The Enhanced Global Leprosy Strategy of WHO 2011-2015, targets reducing the new cases with grade-2 disabilities by 35% by the end of the strategy period. It underlines the importance of early detection and quality of care in an integrated service setting. 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.

Although routinely collected data provide adequate information on the progress and performance, it may not provide an adequate assessment of the quality of care indicators. In this document a set of routine and additional indicators are identified that may be used at every level to assess programme status, identify deviations and institute remedial measures. The procedures for collecting information on epidemiology and control of the disease are well established in the earlier guidelines on Leprosy Elimination Monitoring (LEM). This document includes additional indicators and methodologies adapted to the current needs.
Monitoring
Enhanced Global Leprosy Strategy
Contents

<table>
<thead>
<tr>
<th></th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Introduction</td>
</tr>
<tr>
<td>2.</td>
<td>Purpose of monitoring enhanced global leprosy strategy</td>
</tr>
<tr>
<td>3.</td>
<td>Overview</td>
</tr>
<tr>
<td>4.</td>
<td>The protocol</td>
</tr>
<tr>
<td>5.</td>
<td>Summary table of key indicators</td>
</tr>
<tr>
<td>6.</td>
<td>Further reading</td>
</tr>
</tbody>
</table>

Annexes

<table>
<thead>
<tr>
<th></th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Patient Satisfaction Survey – Sample questionnaire</td>
</tr>
<tr>
<td>2.</td>
<td>Community perception about leprosy – Sample questionnaire</td>
</tr>
<tr>
<td>3.</td>
<td>Survey on Perceived Stigma – Sample questionnaire</td>
</tr>
</tbody>
</table>
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

<table>
<thead>
<tr>
<th>Indicator group</th>
<th>Key indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Group I</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Case detection indicators</strong></td>
<td>1. Case finding activities</td>
</tr>
<tr>
<td>Internal validity of information on detection (crude and specific) and analysis of trends. This will be based on the analysis of existing information and review/updating of leprosy registers.</td>
<td>1.1 Proportion of new cases with Grade 2 disabilities</td>
</tr>
<tr>
<td></td>
<td>1.2 Average delay in diagnosis</td>
</tr>
<tr>
<td></td>
<td>1.3 Proportion of children among new cases (or age-specific detection)</td>
</tr>
<tr>
<td></td>
<td>1.4 Proportion of MB cases among new cases</td>
</tr>
<tr>
<td></td>
<td>1.5 Proportion of females among new cases (or sex-specific detection)</td>
</tr>
<tr>
<td></td>
<td>2. Prevalence: absolute numbers and rate</td>
</tr>
<tr>
<td></td>
<td>2.1 Reported prevalence</td>
</tr>
<tr>
<td></td>
<td>2.2 Prevalence after applying standard definitions</td>
</tr>
</tbody>
</table>
Group I: Case detection indicators

Group I: 1. Case-finding activities

Internal validity of information on detection (crude and specific) and analysis of trends. This will be based on the analysis of existing information and review/updating of leprosy registers.

(Sample for all except for 1.2- if less than 100 new cases were detected in the reference period include all; if more than 100, restrict the sample to 100. For 1.2. The new cases selected for the indicators could be stratified into adults and children. 50% of adults, randomly selected, and all children could be included for interview)

<table>
<thead>
<tr>
<th>Purpose</th>
<th>To assess the effectiveness of case-finding activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition</td>
<td>New cases diagnosed during one year and who have never been treated for leprosy.</td>
</tr>
</tbody>
</table>

Case-finding activities will be evaluated through a set of five indicators, describing the status of a sample of patients. One year can be defined as during the past one
year from the time of the visit. Should information be unavailable, this can be
modified provided it is discussed and agreed before the start of the exercise.

1.1 **Proportion of newly detected cases with grade 2 disabilities:**

The number of patients newly diagnosed with grade 2 disability (see
definitions below) divided by the number of newly detected patients for
whom disability status is recorded.

1.2 **Average time between recognition of the disease and diagnosis**

Based on individual records and/or interviews of a sample of patients, this
is the average time (in months) between the first recognition of symptoms
and the date of diagnosis.

