Summary report on the

WHO-EM/CTD/070/E

# Programme managers' meeting on leprosy elimination in the Eastern Mediterranean Region

Islamabad, Pakistan 10–12 December 2013



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#### WHO-EM/CTD/070/E

#### 1. Introduction

The WHO Regional Office for the Eastern Mediterranean organized a regional meeting of national programme managers of leprosy control programmes from 10 to 12 December 2013. The meeting was held in Islamabad, Pakistan. Its objectives were to:

- Provide an update on the epidemiological situation of leprosy at global and national levels;
- Discuss the progress of implementation during 2012–2013 of the "Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy (plan period: 2011–2015), and outline the plans for 2014–2015; and
- Update the participants on technical issues related to leprosy control.

The meeting was attended by participants from Djibouti, Egypt, Islamic Republic of Iran, Morocco, Oman, Pakistan, Tunisia and Yemen. Among the partner organizations, AID to Leprosy Patients (ALP) in Pakistan, Arkanjelo Ali Association (AAA) in Kenya, The Nippon Foundation and Sasakawa Memorial Health Foundation (SMHF) were represented in the meeting. Attending from WHO were staff from headquarters, the Regional Office and the following country offices: Afghanistan, Pakistan, Somalia, South Sudan and Yemen.

The meeting was opened by Dr Nima Abid, Acting WHO Representative in Pakistan, who delivered the opening remarks. He referred to the International Leprosy Summit that had taken place in Bangkok, Thailand, in July 2013, where the Bangkok Declaration was endorsed and signed by the Ministers of Health from the 18 countries with highest leprosy burden. He also drew attention to the field visit that had taken place on the third day of the meeting. Mr Masato Seko, Chief Manager, The Nippon Foundation, introduced a video message from Mr Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination. The objectives of the meeting were presented by Dr Riadh Ben Ismail,

Regional Adviser, Neglected Tropical Diseases, WHO Regional Office for the Eastern Mediterranean. Dr Chris Schmotzer (AID to Leprosy Patients, Pakistan) was elected chairperson for the meeting.

# 2. Summary of discussions

There are 14 countries in the Eastern Mediterranean Region with very low leprosy burden, including three countries that reported zero cases in 2012 (Jordan, Palestine and Tunisia). There are five countries with stable or declining leprosy burden: Egypt, Islamic Republic of Iran, Morocco, Pakistan and Yemen. There are four countries, however, that are in complex emergency situation: Afghanistan, Somalia, South Sudan and Sudan. South Sudan is the country reporting the highest number of new leprosy cases, with more than 1000 new cases every year. The Region reported 4235 new cases in 2012 with 700 cases with grade 2 disabilities. In 2013, the regional programme supported Egypt and Sudan in monitoring and supervision. It also supported a consultant visit to the Islamic Republic of Iran and facilitated another consultant visit to Qatar. The programme helped Pakistan to build capacity of its health care workers in leprosy. The programme was also represented in a number of international leprosy meetings including the International Leprosy Summit in Bangkok.

Globally, 90% of the disease burden is distributed in 18 countries only, which include two countries from the Eastern Mediterranean Region: South Sudan<sup>1</sup> and Sudan.

<sup>1</sup> South Sudan was a member of the WHO Eastern Mediterranean Region until May 2013, after which it became part of the WHO African Region.

In Afghanistan, which is a country in complex emergency, leprosy is a neglected disease. The programme suffers from limited facilities. It faces a number of challenges such as stigma, low priority, political instability and low number of trained health care workers.

Djibouti has a very small number of cases every year. Most of the reported cases are Ethiopians who cross the borders freely. The programme suffers from lack of human and other resources, with only two dermatologists available in the country and only one hospital providing dermatology services. There is also a problem of lack of data, especially in relation to Ethiopian cases.

Egypt eliminated leprosy nationally in 1994 and at governorate level in 2004. There is, however, one district only that did not achieve elimination. In 2012, the country reported 644 cases. During 2012 the programme conducted a number of activities in the four governorates with highest numbers of cases which are all in Upper Egypt: Sohag, Qena, Luxor and Aswan. The activities included contact examination, training of health staff, monitoring and supervision and rehabilitation. Challenges facing the programme are stigma and discrimination, and absence of a referral centre in Upper Egypt. There are plans to solve the latter challenge in the near future.

