

PART I

**Consensus-Building and Integration
of NLEP with the
Primary Health Care System:**

A study in Digapahandi and Mohana Blocks of Orissa

2001

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Contents

Executive Summary	9
Introduction	11
Objectives	12
General objective	12
Specific objectives	12
Background	14
Characteristics of study population	14
The leprosy situation	15
Training and experience in leprosy work	16
Service provision profile	16
Rationale for study and intervention	17
Methodology	18
The intervention	18
Sampling	22
Sources of data	23
Study instruments	24
Pre-testing	24
Data collection, compilation and analysis	24
Timeframe	25

Results	26
Perspectives of service-providers	26
Perspectives of leprosy patients	37
Community responses	43
Conclusion	48
Recommendations	51
Annexures	
1 Programme for Consensus-Building Workshop at Primary Health Centre	52
2 Guideline by Government of Orissa for Implementation of revised operational strategy in NLEP	53
3 Training for Capacity-Building and Development of Sector-wise Action Plan	60
4 Guidelines to be used by the facilitator in a FGD session before and after the intervention (for community members)	61
5 Self-administered questionnaire for medical officers	62
6 Questionnaire for health workers (M and F)	63
7 Questionnaire for paramedical workers	64
8 Questionnaire for health supervisors	65
9 Questionnaire for personal interview with leprosy patients	66



List of Tables

Table 1:	Registered case-load of leprosy 1997-2000	15
Table 2:	Health facilities and PHC-level staff in the study blocks (Nov. 2000)	17
Table 3:	Sample size	22
Table 4:	Profile of cases detected in Bomokai before and after intervention	26
Table 5:	Profile of cases detected at Mohana before and after intervention	27
Table 6:	Patient adherence for regular treatment	28
Table 7:	Perception of HW (M and F) on job responsibility in leprosy	28
Table 8:	Perception of PMWs on job responsibilities in leprosy work	30
Table 9:	Involvement of sub-centre HWs in NLEP (verified from records)	33
Table 10:	Completeness and regularity of reporting from SCs in the post-intervention period	34
Table 11:	No. of leprosy patients interviewed	37
Table 12:	Distribution of cases by age, sex and category	37

Table 13: Time-gap between onset of symptoms and reporting for diagnosis	38
Table 14: Leprosy diagnosis by HWs	38
Table 15: Local names used for leprosy	39
Table 16: Persons involved in suspecting leprosy cases	39
Table 17: Staff involved in leprosy diagnosis	40
Table 18: Place of diagnosis of leprosy cases	40
Table 19: Information provided at start of leprosy treatment	41
Table 20: Source of MDT drugs	41
Table 21: Mode of collection of MDT drugs	42

List of Figures

Figure 1: Map of Orissa showing Mohana and Digapahandi blocks in Ganjam and Gajapati districts, respectively	15
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Executive Summary

In September 1999, the Government of Orissa issued an order for the implementation of the revised operational strategy for the integration of the National Leprosy Elimination Programme (NLEP) functions into the primary health care (PHC) system. However, there was no consensus on job responsibilities at the field level, and the programme was not running uniformly and smoothly. Therefore, a training and consensus-building intervention strategy was developed at the block and sector PHC levels to facilitate the integration process. Against this background, the present study was commissioned by DANLEP (Orissa) to assess the impact of consensus-building and training.

Two block primary health centers (PHCs) were selected for the study. These were: 1) Mohana tribal area, and 2) Bomokai rural area (Digapahandi block) under the MKCG Medical College, Berhampur, with low and high prevalence of leprosy respectively.

After necessary preparations the research team went to collect information based on the pre-designed formats from primary health centres and sub-centres (SCs), including interviews with different health care providers. Four focus group discussions (FGDs) were conducted in each block before and after the intervention to assess community awareness and involvement in leprosy services. Both patients and health staff were interviewed. Following the intervention, there was improvement in case-detection and utilisation of services by patients. Health staff became more aware of their job responsibilities and their involvement improved. After the intervention, medical officers (MOs) were involved in case-confirmation, initiating treatment, and review and coordination of leprosy work at the sector PHC

level. The female case-detection rate increased by 24.3% and the child case-detection rate increased by 27.3% in Mohana block.

Other significant findings included:

- Reporting from sub-centres gradually increased and became regular in the post-intervention period.
- Supervision of leprosy work by medical officers (MOs) and health supervisors (HSs) improved.
- Patients were satisfied that drugs were available with the sub-centre close to their village.
- The average time gap between the onset of the signs and symptoms of leprosy and reporting for diagnosis was 9.2 months (maximum 26 months and minimum 2 months).

The following recommendations were made to support the integration process, based on the findings of the study:

- Training and consensus-building on job responsibilities of different categories of staff of PHC and NLEP systems should be carried out.
- Block PHC should act as a coordinating agency.
- Area- and problem-specific comprehensive and coordinated activity plans in each sector PHC area should be prepared for the implementation of the programme.
- Continuing education, training and review of NLEP activities should form a part of sector-level meetings.



Introduction

The World Health Assembly, at its 44th session in May 1991, adopted a resolution declaring its commitment to promote the use of all control measures, including multi-drug therapy (MDT) and case-finding, to attain the global elimination of leprosy as a public health problem by 2000. The Government of Orissa is also committed to this goal of leprosy elimination, and, to hasten the process, it issued instructions for a “Revised Operational Strategy” in September 1999, whereby the involvement of the primary health care system in the NLEP service delivery was a key element. However, PHC functionaries in many areas were neither aware of nor understood their new role in the revised programme. These factors affected the operationalisation of the programme and made it difficult to sustain NLEP activities. Therefore, an interventional strategy was developed to facilitate the integration process in two blocks of south Orissa: the rural block of Digapahandi and the tribal block of Mohana.



A physician providing MDT drugs to a patient at a primary health centre.



Objectives

General objective

The general objective was to study the effectiveness of consensus-building, training and continuing education for integrating NLEP functions in the PHC system in Digapahandi and Mohana blocks.

Specific objectives

These were:

- To determine the understanding of job responsibilities in leprosy activities by NLEP and PHC workers before and after the intervention.
- To assess the involvement of PHC field workers in NLEP functions in terms of suspecting cases, case-holding, irregular case retrievals, management of adverse reactions, record-keeping, reporting and IEC activities.
- To assess the extent of involvement of PHC medical officers in NLEP functions.
- To compare the number of male and female cases detected during the study period with the corresponding period in the previous year (MB, PB, SSL, child and deformity cases).
- To compare patient adherence before and after the intervention.

- To determine the completeness and regularity of reporting from sub-centre and PHC to block level.
- To determine the frequency of supervision provided to field staff.
- To study patient satisfaction after the intervention.
- To study community awareness about the new system of service delivery.
- To make recommendations based on the findings of the study.



Background

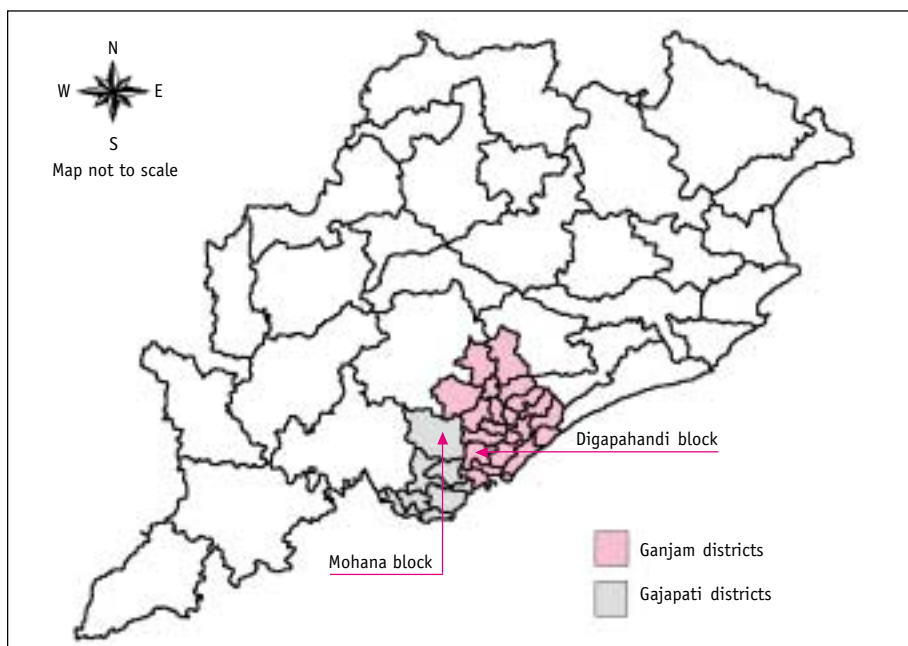
The reorientation of medical education (ROME) scheme was implemented through the Rural Health Training Centre, Digapahandi, and there were three PHCs under the overall control of the Department of Community Medicine of the MKCG Medical College, Berhampur, for this purpose. The PHCs in question were: Bomokai (Digapahandi block), Sheragada and Mohana, of which CHC, Mohana, is in Gajapati district and the other two are in Ganjam district. Mohana is a typical tribal block having many inaccessible areas, low levels of literacy and poor socio-economic conditions. Sheragada and Digapahandi are representative of the non-tribal rural blocks of Orissa. Based on these characteristics, as well as the leprosy prevalence rate (PR), Digapahandi and Mohana were selected for the purpose of this study. The block-level PHC for Digapahandi is situated at Bomokai and that for Mohana is situated at Mohana. The same institution is responsible for all health activities in the entire block. For this reason the name Bomokai is often used for Digapahandi in this document.

