

The Sahariya Leprosy Initiative

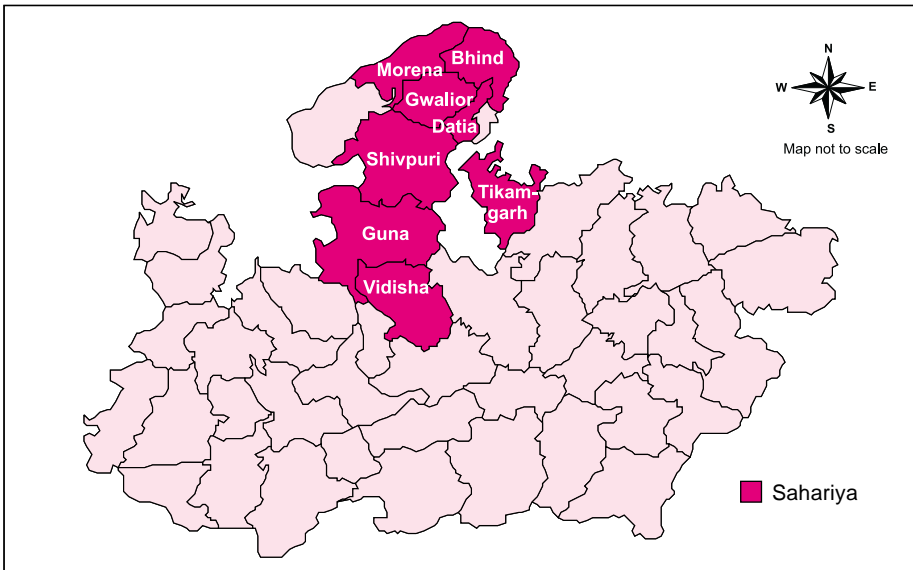


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Background

The Sahariya tribe inhabits the Chambal area in Madhya Pradesh and parts of Bundelkhand in UP. Originally hunters and gatherers, the Sahariyas were driven further into the forest by settlers from the Gangetic plains. A large number became bonded labourers in the farms and quarries of landowners. Today, they form a severely marginalised group. They are found in the districts of Gwalior, Guna, Shivpuri, Morena, Vidisha, Datia, Bhind, Sagar and Tikamgarh.

Figure 1: Districts in Madhya Pradesh with a concentration of the Sahariyas



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Sahariyas are generally quiet people and do not interact much with outsiders. They live in small hamlets. Their villages are located in forests and difficult terrain without adequate road communication. Services like health and education have not reached them to any notable degree. For any health problem, their first referral point is the local healer and places of worship. The Sahariyas have strong beliefs in spirits and ghosts. There are elaborate rituals to seek relief from diseases and suffering attributed to supernatural factors.

Agriculture is the predominant occupation. Wheat, *jowar*, *bajra* and maize are the main cereal crops. Gram and *arhar* are the main pulses. Agriculture is largely rain-dependent, with only two per cent of the total land area being irrigated. The area supports poor types of forest, as the soil is shallow. Collection of minor forest produce, such as *mahua* and *tendu* leaves, gum, bamboo, medicinal herbs and firewood is a major preoccupation during the agriculturally lean season. The minor forest produce is sold to local tradesmen at very low prices due to indebtedness and lack of access to alternate markets.

The administration has a very indifferent attitude towards the Sahariya tribe. Government officials consider a posting in a tribal area as a punishment.



Two women in a Sahariya village.

Though the area comes under the Sahariya Vikas Abhikaran (Tribal Development Agency) and innumerable schemes are planned for the Sahariyas, their reach has been very poor. This could partly be due to the lack of demand on the delivery systems, since the tribal communities lack information about the available schemes and their mode of utilisation, and partly due to the callous attitude of the local administration. The impoverishment and marginalisation are exacerbated by the strategic alignment between local landlords, entrepreneurs and bureaucrats. The socio-economic conflicts are played out over such critical issues as land rights, entitlements, self-governance, health and education.

Many Sahariya tribals are engaged in stone quarrying. Despite being banned, bonded labour in the mines is quite common. Land dispossession by more powerful groups such as the landed Gujars is also prevalent. The police does not take much interest in protecting the interests of the Sahariyas or punishing the wrong-doers. Liquor is another mode of well-planned exploitation. Liquor is often sold by the mine owners at the site of the mines, rendering the workers more vulnerable to exploitation. On account of these reasons, most Sahariya families are found living substantially below the poverty line.

