

# The Kirnapur Alternative Approach

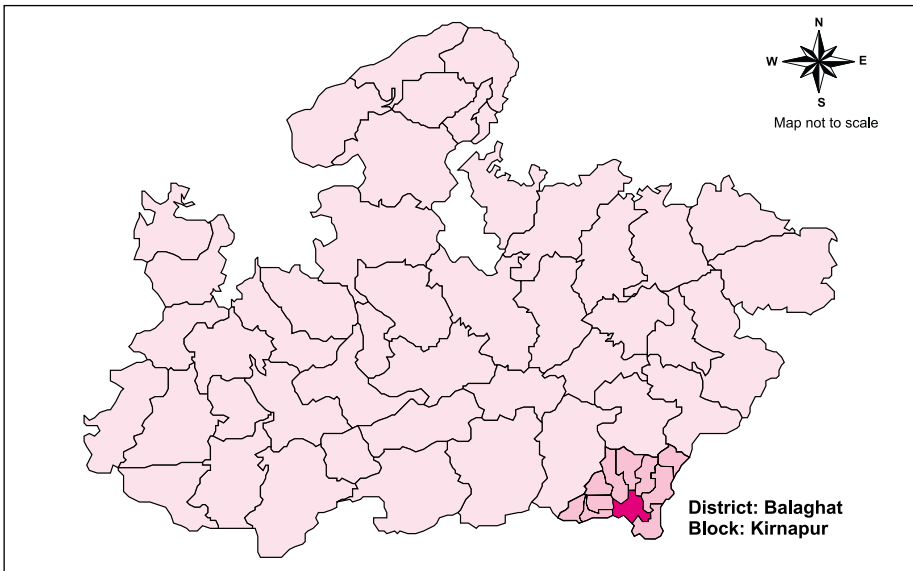


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## Background

A large number of new leprosy cases had been identified through special campaigns such as MLEC and SAPEL, but a large pool of hidden cases is believed to remain in the community. Innovative strategies are required to identify these hidden cases. In such a situation, it is necessary to involve the community in the health campaigns. This is exactly what happened in the Balaghat district of Madhya Pradesh.

**Figure 1: Kirnapur block in Balaghat district, Madhya Pradesh.**



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This chapter narrates the process of involving the community in the leprosy eradication programme and the influence its involvement had on case detection and treatment. The account highlights the differences in outcome between health worker-driven and community-driven campaigns.

India is committed to eliminating leprosy from the country. To some extent, this depends on the performance of Madhya Pradesh, being the largest state in the country. Although the prevalence of the disease has dropped dramatically in the state, mainly due to the availability of MDT, certain parts of the state – backward districts and hilly, inaccessible regions – lagged behind. A new approach specifically targeting hidden cases was required.

### Rationale for an Alternative Approach

It was observed that routine leprosy elimination programmes did not reduce the prevalence of the disease to a desirable level. Continuing problems in case detection and case-holding may result in development of disabilities and deformities since the infection is not halted in the early stages of the disease. How could the prevalence rate be brought down? The WHO in its 'Report on Third Meeting of the WHO Technical Advisory Group on Elimination of Leprosy' states:



*The Final Push strategy is now zooming in on national and subnational levels in order to achieve the goal of elimination at national level in all remaining countries. New case detection rates become reduced when LEC is repeated in the same area. Therefore, though LEC is needed in some countries, it should be focused on selected areas and carefully identified LEC components. It can also serve as a tool to reach marginalised or underserved population groups and reduce the gender imbalance, which is often seen in routine programmes.*

(WHO: 2002:2-3)

This recognition of focusing on selected areas led the Government of India to launch a series of Modified Leprosy Elimination Campaigns (MLECs). The main objective of MLEC I, II and III was to search for new cases of leprosy

and put them on MDT. MLEC I and II were largely done by the health workers, who conducted house-to-house searches for leprosy cases using flash cards. The modified leprosy elimination campaigns were largely successful in their objective of reducing the prevalence of the disease. However, pockets such as the Kirnapur block in Balaghat district of Madhya Pradesh continued to show a high prevalence rate. An alternative approach to flush out hidden cases with the involvement of community volunteers, therefore, became imperative.

## **Kirnapur Block, Balaghat District**

The block comprises 134 villages. Its population is 1.6 lakh (1991 census), with a sex ratio of 1,002 females per 1,000 male population. About 15% of the population belongs to the Scheduled Castes and the Scheduled Tribes. Over 60 villages in the block remain inaccessible for four to five months in a year. The block also witnesses considerable seasonal migration for employment.