1.3 **Proportion of children (age-specific detection)**

The number of newly diagnosed patients below the age of 15 divided by
the number of newly detected patients for whom age is recorded.

1.4 **Proportion of MB cases**

a) Clinical classification: The number of newly diagnosed patients
classified as MB patients divided by the number of newly detected patients
for whom classification is recorded.

b) Bacteriological classification: Wherever possible: the number of newly
diagnosed patients showing a positive skin smear examination divided by
the number of newly detected patients for whom skin smear examination
results are recorded.

1.5 **Proportion of female (sex-specific detection)**

The number of newly diagnosed female patients divided by the number of newly
detected patients for whom gender is recorded.

| **Pre-requisites** | Checking leprosy registers and individual records. Whenever necessary, by
interviewing a sample of patients as for 1.2. |
|--------------------|--------------------------------------------------------------------------------|
| **Interpretation** | This set of indicators will only give some indications on the quality and delay for
diagnosis. It is not intended to give epidemiological information (detection rate,
incidence rate, the intensity of transmission). |
| **Difficulties and potential biases** | Information might be difficult to collect in programmes having a poor recording system. Considering that the required sample size is significant, monitors may have to collect information in several places, including visits to patients. Since in many situations the number of new cases detected may be small, one may have to adapt an appropriate sampling strategy. |
### Definitions of disability Grade 0 1 2:

**Hands and feet:**
- Grade 0: No anaesthesia, no visible deformity or damage
- Grade 1: Anaesthesia but no visible deformity or damage
- Grade 2: Visible deformity or damage present

**Eyes:**
- Grade 0: No eye problems due to leprosy; no evidence of visual loss
- Grade 1: Eye problem due to leprosy present, but vision not severely affected as a result (vision 6/60 or better; can count fingers at six metres).
- Grade 2: Severe visual impairment (vision worse than 6/60; inability to count fingers at six metres), lagophthalmos, iridocyclitis and corneal opacities.

### Group I: 2. Prevalence

<table>
<thead>
<tr>
<th>Purpose</th>
<th>To measure progress and efficiency in patient treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definition</strong></td>
<td>For the purpose of the study, monitors will adhere to the following definitions:</td>
</tr>
<tr>
<td></td>
<td>Calculation of prevalence indicators at a given point in time;</td>
</tr>
<tr>
<td></td>
<td>A case of leprosy is a person presenting clinical signs of leprosy (with or without bacteriological examination) who has yet to complete a full course of treatment.</td>
</tr>
<tr>
<td></td>
<td>A patient who has completed a full course of fixed duration MDT (6 doses for PB and 12 doses for MB) has completed treatment.</td>
</tr>
<tr>
<td></td>
<td>A PB patient who has missed more than three months of treatment or an MB patient who has missed more than six months of treatment is a defaulter.</td>
</tr>
</tbody>
</table>

Monitors will collect information on the following three prevalence indicators:

2.1 Reported prevalence: absolute number and rates  
2.2 Prevalence after applying standard definitions  
2.3 Prevalence trend over the last five years

| Pre-requisites | Compiling national and sub-national reports, checking leprosy registers at health centre level, and discussions with national programme managers. |
| Interpretation | Treatment completion rate should be 85% or more. It reflects efficiency in patient management. |
| Difficulties and potential biases | The main difficulty will be to collect information on denominators (population by sub-national levels over the last five years) |

### Group I: 3. Detection

<table>
<thead>
<tr>
<th>Purpose</th>
<th>To evaluate the leprosy situation changes over time</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definition:</strong></td>
<td>Monitors will collect information on these four detection indicators at the national and sub-national levels:</td>
</tr>
<tr>
<td></td>
<td>3.1 Detection trend over the last five years</td>
</tr>
</tbody>
</table>
### 3.2. Grade-2 disability trend
### 3.3 MB detection trend
### 3.4 Child detection trend

Detection trend is disaggregated into age, sex, mode of detection, skin smear positivity\(^1\), type of leprosy, and disability grading, if available. These are optional and will be useful in analysing transmission trend over time. The decisions should be made beforehand.