Characteristics of study population

Digapahandi is a thickly populated block with 1, 43,290 persons (January 2000) spread over an area of 296 km². There are 233 villages, 23 *gram panchayats* (village councils) and one Notified Area Council in the block. The sex ratio was 941 females per 1,000 males, and the Scheduled Castes (SC) and Scheduled Tribes (ST) formed 15% and 6.2%, respectively, of the total population. Nearly two-thirds of the households lived below the poverty line. The literacy rate was 61.5% in 2000.

Mohana block had a sparsely distributed population of 1,08,531 (January 2000) in an area of 1303 km². There are 529 villages and hamlets and 20 *gram panchayats* in the block. The sex ratio was 999 females per 1,000

Figure 1: Map of Orissa showing Mohana and Digapahandi blocks in Ganjam and Gajapati districts, respectively



males, and the ST and SC population constituted 53% and 7%, respectively, of the total population. More than three-fourths of the families lived below the poverty line. The literacy rate was 33.8% (January 2000).

The leprosy situation

Table 1: Registered case-load of leprosy 1997-2000

Year	Bomokai				Mohana			
	PB	MB	Total	PR	PB	MB	Total	PR
1997-98	127	69	196	14.1	30	08	38	3.6
1998-99	30	35	65	04.6	20	03	23	2.1
1999-00	131	63	194	13.5	24	07	31	2.8

The child rate of leprosy was 33.6% in Bomokai and 16.6% in Mohana in 1999-2000.

The leprosy situations in these two blocks were different. Bomokai was a thickly populated rural area with a high PR where leprosy work was looked after by four paramedical workers (PMWs). Mohana was a difficult inaccessible tribal area with a low PR. The cases were sparsely distributed over a large area. The leprosy work was managed by only three PMWs, who were previously working in the vertical NLEP programme.

Training and experience in leprosy work

While the Medical Officers (MOs), PMWs and Block Extension Educators (BEEs) of Gajapati district, including those in Mohana, had been trained by the Chief District Medical Officer for two days in mid-2000, in monitoring the elimination of leprosy, no such training had been given to the staff in Bomokai. Staff in both places had participated in two rounds of the modified leprosy elimination campaign (MLEC) when they had been trained in case-detection.

Of the ten MOs in position in Bomokai and eleven in Mohana, five and six, respectively, had some experience of leprosy work during the MLEC. The remaining MOs were either newly-posted or were specialists posted in secondary health care facilities, with no experience in leprosy work.

Service-provision profile

While Digapahandi has a block PHC located at Bomokai, Mohana block has a Community Health Centre (CHC). Details of other health facilities and their staff involved in primary health care in these two blocks (as of November 2000) are given below.

One sub-centre (SC) in Bomokai had no staff; six had either a male or a female HW, while 17 SCs had both a male and a female worker. In Mohana, two SCs had no staff, 14 had a male or a female worker and 13 had both.

The Integrated Child Development Scheme (ICDS) was introduced in Digapahandi block in 1999-2000 and 122 Anganwadi Centres had been identified. Sixty Anganwadi Workers (AWWs) and three supervisors were in place in 2000. In Mohana, 120 Anganwadi Centres were functioning, with 108 AWWs and three supervisors.

Table 2: Health facilities and PHC-level staff in the study blocks (Nov. 2000)

Facility/Staff	Bomokai	Mohana
Sector PHCs (PHC (N))	5	5
Government Hospital	1	1
Rural Health Centre (RHC)	1	0
Sub-Centres (SCs)	24	29
Medical Officers (MOs)	10	11
Pharmacists	9	8
Multi-purpose Health Supervisors, Male (MPHS (M))	4	4
Multi-purpose Health Supervisors, Female (MPHS(F))	5	4
Health Workers, Male (HWs (M))	17	15
Health Workers, Female (HWs (F))	19	26
Leprosy Paramedical Workers (PMWs)*	4	3

**Only PMWs were providing NLEP services in the total block area before integration.*

Four non-governmental organisations (NGOs), namely, Pragati Pathagar, Jayanti Pathagar, ISARA and Gram Vikas, were working in the PHC Bomokai area and at times helping in health programmes. Similarly, there were two NGOs, PREM and ISARA, in Mohana block.

Rationale for study and intervention

The limited NLEP staff under the vertical programme was unable to cover all areas when the prevalence of the disease decreased in most parts of the state. It was felt necessary then to integrate the leprosy programme with primary health care to render NLEP services in all parts of the state through the existing infrastructure of the PHC system. To ensure sustained NLEP activities through the PHC staff, the integration process had to be strengthened. Therefore, an intervention strategy was developed to facilitate the integration process.



Methodology

The intervention

Although it was expected that the PHC system would be involved in selected NLEP services, it was observed that the desired result had not been achieved, perhaps because of lack of interest, knowledge, skills, motivation and/or other reasons. Many staff members were not aware of their leprosy-related job responsibilities even if they had been trained.

An attempt was, therefore, made to build a consensus regarding job responsibilities among different categories of health functionaries through a workshop. This was supported by training, development of a coordinated work plan, continuing education and feedback at sector-level meetings so as to bring a qualitative change in their work.

In each PHC, a consensus was developed on the division of tasks and the operational aspects of integrated leprosy activities for case-detection, treatment, surveillance, education, drug distribution and overall effective management of the leprosy programme. Based on the identified training needs for carrying out these tasks, training of staff was conducted. The functionaries, for their respective areas, developed coordinated work plans through group work after sector-wise analysis of the leprosy situation and identification of obstacles in the implementation of the integrated programme. Each group was heterogeneous and consisted of a number of functionaries including health-care providers at the grass-roots level, supervisors and health managers.

At the start of the training, the participants were assessed with regard to their knowledge and respective roles and responsibilities in the revised operational strategy for the leprosy programme. The training needs assessed

during the consensus-building workshop were addressed during this training experience. Further steps were taken to develop an in-built monitoring system and continuing education at the sector PHC level by the concerned medical officers and health supervisors.

Workshop on consensus-building

A one-day workshop was organized for all health functionaries of each PHC with the objective of developing a consensus action plan to facilitate integration of NLEP with the primary health care system at Digapahandi and Mohana (Annexure 1).

A consensus was reached after group work and plenary discussion regarding:

- The extent of the leprosy problem in the block;
- The need for integrating NLEP functions with primary health care and the Revised Operational Strategy;
- Job responsibilities of each category of health functionaries (Annexure 2);
- The role of sector PHCs as functional units to improve leprosy work;
- The key role of medical officers of sector PHCs and health supervisors in coordination and supervision;
- A uniform system of making drugs available in all health facilities. This would be done through monthly procurement of MDT drugs from the district authority and their distribution to the sector PHC by the block PHC/CHC;
- Weekly replenishment of drugs in sub-centres during sector meetings to ensure three months' stocks;
- Timely generation and onward transmission of leprosy reports at different levels;
- Common PHC action plan on Revised Operational Strategy.

Keeping in view the Revised Operational Strategy and area-specific problems, each PHC developed its own action plan. Their common features are presented below:

- Leprosy activities would be coordinated by the medical officers of the respective sector PHCs.
- Emphasis would be placed on early case-detection and regularity of treatment. For early case-detection, contact survey and mass survey or special search activities in low coverage areas were suggested by field workers in Mohana block, while contact examination and examination of family members were suggested for Bomokai area.
- A fixed-day leprosy clinic would be conducted by the PMW once a month in each sub-centre assisted by HWs (F and M) where all types of leprosy work would be carried out. In order to focus only on leprosy work, this day would not coincide with any other clinic at the sub-centre on that day. In Mohana block, the fixed-day clinic could be held as a leprosy outreach clinic in distant villages other than the village where the SC was situated, with prior communication with the community as well as the MO PHC, PMW and HS.
- Every Saturday, sector meetings would be held at sector PHC to review different health activities SC-wise where all categories of health staff would participate. In that meeting detailed planning for the work in the coming week would be done, which would include leprosy activities.
- A survey would be conducted by the PMW, assisted by HWs (M and F) and MPHS (M and F) for at least two to three days around the day fixed for the leprosy clinic in the respective sub-centre, in order to cover all families within the year (covering 1,000 families per sub-centre in a year).
- Identification of inaccessible and difficult areas, considering the distance from the SC and the difficulty of terrain, would be done to enable special planning for their coverage.
- Sub-centres with long-standing staff vacancies would be identified and plans would be made to cover those areas for all health-related activities.

Continuing education on leprosy for field workers would be carried out once a month by the sector MOs during the sector meeting.

- Seeking the help of cooperative volunteers and AWWs for leprosy work was suggested in both areas.
- Community education would be facilitated by HWs (M and F) during their routine family visits through interpersonal communication, printed materials and setting personal examples.
- Planning for holding health education camps would be done in the block PHC meeting in consultation with the BEE, which would be communicated to all workers in the respective areas.

Capacity-building and development of sector-wise action plans

Following the one-day consensus-building workshop and development of the PHC action plan, all workers of the sector PHCs and PMWs were trained and guided to develop a sector-wise action plan for effective coordinated leprosy work in their respective areas (Annexure 3).

This exercise was conducted in batches of about 20 workers who participated in a two-day training and action-plan development programme. The participants were divided into three batches for each block for the above purpose. This training and sector-wise action plan was completed by 22 December 2000. Continuing education was conducted at the sector-level meetings.