The leprosy control programme in the Islamic Republic of Iran has been active, with leprosy eliminated at national level in 1992, at provincial level in 1996 and at district level in 1997. The target of reducing grade-2 disabilities by 35% in comparison with 2010 levels was achieved in 2012. The national programme is trying to maintain expertise by conducting a mandatory course on leprosy for residents of dermatology. Leprosy has been integrated in primary health care for 20 years. There are efforts to support rehabilitation, referral and active case finding. In spite of these efforts there are challenges such as decreasing priority, decreasing expertise and the existence of stigma.

Morocco has a low burden of leprosy. Rural areas form a real challenge for leprosy efforts where most cases with disabilities occur there and stigma is very strong. The national programme carried out a new strategy for single dose rifampicin chemoprophylaxis (SDRP) among household contacts of known leprosy cases recorded in the last 10 years. The strategy had a very good acceptability rate and 1524 contacts had the SDRP.

Oman has very few leprosy cases every year among nationals (2–3 cases) as well as among non-nationals (4–6 cases). The programme provides non-national leprosy cases with the full course of multidrug therapy (MDT) and sends them back to their countries. After they finish their course and are considered cured, they are allowed to return back to Oman. The programme plans to work on raising community awareness and train health care workers.

A very good example of joint collaboration between Ministry of Health and nongovernmental organziations in the field of leprosy could be illustrated in Pakistan. The country has eliminated leprosy since 1996. and reports around 400 new cases every year (377 in 2012). The programme applies active case finding through organizing 'skin camps' where people suffering from all skin diseases seek medical advice at the camps, and leprosy cases are diagnosed among them. The programme has good collaboration with tuberculosis and primary eye care programmes. All leprosy staff are trained as ophthalmology and tuberculosis technicians. The programme collaborates also with the basic dermatology programme and information, education and communication programme. There are 157 clinics providing leprosy services all over the country. There are two main secondary referral facilities: MALC Hospital in Karachi and ALP Hospital in Rawalpindi. Financial resources for the programme are from the government health department, international organizations, as well as local resources from nongovernmental organizations and individuals. The programme faces the challenges of the

need to maintain coverage of services with the vast country area and the large population. It also needs to maintain knowledge, skills and experience despite the very low prevalence. One of the main local nongovernmental organizations working in leprosy in Pakistan is ALP (Aid to Leprosy Patients). It has been a partner in this field since 1969. Its scope of work is leprosy control, primary eye care and rehabilitation. ALP works according to the national guidelines. It runs 18 clinics, nine in Punjab and nine in Khyber Pakhtunkhwa. On the last day of the meeting, a visit was organized to Rawalpindi Leprosy Hospital which is run by ALP. The participants had a good opportunity to see leprosy cases, and to visit the different departments of the hospital. It was clear that the hospital offers a comprehensive package of services and is a very important facility for secondary level care in the country.

Leprosy is a public health problem in Somalia, which is one of the countries in complex emergency, but the disease is more endemic in the south–central part of the country. The most endemic district there is Jilib. The partnerships in the field of leprosy are mainly with World Concern and Benadir University, in addition to six local nongovernmental organizations. There is also a local radio channel which contributes to raising community awareness. Challenges include insecurity which leads to inaccessibility of services in endemic areas. There is also strong social stigma, lack of resources, and decreased priority at the Ministry of Health. For more achievements in the future there is a need to: 1) increase political commitment; 2) integrate leprosy in primary health care; 3) increase financial support; 4) conduct training for health staff; 5) carry out active case finding in the form of skin camps; 6) establish referral facilities in different parts of the country; 7) raise community awareness; and 8) increase partnerships.

South Sudan is the country reporting the highest number of leprosy cases in the Region. Due to its conditions of long lasting civil war and the prevalence of poverty, it has a big number of leprosy cases with

disabilities. Arkanjelo Ali Association (AAA) is a nongovernmental organization that works on leprosy control in South Sudan. It provides outreach activities and surgical reconstruction for disabled cases in need. It also supports social and economic activities for people affected with leprosy. In addition it supports capacity building for health care workers. Challenges facing AAA include high levels of stigma, decreased funding, scarce human resources and poor infrastructure.

Tunisia has eliminated leprosy since 1980 and reports a very low number of cases (0–2 cases annually). The programme applies contact tracing and rehabilitation for cases with disabilities.

In 2000, Yemen became a hypoendemic country for leprosy. It reports between 350 and 400 cases every year. The programme has 36 clinics providing MDT services; four of them are regional clinics. Their clinics are run by primary health care workers trained in the leprosy programme. Challenges include political instability, stigma and budgetary problems.

