SERIES NO. 5

LEAP
LEPROSY
ELIMINATION
ACTION
PROGRAMME

APR, 10

FOCUS

Epidemiological Validation Drive (EVD)

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Focus on Epidemiological Validation Drive (EVD) : Operational Guidelines

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EVD through sample survey –
an important tool to validate leprosy situation

Despite the significant historical achievements during MDT era and the claims of reaching the apex of leprosy control, leprosy is still lurking in our society as a public health problem. The increasing trend in new cases of leprosy makes the situation serious and a cause of concern. Such a concern needs a professional and scientific response to validate the situation of leprosy in real terms, from time to time.

Without reliable information, both baseline and current disease burden, the programme managers will be misguided and undermine the leprosy control efforts required at all levels of public health during the integration phase. Leprosy cannot be wished away without planned interventions. Absence of relevant information to guide our actions can lead to a resurgence of leprosy and the situation can become grave!

This issue of 'Focus' is precisely aimed to share the above concern with those who are interested in ascertaining the leprosy situation to provide feedback to the programme managers.

The issue also includes the results of the EVD undertaken in Mumbai on a pilot basis. Based on this exercise, several EVDs are planned in urban and rural Maharashtra in partnership with the NLEP unit of Govt. of Maharashtra and NGLOs.

We hope this guide will be used by the leprosy programme managers to gather reliable information to guide our collective effort to control leprosy and promptly reach out to all the leprosy affected persons!

30th April 2010
Mumbai - 400 022

A. Antony Samy
Chief Executive

EPIDEMIOLOGICAL VALIDATION DRIVE (EVD)

Operational guidelines

ALERT-INDIA, B – 9, Mira Mansion, Sion (West), Mumbai – 400 022, India

Introduction

At the request of the Mumbai District Leprosy Elimination Committee represented by all the NLEP units working in Mumbai city, ALERT-INDIA proposed a sample survey as an ***'Epidemiological Validation Drive'*** *(EVD) in 2007. Under EVD, a sample population survey was carried out in 8 out of 169 Urban Health Posts (UHPs) in Mumbai. This project was particularly pertinent to validate the epidemiological trend of leprosy as reported under NLEP.*

The objectives of the EVD were a) to identify all people who have signs of leprosy remain undetected in the community and b) to collect and analyze basic demographic, socio-economic and clinical information on the new leprosy cases detected.

A representative number of UHPs or PHCs was selected on the basis of high MB% in the districts having high PR based on the population. Enumeration of the population was done by trained 'Enumerators' and examination was done by trained leprosy workers.

ALERT – INDIA developed a standard methodology and guidelines as well as prepared training materials, printed the forms. Special teams managed the operation for field data collection and data processing through responsible NGO partners together with NLEP Unit of the district.

The data from the EVD provided good indications on the epidemiological profile of leprosy in a given area. The final report with the findings of EVD and outline for policy recommendations was presented to the Government and shared with all participating agencies through a dissemination Workshop.

Information collected by the EVD could subsequently used to develop a policy guideline and to propose actions for disease surveillance and validating the trend of new case detection.

I. EVD: The context and the need

(a) Sample Survey – a tool for epidemiological validation

The 'intermediate' goal of leprosy elimination, < 1 case per 10,000 population, has been achieved in India by December 2005. However, the trend of prevalence and new case detection during 2003 to 2005 have shown a sharp decline (Refer Fig 1 & 2), which was possibly due to several operational factors such as discontinuation of all active new case detection activities. Besides, the social stigma and trouble free signs of leprosy also contributed to reduction in new lprosy cases reporting voluntarily.

In fact, with the large number of general health workers inducted and entrusted with leprosy control activities, more number of new leprosy cases should have been reported and registered for MDT with the general health care (GHC) system during the integration phase. Instead, the number of new leprosy cases drastically declined.

Hence, this phenomenon warrants a validation exercise in order to ascertain the

Fig. 1: Trend of PR in India: 2000 to 2005

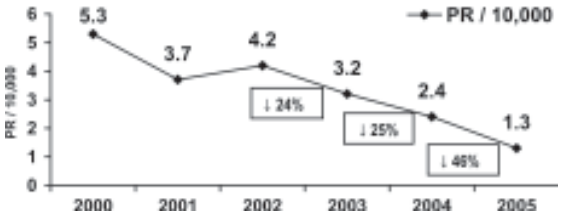
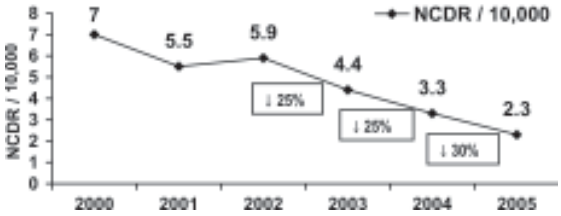


Fig. 2: Trend of NCDR in India: 2000 to 2005



real burden of leprosy in the community. Additionally this would help to validate the achievements of leprosy elimination and to strengthen the efforts made towards integration till now. This exercise will also generate community awareness about leprosy and eventually promote voluntary reporting of all new leprosy cases to the GHC system.

The EVD of this kind, if scientifically planned and undertaken, can serve as a tool for epidemiological surveillance in different geographical and socio-economic context.

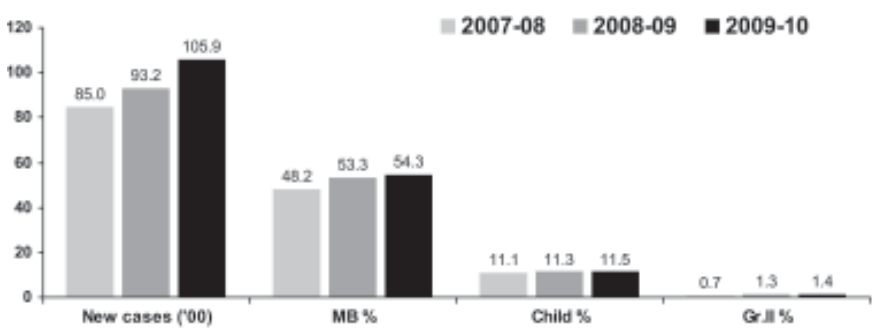
(b) Situation Analysis

The Govt. of Maharashtra had reported an increasing trend of new case detection under NLEP as well as an increase in the proportion of MB, Child and Gr.II cases in the state since 2007 (Refer Fig 3). This clearly indicate that there is a considerable delay in new case detection, which predict active transmission in the community. These factors points towards the importance of strengthening the activities related to early new case detection and thus reducing disease morbidity.

WHO stated *that some new cases never come for diagnosis and treatment, so the number of cases detected is lower than the number of incident cases and recommended that there is an urgent need to identify, through independent assessment, geographic areas where the transmission of leprosy is high, which will reflect the true epidemiological picture*.

It also admits that *'there are no tools at the moment to carry out such an exercise and existing epidemiological surveillance systems are not yet sufficiently effective'. (Ref: Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities (2006–2010), WHO/CDS/CPE/CEE/2005.53)*

Fig. 3: NLEP - Trend of new cases detected and key indicators (Maharashtra)



Source: Health indicators: Leprosy, November 2009 Govt. of Maharashtra, http://www.maha-arogya.gov.in/hmis/ 34%20INDICATORS%20OCT%2009.pdf, Accessed on 15 January 2010.

In response to this concern, ALERT-INDIA proposed *'sample survey'* as an effective tool for epidemiological validation of leprosy burden in 11 UHP areas of Mumbai (urban) in 2007. The results showed that the prevalence of leprosy in the sample survey areas is 5 times more than the PR reported by the NLEP *(See full articles on page nos 12-26).* It also helped to confirm the actual disease burden and to consolidate the success of the leprosy control programme in the state.