Assessment of the effectiveness of the integration strategy

Health functionaries of various categories and levels were allowed to work for a period of six months to carry out activities in their respective areas along with other routine work. The investigators conducted an evaluation after this period. A sample of health functionaries, patients and community members were assessed to measure the effectiveness of the intervention. The evaluation was carried out in July 2001.

Sampling

Table 3 shows the actual number of workers and patients interviewed.

Table 3: Sample size

Group of participants	Sample size			Comments
	Planned	Actual		
		Pre-intervention	Post-intervention	
Block PHC/CHC	2	2	2	
Sub-centres	40	51	44	All staff of SCs. Seven SCs had no staff due to transfers
Medical officers	20	9	9	Four vacant posts; Three MOs on long leave; four specialists not part of PHC work
Health workers	40	56	55	Total number of HWs: 77
Health supervisors	17	17	13	Total available population (one retired, one suspended, two transferred)
Paramedical workers	7	7	6	Total available population (one on long leave)
Leprosy patients <i>Mohana</i>	All patients	–	13 under treatment	Convenience sampling: those patients who were available in the village on the day of visit by investigator
<i>Digapahandi</i>	>30	–	24 RFT* and 28 under treatment	
FGDs** with community members <i>Mohana</i>	4	4	4	In eight different sectors
<i>Digapahandi</i>	4	4	4	

*) RFT = Released from treatment

**) FGD = Focus group discussion

While the medical officers were assessed through an open-ended self-administered questionnaire (Annexure 5), other participants responded to pre-designed and pre-tested open-ended questionnaires.

Between January and June 2001, 48 male and 28 female patients were detected in Bomokai and six male and ten female patients were detected in Mohana block (excluding single skin lesion cases). Of these, 12 male and 16 female patients were interviewed in Bomokai and five male and eight female patients were interviewed in Mohana. In addition, 21 male and three female patients, who had completed treatment during the reference period, were interviewed in Bomokai. No patient had completed treatment during this period in Mohana. All the patients were selected on the basis of convenience, i.e. their availability at the time of the interviewer's visit.

Each focus group consisted of six to eight participants, selected on the basis of their availability. Members included teachers, patients, AWWs, *mahila samiti* (women's group) members, local leaders, *gram panchayat* members and other elected representatives, and local volunteers involved in other health programmes. All groups included both male and female participants. FGD participants did not include service-providers to avoid this particular source of bias during discussions.

Sources of data

Data were collected from sub-centre records as well as through interviews with male and female health workers, leprosy workers, multipurpose health supervisors, patients and medical officers. Focus group discussions were also conducted about the ongoing leprosy programme.

For the FGDs, two investigators mediated each discussion. One of them facilitated the discussion as per the points described in the FGD guidelines (Annexure 4) while the other recorded them on a tape-recorder and also took notes on the observations made during the meeting.

Study instruments

Three separate formats for secondary data collection were used to record:

- The number of patients registered, suspected and confirmed;
- The number of patients under treatment and the number who had received drugs;
- The number of reports generated, the proportion of correct reports and the dates of submission.

Five different interview schedules were also developed for medical officers, multipurpose health supervisors, health workers, PMWs and patients. While the medical officers were given a written questionnaire to complete, all other respondents were interviewed by the research team members. Open-ended questionnaires were designed and pre-tested for qualitative assessment.

Pre-testing

A pre-test of all study instruments was conducted in the area of Chandanpur CHC in September 2000, on the basis of which some revisions were made in the questionnaires.

Data collection, compilation and analysis

Data collected by verification of institution records, interviews and through FGDs were compiled and both quantitative and qualitative analysis were done. General opinions raised during discussions in FGDs along with the varied opinions by individual members were recorded and taken into consideration during the analysis. The quantitative analysis was done by comparing different leprosy indicators following the intervention with the same indicators for the same months during the previous year. Data generated by questionnaires, interviews and FGDs were correlated with the change in the leprosy situation, and a qualitative analysis was carried out.

Timeframe

The proposal for this study was prepared in a workshop at Puri in September 2000. A one-day workshop was held in December 2000 in each PHC for all health functionaries, with the objective of developing a consensus and action plans to facilitate the integration of NLEP with the PHC system. These workshops were followed-up with training.

The intervention was implemented in January 2001 after which date the NLEP services were rendered through the primary health care system. Data on the effectiveness of the intervention were collected after six months, i.e. in July-August 2001, followed by compilation and analysis.

A draft report was submitted in May 2002. This was discussed and revised based on the discussions held during a data analysis and report-writing workshop held at Puri in April 2003. The final report was submitted in May 2003.



Results

This chapter presents the findings based on the views expressed by service-providers, patients and FGD participants.

Perspectives of service-providers

Profile of cases detected

Table 4: Profile of cases detected in Bomokai before and after intervention

Type of cases	Bomokai					
	Before Jan-June 2000			After Jan-June 2001		
	Male	Female	Total	Male	Female	Total
SSL	10	4	14	17	7	24
PB	30	12	42	34	22	56
MB	13	11	24	14	6	20
Total	53	27	80	65	35	100
Child	9	1	10	13	6	19
Deformity	0	1	1	1	0	1

In Bomokai prior to the intervention, of the 80 cases detected during the six months, 17.5% were of SSL, 52.5% of PB and 30% were of MB type. After the intervention, of the 100 cases detected during the same period, 24% were of SSL, 56% of PB and 20% were of MB type. The proportion of female cases was 33.8% and 35% before and after the intervention respectively. The child rate was 12.5% before the intervention and 19% after the intervention. One case of deformity was registered in the pre-intervention period and another in the post-intervention period.

Following the intervention, new case-detection got improved in Bomokai. It increased in absolute numbers. Detection of leprosy cases in the early

stage (SSL and PB) also increased, both in numbers and proportion. More child cases were detected during the post-intervention period. More female cases were detected in proportion to the increase in the total number of cases detected. All these improvements could be due to the changed orientation of PHC functionaries towards the programme after the intervention.

Table 5: Profile of cases detected at Mohana before and after intervention

Type of cases	Mohana					
	Before Jan-June 2000			After Jan-June 2001		
	Male	Female	Total	Male	Female	Total
SSL	1	2	3	2	1	3
PB	6	1	7	5	10	15
MB	3	2	5	1	0	1
Total	10	5	15	8	11	19
Child	2	1	3	2	7	9

In Mohana before the intervention, of the 15 cases detected, 20% were of SSL, 46.6% of PB and 33.3% of MB type. After the intervention, of the 19 registered cases, 15.7% were of SSL, 78.9% of PB and 5.3% of MB type. The proportion of female cases was 33.3% and 57.9% before and after the intervention respectively. The child rate was 20% before the intervention and 47.3% after the intervention. No deformity cases were reported either in the pre- or post-intervention periods.

In a low endemic area like Mohana the detection of new cases was only marginally improved. This reflected the actual leprosy situation in this block. The new cases were in the form of women and children and in the early stage of the disease, i.e. PB form.

In both the areas the female PB case-detection was nearly doubled. The increased case-finding in women and children after the intervention could be due to the involvement of PHC functionaries at the grass-roots level.

Treatment adherence

The proportion of the patients treated regularly at Bomokai was 72% and 94% in the pre- and post-intervention periods respectively. The proportion of the relatively few cases who were treated regularly at Mohana was 75%

Table 6: Patient adherence for regular treatment

Regularity of taking treatment	Bomokai				Mohana			
	Pre-intervention as of June 2000		Post-intervention as of June 2001		Pre-intervention as of June 2000		Post-intervention as of June 2001	
	Total	%	Total	%	Total	%	Total	%
Regular	88	72.1	95	94	9	75	16	100
Irregular	34	27.9	6	6	3	25	0	0
Total	122	100	101	100	12	100	16	100

in the pre-intervention and 100% in the post-intervention periods.

The leprosy patients' adherence to regular treatment was remarkably improved following the intervention, because MDT services were made available close to the patients through the SC workers, and a continuous rapport between service-providers and patients was established.

Perception of HWs (M and F) on job responsibility

To assess the understanding of health workers regarding their new roles and responsibilities in the leprosy programme, open-ended questionnaires (Annexure 6) were administered to HWs (M and F).

During the pre-intervention period in Bomokai, all 24 HWs (M and F) perceived case-suspension as a duty included in their job responsibilities.

Table 7: Perception of HW (M and F) on job responsibility in leprosy

Tasks	Bomokai		Mohana	
	Pre-intervention N=24 (7M+17F)	Post-intervention N=25 (10M+15F)	Pre-intervention N=32 (10M+22F)	Post-intervention N=30 (8M+22F)
To suspect cases	24	25	32	30
Get cases confirmed by MO/PMW	2	23	12	29
To distribute drugs	18	23	16	30
To follow-up cases	5	22	4	10
To maintain record	9	14	23	29
To report	2	17	18	27
Health education	1	3	8	20

This was followed by drug distribution (18) and record maintenance (9). Awareness regarding case follow-up, getting cases confirmed by MO/PMW, reporting and health education was poor. In the post-intervention period all 25 respondents saw case-suspicion as their job responsibility, followed by drug distribution (23), getting cases confirmed by MO/PMW (23) and case follow-up (22). Seventeen HWs included report-generation and 14 record-maintenance among their professional duties, and only three saw health education as part of their responsibilities.

Perceptions of tasks were more inclusive among the HWs in Mohana as compared to those in Bomokai. There was a significant change in the awareness levels about their job responsibility in almost all the components after the intervention, including health education, in Mohana. During verification of records and reports, it was observed that, although the records were available at the sub-centres, they were generally not properly maintained. In most of the SCs there were no leprosy cases, so there was no need to maintain records. But the HW did not submit a zero report every month.

