Monitoring Enhanced Global Leprosy Strategy

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1. Introduction

Leprosy control has made impressive strides especially in the last decade. Intense campaigns to detect backlog of cases, simplified strategy and guidelines, integrated delivery of primary leprosy services and focussed and constructive efforts based on collaboration with stakeholders have led to a considerable reduction in leprosy burden. This does not mean leprosy has disappeared. New cases continue to occur in almost all the endemic countries. Even within low-disease-burden countries there are high-burden pockets. It is also becoming rather difficult to sustain leprosy control efforts and provide equitable access to leprosy services in resource-poor settings.

Multidrug therapy (MDT) has remained the cornerstone of leprosy control. The strategic orientations given to the programme since the introduction of MDT have been centred on this simple technology. However, challenges in meeting the special needs of the persons affected and the programme remain. The challenge is to further reduce the leprosy burden as described in the Enhanced Global Leprosy Strategy of WHO (2011-2015).

Intensified, focussed activities with MDT have reduced the leprosy burden. It is now becoming increasingly difficult for leprosy control programmes to retain the same level of commitment and focus.

The Enhanced Global Leprosy Strategy of WHO targets reducing the new cases with disability by 35% by the end of the strategy period (2015) compared to the baseline at the beginning of 2011. It underlines the importance of early detection and quality of care in an integrated service setting. Routine data look at progress and performance but give inadequate attention to quality of care issues for various reasons including complexities in managing the data.

2. Purpose of monitoring enhanced global leprosy strategy

For leprosy control to achieve greater success it is essential to have the concept and practices of monitoring and evaluation well established in the programme. Monitoring is done through a minimum set of indicators that describe the leprosy services in terms of impact, effectiveness, efficiency, relevance and sustainability. These indicators provide the basis for before-and-after analyses to evaluate the effects of programme interventions.

Monitoring should be quick and cost-effective. It can be routine or special. Routine monitoring is the principal and essential component in assessing the leprosy situation. It needs to be programme oriented, simple and speedy. It consists of continuous flow of information on progress and performance. A set of indicators are identified based on

relevance, objectivity, ease of collection, and the information that is generated is used at every level to assess programme status, identify deviations and institute remedial measures. It is important to conduct special monitoring studies periodically. A mix of methods may be employed- survey, structured interview, process analysis, qualitative approaches (beneficiary assessment). These provide complementary evidence on programme performance. Such monitoring exercises:

- Provide a basis for decision making on improvements, strategies, management, procedures;
- facilitate the use of best practices and scientific knowledge to monitor;
- ensure the development of monitoring skills country-wide;
- help develop best professional processes in funding arrangements;
- make the programme progressively more cost-effective by building on the lessons learned;
- motivate programme managers to take more initiative; and
- help the programme establish favourable linkages with overall development plans and strategies.

The procedures for collecting information on behaviour of the disease and programme through indicators are well established in the earlier guidelines on Leprosy Elimination Monitoring (LEM). This document which includes methodologies, framework and indicators is an extension to the LEM guidelines appropriately oriented to the current needs. They are applied in the field in a standardized manner by 'monitors', in collaboration with national programmes and WHO. Monitors collect information complementing routine leprosy information systems to address specific issues, such as epidemiological trend, completion rates, impact of interventions, changing patterns of leprosy and quality of services. Information on age, sex, type-specific detection, smear positivity, if available and the delay between onset and diagnosis help in better describing indicators used for monitoring progress. It is equally important to validate key indicators, such as quality of diagnosis and G2 disability, by applying internationally recommended definitions. Wherever possible, trend analysis over the last five years should be used to assess the impact of leprosy control activities.

3. Overview

All the indicators collected through these exercises are well standardized, have been in use for several years in many countries and are well known to programme managers. The required information could be gathered from existing patient records, leprosy registers, reporting forms and stock bin cards in selected health facilities as well as from interviews of affected persons and the community. The selected health facilities should reflect the situation prevailing in a specific geographical or administrative area at a given point in

time. Careful consideration should therefore be given to the selection of the sample and sample size.

The monitoring exercise will have to be repeated in order to assess the impact of interventions and changes over time. These studies should be carried out by independent monitors, who will visit selected units to collect information through standardized methods, and report their findings on compiled data to the national programme managers and WHO.

The monitoring should be time-limited and the complete cycle (from design to report) should not exceed four weeks. Selected health facilities should be informed in advance of the monitors' visit so that they have time to mobilize affected persons.

Indicators and methodologies described in this document will be adapted/ reviewed as and when needed.

4. The protocol

The protocol is a compendium of indicators with definitions and criteria to be focussed upon. Details of the procedures for most of these indicators are already available in the LEM guidelines which can be adapted to local situations as needed.

In the following section a summary list of key indicators is given followed by detailed explanations on each. For methodological issues of how to collect the data for most of these indicators one can refer to the earlier LEM guidelines. Five new indicators have been added. Sample questionnaires for the three indicators on patient satisfaction, community perception and perceived stigma are given in the annexures.

5. Summary table of key indicators

Indicator group	Key indicators
Group I **Case detection indicators** Internal validity of information on detection	**1. Case finding activities** 1.1 Proportion of new cases with Grade 2 disabilities

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