Another study on active new case detection in 5 PHC areas at Panvel taluka (rural) of Raigad district elicited a prevalence of Gr.II cases up to 18% among newly detected cases of leprosy, whereas the NLEP projected about 2 – 4% only. *(Ref: Shetty et al, Detection of previously undetected leprosy cases in a defined rural and urban area of Maharashtra,Western India, 2009, Lepr Rev, 80, 22-33)*

These studies underscores the need for validating the new case detection in leprosy in order to obtain the actual disease burden in the community. The new case detection trends need to be interpreted in the context of various factors that exist in urban and rural areas. This can be achieved by undertaking **'Epidemiological Validation Drive (EVD)'** in the selected urban and rural areas that will help to measure real epidemiological profile of leprosy.

(c) Aims and objectives

1. To ascertain the disease burden and the epidemiological trends of leprosy in urban and rural areas of India.
2. To assess the clinical profile of new cases detected and the reasons for late or not reporting to the GHC for diagnosis.

II. Action Plan for EVD – An overview

The detailed methodology for implementing EVD is elaborated below:

1. The State Leprosy Officer (SLO) will analyze the data on leprosy from all the districts and select the districts based on the suggested sampling design for implementing EVD as an operational study as per the set guidelines.
2. The SLO to jointly propose an action plan in collaboration with the respective District Leprosy Officer (DLO) of the districts selected and organize sensitization Workshop for the NLEP team to implement EVD in the selected areas.
3. The DLO to select a UHP / PHC in the selected district and prepare a proposal in a prescribed format and coordinate with the NLEP staff of the district.
4. A team consists of Officials from the office of the DLO and Epidemiological Monitoring & Evaluation Unit (EMU) of ALERT-INDIA is responsible to monitor the EVD implemented by the NLEP unit in the selected districts.
5. The Non-Medical Supervisor (NMS) of the respective NLEP unit to collect and prepare the list of all known leprosy cases (active cases / RFT cases / Cured deformed cases) registered in the past 3 years and living in the areas under UHPs / PHCs selected in the district for EVD.
6. A team of trained leprosy workers (Non Medical Assistant / Leprosy Technician / Leprosy Inspector / Paramedical Worker) available at the respective NLEP unit to undertake EVD in the selected UHPs / PHCs, recruit and train required number of Enumerators.

7. Each Enumerator will enumerate a minimum of 50 (Urban) & 25 (Rural) households in one day among the population living in UHP / PHC areas selected for EVDs. Thus 25,000 population will be enumerated within 5 and 10 days in urban & rural areas respectively.
8. Overall, 20 trained Enumerators to enumerate 25,000 population in each of the UHPs / PHCs selected in the district. Thus approximately, 2 lakh population to be targetted in 8 units (4 UHPs & 4 PHCs) from 4 districts selected in the state.
9. The trained leprosy staff of the respective NLEP units take up the total examination of all the enumerated population (not less than 80% of the total population enumerated) from the areas under selected UHPs / PHCs prferably in 3 rounds and list all the suspect with definite signs and symptoms of leprosy.
10. The **1st round** of examination to be done during working days between 9 am to 2 pm; the **2nd round** to be done during early morning (7 am to 9 am) and during late evening (5 pm to 7 pm) and the **3rd round** during weekly / public holidays.
11. A team of 'validators' (leprosy trained Medical Officer of NLEP / PHC / NGO) will confirm the diagnosis of all suspects identified and listed as per the list within 15 days from the date of detection, till then, no case should be registered and started on MDT.
12. After confirming the diagnosis, the Validators to fill a **Patient Information Card** *(see Annexure 12 in page 24& 25)* for each new leprosy patient and refer them to the respective UHP / PHC *(in case of reaction / deformity / skin smear examination refer to LRC)* for registration and treatment with MDT.
13. The DLO will consolidate the population coverage and the details of all new leprosy cases detected in the selected UHPs / PHCs along with Patient Information Card and submit a detailed report of the EVD along with the statement of accounts to the SLO.
14. The data collected from EVD will be compiled and analysed by the SLO in coordination with EME Unit of ALERT-INDIA and prepare a final report along with the recommendations for submission to the Central Leprosy Division (CLD), New Delhi for future course of action.

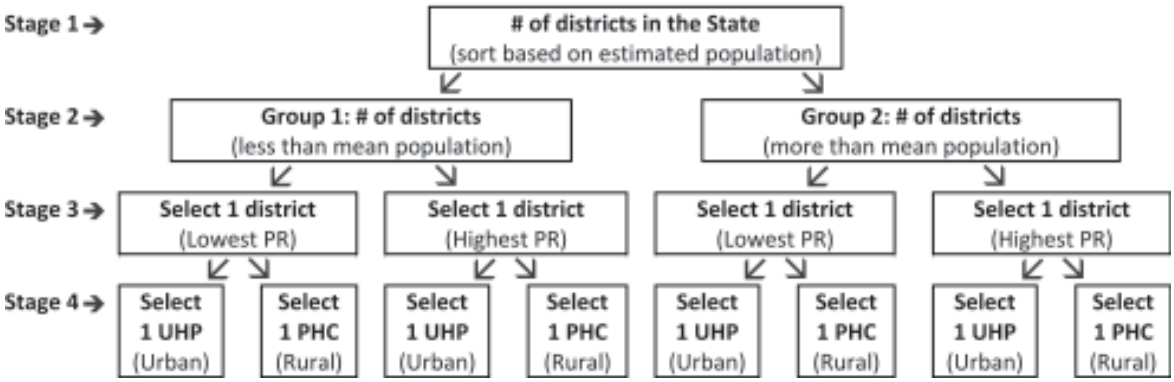
III. Operational plan

(a) Sampling design for EVD

For the purpose of operational effeciency, EVDs can be limited to a manageable size of population and unit in selected geographical area. A representative number of UHPs or PHCs are to be selected as a 'sample' unit based on the population and the prevalence of leprosy. The following steps can be used to determine the sample units (4 UHPs + 4 PHCs) and sample size (2 lakhs population) for EVD in selected districts and states.

Step 1: Prepare a list of all districts with estimated population, details of new leprosy cases registered for MDT during the past 3 years and the key epidemiological indicators of the districts. Sort the list of districts based on estimated population and calculate 'Mean' (or 'Median', when frequency distribution is skewed) population.

(i) Method for selecting 'sample' units:



Step 2: Out of all districts, list 2 groups - **1** consists of districts with less than mean population and **2** consists of all districts with more than mean population.

Step 3: From these 2 groups of districts, select two districts one with lowest PR and another with highest PR as reported by NLEP at the end of year (31st March).

Step 4: Prepare a list of UHPs and PHCs with the number of MB among new leprosy cases registered during the previous one year (1st April to 31st March) period and select 1 UHP and 1 PHC each in these 4 districts. On the whole, a total of 8 (4 UHPs + 4 PHCs) sample units to be selected as per the suggested criteria from 4 districts in the state.

(ii) Criteria for selection of UHP (urban) : The UHP should have slum population in a defined cluster (slum areas or pockets under Municipal Corporation or Council) with approximately 50,000 to 1,00,000 population. In case, if the selected UHP have less than 50,000 population, select one or more adjacent UHPs in the same district so as to reach minimum 25,000 slum population.

(iii) Criteria for selection of PHC (rural): The PHC should have rural / tribal population in a defined cluster (villages and padas) with 30,000 to 50,000 population. In case, if the selected PHC have less than 30,000 population, select areas from adjacent PHCs so as to reach minimum 25,000 rural population.

(iv) Method for selecting 'population':

- 25,000 population (Approximately 5,000 households) in each of the UHP or PHC area to be surveyed assuming that the average size of each household is five.
- Every households to be selected and all people residing should be enumerated by trained enumerators (such as local community Volunteers).
- People living in places such as housing colonies of High & Middle Income Groups, schools, shops, offices and commercial establishments are to be excluded from enumeration.