In 1994, when MDT was introduced in the district, the prevalence rate of leprosy in Kirnapur block was 8.24 per 10,000, which was significantly lower than the district's prevalence rate of 11.6. Later on, DANLEP, in consultation with the GoMP, chalked out a series of MLECs. Two Modified Leprosy Elimination Campaigns were carried out in this area, as well as in the rest of the state. In addition, a Special Project for Elimination of Leprosy (SAPEL) was implemented in 64 villages. But it was realised that a large number of hidden cases continued to exist, and that the level of awareness about leprosy remained low.

## **Differences between MLEC and the Alternative Approach**

The MLECs were mainly health worker-driven. As part of the implementation strategy, a team of three volunteers, of which one was a general health worker, was selected for each village. The team was expected to cover a population of about 3-5,000 (about 600-900 families) in six days. No body survey was expected. The family members were shown a card depicting signs and symptoms of leprosy, and were asked if there were any members of the household with these symptoms. This method did not ensure 100% coverage of selected villages, nor of all individuals in the surveyed households. Furthermore, the volunteers did not belong to the same village, except for one *panch* and a villager who provided logistic support.

## The Alternative Approach

The goal of the alternative approach was to identify all hidden cases of leprosy in 70 villages of Kirnapur block, and treat them with MDT. The approach was termed 'alternative' because it relied on involving the community in the detection of suspected cases and treatment of diagnosed patients. It was envisaged that the community would be represented by the *panchayat* system, community-based organisations such as *mahila mandals*, village volunteers, such as *anganwadi* workers, community health workers, and concerned citizens. It was decided to establish search teams for detecting suspect cases in the community and for putting confirmed cases on regular treatment.

### Planning

The conceptualisation of the entire campaign began in May 2000. A meeting was held at Balaghat between the government health functionaries (the civil surgeon, DLO, BMO, Kirnapur, and NMS) to discuss the possibility of piloting the alternative approach. Five days later, DANLEP functionaries from Delhi, Bhopal and Jabalpur met with the DLO, the BMO and the general health services (GHS) and NLEP staff in Kirnapur to plan the initiative. Among other things, they discussed the selection procedure of volunteers from each village. The group decided to involve the health staff, community health volunteers (CHVs), *jana swasthya rakshak* (JSR) and AWWs. Among the *panchayat* members and representatives of social institutions were the *panchs*, *mahila mandals*, *kotwars* and students. It was also decided to include patients released from treatment (RFT) among the volunteers. A complete list of the villages to be covered was prepared. It was also decided to prepare a list of volunteers from each village in consultation with the local *sarpanch* before approaching the selected volunteers.

### Research focus

The alternative campaign was guided by a research focus that aimed at quantifying its outcome. The research agenda aimed to-

- determine whether, and to what extent, increasing the search-time and allowing search teams to work at their own pace increased the actual number of persons examined for leprosy;
- assess to what extent community volunteers were able to complete body charts;

- and to determine the level of awareness about leprosy and its treatment among confirmed cases.

## Implementation

The alternative approach at Kirnapur principally aimed at:

- improving case detection at a faster pace;
- putting confirmed cases on regular treatment;
- ensuring the regularity of treatment; and
- creating wider awareness about leprosy in the general population.

A two-pronged approach was evolved to implement the strategy, namely:

1. Identification and training of master trainers.
2. Selection and training by master trainers of community volunteers.

The NLEP and GHS staff identified 20 master trainers. They were mainly field health workers (NMAs, MPWs, LHVs, and ANMs). The DLO, the BMO and the NMS trained them. The master trainers were in turn responsible for training the search teams. The search teams comprised male and female volunteers. The members of search teams were given a one-day training on:

- how and what to inform people about leprosy and its treatment;
- how to examine people;
- when to suspect leprosy;
- and how to fill up the body chart for each individual.

During training, the team members were informed about the procedure for confirmation including where and when to refer suspects, and about the MDT distribution system. The one-day training included pre- and post-test of active knowledge gained by the volunteers on the day of training. The results of the assessment were communicated in feedback orientation sessions.