<table>
<thead>
<tr>
<th><strong>Pre-requisites</strong></th>
<th>Compiling national and sub-national reports, checking leprosy registers at health centre level and discussions with national programme managers.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interpretation</strong></td>
<td>Detection trends should be interpreted with caution. Influence of operational factors should be kept in mind.</td>
</tr>
<tr>
<td><strong>Difficulties and potential biases</strong></td>
<td>The main difficulty will be to collect information on denominators (population by sub-national levels over the last five years).</td>
</tr>
</tbody>
</table>

\(^1\) Skin smear is not needed for diagnosis or classification. However, if it is being done, it will be useful to collect information.
Group II Integration indicators

The availability of MDT blister-packs and geographic coverage of MDT services. This will be based on a cross-sectional survey of randomly selected health facilities and interviews of patients.

‘MDT services’ refers to comprehensive health activities, including: diagnosis, classification, prescription of treatment, delivery of MDT, case-holding, cure of leprosy patients and patient counselling. Quantitative aspect of MDT services are monitored through these indicators. (See Group III).

Group II 1. Proportion of existing health facilities providing MDT

<table>
<thead>
<tr>
<th>Purpose</th>
<th>To assess accessibility to MDT services</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definition</strong></td>
<td>Proportion of health facilities where MDT is available among health facilities which have reported at least one leprosy case a year for the past five years in a given area. At least two months of drug stock should be available in these facilities. Definition of health facilities should be given beforehand in consultation with the relevant authorities.</td>
</tr>
</tbody>
</table>
| **Pre-requisites** | a) Obtaining lists of all existing health facilities and those which have reported at least one case a year in the last five years providing MDT from national and/or regional authorities.  
b) Visiting selected health facilities to check whether or not they have stocks of MDT (at least two months of stock). |
| **Calculation** | a) Proportion calculated by dividing the number of health facilities which have reported at least one case a year for the last five years and having stocks of MDT by the total number of health facilities in the area which have reported at least one new case a year for the last five years.  
b) Proportion calculated by dividing the number of such health facilities having stocks of MDT by the total number of such health facilities visited. |
| **Example** | a) Based on administrative information, 20 out of the 200 existing health centres have reported at least one new case a year for the last five years. Out of which as reported, all the 20 have stocks of MDT (100%).  
b) Out of five such health centres visited, only four had available stocks of MDT (80%) when visited by monitors. |
| **Interpretation** | A low geographic coverage can reflect a combination of factors, such as: national policy of providing MDT only to specialized centres; lack of MDT and personnel; delayed process of integration. |
| **Difficulties and potential biases** | Data collected from health authorities could be out-of-date. Some MDT services, such as NGOs projects or MDT clinics organized from the regional level, might not be included in the calculation. The monitors will have to analyse the situation carefully in order to give an accurate estimate of the geographic coverage. |
Group II 2. Accessibility to MDT

<table>
<thead>
<tr>
<th>Purpose</th>
<th>To evaluate the extent to which patients have easy access (geographical, financial and technical) to MDT services.</th>
</tr>
</thead>
</table>
| Definition | Accessibility will be estimated through a set of four indicators collected in a sample of patients diagnosed and treated during the year.  
(The new cases selected for the indicators could be stratified into adults and children. 50% of adults, randomly selected, and all children could be included for interview. Guardians of children could be interviewed.) |
| 2.1. Delay in starting treatment | Based on interviews of a sample of patients using a set of two questions: when was the patient diagnosed at the health facility and when was the treatment with MDT started. |
| 2.2 Average distance travelled to collect monthly dose of MDT | Based on individual records and/or interviews of a sample of patients, this is the average distance (in kilometres) patients are actually travelling monthly to receive their treatment. |
| 2.3 Estimated costs for patients | Based on interviews of a sample of patients, ascertain whether there are any costs incurred for the service. |
| 2.4 Flexibility in delivering MDT | Based on discussions with health workers and patients, the monitors ascertain whether the health centre (where patients are still under treatment):  
- provides treatment only on a fixed day of the month or on several days of the month (specify number of days)  
- offers to patients that more than one month treatment can be given if needed (accompanied MDT)  
- can manage complications (reactions, disabilities)  
- is a specialized or integrated centre  
- stocks and uses steroids. |
| Difficulties and potential bias | In analysing information gained through interviews of patients, it should be noted that there is a built-in bias to those with better access to health centres. |