The Study

A research-cum-intervention study entitled 'Perceptions and Practices of Sahariya Community towards Leprosy' was undertaken by the Gwalior-based NGO Sambhav. The main aims of the study were:

- To assess the knowledge-levels, customs, beliefs and attitudes towards leprosy of the Sahariya community.
- To assess knowledge-levels concerning the Government Leprosy Eradication Programme.
- To identify and implement necessary interventions on the basis of the above information.

Study areas

The four tribal districts of Gwalior, Sheopur, Shivpuri and Guna were identified for the study.

Table 1: Demographic profile of selected districts

Name of the district	Sheopur	Gwalior	Shivpuri	Guna
Population	559,715	1,629,881	1,440,666	1,665,503
Male	295,630	882,258	775,473	883,433
Female	264,085	747,623	665,193	782,070
Schedule castes (SC)	90,234	318,720	160,340	295,036
Scheduled Caste (%)	2.1	2.9	11.3	12
Scheduled Tribes (ST)	180,340	60,976	219,384	190,752
Scheduled Tribes (%)	14	20.4	19.4	18.1
Females per 1,000 males	893	847	858	855
Literacy (%)	47	70	60	60
Male literacy (%)	62	81	75	75
Female literacy (%)	29	57	42	43

Five selection criteria were used for the choice of three villages from each of the four districts. The criteria were:

- predominance of Sahariya tribals in the population;
- presence of leprosy patients;
- continuous reporting of leprosy cases during the past couple of years;
- half of the villages should be adjacent to a main road;
- half of the villages should be situated two or more km. from a main road.

The following table presents an overview of the blocks and villages selected in the four districts.

Table 2: Overview of study Sites and Duration of Sambhav's Study on the Sahariyas

District	Block	Days of field work	Village
Shivpuri	Shivpuri	24	Kalothara, Amarkhoa, Sakalpur.
Sheopur	Karahal	13	Sesaipura, Karahal (Shripura Mohalla), Khirkhiri.
Gwalior	Ghatigaon	14	Pulkapura, Dursedi, Dhyampur.
Guna	Chanderi	10	Naron, Baroda, Nidanpur.

Scheduled tribes constitute a sizeable, if not majority, section of the total population in all the sampled villages. The demographic profiles of the sampled villages are presented in the table below.

Table 3: Demographic profile of sampled villages

District	Block	Village	Population		
			Total	SC	ST
Shivpuri	Shivpuri	Kalothara	611	11	503
		Amarkhoha	606	6	454
		Sakalpur	888	19	488
Sheopur	Karahal	Khirkhiri	1,079	163	536
		Karahal	6,212	529	2,499
		Sesaipura	995	81	469
Gwalior	Ghaatigaon	Pulkapura	1,307	NA	1,307
		Dursedi	583	413	80
		Shyampur	583	345	90
Guna	Chanderi	Barodia	618	NA	400
		Nidanpur	1,400	NA	625
		Naron	553	NA	270

The distance to the main highway and to the nearest government health facility of the different villages is presented below.

Table 4: Distance of sampled villages from nearest highway and health facilities

District	Block	Village	Distance	Distance	Distance	Distance
			highway from in km.	from health sub-centre in km.	from PHC in km.	from district hospital in km.
Shivpuri	Shivpuri	Kalothara	3	5	30	45
		Amarkhoha	6	8	16	12
		Sakalpur	1	0	5	21
Sheopur	Karahal	Sesaipura	0	0	15	55
		Karahal	0	0	0	35
		Khirkhiri	6	0	6	41
Gwalior	Ghatigaon	Pulkapura	0	0	20	35
		Dursedi	2	4	9	40
		Shyampur	0	8	8	42
Guna	Chanderi	Natrona	1	6	9	80
		Nidanpur	3	5	11	11
		Barodia	7	3	21	77

The study

Training

The study involved training of two groups, viz.,

1. Sambhav members were trained in the use of participatory rural appraisal (PRA) modules, data collection and analysis.
2. Local volunteers from the villages, where the study was undertaken, were oriented on the basic facts of leprosy and its treatment.

This was one way of gaining community participation. The local volunteers not only facilitated access to the community in general, but played a major role in organising group discussions and functioning as interpreters in the development of case studies. The participation of female volunteers was very encouraging and went a long way in involving women of the community in the study.