(b) Sensitization Workshop on EVD

(i) Participants from NLEP Units:

- Medical Officers
- NMS
- NMA / LT / PMW

(ii) Topics for Sensitization Workshop:

- Introduction & Purpose of EVD with Q & A session
- Methodology of EVD & role of NLEP staff with Q & A session
- TOT (Training of Enumerators for enumeration)
- Logistics, norms for personnel / coverage / budget / information system, etc.
- Preparing draft proposal and Action Plan by the NLEP Units – group session
- Presentation of draft Action Plan & Concluding remarks

(iii) Proposal for EVD in the selected UHP / PHC

- The DLO of the respective district to prepare and submit a proposal in the standard format ***(see Annexure 1 in page 27)*** along with the requisition for release of funds (1st Installment) to SLO for undertaking EVD.
- Upon receiving the EVD proposal, SLO to give approval and also provide all the required stationery and release the advance payment (1st Installment) to the respective DLO of the selected districts.

(c) Enumeration of population

(i) Selection of Enumerators

- NMA / LT / PMW of the NLEP unit to select 'Enumerators' among any of the following from the respective areas under the UHP or PHC for enumerating the population during EVD.
    1. Community Volunteers (CVs) residing in the slum / village selected for EVD
    2. Community Health Volunteers (CHVs) from the UHP selected for EVD
    3. Multipurpose Workers (MPWs) from the PHC selected for EVD
    4. ASHA / USHA from the PHC / UHP selected for EVD
    5. Field workers of health or development NGOs / CBOs
- **Approximately,** 20 – 25 Enumerators to be selected and trained for enumerating maximum 25,000 population in the selected areas based on their knowledge and understanding on the survey methods and the geographical locations of area.
- In consideration of possible dropouts, select more number of Enumerators for the training with equal number of male and female enumerators.
- The NMA / LT / PMW of the NLEP unit to prepare a list of Enumerators selected from the respective area for the EVD along with micro action plan containing details of area and population for enumeration and submit to the NMS of NLEP unit.

Use EVD Form No. 1 (Annexure - 2)

(ii) Training of Enumerators

- NMS / LT of the respective NLEP unit to organize one-day training at the UHP or at the PHC for all 25 Enumerators in one session.
- **Suggested topics for the training:** Leprosy Orientation (signs & symptoms, treatment, misconceptions, etc.); purpose & methodology of EVD, role of Enumerators, procedures of enumeration, records to be kept (demonstration) etc.

(iii) Incentive to Enumerators

- Fixed incentive to be paid to all the Enumerators at the end of training on the same day and obtain receipt of payment.

- The LT / NMS prepare a list of Enumerators trained along with the details of payment attested by the Medical Officer with his signature for submission.

Use EVD Form No. 2 (Annexure - 3)

(iv) Preparing action plan for enumeration of population

- The LT / NMS in concurrence with Medical Officer of the NLEP unit will prepare an Action plan on the estimated population in the selected area to be enumerated by trained Enumerators.
- The action plan to give details of Enumerators to be engaged, tentative dates of enumeration, target families, staff engaged for supervision etc.

Use EVD Form No. 3 (Annexure - 4)

(v) Enumeration of population

- Population living in the households from the slum areas / pockets under the selected UHPs and population from the villages / padas under the selected PHC areas are to be enumerated for EVD.
- 20 Enumerators to be engaged for enumeration of 25,000 population - 1 Enumerator for 1000 - 1500 population or 200 - 250 households to be covered (5 days in urban and 10 days in rural areas.
- Each Enumerator to enumerate 50 households per day (minimum 250 population) in urban areas and 25 households per day (minimum 125 population) in rural areas and fill up Family survey form.

Use EVD Form No. 4 (Annexure - 5)

- Exclude all locked houses, schools, offices and business establishments like shops / hotels from enumeration. Every house enumerated to be marked identification numbers to avoid duplication.
- The LT / NMS of the NLEP unit to perform random supervision and provide guidance during enumeration activity and verify the forms.
- Stop enumeration on reaching the target of 25,000 population under selected UHP / PHC.
- The EVD teams to carry out IPC activities during the supervision of Enumeration activities and also distribute available IEC materials on leprosy.
- The NMS of the concerned NLEP unit to make the payment to the Enumerators for the number of days engaged for enumeration.

Use EVD Form No. 2 (Annexure - 2)

- The NMS of the concerned NLEP unit to compile the enumeration data, verify the details and submit a report to the DLO in the prescribed form.

Use EVD Form No. 5 (Annexure - 6)

(d) Examination of population

(i) Preparing Action plan for examination

- NMS of the NLEP unit to prepare micro action plan for examination of population in the selected area in three rounds by trained leprosy workers / health workers of the concerned UHP / PHC in concurrence with the MO of the PHC.
- The micro action plan for Examination to contain details of leprosy workers to be engaged, date and time for examination, areas to be covered, number of families targeted, plan for supervision etc.

Use EVD Form No. 6 (Annexure - 7)

(ii) Examination of enumerated population

- Pairs of male and female - trained leprosy workers to examine all enumerated population in the area as per Action plan.

Use EVD Form No. 7 (Annexure - 8)

- In case if the required number of trained leprosy workers are not available to make teams, the staff from NGOs or MPWs (PHC) / CHVs (UHP) can be engaged for this purpose. However, every team must have minimum one trained leprosy worker from the same or from the nearest NLEP unit in the district.
- The EVD team can be accompanied by respective Enumerators ONLY for the first round who have enumerated the population in the area. ***Do not engage Enumerators in Round 2 & 3.***

Examination of enumerated population to be done in 3 rounds as per the following method:

Round 1

- Each EVD team to examine minimum 200 individuals (approx. 50 households) in urban areas and 100 individuals (approx. 25 households) in rural areas, out of those already enumerated by the Enumerators in ONE working day between 9 am to 2 pm (Minimum 5 hours).
- The EVD team to ensure the examination of maximum skin surface (face, hands and feet) and common peripheral nerves (Ulnar & Lateral Popliteal nerves).
- ***It is expected to achieve coverage of 60 - 65%, at least, of the enumerated population in the first round by the EVD teams.***

Round 2

- After completion of first round, the EVD team to conduct 1st absentee survey (households members who were not available for examination during the first round) in the reverse direction during all working days between 7 am to 9 am (early morning) and 5 pm to 7 pm (late evening).
- The EVD teams to visit minimum 50 households in urban areas and 25 households in rural areas and examine those were not covered during the first round for examination. Continue visiting the households till the target is completed.
- ***It is expected to achieve coverage of 10 - 15 % of the enumerated population missed in the first round by the EVD teams.***

Round 3

- After completion of second round, the team to conduct 2nd absentee survey (households members who were not available for examination during the second round) in the reverse direction during weekly or public holiday in the morning (7 am – 11 am) and during afternoon (2 pm – 5 pm) in the same area in order to achieve maximum examination of the left over population
- ***It is expected to achieve coverage of 5 - 10 % of the enumerated population missed in the first and second rounds by the EVD teams. The Round 3 should be completed in one day.***

The examination of population may take 2 to 3 weeks by three rounds of survey depending on geographical terrain (urban and rural) and the number of EVD teams engaged.

(iii) Identifying Leprosy Suspects

- The respective EVD teams to make provisional diagnosis of all the suspects identified / reported during the population examination.
- Take utmost care to eliminate obviously non-leprosy cases and do record all the old (cured) leprosy cases after verifying

detail history and past treatment / records.

- Each EVD team to prepare a list of suspected cases along with the Family Survey Form and submit to respective NMS on daily basis.