Group II 3. Availability of MDT drugs

<table>
<thead>
<tr>
<th>Purpose</th>
<th>To identify potential surplus stocks or shortage of MDT supply at the health centre, or district and regional stores.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition</td>
<td>Availability of MDT blister packs at time of visit, expressed in terms of months supply, for the given patient caseload in a health centre which has reported at least one case a year for the last five years.</td>
</tr>
</tbody>
</table>
**Pre-requisites**

- Getting the list of health centres which have reported at least one case a year for the last five years.
- Checking of MDT stocks and/or stock records in these centres, discounting any expired drugs.

**Calculation**

- Availability of blister packs in months is simply the number of blister packs of each category in stock, divided by the number of registered cases for each category.

## Group III: Quality of MDT services

Diagnosis, case-holding and information. This will be based on a review of individual records, leprosy registers, and interviews of individuals in communities. The quality of MDT services will be reviewed on the basis of cohort analysis.

MDT services refers to comprehensive health activities, including: diagnosis, classification, prescription of treatment, delivery of MDT, case-holding, completion of treatment and patient counselling. Some of these are monitored by Group II indicators.

## Group III: 1. Case holding

Fixed duration of MDT should lead to the cure of leprosy patients in a relatively short period of time. It is essential to collect reliable information on the outcome of the treatment. The role of monitors will be to evaluate treatment outcome indicators through the analysis of cohorts of sample patients. The information is collected from records and treatment registers.

<table>
<thead>
<tr>
<th>Purpose</th>
<th>To measure the outcome of case-holding activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition</td>
<td>Treatment outcome will be evaluated through a set of three indicators that can be collected by analysing cohorts of patients having started treatment during a given year.</td>
</tr>
</tbody>
</table>

2.1 **Completion rate: proportion of patients who have completed treatment on time**

- The number of patients who have completed treatment divided by the number of patients *supposed to have completed treatment* in the same cohort (PB and MB).

2.2 **Defaulter rate:**

- The number of PB patients who have missed three doses or MB patients who missed six doses of treatment divided by the number of patients *supposed to have completed treatment* in the same cohort (PB and MB).

2.3 **Proportion of patients continuing treatment after having completed treatment**

- The number of patients continuing treatment after having completed fixed duration treatment of MDT, six doses for PB and 12 doses for MB, divided by the number of patients *supposed to have completed*.
**Pre-requisites**

Checking treatment registers and individual records. Monitors will have to collect information on:

- Cohorts of MB patients defined as patients having started MB MDT 24 months before the date of the monitoring exercise or monitor’s visit;
- Cohorts of PB patients defined as patients having started PB MDT at least 12 months before the date of the monitoring exercise or monitor’s visit.

The size of each cohort depends on the number of cases detected. Supposing the monitor is visiting on January 2012, all cases registered from January to December 2009 should be checked in the register to find out whether each patient has completed 12 or six pulses in 18 or nine months from the date of starting. Then the three indicators will be calculated using as a denominator the total number of patients (PB or MB) registered in the reference period.

**Example**

In Nepal, treatment outcome of the 2009 MB cohort was: completed 57%, treatment continued 17%, defaulter 8%, other 18%. For 2010, the PB cohort was: cured 78%, treatment continued 3%, defaulter 4%, other 15%.

**Interpretation**

This set of indicators is very useful to evaluate the performance of the programme and the appropriate use of MDT. It will also help in better estimating drug requirements at various levels.

**Difficulties and potential biases**

Information might be difficult to collect in programmes having a poor recording system. The process of compiling many registers or individual records might be time-consuming.