Methodology

Participatory rural appraisal techniques were used to study people's understanding and perceptions about leprosy. The table given below shows the different PRA modules used and the kind of data they were aimed at generating.



Sahariya woman carrying water

Table 5: PRA modules used in the Sahariya study

Name of the Module	Information Collection	Use of the information	No. of participants
Social Map	Population of the village (people per sq. km.) Health position, house of <i>panch</i> and <i>sarpanch</i> , houses of leprosy patients.	To establish relationships between the physical location and the social position of individuals within the village community.	200
Mapping	Information regarding available health services in and outside the village and the distance to them.	To relate the health infrastructure available to the villagers to reported illnesses and health-seeking behaviour.	160
Matrix	On the basis of symptoms to identify the disease by its different names and the treatment sought.	To learn current practices and health seeking behaviour in connection with different skin problems.	150
Chapatti	The chapatti module is used to know the priority in the treatment of disease.	To learn about the treatment for leprosy.	120
Pie	How many people use health services?	Utilisation of health services.	120
Time line table	To know the previous history of leprosy: When was the first patient of leprosy seen, what was the reaction of the family members and neighbours, and what treatment was given at that time and in which manner?	To know the previous methods used for the treatment of leprosy.	100
Graphics	To learn about the attitudes of Sahariya Community towards leprosy.	To know the attitudes of the Sahariya community towards leprosy.	50
Economic classification	On the basis of village <i>mukhias</i> list, to classify the leprosy patients in terms of socio-economic status.	To know whether leprosy is associated with any economic factor.	100
Focus group discussion	Knowledge can be gained about leprosy by the group discussion among teachers, health workers, women group, leaders etc. Their opinion and perceptions about leprosy was taken into consideration.	Plan intervention in society on the basis of gained information about leprosy from different people.	150
Case study	Some leprosy patients were identified for case study.	To develop a better understanding of leprosy patients on the basis of their personal experiences.	14

Problems encountered during the study

Due to the geographical isolation and specific social and economic context of the Sahariya community, the following problems were encountered in the course of the study:

1. To contact the people, the worker had to take permission from the *patel* or another senior person of the community. Otherwise, people would not participate in any activity. This was essential for organising group meetings.
2. The issue of incentives was routinely brought up, as people wanted to know how they would benefit from participating in the study.
3. Knowledge about leprosy was not very high, because people had not seen many leprosy patients in their village.
4. Men and women did not sit together. Separate meetings had to be organised.
5. Men were not available frequently, because they went for work in nearby industries.
6. Due to the general negative attitude towards the local administration, people did not have much faith in government programmes and personnel, including the health workers.



Sambhav workers and community members during PRA exercise.

Results

The following inferences were drawn from the group discussions conducted on the issue of leprosy in the different villages.

Local terminology of skin diseases

When the discussion began with verbal descriptions of the symptoms of leprosy, people would say they had never heard of such a disease, with the exception of those who had themselves taken the medicines for leprosy or those who had participated in the SAPEL. But when the topic was introduced with pictorial representations depicting the various stages of the disease, recognition was immediate. Not only did the pictures aid in stimulating discussion on the various facets of leprosy, but the whole repertoire of skin afflictions and their treatment also became integral to the discussion.

In addition to wounds and pimples, the Sahariyas had several semantic categories to describe dermatological problems. Numbness in any part of the body was referred to as *sunnbai*. While *sun* in Hindi refers to loss of sensation, *bai* is a generic term referring to various types of gout and arthritis. The tingling in fingers was associated with *bai*.

While on the one hand, white spots in general were described by participants in all the villages as the early signs of leprosy, there was a further sub-categorisation of different types of white spots. For instance, *ban-ruff* was described by many participants as a skin problem, which appears similar to scabies or eczema. The term *khodi* was also used by some interviewees when describing different types of white patches. Scars and spots on the body and general numbness were collectively called *banda* by residents of Baroda village in Guna district.

A symptomatic classification of leprosy led to four terms occurring most often in the group discussions, and people were able to identify it by its different names. White spots were called leprosy or *korh*. An itching spot on the hand and foot was known as *chazon*, and deformity and numbness in fingers was termed as '*sunnbai*'. A resident of a village in Karahal of Sheopur district said that if hands are deformed, it was known as *kukara bai*.

