



# Guidelines for Sparsh Leprosy Awareness Campaign

## National Leprosy Eradication Programme



Central Leprosy Division  
Directorate General of Health Services  
Ministry of Health and Family Welfare  
Government of India





## SPARSH LEPROSY AWARENESS CAMPAIGN (SLAC)

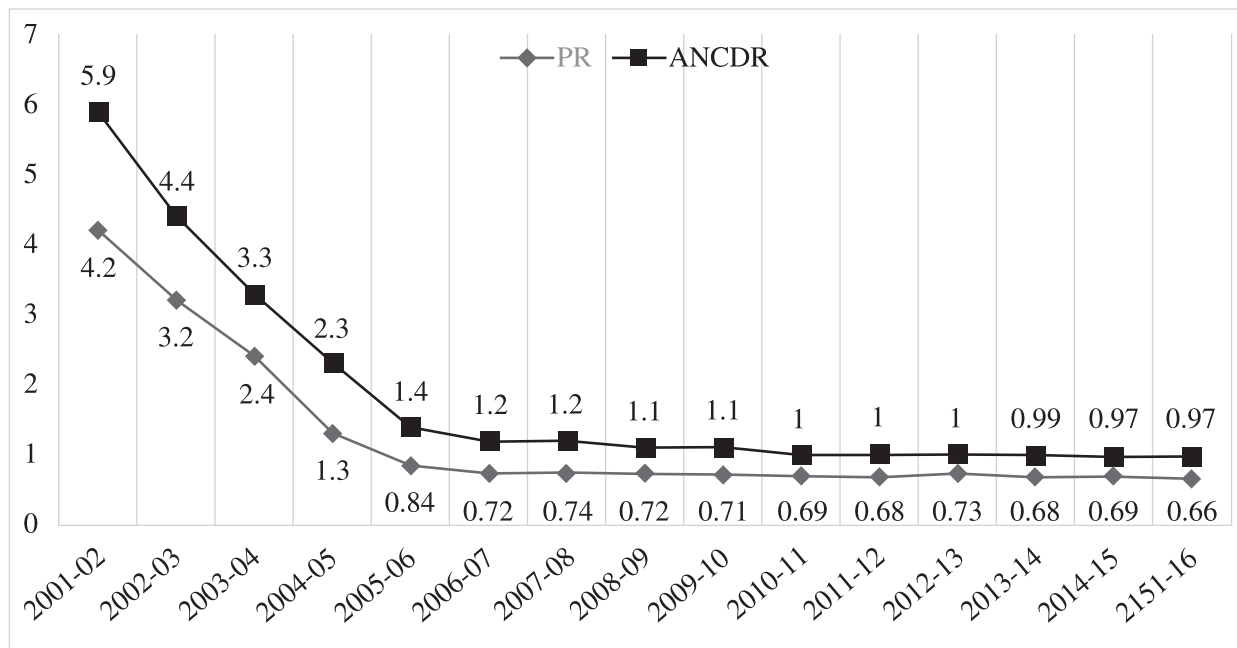
### BACKGROUND

As a result of substantial progress achieved by NLEP with help of MDT, the prevalence rate which was 57.60/10,000 population before start of MDT in 1983 reduced to 0.66/10,000 by March 2016. Leprosy is a chronic disease with a long incubation period (average 5-7 years). Although the disease has been eliminated at the National Level, there are still some Districts & Blocks which are continuously reporting a prevalence rate >1/10,000 population. As per the epidemiology of Leprosy disease, the major source of infection in the community is an untreated case i.e., a hidden case of leprosy lying undetected in the community, who transmit the disease agent to other people of the community. Early Detection of same will lead to depletion of source of infection in the community, interrupt the active transmission of disease, reduce the complication of case management and reduce the disability.