---

**Group III. 2. Patients developing new disability following registration**

(All cases under treatment at the time of visit and cases released from treatment in the last two years are visited, examined and interviewed. Information is therefore collected from recorded data and interviews).

**Purpose**

To measure the quality of patient care

**Definition**

Proportion of cases who have developed new disability either during or after release from treatment (RFT). For example a person whose disability status at the start of treatment is grade-0, developing anaesthesia or paralysis in the hand during or after release from treatment is regarded as new disability.

**Pre-requisites**

Checking treatment registers and individual records. Monitors will have to collect information on:

- Clinical status including disability assessment of all cases that have been released from treatment for the last two years and under treatment (to the time of visit by monitors)
- Total number actually visited is the denominator.

**Example**

In Nepal, the number of cases released from treatment (the monitor is visiting in October 2011) from October 2009 was 20. Out of which the monitor could visit 15. Similarly, the number of cases under treatment was five and all five were visited. One was found to have developed new disability as per the statement from the patient and verification of records. The proportion is 1 out of 20 (5%).

**Interpretation**

This indicator is very useful to evaluate the quality of care. One should, however, keep in mind the procedures employed in following the patient, completeness of record as far as disability is concerned.
Group III. 3. Patient satisfaction
(The information is collected from registers and interviews. Sample questionnaire is given in Annexure-1)

<table>
<thead>
<tr>
<th>Purpose</th>
<th>To measure the quality of patient care. It may help in placing a demand for improvement in quality of service.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition</td>
<td>Proportion of cases who have developed new disability either during or after release from treatment (RFT). For example a person whose disability status at the start of treatment is grade-0, developing anaesthesia or paralysis in the hand during or after release from treatment is regarded as new disability.</td>
</tr>
</tbody>
</table>
| Pre-requisites | Checking treatment registers and individual records. Monitors will have to collect information on:  
- New cases registered in the last one year.  
- Try to contact all these cases and interview using questionnaire.  
- Total number actually visited is the denominator.  
- The new cases selected for the indicators could be stratified into adults and children. 50% of adults, randomly selected, could be included for interview. |
| Interpretation | This indicator is very useful to evaluate the quality of care from the perception of affected persons. One should, however, keep in mind that perception of quality from the affected persons depends on personal experience and the standard of care as expected by him/her. One should be careful in interpreting the results. |

Group III. 4. Community perception
(Sample questionnaire is given in Annexure-2)

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Helps in measuring awareness levels and also impact of IEC activities. Indirectly, it reflects on quality of services.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition</td>
<td>Proportion of community members who are aware of the disease and the programme.</td>
</tr>
<tr>
<td>Calculation</td>
<td>At least five persons from every village visited could be selected and interviewed individually, not in groups.</td>
</tr>
<tr>
<td>Interpretation</td>
<td>This indicator is very useful to assess awareness levels and indirectly the quality of care from the perception of end users of service. One should, however, keep in mind various biases and therefore should be careful in interpreting the results.</td>
</tr>
</tbody>
</table>

Group III. 5. Perceived stigma
(Sample questionnaire is given in Annexure-3)

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Helps in measuring prevalence of stigma and discrimination as perceived by affected persons.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition</td>
<td>Proportion of affected persons who report on discrimination as perceived by them.</td>
</tr>
<tr>
<td>Calculation</td>
<td>Interview of all persons released from treatment in the last two years. Obtain the list from health facilities and contact them for interview. A sample questionnaire is given in the annexure. It can be used with suitable modifications</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Interpretation</td>
<td>This indicator is very useful to assess prevalence of negative attitudes among the community.</td>
</tr>
</tbody>
</table>

6. **Further reading**


(4) C. Salisbury et al. Family Practice (Oct 2005)22(5): 560-569


(10) Ware, JE, Snyder, MK, and Wright, WR. Development and validation of scales to measure patient satisfaction with medical services. NTIS Publication no. PB 288-329. 1976.