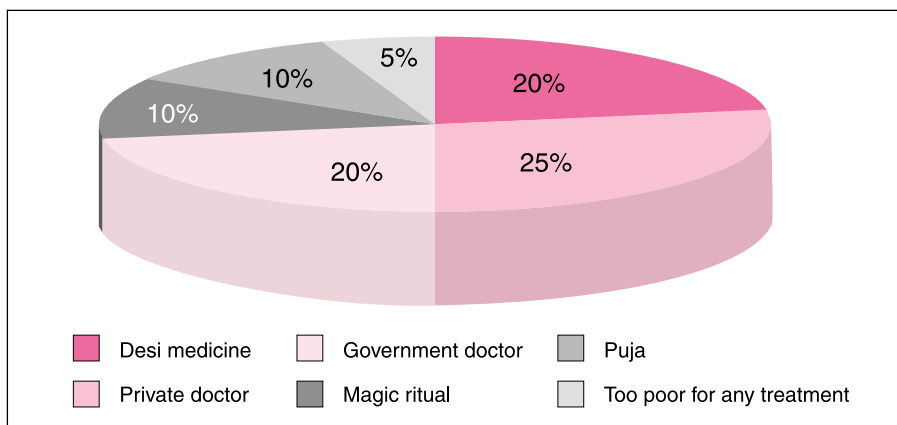
Causation and treatment of leprosy

Once the disease is identified as leprosy, there were several theories of causation for the affliction. The most common explanation was that leprosy was a punishment for an individual's evil deeds. Spoiling of blood and changes in food habits could lead to the development of new diseases like leprosy. Some women of the village Dursedi in Gwalior district said that this disease occurred due to unhygienic habits. Other residents of the same village attributed the origin of the white spots to wearing shoes in summer.

While a multitude of treatment options were enumerated in the course of the group discussions in the different villages, ranging from herbal treatment to allopathy, the issue of physical distance and accessibility need to be borne in mind. Herbal and magico-religious treatments emerge as the first pattern of resort for any affliction including leprosy, not only because of their actual or perceived effectiveness but simply because they are the most widely available. The nearest PHC may be as far as 20 km., and the government health facilities may only be accessed in connection with very debilitating and life threatening conditions.

In an analysis of health care service utilisation of leprosy patients in Karahal village of Sheopur district, 20% of the patients used traditional (*desi*) medicines, 25% went to private doctors, 20% went to government doctors, 10% opted for some magico-religious rituals, 10% had a *puja* performed, and 5% were too poor to spend money on any form of treatment (Figure 2).

Figure 2: Health-seeking behaviour in Karahal village, Sheopur district



Perceptions of the General Health System

In addition to the barrier to access posed by the distance factor, the discussions revealed that people, by and large, did not have a favourable attitude to the government health facilities. Some of the reasons for not approaching the PHC were:

1. it remains closed;
2. the staff has a negative attitude;
3. medicine is not available; and
4. there are long waiting periods.

Some participants pointed out that the government health worker did not conduct leprosy surveys in their villages. Even when cases were identified, there was no follow-up of treatment by the health workers after the first dose of medication. They did not visit the villages regularly, if at all. Furthermore, since patients were not informed about the side effects of MDT, many patients stopped taking drugs when they experienced loss of appetite and nausea.

While indigenous beliefs and practices may result in delayed treatment for leprosy, the role of other deterrent factors from the providers' side should not be under-estimated. For instance, in some of the sample villages where a SAPEL had recently been conducted, two new patients were found, who had apparently been missed out during the SAPEL campaign.

Case studies

Leprosy was not perceived as a single unitary disease. The various symptoms were treated as separate illnesses with specific treatments, which were often a combination of herbal and magico-religious therapies. The most striking feature of leprosy in the Sahariya tribe was the absence of stigma and discrimination of leprosy-affected persons and their families. Even though divine retribution was cited as an important etiological factor for the onset of leprosy-like symptoms, it was observed that patients under treatment were leading normal lives. They were neither physically isolated nor socially discriminated against. Furthermore, the diagnosis of leprosy evoked strong emotional reaction neither in those affected by the disease, nor their relatives and friends.

The following table summarises the status of 34 leprosy patients in the four districts in which the study was undertaken.

Table 6: Disease-profile of leprosy patients in the four districts

Block	Leprosy			SSL			PB			MB			Completed treatment		
	M	F	T	M	F	T	M	F	T	M	F	T	M	F	T
Shivpuri	6	5	11	1	1	2	2	3	5	1	3	4	1	2	3
Karahal	2	3	5	–	–	–	–	1	1	2	2	4	1	–	1
Chanderi	9	3	12	1	1	2	7		7	3	–	3	7	1	8
Ghatigaon	3	3	6	–	–	–	2	1	3	–	3	3	1	2	3
Total	20	14	34	2	2	4	11	5	16	6	8	14	10	5	15

M=male, F=female, T=total, SSL=single skin lesion, PB=paucibacillary, MB=multibacillary.