Health workers in both areas had been involved in MLEC activities and understood their role in case-suspicion even before the intervention. For the same reason they did not appreciate their role in diagnosis and case follow-up, as they were not involved in such activities. Record-keeping and reporting were ill-perceived in Bomokai as these were practically done by the PMWs and no uniformity was maintained. The difference in understanding of the staff in the two blocks could be due to the training input given in Mohana before the intervention. Health education about leprosy was communicated to the patients, their families and some community members by the Mohana HWs as revealed by the patients and other FGD participants. The workers did not mention health education, as it was not taken up separately in an organized manner.

In both areas, AWWs were assisting HWs in carrying out leprosy activities. Sometimes ward members, teachers, voluntary health groups (VHG) and trained traditional birth attendants (TBAs) also helped. In none of the two sites was leprosy work perceived as an extra workload for the workers. However, as stated by HWs, in addition to the inaccessibility of areas in Mohana, difficulties were encountered due to poor coordination between the PMWs and HWs in both areas.

Perception of PMWs on job responsibility

There were altogether seven PMWs in these two blocks, four in Bomokai and three in Mohana, covering two sectors each. During the consensus-building session it was agreed that the PMW will visit each sub-centre on a fixed day every month (fixed-day clinic). On that day he/she was supposed to confirm the suspected cases, visit the houses of defaulters for retrieval, assist HWs in updating the registers and generating the monthly report, and conduct the survey, health education (HE) and prevention of disabilities (POD) activities with the help of the HWs of the concerned sub-centres. He/she was expected to manage the complicated cases, including the reaction cases. Furthermore, the PMWs were to conduct clinics at the sector headquarters

Table 8: Perception of PMWs on job responsibilities in leprosy work

Tasks	Bomokai and Mohana	
	Pre-intervention N=7 (4+3)	Post-intervention N=6 (3+3)
Special survey	2	2
Village survey	7	6
Contact survey	4	5
School survey	5	6
Attend leprosy clinics	0	2
Case-detection and diagnosis	4	6
Drug distribution to SCs and health institutions	1	4
Reaction management		
By self	3	0
With help of MO	3	6
Deformity management	0	1
Drop-out management	0	3
Surveillance	2	3
Released from treatment	4	6
Treatment of patient	2	4
Record maintenance		
By self	7	3
Assisted	0	3
Assist in report preparation	4	6
Report consolidation	2	6
Report transmission to PHC and Leprosy Elimination Unit	3	6

(PHC-N), preferably on the day of sector meeting once every fortnight. He/she was also supposed to attend the monthly meeting at the block PHC level.

Considering the limited number of PMWs in the study area, the data was aggregated to evaluate their perception on job responsibilities (Annexures 2 and 7).

All PMWs mentioned the village survey, five mentioned the school survey, and four the contact survey as the tasks included in their job responsibilities during the pre-intervention period, whereas all the six PMWs interviewed in the post-intervention period considered the village survey and the school survey and the majority (five out of six) considered the contact survey as included in their job responsibilities in the revised strategy. Attending the leprosy clinic, assisting HWs in record maintenance, and reaction and deformity management were poorly perceived by PMWs as their job responsibilities in the pre-intervention period. But in the post-intervention period, only two of the six respondents had attended the clinic at the sub-centre level and assisted in record maintenance. One PMW appreciated POD care as his responsibility, while three PMWs were aware of defaulter retrieval as their job.

Before the intervention, four PMWs were distributing MDT drugs to patients directly, but after the intervention it was found that one PMW still continued to provide MDT drugs and another PMW was providing the first dose of MDT drugs on clinic days.

It was observed that in the pre-intervention period all PMWs were maintaining records by themselves, whereas after the intervention 50% of them assisted HWs in record maintenance and 50% continued to maintain records on their own. After the intervention all PMWs were assisting HWs in report preparation and consolidation of reports at the sector and PHC levels.

The PMWs were uncertain regarding their jobs after the integration. This caused some apprehension and difficulties in their accepting the revised operational strategy for the integration of NLEP in primary health care. Like the HWs, they felt they would lose their professional identity in the post-integration period.

Perception of Health Supervisors on job responsibility

All 17 HSs (M and F), seven in Bomokai and ten in Mohana, were interviewed before the intervention, and five and eight respectively responded in the post-intervention assessment (Annexures 2 and 8).

During the consensus-building workshop, the HSs were entrusted the task of ensuring case-confirmation of all suspects, drug availability at all sub-centres and health centres, facilitation of survey work, proper maintenance of records, timely collection of reports and provision of health education.

In the pre-intervention period, only three of the 17 multi-purpose health supervisors (MPHSs) (M and F) saw it as their role to ensure adequate drug supplies at sub-centres and health institutions. Facilitating record-keeping and record verification was acknowledged by two, health education by two and report collection by one. None of them included ensuring case-confirmation and facilitating survey work in their job responsibilities in NLEP. However, two responded that supervision and ensuring drug supply to patients and sub-centres were parts of their responsibilities. Surprisingly, one responded that leprosy work was none of his concern.

In the post-intervention period, eight of the 13 respondents perceived ensuring case-confirmation, six perceived ensuring drug availability at sub-centre and health institution, seven perceived facilitating survey work, five perceived facilitating record-keeping and record verification, four perceived report collection and four perceived health education as parts of their job in the leprosy programme.

Involvement of sub-centre Health Workers in NLEP

On verification of records at the sub-centres, 53 cases were confirmed during the pre-intervention period in Bomokai, but only 30 suspect cases were registered in the suspect register. Hence, the decreased suspected/confirmed case ratio is not applicable in Bomokai. Most of the HWs were not maintaining the suspect register. Therefore, the confirmed cases outnumbered the suspects. HWs tended to refer the suspects directly for diagnosis without keeping any record in the suspect register. In the post-intervention period, the number of suspects registered was 94, out of which 89 were confirmed. In Mohana, the suspected and confirmed cases were 25 and ten respectively before the intervention and 109 and 17 respectively in the post-intervention

Table 9: Involvement of sub-centre HWs in NLEP (verified from records)

	Bomokai			Mohana		
	Pre (24 SCs)	Post (20 SCs)	Change %	Pre (27 SCs)	Post (24 SCs)	Change %
No. of cases registered in suspect register	30	94	313	25	109	436
No. of cases confirmed	53	89	68	10	17	70
Registered/confirmed case ratio	1.8	0.9	NA	0.4	0.2	-50
No. of cases on MDT / under treatment	88/99	95/97	10	9/11	16/16	22
No. of irregular cases retrieved	0/11	2/2	100	0/2	0/0	-
No. of reaction cases referred	1	0	-	0	1	-
Records maintained at SC	7/24	20/20	343	20/27	22/24	24
Reports submitted by SC	0/24	20/20	100	0/27	24/24	100

Pre=Pre-Intervention; Post=Post-Intervention; Change=Indication of relative change in percentage from Pre- to Post-intervention period; SC=Sub-Centre

period. In the pre-intervention period workers in Mohana did not maintain suspect registers properly. Some of the HWs noted all persons with skin lesions in the suspect register resulting in artificially high figures for suspects in the post-intervention period. This was presumed to be due to lack of practical experience with leprosy, as there was no leprosy case in many of the sub-centres.

Before the intervention the 18 sub-centres in Mohana had no experience with leprosy, whereas after the intervention this number decreased to 14. In Bomokai all the sub-centres had leprosy cases.

In Bomokai, 88 of the 99 cases and 95 of the 97 cases were given MDT in the pre- and post-intervention periods respectively. In Mohana, nine of the 11 and all of the 16 cases in the pre- and post-intervention periods respectively had received MDT drugs.

No irregular cases were retrieved in Bomokai or Mohana in the pre-intervention period. Irregular cases were retrieved in Bomokai after the intervention, and there were no irregular cases in Mohana post-intervention.

Seven of the 24 sub-centres in Bomokai were found to be maintaining the leprosy records in the pre-intervention period whereas all the 20 verified sub-centres were maintaining records in the post-intervention period. Twenty of the 27 sub-centres were maintaining records in Mohana during the pre-intervention period whereas 22 of the 24 sub-centres were found to maintain records in the post-intervention period.

None of the sub-centres in Bomokai and Mohana was submitting reports before the intervention whereas all verified sub-centres of Bomokai (20) and Mohana (24) were submitting monthly leprosy reports following the intervention.

In the post-intervention period, the gap between the number of suspects and the number of confirmed cases decreased in Bomokai, which reflected the involvement and effectiveness of SC workers after the intervention. Increased effectiveness was also observed in case follow-up, defaulter retrieval, record-keeping and reporting in both areas.

Summing up the findings given in the 'Change' columns of Table 9, the main differences between the pre- and post-intervention periods can be identified as case-suspicion and detection, and record-keeping and reporting. However, in Mohana, case-detection, while probably effective in finding more cases, was seen to be inefficient, as most suspected cases turned out not to have leprosy.