### *Selection and training of volunteers*

The *panchayat* Chief Executive Officer (CEO) wrote to all *panchayat* members requesting their cooperation in the campaign. Following this appeal, health workers contacted the *gram panchayats* and all NGOs and CBOs in the area

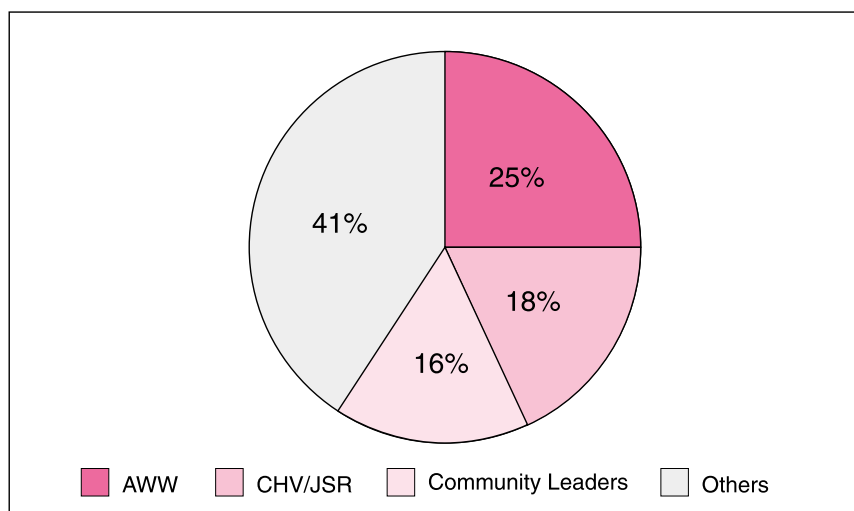
potentially interested in participating in the campaign. The health workers and *the panchayats* jointly selected the volunteers. The volunteers were mainly *panchs*, *jana swasthya rakshaks*, and *anganwadi* workers. They also belonged to organisations such as Gayatri Pariwar, youth groups (*yuva mandals*), *mahila mandals*, etc. At least one search team was assigned per village. However, in larger villages, more than one team was selected, depending on the size of the population. Two volunteers, one male and one female, were selected to cover a population of 500.

**Table 1: Gender distribution of community volunteers**

	Male	Female	Total
<b>Selected</b>	216	216	432
First training (February 2001)	163	161	324
Survey done (April-September 2001)	191	190	381
Feedback sessions (June 2001)	151	138	289

The training of 324 community volunteers (CVs) was undertaken during February March 2001. But, in reality, 381 community volunteers participated in survey work, of which 191 were male and 190 were female volunteers. The break-up of community volunteers selected for the survey is given in Figure 2 below.

**Figure 2: Volunteers participating in the Kirnapur survey by category**



The entire pool of community volunteers was reconstituted into 45 teams for conducting the survey. Over half of the total number of volunteers were 20-30 years of age and had studied between class VIII and XII. No incentives were provided to the community volunteers.

### The IEC package

Information, education and communication (IEC) activities were conducted in March 2001 to create awareness about leprosy. The media employed for this purpose were *kotwar munadi*, *gram sabha meetings*, a school rally, slogans during school prayers, slogan writing in the village, interpersonal communication (IPC), street plays and religious services (*bhajan*, *kirtan*). Through these activities, the community was informed about leprosy as a disease, its treatment, the importance of regular treatment, of the availability of free treatment and about the body chart survey. More intense and focused interpersonal communication took place during house-to-house search operations. The following table provides an overview of the IEC component of the alternative approach.

**Table 2: IEC component of the Alternative Approach**

IEC Activities March 2001	Total
Meetings	223
<i>Kotwar munadi</i>	171
<i>Gram sabha meetings</i>	64
Rallies	35
Slogan-prayers (schools)	146
Wall writing	351
IPC	267
Folk media	18

### Search operations

The search teams worked at their convenience over a period of two to three weeks. No fixed deadlines were set for search operations. It was assumed that this method would ensure complete coverage. Unlike the MLEC searches, which were limited to one visit per household, repeated visits were made. The teams recorded which members of the family were not available and why. They also documented which persons present at the time of the survey were likely to migrate in the near future. The search and charting activities took place over a period of six months from April to September 2001.

### The body chart

An important component of the alternative approach was the body survey with the help of body charts. Body surveys helped identify the lesions in

covered areas of the body that are not normally examined even during routine physical examination. All the parts of the body, divided into eight sections on the body chart, were examined. Among the males, private parts were examined only for 22% in front and 29% at the back. Among the female group, front bust was examined only for 52% and the back region for 56%. Body charting was not done for known leprosy cases, but information was noted in the format on whether or not the patient was a) currently under treatment, b) defaulter, or c) RFT. In all, about one lakh charts were completed.