From a social-psychological perspective, the most interesting finding of this study is that leprosy patients are not subject to any overt discrimination in the family or community among the Sahariyas. The absence of social

Case 1

'S', A sixty year old woman with no contact with her family, who makes a living on the basis of daily wages.

S is living in a colony Karahal Block of Sheopur District. Ten years ago she felt numbness in her left hand, while she was grinding flour with a stone. She told the villagers about her problem. They said that it was a disease called *sunbai* and that only a holy man (*baba*) could treat it. S took *desi* medicine from that *baba* for a period of three years but there was no improvement, and her fingers eventually became deformed. Then she was told that an evil spirit was residing in her home. She worshipped her house god, but in vain, and her fingers started rotting. She visited a village doctor. The doctor gave her some medicines which gradually stopped the rotting of her fingers, but small blisters appeared. Now, S is again taking *desi* medicine. She has continuous pain in her stomach, and blisters are prominent on her fingers. In her own words: "I have no children. My brother is taking care of me. I did not get any help from the village panchayat. Whenever I clean the utensils, the blisters appear on my fingers. Numbness is always present in my hands. I feel very uneasy, but no one treats me badly."

stigma qualitatively alters the experience of leprosy at both individual and community-levels. Unfortunately, this study fails to provide any further information on this crucial theme beyond the simple statements that the patients lead normal lives. Some of the case illustrations presented below, however, shed some light on the illness trajectory of individual patients.

Case 2

'D', an elderly man of unknown age, who works in the fields.

Twenty years ago D felt pain in his ankles, and his toes became numb. When he informed a relative about these problems, he was told that it was the *sunnbai* disease. Other villagers agreed. Initially, he took *desi* medicines but there was no improvement in his condition. Then, he went to a temple where the priest told him that a particular god was not pleased with him. To please the god, he sacrificed a goat and arranged a party. Gradually, pus began accumulating in his feet and fingers. He sacrificed more goats to appease the gods. When a camp was organised by Sambhav in Karahal, he was given some medicines by the camp doctors. Subsequently, his fingers improved. D says he has spent more than Rs. 20,000 on his disease. He has continued living with his family, and there is no discrimination. He goes to his relatives' home often and eats with them. They treat him normally.

Case 3

'A', a forty year old male cultivator.

A has lost some of his fingers due to leprosy. He tells that a decade ago when he was cutting a bush, his nail was removed from his finger. Gradually, the wound became larger and the fingers got decomposed. When he visited Dr. J., the doctor cut off the affected finger. Then another finger got affected. He again went to the doctor who said someone must have cast a spell. A tells that he does not have any numbness but he does feel pain. When asked why he does not consult a doctor for the pain, he explains that he is told that the disease will grow worse, if he goes.

Case 4

Dr. and Mrs. 'V'

Both Dr. V, a veterinarian, and his wife have leprosy spots on their bodies. His wife said that initially, there was only a small spot, but soon her whole body was covered. She also had numbness in some parts. One day her hand got injured and swelled. She was treated in Gwalior. At the time of treatment she had no pain. Thereafter she took treatment from Dr. G, but there was no improvement. One day a leprosy eradication worker was sitting in Dr. G's clinic. He said that it was leprosy and advised her to take some tablets for a period of one year. After taking medicines, the scars and spots disappeared from her body. Her husband, who also had leprosy spots, took the same medicine. Now both of them are fine and live a normal life.

The IEC campaign in Pohri block of Shivpuri district

Based on the research component, an applied component was developed with a focus on the use of different IEC strategies for enhancing awareness about leprosy in ten villages of Pohri block, which had not been involved in the research activities. The aims of the IEC initiative was:

1. To increase mass awareness about leprosy through surveys, exhibitions, meetings and dramas.
2. To prepare volunteers at village-level for leprosy work.

IEC activities

Workshops with women

Keeping in view the need to focus on case identification and treatment completion among women, over 25 workshops on leprosy were organised by Sambhav workers with AWWs, ANMs, MPWs (female), teachers and the SHGs and *mahila mandals* in different villages in the four blocks between October 2002 and January 2003.