Completeness and regularity of reporting

On verification of the month-wise reports received at the block PHC level, no report was received during the pre-intervention period from the sub-

Table 10: Completeness and regularity of reporting from SCs in the post-intervention period

Study area		No. of reports					
		Jan '01	Feb '01	Mar '01	Apr '01	May '01	June '01
Bomokai (N=24)	Received	13	18	21	23	23	24
	Complete	13	17	21	22	22	24
Mohana (N=27)	Received	18	25	28	28	26	26
	Complete	14	22	26	26	25	25

centres in both PHC areas of Bomokai and Mohana. In the post-intervention period, where 24 reports were expected in Bomokai in June 2001, the number of reports received increased from 13 in the first month to 24 in the sixth month of the study. In Mohana, where 28 reports were expected every month, the number of reports received increased from 18 in the first month to 26 in the last month of the study period. Almost all reports were complete towards the later months of the study period. Eighteen of the verified 20 sub-centres in Bomokai had submitted the reports to the PHC regularly whereas 22 out of the 24 verified sub-centres in Mohana had submitted reports regularly following the intervention.

Temporary absence or transfer of SC workers during the reporting period resulted in the reporting not being undertaken in certain months. Care was taken to supplement the missing reports by reports from the supervisory staff. In both the blocks, there was quantitative as well as qualitative improvement in reporting. The SC workers in Mohana started to submit zero reports for the sub-centres without any leprosy case.

Involvement of Medical Officers in leprosy programme

Before the intervention, eight of the nine MOs were aware that leprosy was included in the health programmes under their responsibility, but they had not perceived it as a priority programme. Though three MOs had received training in leprosy, only one of them was aware of the MLEC. The new strategy for the integration of the leprosy programme was not known to any of the MOs. Though sector meetings were conducted, there was hardly any discussion about leprosy. Reports were generated and transmitted from the block PHC by the MOs in-charge.

Following the intervention all nine MOs were involved to a greater extent in the programme. For instance, three MOs conducted six sector meetings each and five MOs conducted eight sector meetings each and reviewed leprosy activities. Five MOs were involved in the confirmation of leprosy cases, provision of the first dose of MDT and supervisory services. Four MOs mentioned that they were ensuring drug supplies to HWs and patients. Three MOs mentioned that they were involved in record verification and treatment of complications in leprosy patients. However, only one MO stated that he was involved in case-detection during regular OPD hours. Hence, it may be seen that MOs were more involved in supervision, monitoring,

diagnosis and treatment after the intervention, but they did not sufficiently include case-detection as part of their routine work.

Orientation training was imparted to workers from time to time in the monthly meetings. The reporting system was streamlined and reports were submitted timely through the sector MOs.

Long-term vacancies and short-term assignments (one-year posting before going for postgraduate study) by some of the medical officers were identified as a hurdle in the implementation of the health programme. However, the involvement of MOs in NLEP was reflected in their participation in leprosy diagnosis, treatment, reporting and monitoring in sector meetings and in the overall implementation of the programme after integration.

Frequency of supervision of leprosy work

During the consensus-building workshop it was agreed that it was not possible for the sector MOs and HSs to visit the sub-centres on a regular basis due to problems like the non-availability of transport at the sector PHC level. However, they would supervise and monitor leprosy activities during the sector meetings.

Before the intervention, on verification of leprosy records at the sub-centre level, it was observed that no supervisory visits were made by any MO in PHC, Bomokai, whereas five of the 24 sub-centres were irregularly visited by concerned HS in relation to leprosy work.

After the intervention, MOs carried out the supervision of sub-centres through weekly sector meetings, though supervisory visits were not made to health supervisors and sectors.

In Mohana, before the intervention, only two of the 27 sub-centres were visited by the sector medical officer in connection with leprosy work and ten sub-centres were visited by the HS, of which seven were covered regularly, two irregularly and only three on fixed days. Following the intervention, HSs visited ten sub-centres regularly. Here also, MOs only reviewed and supervised the activities through sector meetings.

During the consensus-building workshops, a calendar was drawn up for the PMWs to visit each sub-centre on a fixed day once a month. In Bomokai,

nine sub-centres were visited once a month on a fixed day by the PMW and two sub-centres were visited irregularly. In Mohana 14 sub-centres were visited by the PMWs on a fixed day and three were visited irregularly.

Perspectives of leprosy patients

As the intervention strategy was the same for both areas and integrated NLEP functions were rendered through primary health care, the ultimate beneficiaries (patients) were interviewed to assess the quality of service and involvement of different health care functionaries after the intervention (Annexure 9).

Table 11: No. of leprosy patients interviewed

Place	Male	Female	Total
Bomokai*	33	19	52
Mohana	5	8	13
Total	38	27	65

* Interviewed cases in Bomokai included 21 male and 3 female RFT cases during study period.

A total of 65 patients from the two blocks were interviewed. They included 38 male and 27 female patients. As evident in Table 11, the sampling of patients was skewed in favour of Bomokai, which reflected higher PR in this area. Hence, the results discussed below represent Bomokai to a higher degree than Mohana.

Table 12: Distribution of cases by age, sex and category

Sex of patient	MB Adult	MB Child	PB Adult	PB Child	Total
Male	18	1	13	6	38
Female	9	0	9	9	27
Total	27	1	22	15	65

Of the 38 males, 31 were adults (MB-18; PB-13) and seven were children (MB-1; PB-6). Of the 27 female patients interviewed, 18 were adults (MB-9; PB-9), and nine were children (MB-0; PB-9). The interviewed patients also included 24 RFT cases in Bomokai, who had completed their treatment during the study period. For the child patients, seven fathers and nine mothers were interviewed to obtain the information.

Time-gap between onset of symptoms and diagnosis

Of the 65 patients interviewed, 20 (30.7%) had reported for diagnosis within six months, 33 (50.7%) within 6-12 months and 12 (18.5%) after one year of the appearance of symptoms. The delay in the diagnosis of patients varied from two to 26 months, with an average of 9.2 months.

Table 13: Time-gap between onset of symptoms and reporting for diagnosis

Time-gap	Male	Female	Total
< 6 months	10 (26%)	10 (37%)	20 (30%)
6-12 months	19 (50%)	14 (51%)	33 (50%)
> 12 months	9 (23%)	3 (11%)	12 (18%)
Total	38 (100%)	27 (100%)	65 (100%)

Proportionately, more female patients reported early for diagnosis. This could be due to increased access for women to leprosy case-detection at the household level by HWs. However, Table 14 below does not clearly point to this conclusion.

Table 14: Leprosy diagnosis by HWs

		Patients		
		Male	Female	Total
Sex of HW suspecting	Male	8	7	15
	Female	15	13	28
	Total	23	20	43

However, other factors may also be taken into account, e.g. female patients may be more reluctant than male patients to admit to male interviewers a large delay from the time of suspicion to reporting for diagnosis.

Naming the disease for which patients are being treated

Out of the 65 patients interviewed, 52.3% said they were suffering from *chhau*, 20% from *jadu*, 18.4% from *kustha*, 7.7% from leprosy and 1.5% said it was *dhabala kustha*. This variation in the naming of the disease the patients suffered from could be due to the fear of being ostracised because of the stigma associated with leprosy.

Table 15: Local names used for leprosy

	Total	Percentage
Leprosy	5	8
<i>Kushta</i>	12	18
<i>Chhau</i>	34	52
<i>Jadu</i>	13	20
<i>Dhabala chhau</i>	1	2
Total	65	100

The term '*kushta*' in Oriya or Hindi is the same as leprosy. Samba, the son of Lord Krishna, suffered from *kushta* and worshipped the Sun God to get cured. Due to the stigma caused by fear of leprosy, people are reluctant to utter the term *kushta*. Therefore, different words are used, including *chhau* (patch) or *jadu* (itchy patch), which are usually skin lesions caused by fungal infection, or *dhabala chhau* (white patch), indicating leucoderma. Even the English term 'leprosy' may be more acceptable than its Hindi/Oriya equivalent.

While ideally it would be desirable to always use the appropriate name for the disease, specific circumstances may require a deviation from this principle and the use of alternative local terminology in order for the patient to undertake treatment and/or for the family and community to accept the person concerned.

Suspecting and diagnosing leprosy

In the majority of cases (66%), leprosy was suspected by a HW (M and F). Voluntary reporting for diagnosis was observed in 15.4% of the cases. Voluntary reporting by patients to HW(M and F) was also possible during

Table 16: Persons involved in suspecting leprosy cases

Person suspecting leprosy	Total	Percentage
HW (M&F)	43	66
PMW	7	11
Self (patient)	10	15
Others	5	8
Total	65	100

home visits, but, here, voluntary reporting refers to self-reporting for diagnosis at an OPD (PHC) or SC clinic without referral by a HW(M/F).

Table 17: Staff involved in leprosy diagnosis

Category of staff	Total staff	Percentage
Medical officer	39	60
Paramedical worker	24	37
Non-medical supervisor	2	3
Total	65	100

Medical officers diagnosed 60% of the cases. The others were diagnosed by the NLEP staff. This shows an increased level of involvement of MOs in NLEP functions implying strengthening of integration following intervention.

Table 18: Place of diagnosis of leprosy cases

Place of diagnosis	Total cases	Percentage
PHC (OPD)	36	55
SC Clinic	12	19
Patients' Home	10	15
Health Camps	7	11
Total	65	100

More than half of the cases (55%) were diagnosed during OPD visits, 15% in SC clinics and 11% in health camps. Fifteen per cent of these patients were diagnosed at their homes. Medical officers diagnosed the cases in health institutions or camps, whereas they were confirmed in a SC clinic or patients' home by PMWs. This also reflected the involvement of the PHC system in terms of progress in integration.