Use EVD Form No. 8 (Annexure - 9)

(iv) Diagnosis of Leprosy Suspects

- At the end of 3 rounds, the respective NMS to consolidate all the list of suspected cases (EVD Form No. 9) from the leprosy workers and prepare a plan for validation by the Medical Officer (MO) for the confirmation of diagnosis.
- MO of NLEP unit to thoroughly examine all the suspect cases and confirm the diagnosis. In case of doubtful clinical lesion, recommend for skin smear examination to confirm the diagnosis from the nearest health facility or Leprosy Referral Centre.
- **Registration of new leprosy case for MDT to be done only after the new case is examined and confirmed by the designated Medical Officer (Validator).**
- *If the new leprosy case has complications like acute reaction or neuritis or disabilities at diagnosis, refer immediately to the designated Leprosy Referral Centre for appropriate management.*
- MO of NLEP unit to fill the Patient Information Card ***(Annexure - 12)*** for all the new leprosy cases detected and confirmed through EVD.
- MO of NLEP unit to prepare a list of new leprosy cases confirmed and then refers them to the MO of concerned UHP / PHC along with a referral note.

Use EVD Form No. 9 (Annexure - 10)

- The concern Medical Officer of UHP / PHC to ensure the regular MDT for the patient and the same must be followed-up by the respective LT / NMS.

(v) Data analysis and reporting

- MO of the NLEP unit to collect all the records related to EVD from the Enumerators / Leprosy workers / NMS, duly verify and submit the same to the concerned DLO.
- DLO to prepare a report on EVD and submit the same to SLO along with the requisition for balance funds (2nd installment) towards the expenses for EVD.
- The concerned DLO of the district to arrange procurement of Stationery (Family Survey forms & Records) pays Honorarium / travel and incidental expenses to the MO / NMS / LTs (with a list of NLEP staff) engaged for EVD and obtain receipt.

Use EVD Form No. 10 (Annexure - 11)

- The concerned SLO to review and analyze the report submitted by the DLO on EVD along with the requisition for balance funds (2nd installment) and arrange release of funds, consolidate and prepare a final EVD report for submission to Central Leprosy Division along with the recommendations.

The entire EVD is to be completed within 15 working days in urban areas and within 30 working days in rural areas as per the sampling design proposed.

Acknowledgement

We wish to thank Prof. P. Ramachandran, Consultant & Former Head, Department of Health Research, Tata Institute of Social Sciences, Mumbai for his valuable guidance.

Estimated cost for undertaking EVD

S. No.	Description	Total cost of one EVD	
		Urban	Rural
1	**Incentive to Enumerators**		
1.1	Incentive for one day training: *Urban & Rural : Rs.50 x 25 persons*	1,250	1,250
1.2	Incentive for Enumeration: *Urban: Rs.75 x 20 persons x 5 days* *Rural: Rs.75 x 20 persons x 10 days*	7,500	15,000
1.3	Incentive for Examination: *Urban: Rs.75 x 20 persons x 5 days* *Rural: Rs.75 x 20 persons x 10 days*	7,500	15,000
2	**Honorarium to NLEP staff**		
2.1	PMW for Examination: *Urban: Rs.100 x 10 days x 12 PMW* *Rural: Rs.100 x 20 days x 12 PMW*	12,000	24,000
2.2	NMS for Supervision: *Urban: Rs.150 x 10 days x 2 NMS* *Rural: Rs.150 x 20 days x 2 NMS*	3,000	6,000
2.3	MO for Validation: *Urban: Rs.200 x 10 days x 2 MO* *Rural: Rs.200 x 20 days x 2 MO*	4,000	8,000
3	**Travel expenses for EVD team**		
3.1	PMW for examination: *Urban: Rs.40 x 12 PMW x 15 days* *Rural: Rs.60 x 12 PMW x 30 days*	7,200	21,600
3.2	NMS for Supervision: *Urban: Rs.40 x 2 NMS x 15 days* *Rural: Rs.60 x 2 NMS x 30 days*	1,200	3,600
3.3	MO for Validation: *Urban: Rs.40 x 2 MOs x 15 days* *Rural: Rs.60 x 2 MOs x 30 days*	1,200	3,600
4	**Administrative expenses**		
4.1	Training / Workshop	3,250	4,750
4.2	Stationery	1,000	1,000
4.3	Incidental expenses	900	1,200
	Total cost per EVD	**50,000**	**1,05,000**

EPIDEMIOLOGICAL VALIDATION DRIVE (EVD) - A TOOL TO ASSESS THE LEPROSY STATUS IN SLUMS OF GREATER MUMBAI*

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Summary

*At the request of the Mumbai District Leprosy Elimination Committee represented by all the NLEP units working in Mumbai city, ALERT-INDIA proposed an **'Epidemiological Validation Drive'** (EVD) in 2007. Under EVD, a sample population survey was carried out in 8 out of 169 Urban Health Posts (UHPs) in Mumbai.*

The objectives of the EVD were a) to identify all people who have signs of leprosy remain undetected in the community and b) to collect basic demographic, socio-economic and clinical information on the new leprosy cases detected. 154,200 (76.6%) out of the 201,302 enumerated population were examined by trained leprosy workers. 79 new leprosy cases among the suspects identified during EVD were diagnosed by Leprologists.

The proportion of MB cases was only 14%, which was much lower, however the proportion of child cases and disabled cases were 24% and 5% respectively was slightly higher than the rates reported by NLEP. The NCDR was 5.18 per 10,000 population, which was 4 times higher than the NCDR reported by the NLEP. This study was pertinent to gather adequate evidence to validate the epidemiological trend of leprosy in Mumbai and to propose actions for disease surveillance under NLEP.

Introduction

Mumbai has a population of more than 13 million people (Population: 134,49,147) and about 60% of them live in slums and squatter areas. Officially, the 'intermediate' goal of leprosy elimination (prevalence of < 1 case per 10,000 population), has been achieved in Mumbai by the end of March 2005. However, the trend of reduction in the incidence of leprosy during 2003 to 2005 in Mumbai suggests that several other operational factors have contributed to this unprecedented decline.

The main operational reason for such rapid decline is the stopping of all active new case detection activities and relying only on the self reporting of new cases or referrals by the vertical leprosy agencies to the GHC centres. A changing trend in the profile of new cases has been observed following the total discontinuation of active case finding activities as a policy by NLEP after 'integration' in urban areas of Mumbai.[1] This study indicates delayed detection that has contributed to an increase in number of MB cases (34%) and Grade 2 deformity cases (8%).

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Although the studies have predicted that the trend of decline in incidence of leprosy per year may range between 2 to 12 %, it was observed that the rate of decline in NCDR was 53 % during 2005 as compared to 25 % during 2004 in Mumbai.[2] Therefore, in order to ascertain the present leprosy situation in the Mumbai city, the Mumbai District Leprosy Committee represented by the Municipal Corporation of Greater Mumbai (MCGM) proposed to review the 'leprosy elimination' that was claimed to have been achieved. ALERT-INDIA volunteered to undertake the process of validation by a multi-centric study called 'Epidemiological Validation Drive' (EVD) as a measure to review the leprosy status in Mumbai city with the active involvement of all NLEP units.

Materials and methods

In the course of EVD, a total population survey was undertaken by 4 NLEP units in 8 out of 169 Urban Health Posts (UHPs) randomly selected in Mumbai during January to July 2007 (Duration: 7 months). In all, 697,483 population from 8 UHP areas were targeted, which was approximately 5.2 % of the entire population of Mumbai.

