

Methodology



Review and Reconnaissance

The study began with an orientation to leprosy and the National Leprosy Eradication Programme (NLEP) by the state project coordinator, DANLEP, and review of relevant data and literature. This included project documents, review and evaluations reports of the leprosy programme of the government being implemented in these districts as well as documentation available with DANLEP. Discussions were held with people associated with the project and key respondents were interviewed. Based on these discussions, the design of the study was crystallised. The detailed study protocol clearly defining an acceptable sample, survey instruments and methodology was finalised in consultation with DANLEP. The blocks were selected keeping in mind the tribal population and prevalence rate.

A preliminary visit was made to the three sample districts and information related to Gond LAPs was collected. From the running list, patients and villages for the study, and LAPs for case studies were identified. This was done taking into consideration the availability of Gond population, prevalence of leprosy in the block and the accessibility (which was hampered due to the monsoons). The patients and villages were identified keeping in mind that a diverse cross-section is



represented. Care was taken to study non-Gond tribal villages and LAPs to gain appreciation of the differences and similarities between the two.

After selecting the sample villages, a reconnaissance was done in Kala Akhar village of Kesla Block of Hoshangabad district. The checklists and other schedules for PRA, FGDs and case studies were tested and accordingly redesigned.

The PRA exercises conducted:

1. Social Mapping
2. Health Institutional Mapping
3. Venn Diagram of Health Institutions
4. KAP Matrix of Disease Prevalence
5. Popularity of Health Service Providers
6. Seasonal Health Calendar.

The Study Protocol and Tool Box

In each village, a PRA was undertaken to understand the condition of health facilities, the health seeking behaviour, perceptions about health service providers and diseases. Wherever possible, the

Social Map of Kala Akhar



The broad areas for focus group discussions were

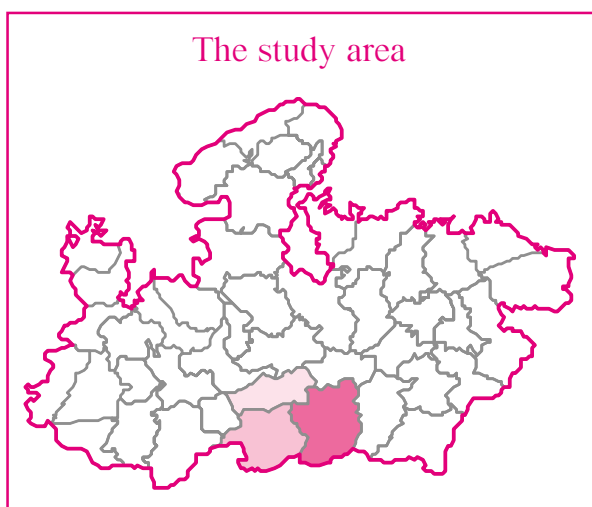
1. What is 'Disease' and why do we get ill?
2. What are your views and experiences regarding the government health service?
3. Where do you go for treatment?
4. What is leprosy and what are its symptoms?
5. At what stage does it become leprosy?
6. What causes leprosy, is it hereditary?
7. Are there leprosy patients in your village? How many?
8. What food and living habits are to be followed while suffering from leprosy?
9. Is leprosy curable?
10. Is it terminal?
11. What is the treatment?
12. What do you mean by leprosy being cured?
13. What are practices related to marriage and socialisation? (*Beti and Roti*)
14. Is ostracism prevalent, if yes, then in what way?
15. Who suffers from leprosy?
16. What precautions are to be taken to avoid leprosy?



information was ranked to understand the relative importance. Focus group discussions (FGDs) were held to understand the knowledge, attitude and practices (KAP) related to health problems in general and leprosy in particular. A detailed study of select LAPs was done to develop case stories. These cases helped in arriving at an understanding of the problem of leprosy from the patient's point of view and also gave us access to aspects of leprosy that are difficult to obtain in a group setting.

The data gathered was analysed to develop information on the beliefs and practices that are prevalent with regard to leprosy and also to identify the barriers in effective leprosy eradication work.

The analysis used an appreciation-influence-control matrix to study



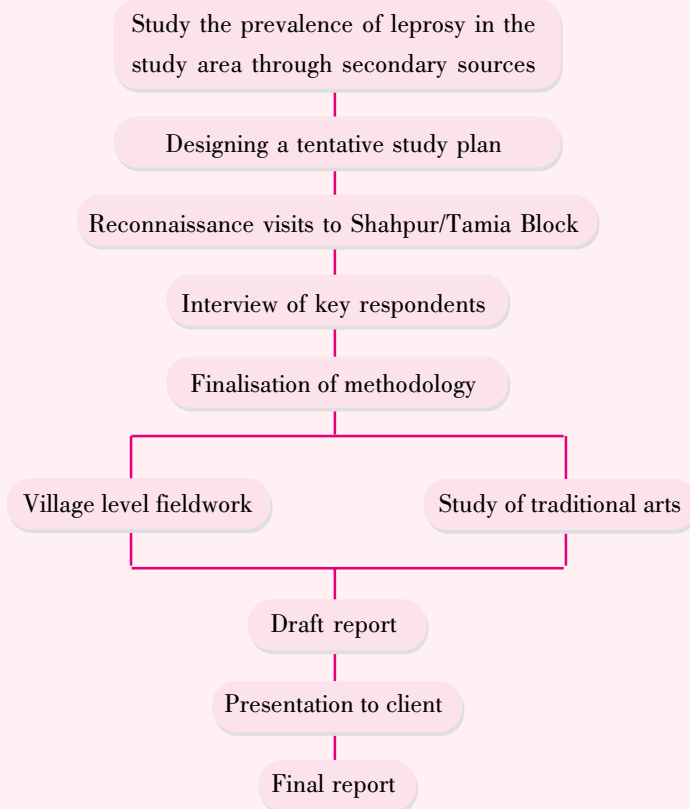
centrality of power relations; a beneficiary assessment to systematically analyse perceptions of the beneficiaries and other stakeholders to ensure that their concerns are heard and incorporated into strategy. Gender analysis was used to address specific barriers faced by women in accessing the NLEP and health services as such.

In addition, *haats*, folk art and folk art groups were studied to help identify a communication strategy for leprosy awareness among the Gonds.

Sample

The sampling was stratified-random-purposive. In the first stage, blocks with high ST population were selected. In the second stage, blocks with very low prevalence rate were discarded. Within this sample universe, the blocks were randomly selected. In each block, LAPs and villages

The Steps of the study



were purposively sampled to cover a cross section of socio-economic differentials.

During July-August 2001 fieldwork was conducted in over 12 villages in 4 blocks of the three districts of Chhindwara, Hoshangabad and Betul. The list of villages is given for every block.



The Sample

Hoshangabad District

Kesla Block

Kala Akhar
Kasda Kurd
Junkar

Betul District

Shahpur Block

Aamdhana
Palasp
Chhatribad
Barbatpur
Shahpur

Chhindwara District

Bichhua Block

Ulhawadi
Kanhargaon
Badosa

Junnardev Block

Jaatasemar