Information given to patients at time of starting leprosy treatment

The patients were informed about the regular intake of drugs during the treatment period (97%), MDT and its availability (84%), and about the

Table 19: Information provided at start of leprosy treatment

Type of information	Total (N=65)	Percentage
Need for regular treatment	63	97
MDT and its availability	55	85
Curability of leprosy	59	91
Correct duration of treatment	59	91

curability of the disease (91%) (Table 19). They all knew the correct duration of the treatment. Six RFT cases felt that the disease was not curable because of the persistence of lesion even after completing the full course of treatment.

Source of MDT drugs

Table 20 below shows the patients' perceptions about the source of MDT drugs: 56 (86%) patients were aware about HWs (M and F) as the source of MDT; nine (14%) answered that MDT was available from health institutions. Three patients still believed that PMWs were a source of MDT.

Table 20: Source of MDT drugs

Source of MDT	Total (N=65)	Percentage
Health worker (male)	22	34
Health worker (female)	34	52
Paramedical worker	3	5
PHC/SC (health institution)	9	14

The former patients who had been included in the study were released from treatment in the post-intervention period and were, therefore, to some degree, exposed to the changes in the NLEP services. The noted responses, therefore, were supposed to point to the time of interview, i.e. after the intervention, rather than the patients' past experiences. However, it cannot be ruled out that the patients who had previously received their drugs from PMWs referred to that experience.

Mode of MDT collection

Table 21: Mode of collection of MDT drugs

Drugs collected at:	Total	Percentage
Home	26	40
Clinic - By patient	28	43
- By others	11	17
Total	65	100

Twenty-eight (43%) of the patients collected MDT drugs themselves and 17% had their family members collect the drugs from the clinic. Twenty-six (40%) of the patients received their drugs from HWs at home (Table 21).

Distance of drug distribution point from home

Thirty-three (51%) patients travelled less than five km to collect their drugs and 14 (22%) patients had to travel more than five km to receive MDT. The longest distance travelled by a patient was 12 km. However, all the 65 patients said that they got the MDT regularly every month.

Only four patients had faced problems due to living in hilly areas or otherwise difficult geographical situations, non-availability of health workers and long distances to travel. However, 11 patients said that if the distances were reduced it would be easier for them to collect the medicines.

Consultations with service-providers in case of problems

In case a problem arose in connection with the treatment, 42 (65%) patients would prefer to consult the MO. Of these 42 patients, 37 had also seen the MO for confirmation of the disease. One had consulted the MO to discuss the risk of the disease to her children, another for the persistence of patches, and three patients had met the MO for a check-up.

Fifty-three (82%) patients would prefer to consult the HW during the normal course of treatment, whereas 15% preferred to consult the PMWs. Again, the inclusion of patients with a longer treatment experience may have accounted for this result.

Acceptance of leprosy patients by family and community

Two patients answered that their families were upset because of their disease even though they continued to live with the family. Neither of these patients was having any deformity. All other patients answered that their families accepted them. Less than half of the patients (28) felt accepted by their neighbours and community, and 24 (37%) patients said that their community and neighbours were unaware of their disease. Thirteen patients responded that their neighbours and community members remained indifferent to their condition.

Suggestions made by patients

Eleven patients suggested that MDT drugs should be available at more nearer places.

Seven patients felt that vitamins should be given along with MDT.

One patient proposed that a certificate should be issued to a patient when he/she was cured of the disease.

Six patients suggested that a yearly campaign should be carried out to identify hidden cases in order to eliminate the disease.

Service delivery in post-intervention period

The NLEP services were rendered through primary health care functionaries after the intervention. They were involved in different activities as defined in their job descriptions. Due to the involvement of PHC functionaries, there were quantitative and qualitative improvements in leprosy services provided to the patients.

Twenty-four patients had started treatment prior to the intervention. When asked about the changes in service provision, all of them felt that the MDT service had improved. They mentioned that it was easy to collect medicines from the nearby sub-centres. Furthermore, they could share their problems with the HW and collect their drugs regularly free of cost.

Community responses

Eight FGDs were conducted before and after the intervention to assess the community's knowledge and attitudes and seek suggestions for further

improvement of the health care services in Bomokai and Mohana. Selected community members, including AWWs, teachers, community leaders, MSS members, cured and current patients, MLEC workers and members of NGOs, took part in the focus group discussions. The discussion points were defined in the FGD guidelines (Annexure 4) and a qualitative assessment was made. The outcome of the FGDs is given below.

Pre-intervention perceptions of leprosy

Prior to the intervention most of the FGD participants had received information about the disease from television and radio. Other media like newspapers, public campaign (MLEC), leprosy workers, health workers and *Mahila Samiti* (women's group) meetings also played some role in providing information on leprosy.

A majority of the FGD participants said that the disease was communicable and presented mostly with white patches on the skin. Only a few said that the patch presented with a loss of sensation. Some of them opined that the disease might present with skin lesions, *chhau* (patches), ulcers and deformities in the form of loss of limbs. Some considered it a *bada roga*, a 'big' (fatal) disease.

Most of the FGD participants felt that leprosy was like any other disease and was caused by a specific germ. However, a good number of them also felt that it was due to a curse or the result of past sins. A few believed that it ran in the family.

Some did not have any idea of the cause of the disease and some members of the Saura people in Mohana said that it occurred due to eating pigeon meat and *karela* (bitter gourd) seeds, since it is believed by them that it is a cruelty to kill innocent animals and birds, and eating their meat will produce such a dreaded disease. They also believe the bitterness of the *karela* seed spreads in the body and develops the disease.

While a majority of the respondents indicated that the disease was transmitted through physical contact, a number of other modes of leprosy transmission were also mentioned, including contact with a patient, through water and air, coughing, sneezing, sputum, stools, urine, common use of utensils, food and clothing and also by talking. These findings were indicative

of the possibility that patients may have under-reported the experience of stigma in the interviews, as these ideas about modes of leprosy transmission would necessarily imply social isolation of leprosy patients. Feeling ashamed of social isolation and discrimination is a well-known reason for under-reporting in questionnaire studies and interviews.

Most of the FGD participants were aware that drugs could cure leprosy. Some perceived that the number of patients had been reduced in the community due to treatment. Many had the knowledge about MDT availability at PHCs and SCs. Some also opined that it was available with the PMW, whom they referred to as the leprosy doctor. However, while some cited examples of patients cured with MDT in their community, patients with ulcers and deformities were also perceived to be incurable by FGD participants.

Post-intervention perceptions of leprosy

In the post-intervention period FGD participants stated sources of leprosy information as TV, radio, newspapers, interpersonal communication with HWs, mothers' meetings and discussion at anganwadi centres (AWCs). Also, the local link volunteers helped in creating awareness in the community.

The FGD participants now considered the skin patches as an early sign of the disease. Some opined that deformity persisted even after being cured by taking total course of medicines.

Most of the FGD participants were convinced that the disease was caused by a germ. A few opined that it manifests itself when the body immunity goes down. Some people believed that leprosy is a hereditary disease.

The most important mode of leprosy transmission as perceived by most participants was respiration, coughing and sneezing. Misconceptions about the modes of transmission of the disease persisted even after the intervention, indicating an implicit felt need to avoid leprosy patients. No marked change either was observed regarding the treatment and curability of the disease, and most FGD participants were aware that the MDT/leprosy drugs were available with the Auxiliary Nurse Midwives (ANMs) and sub-centres.

Community attitudes

Most FGD participants did not express any adverse idea or hatred for the leprosy disease or its patients in the pre-intervention period. They felt that social discrimination and misconceptions about leprosy had been gradually reduced. This was attributed to experiences with patients who were cured with drugs; cases of ulcers and deformities were also not so often seen in the community. However, negative feelings may not be expressed in a FGD setting if participants feel they were not acceptable in the FGD context.

Yet, it was evident that some people feared the disease, and patients with ulcers and deformities were still not accepted in the community, although people did not show much concern about patients during early stages of leprosy as they believed they will get cured by taking medicines. These findings pointed to a perceived relationship between incurability, deformity and stigma, whereby deformities not only served to identify individuals as easy targets for negative feelings, but they were also seen as having a potentially incurable condition, which increased hostile feelings and perceived needs for social isolation.

Quality of service

When asked about the quality of different NLEP services in the post-intervention period, some community members did not see any changes during this short study period and remained silent or responded negatively. Others had noticed a new interest and involvement of PHC functionaries (health staff) in leprosy activities, which was not seen previously.

Most of the FGDs expressed satisfaction with the availability of MDT services close to the patients' homes, i.e. through HWs at sub-centres. They were also satisfied as drugs were available free of cost and the disease had been included in the *Pancha Byadhis* (five priority diseases of public health importance, namely, leprosy, malaria, acute respiratory infections, diarrhoea and scabies) by the Government of Orissa.

Community role

Most of the FGD participants felt that they had the responsibility to facilitate case-detection by helping HWs in their villages, motivate the suspect cases for confirmation, and if they lived in their vicinity, follow them for regular

treatment. They appreciated their role in case-detection and follow-up to ensure regular drug intake.

Suggestions by FGD participants

During the FGDs, the participants provided a number of suggestions for further enhancing efforts for the elimination of leprosy. These were:

- To increase awareness in the community so that people will report at the beginning of the disease and will not hide it;
- To involve local volunteers in the leprosy programme to let the cured persons serve as examples to reduce the fear of the disease;
- To develop medical treatment of shorter duration;
- To make corrective surgery available for deformed cases;
- To train patients in ulcer care;
- To develop vaccines to prevent leprosy;
- To further strengthen the involvement of link workers, AWWs and other volunteers to increase coverage and to utilize the services of female volunteers to facilitate case-detection in women and children.