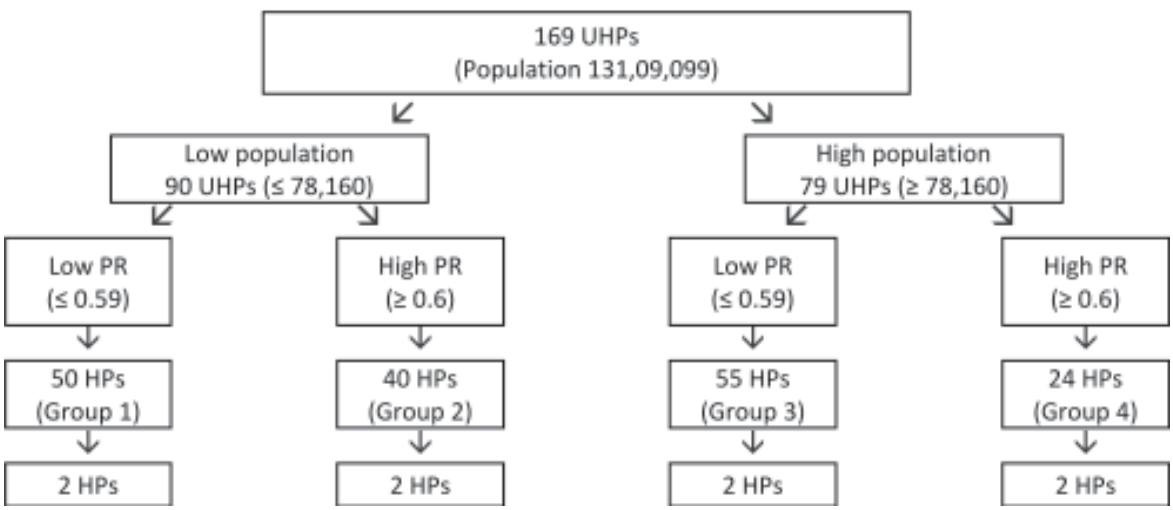
Sampling technique

In order to choose a sample that will represent a good cross section of the entire population of Mumbai, a randomization sampling method was used taking the UHP as a sample unit. Based on the mean population (78,160), all the 169 UHPs were classified into two distinct groups of UHPs with less than and more than mean population. Based on mean PR (0.6 / 10,000), these two groups of UHPs were further stratified into two sub-groups of UHPs having less than 0.59 and more than 0.6 per 10,000 population. From these four groups of UHPs, 2 from each of the 4 groups of UHPs (8 UHPs) were selected through "luck of the draw" method (Refer Chart - 1).

Operational aspects

A sensitization Workshop for 31 leprosy personnel of 11 NLEP units on the standard guidelines was conducted before starting the EVD. Subsequently, 93 leprosy personnel from all the 11 NLEP units were given training on

Chart 1: Selection of HPs for Sample Survey



the methodology of EVD. Following the training, the NLEP staff from the respective UHPs identified and trained Community Volunteers (CVs) for enumeration of the population.

The trained CVs enumerated approximately 25,000 slum population in each UHP areas under the supervision of NLEP personnel. Population living in places such as housing colonies of high and middle income groups, schools, shops and establishments were excluded. In all, 14 EVD teams, each consists of male and female leprosy worker, examined the available population enumerated and performed complete physical examination of maximum body surface and peripheral nerves. After completion of the first round, the EVD teams conducted two absentee surveys during the weekly holidays and even at the odd times, when more number of people are likely to be available for examination in order to achieve maximum coverage.

Validation of new leprosy cases

The teams made provisional diagnosis of the leprosy suspects identified during the survey and referred them to the nearest health centres for the confirmation of diagnosis and validation by experienced medical doctors or leprologists. All the known and cured leprosy cases identified during the EVD in the surveyed communities were excluded from the study.

After the validation of all the new leprosy cases were referred and registered for MDT at the respective UHPs. The entire EVD was coordinated and monitored by the LST of ALERT-INDIA. All the data on EVD was collected and analyzed by the Epidemiological Monitoring Unit of ALERT-INDIA on regular basis.

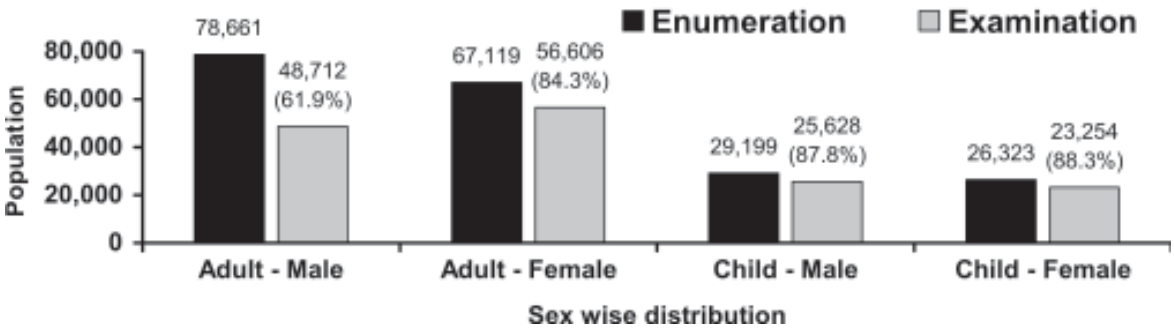
Results

2,01,302 (29 %) slum population from 40,789 household out of 6,97,483 estimated population in 8 UHPs were enumerated by trained CVs. 154,200 (76.6%) out of the 201,302 enumerated population were examined by the EVD teams in three rounds (Table – 1). The proportion of population examined ranged from 70 % to 82 % with one exception of one UHP (96.9 % at Kidwai Nagar), which was attributed to large number of self employed adult population available for examination during survey.

Table 1: Examination of slum population selected for EVD

Name of UHP	1	2	3	4	5	6	7	8	TOTAL
	Colaba	Soutter Street	Kidwai Nagar	Vakola	Dindoshi	Rajawadi	S Phule Nagar	PJK Home	
Total population (Estd.)	111,483	148,300	49,113	80,848	94,276	63,812	83,493	66,158	**697,483**
Slum population (Estd.)	72,463	96,395	31,923	52,551	61,279	41,477	54,270	43,002	**453,360 (65%)**
Population enumerated	24,610	25,775	25,385	25,210	25,158	25,090	25,006	25,068	**201,302 (29 %)**
Population examined	17,320	21,153	24,599	18,018	18,934	18,322	18,115	17,739	**154,200**
%	70.4	82.1	96.9	71.5	75.3	73.0	72.4	70.8	**76.6**

Chart 2: Population examined - sex wise distribution



The sex ratio among the enumerated population was 1000 male: 866 female and the distribution were almost similar in all the UHPs. Despite three rounds of surveys, only 61.9% male adult population could be examined, while the coverage among female adults and children were 84.3% and 86.8% respectively (Chart 2). The average examination of the population was 76.6%, except 2 UHPs (Kidwai Nagar & Soutter street), which are exceptionally higher than the average.

During the EVD, 79 new leprosy cases have been detected and validated by the Leprologists. The NCDR was 5.18 per 10,000 population, however the range of NCDR was between 0.41 to 14.9 per 10000 population in all the 8 UHPs. Incidentally, the UHP (Kidwai Nagar) with maximum population examined (96.9%) had least NCDR. The proportion of MB and child cases among new leprosy cases was 16.4% and 22.8% respectively, while the reported MB and child rate was 51% and 14% respectively during the corresponding period in Mumbai city. Disability rate among new cases was 5% whereas NLEP reported 3% in Mumbai city during the corresponding period. No specific association in sex distribution among the new cases detected was observed.

Discussion

It is stated that the trends of case detection reflect trends of incidence on condition that there has been no important change of detection activities and there is no evidence that once a predefined level of prevalence rate is reached, leprosy will necessarily die out.[3] Therefore, the finding of the EVD is not the reflection of the trend of incidence, but it is an exercise for disease surveillance to ascertain the NCDR for a specific period in a defined geographical location with identical socio-economic population group.

