make decisive changes in the organization of leprosy control, attitude of health care providers and beneficiaries, and in the working arrangements between all partners. The main elements of the new strategy should be as follows:

- Leprosy control activities must be sustained in all endemic countries.
- Case detection should be the main indicator used to monitor progress.
- High quality diagnosis, case management, recording and reporting should be ensured in all endemic communities.
- Routine and referral services should be strengthened.
- The campaign approach should be discontinued.
- Tools and procedures that are home/community based, integrated and locally appropriate should be developed for the prevention of disabilities/impairments, and for the provision of rehabilitation services.
- Operational research should be promoted in order to improve the implementation of a sustainable strategy.
- Supportive working arrangements should be encouraged with partners at all levels.
**Major challenges**
- Improving the community’s awareness about early signs of leprosy.
- Special activities for difficult-to-access remote islands.
- Improving supervision, monitoring and reporting.

**10.5 Sudan**
This country with a population of about 36 million is one of the important leprosy endemic countries in the Eastern Mediterranean Region. The programme continues to sustain leprosy control activities with support of partners in spite of the civil war and security concerns in some parts of the country.

**Major achievements**
- Setting up an efficient network of leprosy clinics within primary health care services.
- Efforts to build capacity of health workers to diagnose and manage leprosy.

**Major challenges**
- High proportion of new cases with grade-2 disabilities.
- To rebuild the leprosy control programme in areas affected by civil war.
- Providing services to displaced communities and nomadic tribes.

**11. Progress with ongoing multicentre clinical trial for treatment of PB leprosy patients with single dose of rifampicin, ofloxacin and minocycline**

The main objective of this trial is to compare the efficacy of a single dose of ROM for the treatment of skin smear-negative PB leprosy patients with the standard six-month PB-MDT regimen. A total of 1526 previously untreated PB patients were recruited from five districts in India. All patients are examined at least once every six months. It was agreed that all of them will be followed up for five years. The results of the trial are due in 2006.

**12. Uniform-MDT regimen for all leprosy patients: progress report**

The multicentre study of uniform-MDT (U-MDT) was launched in September 2003 with the participation of four states (Bihar, Maharashtra, Tamil Nadu and Uttar Pradesh) in India and three districts in Guizhou province in China. A total of 1845 newly detected part of routine vaccination programme during childhood (from the time of birth to the age of five).

The study recruited 5102 contacts of 990 index cases. At the time of initial examination, 267 contacts were diagnosed with leprosy (co-prevalent cases), while 95 new cases (incident cases) were detected during the follow-up. The results of the study suggest that BCG revaccination of contacts is highly effective (99% for MB and 82% for PB). Though not obtained from a controlled trial, these data provide further evidence that BCG is protective against leprosy in many populations.

**7. Validation of diagnosis of newly detected cases in India**

In collaboration with WHO and the National Institute of Health and Family Welfare, New Delhi, the Indian national programme carried out a second new case validation exercise during 2004. The objective was to assess the accuracy of diagnosis and classification of newly detected cases of leprosy, the re-registration of old treated cases, and the proportion of untraceable cases. The methodology was similar to that of the exercise conducted during 2003. The final analyses showed results which were similar to those obtained in 2003 confirming that a significant proportion of newly detected cases were either wrongly diagnosed as leprosy (9.4%) or were old cases who have been registered again as a newly detected case and placed under treatment (18.7%).

The programme has identified capacity building of primary health care staff in leprosy diagnosis and management as an important activity. In addition, health staff will be trained in proper history-taking and good registration practices.

**8. Ensuring the accuracy of the diagnosis of leprosy in routine control programmes**

Apart from inaccurate statistics, wrong or over-diagnosis of leprosy causes unnecessary suffering to the persons concerned and their families. Similarly, missed cases or under-diagnosis could be a problem, particularly in areas with limited awareness about the early signs of the disease among community and health care staff. Quantifying the magnitude of missed cases is more difficult than quantifying the extent of wrong or over-diagnosis.

As leprosy is increasingly being diagnosed by staff with limited previous experience of the disease, there is a need for practical methods for checking the accuracy of diagnosis of newly detected cases under programme conditions. One approach would be for supervisors within the health services to review the diagnosis of newly detected cases with their staff as a routine and to continually upgrade staff performance through on-the-job training. In special situations, it may be possible to arrange for the validation of newly detected cases as a part of “external” quality control exercises.
31 January to 3 February 2005

This was the second time that such a meeting was organized for Africa, the last being in Cairo, Egypt in 1938. The Congress was attended by about 270 representatives from 42 countries including some from outside Africa. For the first time, 32 persons affected by leprosy and representing several endemic countries attended the congress. The congress provided a much-needed forum for programme managers and other representatives of endemic countries to discuss challenges and share experiences with their counterparts from other nations.

10. Country presentations: sustaining leprosy control activities beyond 2005

The national programme managers from five endemic countries – Brazil, India, Madagascar, Philippines and Sudan – participated in the meeting. They made brief presentations on the main challenges faced by their programmes in working towards sustaining leprosy control activities.

10.1 Brazil

Brazil is the most leprosy endemic country in the Americas. During 2004, about 50 000 new cases were detected in a population of about 183 million. The disease burden is particularly high in the northern, north-eastern and mid-western regions of the country.

**Major achievements**

- Improved information and reporting systems.
- Decentralization and promoting ownership of the programme to municipalities.

**Major challenge**

- Low service coverage, particularly in major cities.
- High proportion of grade-2 disabilities/impairment among new cases.
- Inadequate referral network to deal with leprosy-related complications.

10.2 India

The disease burden in India remains the highest in the world. During 2004, more than 260 000 new cases were detected in a population of about 1.2 billion. The burden is mainly concentrated in seven states in the northern, north-eastern and central parts of the country which contribute to more than 75% of all new cases detected during the year.

**Major achievements**

- Integration of leprosy control activities within the local primary health services.
- Expansion of community education activities in all states.

**Major challenges**

- Inadequate coordination of leprosy control activities in urban and periurban areas.
- Operational factors leading to low quality diagnostic services and poor registration practices.
- The need for appropriate strategies to deal with prevention of disabilities and rehabilitation.

10.3 Madagascar

Leprosy remains a major public health problem in this country. In spite of many parts of the country remaining inaccessible due to poor communication infrastructure, the programme detects 4000 to 5000 new cases annually in a population of about 18 million inhabitants. Over the last five years new case detection, however, has shown a decline.

**Major achievements**

- Good degree of collaboration with national and international partners and dermatological societies.
- Integration of leprosy control activities with the public health service.

**Major challenge**

- The proportion of disabled among the new cases and children is relatively high.
- Difficulties in access and communication in remote geographical locations.
- Need to improve community awareness about early signs of the disease, in order to promote voluntary self-reporting.

10.4 Philippines

The Philippines is one of the major endemic countries in the Western Pacific Region. The programme detects about 3000 new cases annually in a population of about 86 million inhabitants. New case detection trends have not shown any significant decline over the last few years.

**Major achievements**

- Good degree of collaboration with national and international partners and dermatological societies.
- Integration of leprosy control activities with the public health service.