Sasakawa Memorial Health Foundation (SMHF) and its mother foundation, The Nippon Foundation, are together the largest supporter of leprosy control activities. SMHF has changed its approaches along years of work in the field of leprosy. Initially, from 1974 up to the 1990s, the approach mainly concentrated on the medical aspect, i.e. elimination of leprosy as a public health problem. Then from the 1990s through the 2000s the approach concentrated on both medical and social aspects, i.e. elimination of leprosy as a public health problem, and empowerment and capacity building of persons affected by leprosy. In recent years the approach has mainly concentrated on the social aspect of people affected by leprosy, i.e. empowerment and capacity building of persons affected by leprosy, and development and capacity building of organizations for persons affected by leprosy. SMHF advocates for the importance of learning from the history of leprosy, whether the history of patients, the disease or society.

Among the processes leading to drafting a global leprosy strategy is to hold brainstorming sessions during WHO regional meetings. The present meeting had such a session to discuss proposals for the Global Leprosy Strategy 2016–2020. Usually the strategy has a goal, targets, indicators, milestones and a roadmap. Though not an integral part of the strategy, there are usually other topics mentioned such as guiding principles, focus on specific issues and innovations. Participants proposed to classify the countries into categories according to disease burden and then specify different figures for different categories as targets for reduction of grade-2 disabilities by 2020. For example some countries may have a target of decreasing grade-2 disabilities to 1 per million population; other countries may have a target of reduction to 0.5 per million population and so on. Another suggestion was to achieve 50% reduction in grade-2 disability levels in 2020 compared to the baseline figures of 2015. For the guiding principles the suggested points were: 1) political commitment; 2) encouraging integration of leprosy in the health system; and 3) building effective partnerships. The issues suggested to focus on were: 1) active cases finding among high endemic populations, hard to reach populations, close contacts and urban slums; 2) maintenance of knowledge and expertise; 3) improvement of social determinants of health; 3) establishment of a drug resistance surveillance system in low burden countries; 4) promotion of involvement of people affected with leprosy; and 5) promotion of inclusion of leprosy in national policies related to human rights and to dealing with disabled individuals. For innovations the following were suggested: 1) research chemoprophylaxis, drugs, vaccines, new source and mode of early detection transmission. for new methods and molecular epidemiological studies; and 2) establishment or identification and support of a regional leprosy training institute.

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### 3. Recommendations

#### For Member States

- 1. Encourage/promote early case detection through information, education and communication and training of health workers at primary health care centres in order to reduce grade 2 visible disability.
- 2. Promote political commitment for neglected tropical diseases as priority diseases with a special focus on leprosy.
- 3. Promote research and development on new tools and strategies for early case detection.
- 4. Re-emphasize the integration of leprosy into primary health care and strengthen or establish referral systems.
- 5. Emphasize integration of leprosy rehabilitation in other types of disability services and community-based rehabilitation.
- 6. Advocate to abolish or repeal existing governmental rules which are against human rights and gender equity related to leprosy, and report to the meeting annually on these points as an indicator of fighting stigma and showing political commitment.
- 7. Avoid the use of acronyms for leprosy patients, such as PAL (Person Affected by Leprosy), in documents and instead refer to them as 'persons affected'.
- 8. Include periodic nerve assessment as part of routine case monitoring for early detection of nerve function impairment and its complications.

#### For WHO

- 9. Disseminate the meeting recommendations as soon as possible.
- 10. Support translation and printing of relevant documents in local languages of the Region.

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- 11. Facilitate exchange of experience among Member States in the area of leprosy control.
- 12. Identify and support existing training centres for leprosy in countries to sustain capacity building at national level.
- 13. Establish an e-mail network among leprosy focal points and leprosy experts, for diagnosis, treatment, new approaches and other related issues in order to increase knowledge and skills of leprosy staff.
- 14. Take into consideration the results of the brainstorming session in formulating the next strategic plan.
- 15. Advocate with countries to cease the practice of deporting expatriates diagnosed with leprosy, as this practice is of no benefit once MDT is started and contributes to stigmatization of the disease.
- 16. Support the Nippon Foundation to organize a workshop on ethics and leprosy in the Region.
- 17. Provide countries with an annual epidemiological analysis of leprosy in countries of the Region.
- 18. Support the establishment and expansion of the drug resistance surveillance system in eligible Member States.