Different methods have been proposed by several researchers to validate the incidence of leprosy, but often estimates have proved to be very different from the ground reality. WHO recommended that special monitoring exercises may be carried out periodically to validate case-detection as part of routine supervision or by independent teams on a sampling basis.[4]

In the absence of any rapid diagnostic test available for mass programme, one would really wonder how this can be accomplished by any means other than a sample survey in different geographical areas where new cases continue to occur.[5] Daniel et al also emphasized the need for periodical sample

Table 2: Outcome of EVD

Name of UHP	1	2	3	4	5	6	7	8	TOTAL
	Colaba	Soutter Street	Kidwai Nagar	Vakola	Dindoshi	Rajawadi	S Phule Nagar	PJK Home	
Population examined	17,320	21,153	24,599	18,018	18,934	18,322	18,115	17,739	**154,200**
New cases detected	4	2	1	10	20	26	5	11	**79**
MB cases	1	0	0	2	5	2	1	2	**13 (16.4%)**
PB cases	3	2	1	8	15	24	4	9	**66 (83.6%)**
Child cases (> 14 yrs)	1	1	0	3	5	4	3	1	**18 (22.8%)**
Disabled cases (Gr. II)	0	0	0	0	2	0	0	2	**4 (5%)**
NCDR / 10,000 population	2.31	0.95	0.41	7.08	10.56	14.19	2.76	6.20	**5.18**

surveys to get actual status and prepare estimates through continuous monitoring of trends in different parts of the country.[6]

Assessing the magnitude of the leprosy burden in a metropolitan city like Mumbai is an important, but challenging issue, for the purpose of consolidating the achievements made so far. This multi-centric study facilitated active participation of all stakeholders jointly implementing EVD using a standard methodology. The NCDR of 8 UHPs (5.18 per 10,000 population) confirmed by this study was 4 times higher than the NCDR (1.3 per 10,000 population) reported by the NLEP during the corresponding period in Mumbai. The result of EVD corroborates with the epidemiological findings of leprosy situation in 5 slum areas of Agra city, which showed a prevalence rate of 14.5 per 10,000 following house-to-house survey conducted in 2003, while the reported prevalence was less than 0.5 per 10,000 population.[7] It was pointed out that there is a wide gap between the estimated prevalence of leprosy obtained by active case detection and projected prevalence obtained by passive case reporting underscores the efficiency of the staff involved and also the need for active case detection in leprosy in order to find the actual burden of disease.[8] The wide variation in NCDR (0.41 / 10,000 in Kidwai Nagar to 14.19 / 10,000 in Rajawadi) as seen during EVD indicate the possibility of high and low endemic pockets still exists in Mumbai city. This study also establishes the fact that the leprosy endemicity is not uniform in all geographical regions, particularly in specific slum pockets in urban areas like Mumbai.

Kumar et al established that the findings of active surveys suggests, not only many hidden cases are detected, but also large number of one to few single skin lesion (early PB) leprosy cases got detected, hence the MB ratio decreases.[9] A decrease in the number of MB cases and an increase in the number of child cases as observed in this study indicates the delay in new case detection and the existence of active transmission in the local community.

These emphasize the fact that such exercise helps to detect new cases at an early stage, besides detecting 'hidden' cases in the community.

Further, the decline in numbers of new leprosy cases cannot be considered as the disease is 'fading away'. The recent 'mathematical modelling' of leprosy indicators suggested that leprosy is slowly declining and will not disappear.[10] There is lack of scientific evidence to claim that leprosy is at its fading phase, however it is not established by epidemiological studies. Moreover, the reported incidence of leprosy by the NLEP does not reflect the true epidemiological picture that is crucial to predict the possibility of breaking the chain of transmission spontaneously.

A comparison of NCDR based on the estimated population in the 8 UHPs (January to July 2007) revealed higher rates than the NCDR reported by NLEP during the previous 7 months (June to December 2006) in 6 out of 8 UHPs. Similarly, a substantial increase in the PR was observed in 7 out of 8 UHPs at the end of EVD (July 2007) as compared to the PR before EVD (December 2006). This showed that the leprosy statistics reported by NLEP in Mumbai is far from the reality considering all the operational factors.

Conclusion:

This study clearly proved the fact that people with early signs of leprosy can be detected thus reducing the disease morbidity. Many child cases were detected during the EVD, thus indicating continuing widespread transmission in the slums of Mumbai. Consequently, significant numbers of persons affected by leprosy with visible deformities were detected for the first time. Involvement of community volunteers in EVD has paved a way for sustaining the leprosy awareness in the local community.

The study also indicates that in comparable urban situation it should be possible to identify similar number of new leprosy cases that are epidemiologically significant in reducing the leprosy burden. This EVD also facilitated, for the first time ever, to assess the leprosy situation and bring together all stakeholders for control of leprosy in Mumbai.

Chart 3: Comparison of NCDR - EVD with NLEP

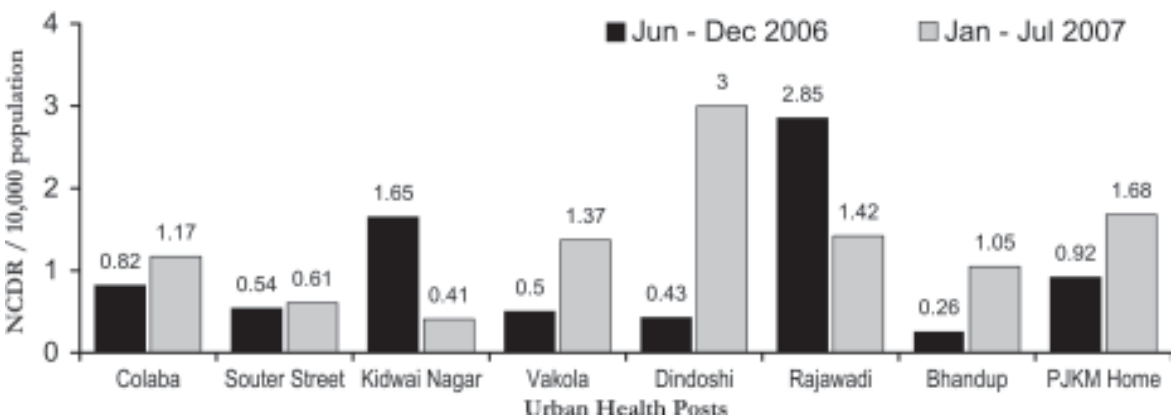
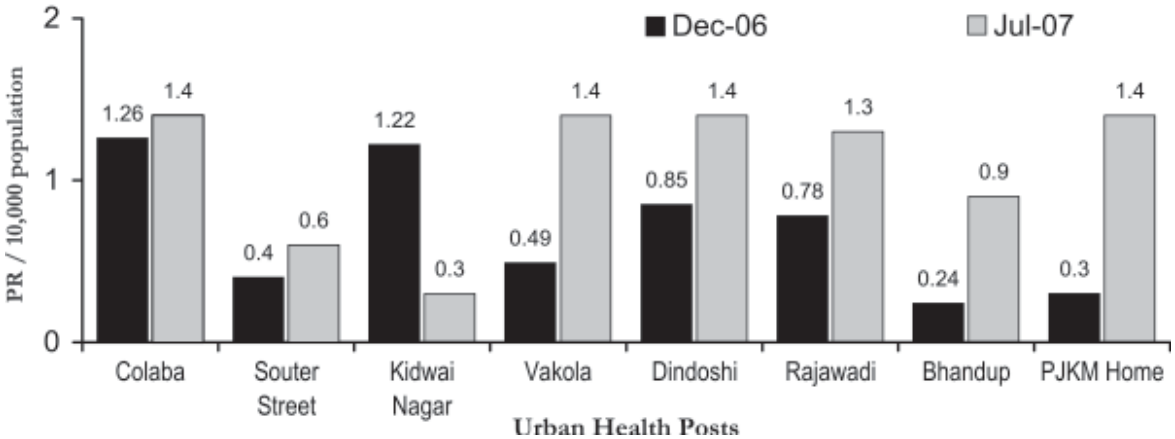


Chart 4: Comparison of PR - EVD with NLEP



We propose that such EVDs undertaken periodically by NLEP as a strategy for epidemiological surveillance and monitoring of leprosy control programme. This will help to assess the true leprosy burden and to focus on early new case detection during the integration phase and eventually arrive at a reliable, evidence based identification of geographical locations, specific blocks in the districts that continue to be the breeding ground for new leprosy cases, which need to be tackled by vigorous efforts and sustained long-term quality care.