Conclusion

The two blocks selected for the interventional study share a common boundary, but they differ in geography and population characteristics. While Digapahandi is a thickly populated rural area with a high prevalence of leprosy, Mohana is a tribal block with a difficult geographical terrain and a sparsely distributed population in pockets and hamlets. It is a low prevalence area for leprosy.

The intervention in the form of consensus-building and training in job responsibilities of different service-providers was taken up in both areas to facilitate the integration of NLEP functions with primary health care. Area-wise coordinated action plans were developed after an analysis of the leprosy situation.

Following the intervention, new case-detection increased in absolute numbers in Bomokai. The detection of new female cases was proportionate to the total number of new cases. The child case-detection rate increased from 12.5% to 19% after the intervention. The new cases detected were mostly in early stages of the disease (SSL and PB). Regular treatment adherence improved from 80.2% to 94.4%.

In Mohana, new case-detection was only marginally increased. The proportion of females among the newly detected cases increased from 33.3% to 57.9% after the intervention. The child case-detection rate also increased from 20% to 47.3%. Following the intervention adherence to regular treatment was improved. It increased considerably from 75% to 97.4%.

More than 50% of both male and female cases were diagnosed and treated within one year of the appearance of symptoms. The average delay in diagnosis was 9.2 months.

In both areas case-suspicion was acknowledged by HWs (M and F) as part of their responsibility both before and after the intervention. About two-thirds of leprosy patients were suspected by HW (M and F) and one-sixth by the patients themselves. Getting case-confirmation by MO/PMW as their responsibility increased substantially from 2/24ths to 23/25ths in Bomokai. SC workers understood the importance of maintaining the suspect register for the diagnosis of patients in the post-intervention period. The gap between the suspects and the diagnosed cases was narrowed due to increased efficiency of HWs. On the other hand this gap was widened in Mohana due to lack of clinical experience with leprosy cases.

Almost all workers recognised drug distribution as their responsibility following the intervention. MDT was delivered to the patients at their homes in 40% of the cases, defaulters were retrieved, and regularity in MDT service was ensured by HWs. HWs also understood their responsibility in case follow-up.

Health education, as included in the health workers' job responsibility, was not well appreciated in Bomokai. However, patients were aware of leprosy and its treatment (source, drug availability, cost, curability and duration) and FGD participants also knew about the availability of MDT services in health institutions.

PMWs described their roles and responsibilities in the revised strategy for integration after the intervention, but this was not reflected in action as was evident from low clinic attendance. Some HWs faced problems in work coordination with PMWs. Probably it was due to their feeling of insecurity and fear of loss of job and professional identity after the integration.

Job responsibilities in leprosy work was not conceived well by Health Supervisors before the intervention. This improved after the intervention, which ensured case-confirmation, drug supply to sub-centres and health institutions and facilitated survey work, record verification and reporting by health workers.

There was hardly any involvement of sector MOs in the leprosy programme before the intervention. This increased appreciably in the post-intervention period. About 60% of leprosy patients were diagnosed by MOs, either as OPD cases (34/39) or in health camps (5/39). They also supervised and monitored NLEP activities in sector meetings and took the overall responsibility for programme implementation.

There was both quantitative and qualitative improvement in record maintenance and reporting in the post-intervention period. The number of reports received from sub-centres as well as the proportion of completed reports increased, and almost all sub-centres started submitting complete reports after a few months.

In Bomokai, before the intervention, regular supervision was neither done by the MO nor by the HS. This situation improved after the intervention. In Mohana, the MO and the HS were making supervisory visits before the intervention. This was further strengthened following the intervention.

More than 90% of the patients interviewed were of the opinion that the disease was curable with treatment. Others felt that the disease was not curable because lesions persisted even after treatment. Eighty-six per cent of the patients said that MDT was available with HWs; and 43% of the patients collected their medicines from the clinics by themselves.

Seventy-four per cent of the patients felt that MDT services had improved. Eighty per cent said they would like to consult health workers regarding their disease condition during treatment. Only very few patients (6%) had faced difficulties in getting MDT medicines due to difficult terrain, long distance and absence of a health worker.

While the bacterial cause as well as the actual mode of transmission was gradually being established among some of the FGD participants, misconceptions regarding the cause of the disease persisted, with potentially stigmatizing consequences. However, people seemed to be convinced about the curability of the disease by regular drug-taking and cited examples of former patients with leprosy patches who had been cured. Most FGD participants were aware about the availability of MDT services at the nearest sub-centre. FGD participants were optimistic about the new system of MDT service delivery through primary health care.



Recommendations

This study shows that there has been considerable improvement in the functioning of and service delivery by staff after the consensus-building and training exercises in both study sites, Bomokai and Mohana. The following recommendations are made to support this process based on the findings of this study:

Training and consensus-building on job responsibilities and roles of different categories of staff of the PHC and NLEP systems should be implemented.

The block PHC should act as a coordination agency.

Area- and problem-specific comprehensive and coordinated sector PHC-wise activity plans should be prepared for the implementation of the programme.

Continuing education, training (including IEC) and review of NLEP activities should form a part of the sector-level meetings.



Annexures

Annexure 1

Programme for Consensus-Building Workshop at Primary Health Centre

- | | |
|-------|-------------------------------------------------------------------------------------------|
| 09:00 | Registration |
| 09:30 | Introduction of participants |
| 10:00 | Objectives of training |
| 10:15 | Need for the integration of leprosy work with primary health care |
| 11:00 | Tea break |
| 11:15 | Appraisal of the leprosy situation in the block |
| 12:00 | Job roles of the different primary health care functionaries in leprosy after integration |
| 13:00 | Lunch |
| 14:00 | Communication: the key to leprosy elimination |
| 14:45 | Group work for the development of coordinated leprosy activities in the block |
| 16:15 | Group presentation in plenary |
| 17:00 | Summing up and closing |

Guideline by Government of Orissa for Implementation of revised operational strategy in NLEP

A. Record/Registers to be maintained at each level

I. Sub-centre

Treatment register

Suspect register

Stock ledger

Case card of under-treatment cases

Monthly reporting formats

II. PHC (N)

Treatment register

Suspect register

Stock ledger

Master register for compilation of Sub-centre-wise reports

Monthly reporting formats

III. CHC/Block PHC

Treatment register

Suspect register

Stock ledger

Master register for compilation of PHC wise reports

Monthly reporting formats

B. Programme implementation

Block PHC will acts as unit.

PHC Sector as a Sub-unit.

Sub-centre as drug distribution centre (DDC).

Anti-leprosy drugs will be available at all general health institutions and sub centres.

Registration/treatment register	will be made
Stock ledger	available at all
Suspect register	S.C. and Health centre

Case card of under treatment cases will be available at all health institutions including sub-centre.

Suspect cases will be referred by health workers from field during their regular visits to sectors Medical Officer. Before referring the suspect the HW will enter the name and address and site of lesion in suspect register available with her/him.

After confirmation of a case the 1st dose of MDT will be delivered at health institution by Medical Officer/Pharmacist. Case card will be filled up by Medical Officer and patient will be asked to collect subsequent treatment from the Sub-centre from where the patient belongs to. If patient desires to take medicine from PHC he can be treated at PHCs. The case card of the patient will kept at the place from where the patient collects drug.

Reporting system will be modified.

Every month the HW will generate report from sub-centre and these will be compiled at sector PHC and consolidated report from sector PHC will be sent to Block PHC where reports will be consolidated and sent to LEU/ADMO (PH/ Lep). The responsibility of consolidation of reports will be of NLEP staff.

Once in a month PMW/NMS will visit Sub-centre/Health Institution on a fixed day. On that day PMW will do a village survey, school survey, contact examination of villages of the sub-centre. He will help HW in confirmation of suspect identified by HW. He will visit houses of defaulters. He will update the registers/card at centres. He will replenish anti-leprosy drugs. He will consolidate the report. He will carryout all above activities along with POD activity in the sub-centre area jointly with HW. The HW will exclusively do leprosy work only on that day. One P.M.W. will conduct survey (group survey) 10 days in month, 8 days clinic at Sub-centre, 2-4 days clinic at Health

Centre, 1 day monthly meeting at Block PHC, 2 days for POD work and 1 day for IEC work (26 days).

C. Job responsibilities

PMW

Attend clinic on fixed date in a month of all Sub-centre of his/her area.

Conduct school/conduct survey during the visit of Sub-centre area.

Deliver the drugs to patients at Sub-centre/DDPs.

Conduct group survey/special survey.

Update case card at Sub-centre and Health institution

Update treatment register Sub-centre and Health centre.

Confirm the suspect cases at Sub-centre during her/his visit days.

Prepare case card and get signed by Medical Officer of sector.

Collect case card of RFT patient submit it to LEU.

Manage Leprosy-reaction cases in the field in consultation with Medical Officer Sector/LEU.

Provide disability care to needy patients.

Keeps the list of patients requiring disability care and type of disability care.

Attend sector meeting atleast once in a month for collection of MPR from the HWS.

Compile the report at sector PHC/CHC or Block PHC level.

Maintain the relevant registers of PHC (N)/CHC.

Organizing HE activities with BEE/HWs in a village.

HW (M and F)

Suspect case of leprosy in the community while his/her regular or routine visits to family of a village of his/her sub-centre area.

Keep diagnostic card/ folded information card with his/her during family visit.

He/she should visit each and every families of his/her Sub-centre area once in a year and should definitely inquire about any body having signs/symptoms of leprosy.

He/she should enter the name/address of suspects in suspect register and also in his/her tour diary.