### **Skin camps**

Skin camps serve multiple functions in the NLEP. They are a good medium for propagating awareness about leprosy. People feel less inhibited to attend skin camps because they do not fear being labelled as leprosy cases. Skin diagnostic and treatment camps offer opportunities for undertaking IEC activities. Cases suspected of leprosy can also visit the camp for confirmation of disease.

12 skin camps were organised in five sectors of the Kirnapur block between April and September 2001. Out of 51 suspect cases that were identified, 18 were confirmed as persons with leprosy.

### **Role of the PRIs**

The *gram panchayats'* contribution to the campaign was significant. All the meetings and the training sessions were held in the *gram panchayat* building. The *gram panchayats* also organised *kotwar munadi* and provided support for the school rallies. The *panchs* acted as community volunteers and participated in the survey. The *sarpanch*, as leader, performed an important role in the selection of community volunteers, in IEC activities and in organising the *gram sabha* to discuss leprosy.

## **Assessment of the Alternative Approach**

### **Comparison of MLEC, SAPEL and the Alternative Approach**

An important part of the alternative campaign was to assess the relative effectiveness of the alternative approach vis-a-vis other campaigns such as MLEC and SAPEL. More precisely, the study attempted to establish the extent to which the involvement of *panchayats*, community-based organisations and community volunteers helped to improve leprosy case detection and

ensure regularity of treatment. The table below presents the research questions and corresponding findings.

**Table 3: Research results from Kirnapur at a glance**

Research questions	Research findings
<i>To what extent has the target-free, community-based approach for case detection increased the coverage of persons examined for leprosy within the period of three to four weeks?</i>	The target-free approach facilitated the body examination of the entire population within a period of three months.
<i>What are the relative coverage and case detection rates attained through survey by community volunteers, MLEC and SAPEL?</i>	In MLEC I, 90% search coverage could be achieved while, in MLEC II, 85% could be achieved. In SAPEL, the search coverage was 99%. In the alternative approach, search coverage has been 95%.
<i>What is the relative rate of case confirmation (as percentage of suspected cases) in the alternative approach in comparison to MLEC and SAPEL?</i>	Confirmation of cases was as follows: MLEC I: 8%; MLEC II: 6.29%; MLEC III: 42.10%; SAPEL: 39.7%. Alternative strategy: 48%.
<i>To what extent and in what detail can the community volunteers complete individual body charts?</i>	All the individuals (105,148 from 70 villages) were examined, and their body charts for the front and back portion were completed, mainly during the period April-June 2001. Body chart area No. 6 referring to private parts could mainly be examined for children.
<i>What is the time gap between suspecting and diagnosis of leprosy, and commencement of treatment?</i>	The majority of the suspects were confirmed as cases or no cases on the same day of survey. Seven patients were confirmed within 5-10 days. 15 cases were confirmed as patients within one to three months and put on treatment.
<i>What is the level of awareness about leprosy and its treatment among suspect cases and patients?</i>	The level of awareness among suspected cases and patients ranged from 90-100% with regard to symptoms, treatment and consequences of irregularity of medication.
<i>What are the sources of information about leprosy for the suspects?</i>	The suspects obtained information about leprosy from community volunteers, from NLEP and health staff, and from public announcements, rallies and skin camps.

A close perusal of the comparative table above shows that the rate of confirmation of leprosy is highest for the alternative approach (48%). The efficacy of this strategy is reinforced when the number of villages covered under each campaign is examined. The number of cases reported in MLEC I and II comes from the entire block of 134 villages. The alternative approach was undertaken in 70 villages. It is interesting to note that the methodology of search in SAPEL and in the alternative approach is similar, and the numbers of suspect cases found by the community volunteers are about as large. The difference between the two strategies is that the SAPEL villages are located in hilly and difficult terrain, and that the volunteers were given monetary incentives. In the case of the alternative approach in Kirnapur, no such incentive was offered.

However, due to the increasing ability of the health system to undertake large health campaigns, the confirmation rate of MLEC III is quite impressive, since it matches the results obtained in both SAPEL and the alternative approach.

The ratio of the suspect and confirmed cases in the three strategies clearly indicates that the search operations undertaken by community volunteers are far superior to those undertaken under MLEC I and II.

In the alternative approach, the majority of the suspects were confirmed as cases or no cases on the day of the survey. However, seven patients were confirmed within 5-10 days. Out of the 74 cases, 15 were confirmed as patients within one to three months, because the persons had left their respective villages during summer.