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Effect of Epidemiological Validation Drive (EVD) in early new leprosy case detection in Mumbai – a descriptive analysis of 79 new leprosy cases*

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Background:

As a policy, the Govt. of India has integrated the basic leprosy services with the general health care (GHC) system in 2002. Despite this proposal, the 'functional' integration took place in Mumbai city only in April 2004. Since then all the active case finding activities were stopped and the NLEP staff of NGOs, Government and Municipal Corporation have been asked to carry out various IEC activities as well as maintain liaison with the Health Post staff in their respective areas. Following integration, the 'intermediate' goal of leprosy elimination, < 1 case per 10,000 population, has been achieved in Mumbai, by the end of March 2005. However, the rate of decline in NCDR and PR are quite steep during the year 2005 at 64 % and 62.5 % respectively, compared to 28.6 % and 20 % during the year 2004.

Granting operational and administrative short comings, one finds it extremely difficult to agree with the policy makers that the decline in epidemiological trend of the disease has fallen to the aspired limit in prescribed time span at all levels to meet the intermediate goal set for leprosy elimination[1]. Hence, an in depth understanding of the epidemiology of the disease in order to identify the outcomes of new case detection based on the epidemiological indicators is necessary. Statistical methods to assess the prevalence and incidence rates, especially for very unevenly distributed events, are less robust. It is clear that data collected by control programmes are mainly target oriented and provide limited information on the epidemiological pattern of the disease[2]. For these reasons, random sample population surveys are conducted only in special situations and in limited places, mainly to make reasonably reliable estimates. Moreover, the demographic and clinical features of all the new leprosy cases detected need to be analyzed for making valid assumptions on the disease epidemiology and setting priorities for leprosy control.

Towards this, ALERT-INDIA proposed 'sample survey' as a strategy for epidemiological surveillance of leprosy control[3]. In 2007, ALERT-INDIA carried out an 'Epidemiological Validation Drive' to assess the leprosy situation in Mumbai city involving all stakeholders. This exercise has resulted in detecting 79 new leprosy cases from

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*** Presented at National Workshop "Strategies for new case detection during integration phase", Mumbai, 11.10.2007**

8 out of 169 Urban Health Post areas randomly selected.

Introduction:

While the goal to eliminate leprosy by the end of 2005 set out by WHO is admirable, mere good intentions are not sufficient. The epidemiological trend of new leprosy case detection in India after 2005 points out the failure of Information Education and Communication (IEC) campaigns to detect new cases 'early' and does not identify specific measures to revive the leprosy control programme at the grass roots level. The NLEP merely states that awareness level of general public regarding leprosy has improved and has made budgetary allocation during the XI Plan Period (2007-08 to 2011-12). Therefore the necessity of effective method to detect leprosy at an early stage during the integration phase in order to reduce the levels of disease morbidity has been stressed.

While the epidemiological validation in selected situations is desirable, it must be fully integrated with the surveillance system of monitoring the current leprosy control programme. This study aims to analyze the key issues such as clinical features at diagnosis, influence of age and sex on type of leprosy, correlation with occupation and economic status and knowledge about disease and treatment with source of information.

Materials and methods:

A descriptive study was instituted to assess the epidemiological and clinical profile of 79 new leprosy cases detected through EVD in Mumbai during January to July 2007. Patient interview technique was adopted using a pre-tested structured questionnaire. The data was analyzed using SPSS software (Version 13).

Results:

The data were grouped into 3 components: a) socio-demographic status; b) clinical profile of the disease and c) knowledge about leprosy and its source.

a) Socio-demographic characteristics:

Age and sex distribution:

Of the 79 leprosy patients studied, the mean age (±SD) was 29.4 years. Amongst them, 46 (58.2%) patients were in the age group of 11 to 30 years (Chart 1) and 18 (22.8%) patients belong to child age group (< 14 years). 39 (50%) patients were female (Chart 2).

Chart 1: Age distribution

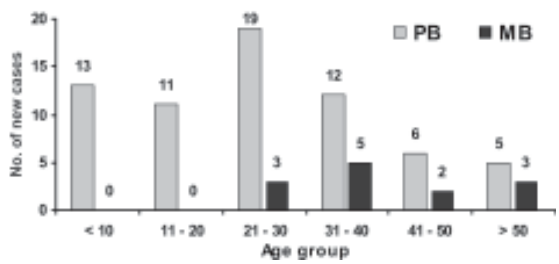
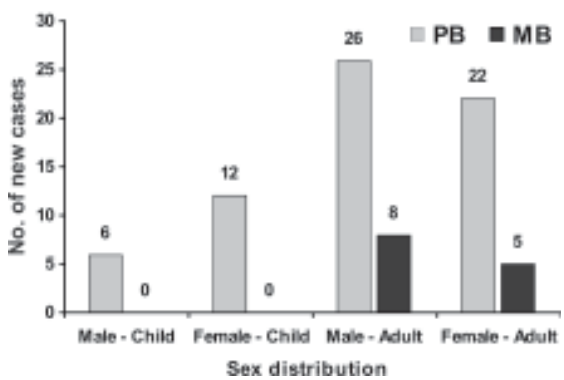


Chart 2: Sex wise distribution



Education and economic status:

Regarding education status, 37 (46.8%) patients have completed secondary level school education, but 11 (14%) patients did not have any formal education (Chart 3). While 27 (48%) out of 56 patients were engaged in regular service (job) and the remaining 23 patients were students (Chart 4). 73 (92%) patients had family income of less than Rs.5,000 per month and 3 (23%) out of 13 MB patients had more than Rs.5,000 per month (Chart 5).

Chart 3: Education status

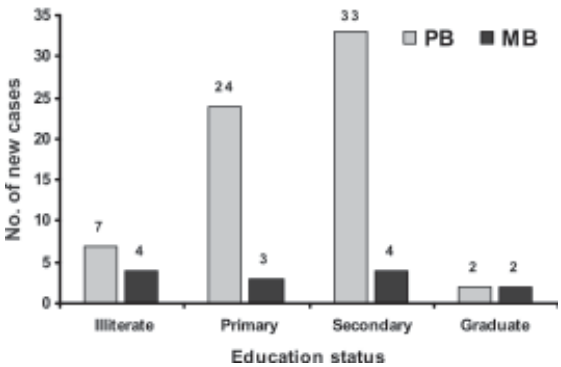
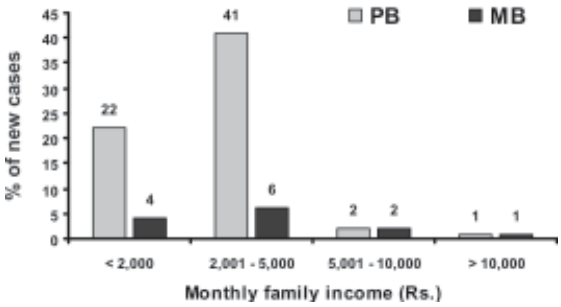


Chart 4: Occupation status

Chart 5: Monthly family income



Origin and duration of stay:

It was revealed that 44 (55.7%) patients originated from Maharashtra state, whereas 21 (60%) out of 35 patients who originated from outside Maharashtra state belong to Uttar Pradesh state (Chart 6). 65 (82%) patients have lived in Mumbai for more than 6 years from the date of detection, which includes all the 13 MB patients (Chart 7).