School surveys and health camps

Schoolchildren were examined in seven schools situated in the different villages. Children were informed about the basics of leprosy and its treatment by NGO workers and local volunteers.

Graffiti, exhibitions, rallies, *munadi* and street plays

Graffiti, depicting through words and pictures the signs and symptoms of leprosy and its treatment, was painted in ten villages. The main sites of the wall paintings and writing were roadside and main village lanes. Four exhibitions using banners and posters on leprosy were installed at local village markets (*haats*) in four villages. Cycle rallies carrying IEC materials were organised. People were encouraged to hold discussions on leprosy with the banners and posters serving as cues.

A local theatre group specialising in street plays (*nukad natak*) at Bilaua village was asked to prepare dramatic presentations on leprosy, not only focussing on dispelling the myths and misconceptions surrounding the disease, but also weave in messages about its curability through free and effective treatment. The group staged performances in more than ten villages.

The outcome of the IEC campaign

It was observed that individual awareness of leprosy was enhanced and that patients voluntarily showed their body scars and patches for examination. There was a willingness to discuss issues pertaining to leprosy, and patients started taking medicines regularly.

At the community-level, knowledge about leprosy and participation in the programme also increased.

Survey in Karahal block, Sheopur district

A house-to-house survey was conducted in 30 villages of Karahal block through the participation of local volunteers.

Training of village volunteers

One man and woman were selected from each of the identified villages to function as link workers for case identification, referral and treatment in their respective area. More than half a dozen one-day workshops to train volunteers were organised by Sambhav in collaboration with the local NLEP functionaries in the selected villages. The presence of the *sarpanch* or *patel* was ensured to confer an official stamp on the programme.

Table 7: Selection and training of volunteers, April 2001-June 2002

Date	Activity
1 April-10 May 2001	Contact reputed persons in the selected villages to get their cooperation and commitment for the initiative.
10 May-10 June 2001	Selection of village volunteers from the 30 villages. Two selection criteria were used: The person should be a) eight class pass and b) should be a permanent resident of the village. 60 volunteers were identified.
20-21 June 2001	One-day training of volunteers, who were divided into two batches. Training was held at Cultural House, Karhal and coordinated by the director, Sambhav, and the DLO Shivpuri.
23 July 2001	Workshop with volunteers coordinated by the director, Sambhav, and a representative from DANLEP Madhya Pradesh.
July 2001-May 2002	Door-to-door survey conducted in the 30 villages. In the first survey, 12,652 persons were surveyed out of which 64 were confirmed cases. In the second survey, of 10,579 persons surveyed, 24 were confirmed cases.
June 2001-June 2002	More than 20 meetings were conducted in the different villages to spread the message of leprosy, focusing on removing age-old myths associated with the disease.

Table 7 outlines the major activities undertaken in Karahal block for developing a local corps of volunteers.

Sambhav monitored the work. More than 10 meetings were organised between July 2001 and September 2002. The aim of these meetings was to discuss the problems faced by volunteers, which could range from relative effectiveness of different methods to spread awareness about leprosy in the community to procedures for filling survey forms.

It is hoped that the awareness campaign generated greater understanding about leprosy in the community, and not only increased participation in leprosy surveys and awareness campaigns but also lead to increase in voluntary reporting.

Suggested Action Points

Based on the above research results and intervention activities, a number of action points have been identified for future activities for leprosy elimination among the Sahariya community:

- A culture-sensitive campaign for building awareness on leprosy should be carried out,
 - improving the capacity of the Sahariya community by organising awareness programmes;
 - organising group meetings regularly to raise the knowledge-level regarding leprosy;
 - training the local voluntary groups at community-level and preparing them as leprosy elimination workers. Workers should help in dissemination of the information on leprosy;
 - organising orientation and cooperation camps among government health workers, *anganwadi* workers, village health workers;
 - organising school health programmes;
 - making use of theatre and other effective communication media for reaching the Sahariya village.
- Individual cases should be followed up to clarify the discomfort experienced after consumption of medicine.
- Availability of medicine should be ensured.
- Motivation of patients should be encouraged through IPC.
- Community-level discussions for increasing the knowledge-level of the Sahariya population should be organised.
- Village-level volunteers should be trained in diagnosis and referral.

It is hoped that the above action points may also be useful for leprosy and other health related interventions in tribal communities beyond the Sahariyas of Madhya Pradesh.

