

**Government of India – WHO-ICMR workshop on
'Monitoring and evaluation of leprosy control in the post-elimination era'**

**National Institute of Epidemiology (ICMR)
Chennai - 77**

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Conclusions and recommendations

Dr. P.L. Joshi, DDG (Leprosy) said that the programme is at turning point with the integration. The programme is functioning under National Rural Health Mission (NRHM) and there are enormous opportunities for funding. He mentioned that he was looking for expert advice from this meeting

Dr. V.K. Pannikar, Chief, WHO-Global Leprosy Programme, gave programme background.

- Laid stress on continuing the commitment for the programme at all levels viz., political, donor's and professional
- Quality of care for patient took a back seat during elimination drive
- Improving quality of care is the priority
- Cautioned about possible emergence of rifampicin resistance
- Wanted the group to look into appropriate indicators in the context of integration

Dr. Joshi, in his presentation raised several issues. He suggested following questions for in-depth analysis by the group:

1. Is eradication of leprosy possible in the next 20 years?
2. Is new case detection / incidence rate appropriate indicator for monitoring and evaluation?
3. Will it be appropriate to measure endemicity of leprosy in terms of prevalence as the yardstick for monitoring and evaluation?
4. Can we say elimination level is achieved in areas reporting fluctuations around the elimination target of 1 per 10,000?
5. What are the appropriate monitoring and evaluation indicators?

Dr. Pannikar took up these issues for discussion by the group.

Eradication

Dr. Pannikar mentioned that the Technical Advisory Group (TAG) of WHO had reviewed the feasibility of developing a strategy for eradication of leprosy on several occasions. The TAG concluded that presently available tools and intervention measures are not adequate to consider leprosy eradication as a goal. In any case, eradication of any communicable disease is a global target; it cannot be considered in the context of one country or region. After extensive discussions, the group unanimously agreed that the present day interventions do not permit consideration of strategies for leprosy eradication.

The group identified that after declaration of elimination in a given state, leprosy programme is losing its priority. Several key posts are remaining vacant at the district level. It has been seen that programme performance in the districts without district leprosy officer has been very poor. Dr. Joshi even suggested that to keep up the momentum, we need appropriate slogan for necessary political commitment. The group recommended that eradication of leprosy is not the right slogan for this purpose. But, the programme may consider "India without leprosy disability". Leprosy eradication should continue to be a long-term aspirational goal.

Elimination

The group further endorsed that the slogan of leprosy elimination has served its purpose of advocacy and vigorous implementation of MDT world over. A stage has now come to remove the term 'leprosy elimination' from the programme dictionary. It is likely to create adverse impact on patient care and management and also research and funding. The group, therefore, strongly advised that after considering elimination at the sub-national level (State, in the Indian context), leprosy programmes should not consider elimination strategy at district and block levels. The focus should be now on sustaining leprosy control and quality care for leprosy patients and provision of referral services.

Fluctuations around elimination target

WHO defined elimination in the national context. For a bigger country like India, it could be useful to consider elimination at the sub-national level (upto State). Once, the prevalence of leprosy at the end of any given year, reached the level of elimination, as per the State govt., records, this fact could be accepted. There is no need to consider prevalence for fluctuations

thereafter. As mentioned earlier, the programme orientation would now shift to a sustainable leprosy control programme focusing on quality patient care.

Prevalence or new case detection

There was extensive discussion on the use of prevalence or incidence rates (new case detection as a proxy) as indicators for monitoring and evaluation. It was observed that with the possible exception of HIV/AIDS, prevalence is not an appropriate parameter for programme monitoring of infectious diseases. New case detection rates provide all the information required by the programme for logistics as well as measuring epidemiological trends, if consistent methods are applied covering the entire region. The group unanimously agreed that prevalence should not be considered as an indicator for monitoring and evaluations. All the participants recommended that new case detection should become the most essential indicator for monitoring and evaluation.

New case detection rates in various states

State Leprosy Officers from Tamil Nadu, West Bengal and Andhra Pradesh made presentations about leprosy programme scenario as well as experience in the context of monitoring and evaluation. Following important points emerged based on the presentations and discussions in the group:

1. Generally leprosy incidence seems to be declining in the country; however, there are several confounding factors and effect modifiers on account of several operational issues. The group agreed that disaggregated analysis at the state levels for the new case detection rates should be taken up on priority basis taking into account special operational factors. The group identified this as a critical issue.
2. The role of private sector needs to be examined and methods should be developed to estimate annual new case detection through private sector. Estimates need to be obtained considering available data and various demographic parameters. The group also suggested considering the data from leprosy referral facilities from NGOs. The participants felt the usefulness and the need for documenting the functioning of various referral centres.
3. Presentation by Dr. M. Madhav Rao, State Leprosy Officer, Andhra Pradesh brought out the importance of the threat of continued pressure on account of elimination strategy. A steep and precipitous drop in the new case detection rates in the past five years was questioned by one and all. This drop could not be easily explained. The

participants unanimously urged the need for reasonable quality of data. The group recommended quality control mechanism at state and national level.

Dr. Joshi strongly pleaded with the programme partners that they should function as eyes and ears for the national programme and bring out these aberrations forcefully to the attention of the programme managers.

Hidden case-load

Dr. Joshi highlighted two issues related to hidden case-load, namely, (1) Magnitude of hidden cases (2) Strategy to deal with the hidden cases.

This issue was extensively discussed by the participants .In some areas health services are available but are not used and in some other areas health services may not be accessible. The group felt that delay in diagnosis could be assessed by grade-2 disability proportion among newly detected cases.

Private sector and Non-Governmental Organizations (NGOs) do contribute in case detection and care of patients. However, there is no appropriate documentation of the contribution made by the private sector for case detection. It will be useful to identify some sentinel sites to assess in data generation on this important component on a trial basis. Based on the results, the issue would be considered further.

It was agreed that provision of quality care by all health facilities and community oriented Information, Education and Communication (IEC) activities will promote self reporting and reduce the burden of hidden cases.

Monitoring indicators

The group recommended to adopt monitoring indicators suggested in the WHO's *Global Strategy for Reducing the Leprosy Burden and Sustaining Leprosy Control Activities: 2006-2010*, viz.,

- Main indicators: *new case detection and treatment completion rate*
- Additional epidemiological indicators: *% grade II disability, % female, % children, % MB*
- Additional quality of services related indicators: *% defaulters, number of relapses, % correctly diagnosed, % with new disabilities*

The group felt that it will be important to review the follow-up activities as a consequence of the conclusions and recommendations of this workshop. It was further agreed that this workshop discussed extensively about the monitoring related issues and recommended the need for another workshop to deal with evaluation related issues.