(12) Guidelines to reduce stigma. Published by the International Federation Anti-Leprosy Associations (ILEP) and Netherlands Leprosy Relief (NLR), London/Amsterdam, 2011.
Annex 1

Patient Satisfaction Survey
Sample questionnaire

We would like to know how you feel about the services that are/ were provided by the government health facility in your area. Your responses to the questions will be directly responsible for improving the services. All your responses will be kept confidential and anonymous.

Thank you for your time.

1. Village...........................Block.................District.................State/ Region....................
2. Name of the health facility referred................................................................................
3. Age.................4. Sex: Male / Female.
5. MB/ PB. 6. Date of start of treatment:............... 7. Current status: UT/ RFT
8. When was the last time you visited the health facility...................................................
9. Who treated you..............................

On a scale of 1 = worst to 5 = best, please rate your experience at the facility
A. Hours the facility is open
B. Days when treatment for leprosy is available
C. Convenience of the location of the facility
D. Waiting time
E. The provider (doctor, nurse, paramedical, medical assistant)
   ~listens to you
   ~spends enough time with you
   ~explains what you need to know
   ~gives you good advice
   ~answers questions
   ~friendly and helpful
F. Other staff
   ~friendly and helpful
   ~answers your questions
G. Cost of service
H. How can you describe your health condition after the treatment
   (excellent, good, fair, worse, not sure)
I. Would you refer any friend or relative with similar condition for treatment at this facility?

( yes, may be, no, not sure)

J. What do you like best about the facility

"...................................................................."

K. What do you like least about the facility

"...................................................................."

Overall, how satisfied are/ were you with the service you receive/ received

(very satisfactory, somewhat satisfactory, not sure, somewhat dissatisfied, very much dissatisfied)
Annex 2

Community perception about leprosy
Sample questionnaire

(This is a sample questionnaire which, after adaptation, may be used if needed)

1. Name of the health facility………………………………. 2. District:……………..
3. State/Region………………..                       5. Date……………………………….
4. Urban/Rural…………………..                       5. Date……………………………….

For the questions below answer: Strongly agree, Agree, Not sure, Disagree, Strongly disagree

(1) Leprosy is like any other disease
(2) It appears as skin patches
(3) Leprosy is not hereditary
(4) It is completely curable
(5) Treatment for the disease is available in the health facility
(6) Treatment for leprosy is free
(7) If untreated it leads to deformity
(8) Leprosy is caused by a germ
(9) I will not refuse casual contact with a person with leprosy
(10) I will not hesitate to buy things from a shopkeeper who has leprosy
(11) You would invite your friend to social occasions even if he has leprosy
(12) I would feel comfortable traveling with someone with leprosy
(13) Person with leprosy should not be excluded from social gathering
(14) Person with leprosy should have the same respect or standing as others in the community
Annex 3

Survey on Perceived Stigma
Sample questionnaire

(This is a sample questionnaire which, after adaptation if needed may be used on persons who have been released from treatment in the last two years)

We would like to know how you feel about yourself. Your responses are used to improve leprosy services. All responses will be kept confidential and anonymous.

For the questions below answer: Strongly agree, Agree, Not sure, Disagree, Strongly disagree

In the last year I have, because of my disease:

(1) Been excluded from social gatherings
(2) Been abandoned by my spouse
(3) Been isolated in my household
(4) Not been visited or less frequently visited by my friends and family
(5) Been teased, insulted or sworn at
(6) Lost customers to buy my goods
(7) Not been able to rent a house
(8) Received less care/attention than others in the hospital/health facility.
The Enhanced Global Leprosy Strategy of WHO 2011-2015, targets reducing the new cases with grade-2 disabilities by 35% by the end of the strategy period. It underlines the importance of early detection and quality of care in an integrated service setting. 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.

Although routinely collected data provide adequate information on the progress and performance, it may not provide an adequate assessment of the quality of care indicators. In this document a set of routine and additional indicators are identified that may be used at every level to assess programme status, identify deviations and institute remedial measures. The procedures for collecting information on epidemiology and control of the disease are well established in the earlier guidelines on Leprosy Elimination Monitoring (LEM). This document includes additional indicators and methodologies adapted to the current needs.