### Epidemiological Situation, as on March, 2016:

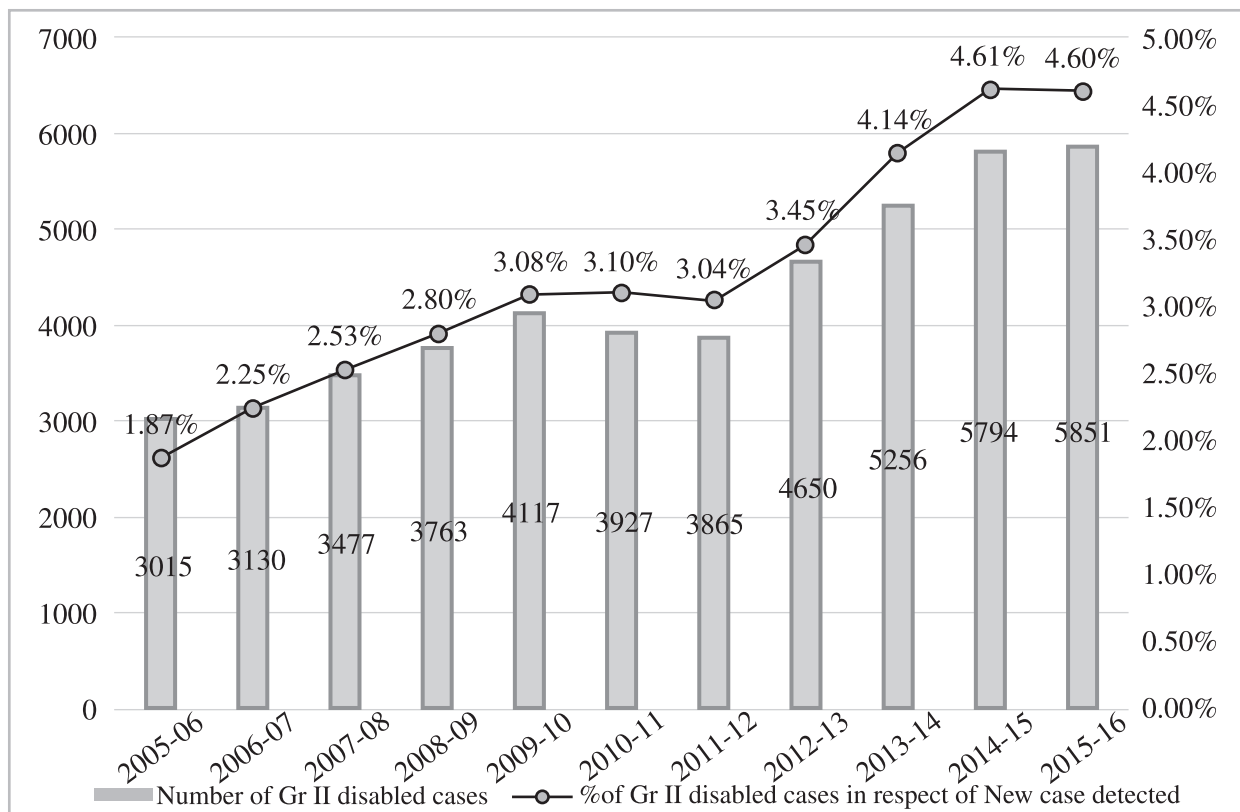
- Elimination at State level achieved in 34 States/UTs out of total 36 States/UTs.
- Chhattisgarh State and UT Dadra & Nagar Haveli yet to achieve elimination.
- Four states namely Delhi, Lakshadweep, Chandigarh and Orissa who have achieved elimination earlier, shown PR >1/ 10000 population.
- Approx. 127326 new leprosy cases detected.
- 86028 cases are on record as on 31st March 2016.

It has been observed that trend of two important indicators of National Leprosy Eradication Program, India i.e. Annual New Case Detection Rate (ANCDR) and Prevalence Rate (PR) are almost static since 2006 – 2007.



Graph 1: Trend of Prevalence and Annual New Case Detection Rate per 10,000 population, 2001-02 to 2015-16.