She/he should deliver or help in delivering MDT on fixed day of month to leprosy patients of his/her Sub-centre area at Sub-centre.

She/he should retrieve the defaulters and deliver the MDT to the patient at their home, if due to any reasons patient could not come for collection of medicine.

She/he should maintain/update the treatment register/Stock ledger.

She/he should help in conduction of school survey/contact survey and special surveys to PMW in her/his Sub-centre area.

She/he should generate simple information system once in a month and submit it to sector Medical Officer on or before 5th of every succeeding month.

She/he should conduct HE activities along-with BEE for detection of hidden cases of leprosy in her/his Sub-centre area.

MPHS

She/he should visit some families in routine manner to require whether HWs have conducted family visit and enquired about leprosy.

She/he should verify relevant records at Sub-centre once in a month.

She/he should help in registration of suspect and subsequent examination of suspects by the Medical Officer Sector or NLEP staff.

She/he should help HWs in report generation.

She/he should help PMW in survey activities.

Help in organizing HE camps.

Help in retrieving defaulter.

D. Report generation

From Sub-centre

To

PHC (N)

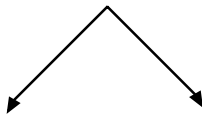
(During last sector meeting)

To

CHC/Block PHC

(On PHC meeting or by 1st week of the month)

To



to

LEU

ADMO (PH)

(on district meeting or by 10th of every month)

to

GOI

State Leprosy Cell

(By 20th of every month)

To

GOI

(By 25th of the month)

National Leprosy Eradication Programme

Monthly Progress Report

For the Month of _____

Name of the SC/PHC (N)/CHC _____

Population of area _____

1. Cases on record at beginning of month
2. New cases detected during the
month
year (April +)
3. Deformity (grade – II) amongst SL. No. 2
month
year (April +)
4. Child cases amongst SL. No. 2 during
month
year (April +)
5. Cases discharged as cured (RFT) during
month
year (April +)
6. Cases discharged other than cured during
month
year (April +)
7. Cases on record at the end of the month
8. Cases actually treated during the month
9. No. of villages with leprosy cases
10. No. of villages without leprosy cases

Job roles for leprosy work (in brief)

TASKS	Who will do
1. Suspect cases at home	HW (F), HW(M)
2. Identify cases in schools	HW (F), HW(M), MO, PMW
3. Follow-up, screen contacts of MB cases	HW (M)
4. Examine patches and nerves	PMW, MO
5. Examine skin smears	Lab. Technicians
6. Confirm cases	MO, PMW
7. Prescribe MDT	MO, PMW
8. Distribute MDT drugs to patient	HW(F),PHC,HW(M),Pharmacist/MO
9. Monitor MDT drug adherence	HW (F), HW (M)
10. suspect and refer drug reactions to PHC	HW (M+F)
11. Confirm and manage drug reactions at PHC	MO/PMW
12. Suspect and refer lepra reactions to PHC	HW (M+F)
13. Confirm and manage Lepra reactions at PHC	MO/PMW
14. Maintain records and registers (treatment, ledger, suspect register, case cards)	HW
15. Prepare reports	PMW
16. Collect and consolidate reports	MPHS/PMW
17. Visit and motivate defaulters	HW
18. Teach patients self care and duration of treatment	PMW
19. Dress ulcers and teach care of hands and feet	PMW
20. Refer for surgical corrections	MO
21. Conduct IEC activities in community	BEE, HW (M+F), PMW, HS, MO
22. Supervise and train staff	MO (PHC), HS, BEE
23. Coordinate NLEP at PHC level	MO (PHC)
24. Ensure availability of MDT drugs at sub-centre	PMW, MO

Training for Capacity-Building and Development of Sector-wise Action Plan

Day 1

- 9.00 - Registration
- 9.15 - Assessment of training needs through oral questionnaire
- 9.45 - Objectives of training
- 10.15 - Leprosy – Understanding the medical aspects
- 11.15 - Tea break
- 11.30 - Job roles, presentation by self (each category of staff)
- 13.00 - Lunch
- 14.00 - Operational strategy in sector (as agreed in Consensus-building Workshop)
- 14.45 - Leprosy registers and reporting at sub-centre and sector (presentation followed by small group discussion)
- 16.45 - Summing up and closing

Day 2

- 9.00 - Minutes of previous day training (by one participant)
- 9.30 - Planning, coordination and monitoring by MO and HS (M and F)
- 10.45 - Tea break
- 11.00 - Sub-centre-wise analysis of leprosy problem (presentation by respective HWs)
- 13.00 - Lunch
- 14.00 - Development and finalization of coordinated action plan (Presentation by MO)
- 16.45 - Summing up and closing

Guidelines to be used by the facilitator in a FGD session before and after the intervention (for community members)

Name of the sub-centre

Facilitator-

Recorder-

Date

Time: From To

DISCUSSION POINTS

1. Knowledge and attitude about leprosy
2. Whether they know that leprosy services are available at sub-centre
3. Opinion about quality of services
4. Role of community members in elimination of leprosy activity
5. Any suggestion to improve programme implementation.

Self-administered questionnaire for Medical Officers

Name of PHC (N) _____ Date _____

No. of years of service at present place _____

What are the priority health programmes you undertake in your area at present?

How many sector meetings did you conduct during the last two months?

What different health programmes did you review and discuss in those meetings? If leprosy was mentioned, what did you discuss?

Did you submit reports on leprosy to PHC during last month? Yes/No

What is your role in ensuring MDT services at sub-centres?

Signature

Questionnaire for Health Workers (M and F)

Name of Sub-Centre:

Date:

Respondent No:

Sex: M/F

1. Who is doing leprosy activities at village level at present?
HW/HS/PMW/MO/AWW/Any other (specify)
2. Do you have any responsibility in leprosy programme?
Yes/No, if yes, describe
3. Who are helping you in leprosy activities?
4. When do you suspect leprosy in a person?
Skin lesion/Anaesthesia/Hypopigmented or red patch/Nerve thickening/Any other (specify)
5. Who confirms the case as leprosy? Self/PMW/HS/MO
6. What are the different types of leprosy? SSL/PB/MB
7. Where from do you get MDT drugs?
8. Do you ever run short of MDT drugs? Yes/No
If yes, when did it occur last time?
9. What leprosy registers do you have? (verify physically)
Suspect Register/Disease Register/Treatment Register/Stock Ledger
10. Do you send leprosy reports? Yes/No
If yes, how often? If not, why not?
11. Do you face any difficulty in doing leprosy work? Yes/No
If yes, describe _____
Give suggestions to solve them _____

Signature of Investigator

Questionnaire for Paramedical Workers

Name of PMW:

PHC/CHC:

Sector:

Date:

1. What is the recent change in leprosy programme?
2. What is your responsibility in revised operational strategy on NLEP?
3. How are new cases detected at present? MLEC/Survey/Contact examination/Voluntary reporting. Mention which is most common.
4. Who is giving MDT to leprosy patients? HW/Yourself/Any other (specify)
5. Are you managing lepra reactions in the field?
If yes, by Yourself/With help of MO
6. What is your role in drug distribution?
7. What registers are maintained by you?
8. What is your role in the reporting system?
9. How often do you visit a SC in your area?
10. Do you face any difficulty in this new strategy?

Signature of Investigator

Questionnaire for Health Supervisors

Respondent No:

Sex: M/F

Sector:

Date:

1. Who is doing leprosy activities at village level at present?
2. What is your responsibility in leprosy programme?
3. What are the different types of leprosy?
4. What is the duration of treatment of different types of leprosy?
SSL _____ PB _____ MB _____
5. How does leprosy spread?
6. What do you do when you visit a SC in connection with leprosy work?
Help HW (F) in preparing report/Help PMW in survey/Health education to community and patient/Defaulter retrieval/Any other (specify)
7. What do you do in sector meeting with respect to leprosy?

Questionnaire for personal interview with leprosy patients

Respondent No. _____ Name _____ Age _____ Sex _____
(To be filled in later)

Address _____ PHC/CHC _____

1. What disease are you suffering from?

Chhau Leprosy

Says *chhau* but interviewer feels patient knows

Any other (specify) _____

2. When did the symptoms appear first?

3. When was it diagnosed?

4. Where was it diagnosed and by whom?

What advice did he give? _____

5. Whom will you consult when you have any problem with this disease?

6. Do you think it is curable? Yes/No

If yes, how it is cured? (If treatment is mentioned probe for length and regularity of treatment)

If no, what is the reason?

7. Have you ever met your medical officer regarding this disease?
(Probe whether patient is referring to MO/PMW)

If MO, for what _____ Number of times

What did he advise? _____

8. Do you know where your medicines are available?

9. How far is the DDC from your house?

10. How do you get your medicine?

11. How frequently do you get your medicine?

Monthly/Others (specify)

12. Is there any difficulty in getting medicines? Yes/No

If yes, what difficulties?

Distance of DDC

Irregular drug supply

Non availability of health worker

Any other, specify (For postintervention evaluation of RFT patient)

13. Has there been any change in provision of services during last 6 months?

No Change/Improved/Deteriorated

Give reasons _____

14. What is the attitude of people towards you after diagnosis of your disease?

(Ask for each of the below)

Family

Neighbour

Community

15. Any suggestion from you to get better care

N.B. To be filled up after interview

Leprosy suspected by Self/HW (M)/HW (F)/PMW/Other (specify)

Leprosy confirmed by PMW/MO

Leprosy confirmed during MLEC/Regular clinic/home visit

Signature of Investigator