### **Awareness and knowledge**

An important objective of the alternative approach was to determine the awareness and knowledge about leprosy among different groups of people, especially the community members, community volunteers, suspect cases and patients. For this purpose, three separate questionnaires were designed. These were administered by four NMAs in their respective sectors in October 2001. A total of 781 respondents were purposively selected and administered the questionnaire. Of these, 512 were community members, 121 were community volunteers, and 148 were suspects and patients. In addition, 1,000 body charts, out of over one lakh body charts collected from 70

villages, were analysed by the NLEP staff. Data about the intervention activities of NLEP were collected from the BMO. Information about awareness of different facets of leprosy was collected from interview schedules/questionnaires and focus group discussions with the members of the community.

This study clearly illustrates the direct measurable impact of the alternative strategy in terms of a higher number of cases detected by the community volunteers. Out of the suspected 154 cases identified by the volunteers, the NLEP staff confirmed 74. Over 85% of the community respondents validated the visit by village volunteers to their homes for inquiry and examination. Moreover, before the implementation of the alternative campaign, 37 out of 70 villages of Kirnapur block had no leprosy cases. After the intervention, two more villages were added to the list of villages with no cases of leprosy.

The long-term advantage from the campaign is that a large number of community volunteers developed an accurate understanding of signs and symptoms of leprosy and its treatment. The community volunteers' pre-training and post-training evaluation showed improvement in their knowledge-levels. The gain in knowledge was impressive. 95% of community volunteers knew the correct signs and symptoms of leprosy, types and dosage of drugs and ill-effects of irregular treatment. Eighty-three per cent of the volunteers were aware that an anaesthetic patch is the cardinal symptom of leprosy. They also knew that leprosy drugs were available free of cost at the government hospital, at the PHC/CHC and with the health worker.

The suspects' and patients' awareness-levels were also high. About 90% of suspects and patients said that anaesthetic patch is the cardinal symptom of leprosy. They knew the correct dosage for different types of leprosy and were also aware of side effects of the drugs, such as change in the colour of urine. Seventy-eight per cent said they got their medicines from the health worker.

Most of the community volunteers belonged to low socio-economic strata and did not study beyond school-level. But they responded positively to awareness and knowledge about various aspects of leprosy such as diagnosis, treatment, consequences of irregular treatment and availability of treatment services, including medicines.

The suspects and patients, who were visited by NLEP and health staff for the second time, had a more correct picture of leprosy as a disease, its treatment and possible effects of irregular treatment. This could be attributed to the effectiveness of the ongoing interpersonal communication between the patients and the health workers.

The analyses of body charts showed sector-and village-wise differences. The differences could have arisen due to the differential performance of community volunteers, or the place in the house available for physical examination. A lesson learnt is that if other family members, particularly male members, are present, undertaking the examination, even by the female community volunteer, is not possible.

The alternative approach underscored the importance of *anganwadi* workers for health programmes. In Kirnapur, they were not only found to be aware of health-related issues, but their association with the community was also strong. Other organisations such as Gayatri Pariwar also played a major role, more particularly in organising skin camps, meetings of *mahila mandals* and disseminating messages on leprosy during *Gayatri Yagnya*.

## Conclusion

The main lessons learnt from the alternative strategy implemented in the Kirnapur block of Balaghat district in Madhya Pradesh are as follows:

1. Trained and motivated community volunteers were a powerful medium for case detection. This study showed they could carry out more extensive surveys and intensive search by body examination. Community participation (through village-based volunteers) helped unearth more cases than mere enquiry of the families, as undertaken under MLEC.
2. Performance of community volunteers in identifying suspect cases and detecting MB cases was better than that of health workers under MLEC. *Kotwar* and *anganwadi* worker have emerged as important change-agents in leprosy work.
3. Due to proper training and monitoring of community volunteers by health workers, less false suspects were identified. The confirmation rate of 48% achieved in the alternative approach was good.

4. Body examination and body charts provided better opportunities for interpersonal communication. This method not only increased the awareness of leprosy within the community, but also improved the skills of the community volunteers. Body examination and body charts also helped to detect hidden lesions in confirmed cases.
5. Skin camps unearthed new and hidden cases.
6. The alternative approach was cost-effective, as no monetary incentives were given to the community volunteers. Expenditure on training is a lifetime investment because diagnostic habits and voluntary reporting, once effectively communicated, become embedded in the family and the community.