In addition, the percentage of grade II disability amongst new cases detected has been increased from 3.10% (2010 - 2011) to 4.61% (2014 - 2015), which indicates that the cases are being detected late in the community and there may be several cases which are lying undetected or hidden. The trend of Gr II disability cases amongst new leprosy cases from 2005-06 to 2015-16 is depicted in the graph below.



Graph 2: The trend of number of Gr. II disabled cases and % of Gr. II disabled cases i.r.o new leprosy from 2005-06 to 2015-16.

As per the report of Midterm Evaluation of the National Leprosy Eradication Programme, India 10 – 21 November, DGHS, MoHFW and WHO joint initiative stated that “It is clear that there are cases occurring in the community and detection capacity is not exactly matching the level and intensity of disease occurrence. This indicates that there are hidden leprosy cases in the community. Major cause of hidden cases is low voluntary reporting by community due to persistent stigma and discrimination against Persons Affected with Leprosy. Sparsh leprosy awareness campaign (SLAC) will have an impact on stigma and discrimination against Persons Affected with Leprosy, through communicating the importance of early detection and treatment of leprosy.

Central Leprosy Division (CLD) along with its partners commemorate 30th January as ‘ANTI LEPROSY DAY’ every year, wherein nationwide message on leprosy awareness is spread through print and other media. In addition the IEC activities for leprosy elimination run for a fortnight. From now onward this day is envisaged to be celebrated as ‘**Sparsh Leprosy Awareness Campaign**’, wherein nationwide Gram Sabhas will be organised in cooperation and coordination with allied sector of health department/ ministries i.e., Panchayati Raj Institutions, Rural Development, Urban Development, Women and Child Development and Social Justice and Empowerment etc. This will be in addition to the activities being conducted by States.

The thrust of this Campaign is to promote community participation to reorient the delivery of the service of diagnosis and treatment of leprosy in its early stages from the centralized top-down delivery driven approach to decentralized community based demand-driven approach to empower the PRIs and local communities to take over the responsibility of sensitizing and motivating people for stigma reduction and discrimination and for early self reporting for diagnosis and treatment. The following four broad areas were kept in mind while preparing Sparsh leprosy awareness campaign (SLAC) strategy for PRIs and local communities.

- (i) *Awareness*: The rural community is being acquainted about bacterial causation of leprosy rather than widely prevailing superstitions and its ramifications on delay in seeking treatment.
- (ii) *Transparency*: The information on late detection and dangers of hiding the disease is being spread.
- (iii) *People participation*: Rural communities is being involved in organizing the IEC and case detection activities keeping in view of the needs, resources and challenges.
- (iv) *Accountability & Responsibility*: People are to be made aware that Gram Panchayat and Gram Sabha may play a key role in cutting the transmission chain of leprosy in community.

### Preparatory activities

Central Level Workshop with State Leprosy Officers Partners and Experts {Last week of December, 2016}.	<ul style="list-style-type: none"> <li>➤ To Chalk out detailed plan of activities</li> <li>➤ Mobilization of Resources</li> <li>➤ Finalization of key IEC Messages</li> </ul>
State Level Meeting {1st week of January, 2017}	<ul style="list-style-type: none"> <li>➤ Finalization of Pamphlets and message</li> <li>➤ To plan the supervision and monitoring strategies</li> </ul>
District level Meeting with District Leprosy Officer & Stake holders {2nd week of January, 2017}	<ul style="list-style-type: none"> <li>➤ Micro-planning of this 'The Sparsh Leprosy Awareness Campaign'</li> <li>➤ Preparing of Checklist of Monitoring this campaign</li> </ul>
Preparatory Panchayat Level Meeting with Members of Panchayat Gao-Pradhan & representative from village {3rd week of January, 2017}	<ul style="list-style-type: none"> <li>➤ Detailed activity will be shared with Panchayat</li> </ul>

### Institutional Framework

For better organization and management it is proposed to formulate special committees at various levels. The existing committees formulated for Leprosy Case Detection Campaign may be utilized which will ensure inter-sectoral coordination between all partners and other departments and review the progress in planning, implementation and monitoring of 'Sparsh Leprosy Awareness Campaign', which will be conducted as an annual activity during the fortnight beginning from 30th January till 13th February. However, non LCDC States may formulate Ad-hoc committees and conduct meeting of the members as per the constitution given below:

### **i) State Co-ordination Committee**

State Co-ordination Committee under the chairmanship of Principal Secretary Health & Family Welfare of the State with State Leprosy Officer as the Member Secretary, will be formed. Other members of the committee would be Mission Director (MD), NHM, Director Health Services (DHS), State level representatives of the key partners like Social Welfare, Education, Panchayati Raj Institution (PRI), Women & Child Development (WCD), Partners i.e. International Federation of Anti-Leprosy Associations (ILEP), World Health Organisation (WHO), Association of Persons Affected with Leprosy (APAL), Senior Regional Director, State Program Manager, Non Govt. Organisations (NGOs) working for Leprosy in the State. In addition two persons may be nominated by Principal Secretary Health & Family Welfare of the State.

### **ii) State Leprosy Awareness Media Committee**

State Leprosy Awareness Media Committee under the chairmanship of DHS/ MD (NHM)/ Director SIHFW of the State with the State Leprosy officer as the Member Secretary will be formed. Representatives from partner organizations like ILEP, WHO, APAL, local NGOs and State Media Cell, local Akashwani and Doordarshan Kendras will be represented in the committee through their state level.

### **iii) District Coordination Committee**

District Coordination Committee under the chairmanship of the District Collector/Magistrate/ Chief Executive Officer, Co-chaired by CMO/ CS/ DMO with the District Leprosy officer as the Member Secretary will be formed. District level representatives from Zila Parishad, APAL, Social Welfare deptt., District Publicity Department, District Health Education Officer, District ASHA Coordinator, District Programme Manager and District Epidemiologist should be a part of the committee.

### **iv) Tehsil / Block Coordination Committee**

Similar to the District Coordination Committee, Tehsil / Block Coordination Committee must be set up under the chairmanship of Sub Divisional Magistrates (SDM) (wherever available) with Block Medical Officer as co-chairman. Further, member of PRI, ICDS, Education, local NGOs, APAL, Social Welfare deptt., ASHA facilitators/ Sahiya Saathi, Community mobilizers, Block development officers and Block MOICs should be a part of the committee.

## **Responsibilities of officers at various level**

### **i) State Leprosy Officer (SLO)**

State Leprosy Officer is the key person to coordinate with Central Leprosy Division, State level authorities and District level authorities, to ensure celebration of 30th January, the first day of Sparsh Leprosy Awareness Campaign fortnight in all Gram Sabhas of States, as per the theme/ prototype provided by Central Leprosy Division.

SLO is responsible for sensitization of all District Leprosy Officers (DLO) and dissemination of various prototypes formulated by Central Leprosy Division to DLO in time.

### **ii) District Leprosy Officer (DLO):**

District Leprosy Officer is the key person to coordinate with State level authorities, District level authorities and Block level authorities including Block PHC Medical Officer to ensure the

implementation of campaign through interdisciplinary approach.

DLO is responsible for sensitization of all Block PHC Medical Officer and dissemination of various prototypes to Block PHC in time.

### **iii) Block PHC Medical Officer (MO):**

Block PHC MO is nodal person who is accountable for celebration of 30th January, i.e., the first day of Sparsh Leprosy Awareness Campaign fortnight in all Gram Sabhas of block, as per the activities given below:

#### **Activities to be conducted at Gram Sabha on 30th January (sample of message from DM, appeal from Gram Sabha Pramukh and pledge will be finalized in consultation with SLOs and supplied):**

- i. Message from District Magistrate (To be read by DM (if available) or Gram Sabha Pramukh)
- ii. Appeal from Gram Sabha Pramukh
- iii. Pledge to be taken by all Gram Sabha members
- iv. Felicitation of representative from person affected with leprosy (if available) by Gram Sabha Pramukh
- v. Questions and answers session based on FAQ provided
- vi. Vote of thanks

The village health and sanitation committee will be responsible for implementation of above mentioned activities. The event may be facilitated by respective multi-purpose worker (MPWs) with active cooperation from village revenue official e.g., *patwari, gramsevik, school teacher, asha, anganwadi worker etc*, at the village level and under the supervision of Medical Officer of Primary Health Centre (PHC).

In addition to above activities various success stories will be made available to media for further dissemination by SLOs/ DLOs during the fortnight, giving positive message to the community. Various IEC activities at local level may be conducted using various media giving message on importance of early case detection and to reduce the stigma and discrimination.

In urban areas DLOs with help of NGOs, International Organisations, Rotary Club, Lion Club etc. will organize various IEC activities giving message on importance of early case detection and to reduce the stigma and discrimination during whole fortnight.

## **Frequently Asked Questions (FAQs)**

### **Q 1. What is Leprosy?**

- ◆ Leprosy is a long persisting (chronic) infectious disease.
- ◆ It appears as a hypo pigmented patch on skin with definite loss of sensation. The onset of leprosy is subtle and silent. It affects nerves, skin and eyes.
- ◆ Of all the communicable diseases, leprosy is most important for its **potential cause for permanent and progressive physical disability**. In addition, the disease and its visible disabilities in particular, contribute to intense social discrimination of patients.

### **Q 2. What causes Leprosy?**

Leprosy is caused by bacteria (Mycobacterium leprae.)

### **Q 3. How is the disease spread?**

- ◆ Untreated leprosy affected person is the only known source for bacteria. Respiratory tract especially nose is the major route of exit of the organism from the body of infectious persons.
- ◆ Disease causing organism enters the body commonly through respiratory system by droplet infections.
- ◆ After entering the body, the organism migrates towards the nerves and skin.
- ◆ If it is not diagnosed and treated in early stages, it may cause further damage to nerves leading to development of permanent disability.

### **Q 4. Is the disease hereditary?**

There is no evidence to say that it is hereditary.

### **Q5. What are the signs and symptoms of leprosy?**

Leprosy should be suspected if a person shows the following signs and symptoms:

- ◆ Dark skinned people might have light patches on the skin, while pale skinned people have darker or reddish patches
- ◆ Loss or decrease of sensation in the skin patches
- ◆ Numbness or tingling in hand or feet
- ◆ Weakness of hands, feet or eyelids.
- ◆ Painful nerves
- ◆ Swelling or lumps in the face or earlobes
- ◆ Painless wounds or burns on hands or feet.



**Q 6. Is Leprosy curable?**

- ◆ The disease is curable. If detected early it can be cured by Multi Drug Therapy (MDT)
- ◆ Recurrence after adequate treatment with MDT is extremely rare.

**Q 7. Why leprosy takes so long to show symptoms?**

- ◆ The symptoms of the disease occur generally after a long period as the incubation period for leprosy is variable from few weeks to 20 years or more.
- ◆ The average incubation period of the disease is said to be 5 to 7 years.

**Q 8. What should be done in case of suspicion of leprosy?**

In case of presence of signs and symptoms of leprosy, please contact ASHA or ANM of your area or visit the nearest dispensary. Treatment of leprosy is available free of cost at all government dispensaries.

**Q9. What is the impact (medical) of leprosy?**

- ◆ It results in physical disability and deformity due to nerve damage resulting in sensory and muscle weakness.
- ◆ All this leads to dry skin - that with added sensory impairments, results in development of hardened skin, blisters and ulcers.
- ◆ If ulcer is neglected, it may further worsen the disability. This is compounded by muscle paralysis leading to deformity.

**Q 10. Where is the medicine for leprosy available?**

MDT is available free of cost at all the Government Health Care Facilities in the country. Under the National Leprosy Eradication Programme, treatment is provided free of cost to all the cases diagnosed each year through the general health care system including NGO institutions.

**Q 11. Can the deformities be corrected by medicine?**

No, but can be prevented by early detection and treatment.

Medicines (MDT) should be started as soon as possible after the person is diagnosed as having leprosy. Those who start the MDT late, after irreversible loss of nerve functions, are left with deformities and become disabled physically. Such deformities can be corrected to a limited extent only with surgery.

**Q 12. Can the deformity be corrected by surgery?**

Only partial deformity can be corrected by surgery.

**Q13. How to prevent disability?**

- ◆ Detect cases as early as possible, before deformities can set in.
- ◆ It is therefore important to take regular treatment (MDT), report immediately in case of loss of sensation or nerve pain.

**Q14. Should a person affected by leprosy be sent to a leprosy sanatorium?**

There is no need to treat leprosy patients in special clinics or hospitals. In many countries, leprosaria have been transformed into general hospitals or other functions.

**Q15. Can I live with a person affected by leprosy?**

Yes, you can live with a person affected by leprosy because it is not highly infectious. People affected by leprosy should not be isolated from their family and community. They can take part in social events and go to work or school as normal.

**Q 16. Can a person affected by leprosy get married?**

Yes, a person affected by leprosy can lead a normal married life and have children.

**Q 17. Is it necessary to examine those in contact with a person affected by leprosy?**

Those who live with a person affected by leprosy are at increased risk of getting the disease. Therefore, it is important to have people living in the same household and close friends examined regularly for leprosy. At the same time, they should also be educated regarding the signs and symptoms of leprosy as well as the type of help they can give to the leprosy patient living with them.

**Q18. What should One know about MDT?**

MDT is a combination of different drugs as leprosy should never be treated with any single anti-leprosy drug.

- ◆ One should complete the full course of MDT as prescribed by a trained health worker according to the type of leprosy.
- ◆ MDT is available free of charge at most health facilities including in remote areas.
- ◆ Any adverse reaction to MDT should be reported to the nearest health facilities.

**Q 19. What if a leprosy patient cannot complete a prescribed course of MDT treatment?**

It is important to understand that a leprosy patient must complete a full course of MDT. However, there are circumstances where a patient is forced to stop the treatment.

In case, the patient has to move out from the place where he/she lives, the following actions are advised:

- ◆ Request for a referral letter from the health care centre where he/she is currently taking the treatment. The letter should contain reports pertinent to his/her diagnosis and treatment.
- ◆ Request from the same healthcare centre for sufficient MDT stock to ensure continuous treatment before he/she reports to the nearest healthcare centre in his/her new place. All health care centres can provide leprosy treatment and care.
- ◆ Identify and report to the nearest healthcare centre in his/her new place by showing the referral letter; inform the new health care centre about new address in detail including contact no., if appropriate.

**Q20. What are the adverse drug reactions with MDT?**

MDT is remarkably safe, and severe adverse reactions are rare.

Minor adverse drug reactions include:

- ◆ Rifampicin: reddish urine
- ◆ Dapsone: anemia
- ◆ Clofazimine: brown discolouration of skin

**Q 21. Is MDT safe during pregnancy and lactation for the mother and the baby?**

Yes.

**Q22. What is a relapse?**

A relapse is defined as the reoccurrence of the disease at any time after the completion of a full course of MDT. Relapse is diagnosed by the appearance of definite new skin lesions.

**Q 23. What is leprosy reaction?**

Leprosy reaction is the sudden appearance of symptoms and signs of inflammation in the skin of a person with leprosy in the forms of redness, swelling, pain, and sometimes tenderness of the skin lesion.

New skin lesions can also appear. Leprosy reaction can occur before, during and after completion of treatment. In case of leprosy reaction, report back to your nearest dispensary.

**Q24. What is the current focus of the program?**

Early detection of all cases in a community and completion of prescribed treatment using MDT are the basic tenets of the Enhanced Global Strategy for Further Reducing Disease Burden Due to Leprosy.

The Strategy emphasizes the need to sustain expertise and increase the number of skilled leprosy staff, improve the participation of affected persons in leprosy services and reduce visible deformities – otherwise called Grade 2 disabilities (G2D cases) – as well as stigma associated with the disease.

*Notes:*