Chart 6: State of origin

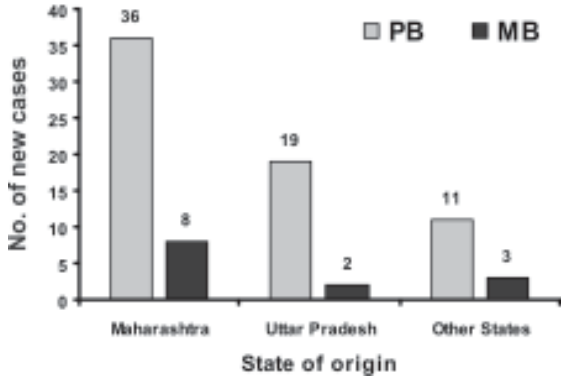
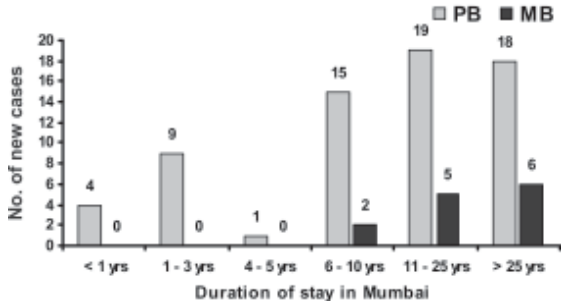


Chart 7: Duration of stay in Mumbai



b) Clinical profile of the disease:

Clinical features & onset of disease:

Out of 79 patients interviewed 13 (16.4%) were MB and 48 (60.8%) patients were borderline tuberculoid (BT) type of leprosy (Chart 8). 74 (93.6%) patients had skin patches and the rest either had infiltration or had non-visible anaesthetic (NVA) patch on the skin surface. 45 (68%) out of 66 PB patients had single skin

lesion (SSL) at the time of diagnosis. 2 (15.3%) out of 13 MB patients have shown skin smear positive.

It was observed that 14 (17.7%) and 29 (36.7%) patients had skin lesions on the face and upper extremities respectively. 16 (20%) patients had shown one or more trunk nerve involvement with definite sensory loss on the distribution of nerve, of which 4 (5%) patients had Gr. II disability (WHO, 1998). 5 (6.3%) patients had history of contact with a known leprosy patients in the family.

Although, 43 (54.4%) patients had duration of disease less than 12 months from the date of detection (Chart 9), 28 (35.4%) patients had the signs and symptoms for more than 1 year.

Chart 8: Type of leprosy (IAL classification)

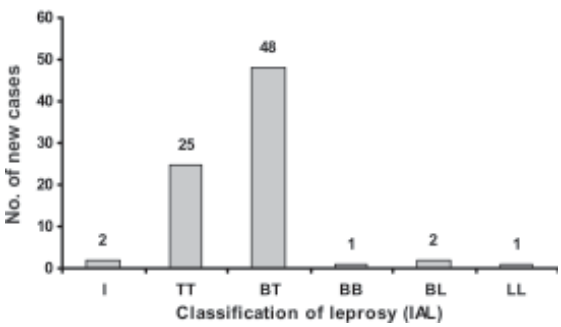
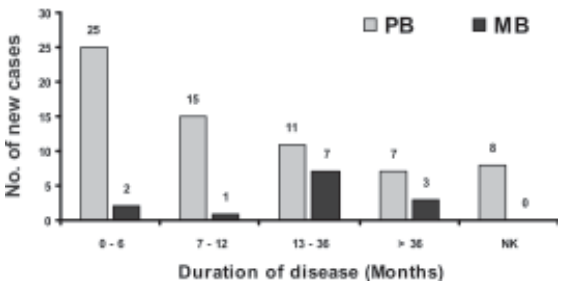


Chart 9: Duration of disease



c) Knowledge about leprosy:

Perception about cause, spread & curability of leprosy:

Though 8 (18.6%) patients know that the leprosy is caused by a bacterium, 18 (42%) patients said that the 'curse and the past sin' is the cause of leprosy (Chart 10). 19 (44%) out of 43 patients responded still of the opinion that the 'beggars' with leprosy spread the disease in the community and only 13 (30%) patients knows that the leprosy germ spread through 'air' (Chart 11).

25 (58%) out of 43 patients said that the leprosy is completely 'curable', however 17 (39.5%) patients were not sure that leprosy is curable (Chart 12). Surprisingly, 35 (81%) out of 43 patients know that 'skin patches' are one of the

Chart 10: Cause of leprosy

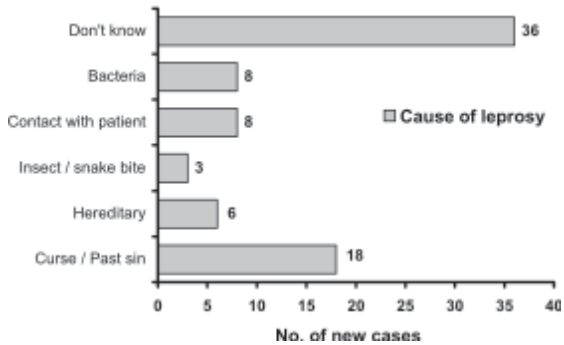
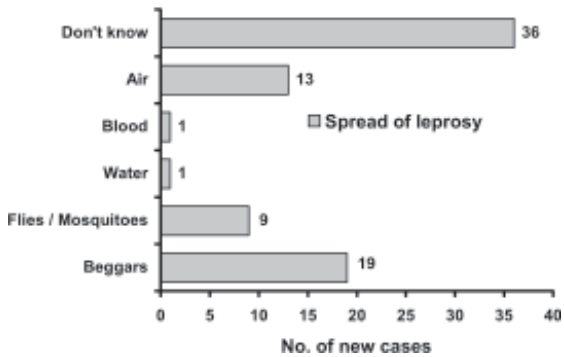


Chart 11: Spread of leprosy



sign of leprosy (Chart 13). In all, 31 (72%) out of 43 patients believe that the disappearance of the clinical signs completely is the definition for 'cure' of leprosy (Chart 14).

Chart 12: Curability of leprosy

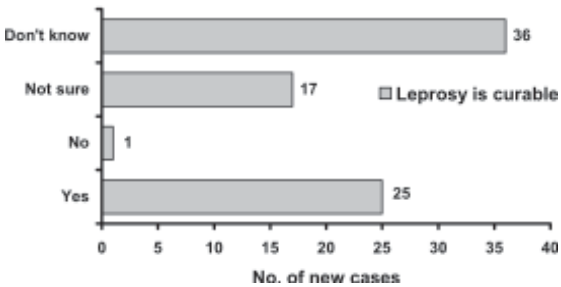


Chart 13: Signs of leprosy

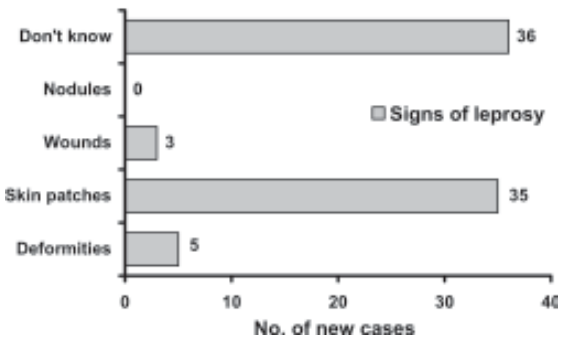
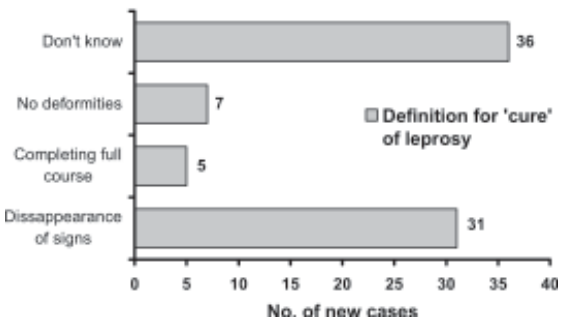


Chart 14: Definition for cure of leprosy



Utilization and visibility of leprosy services:

An overwhelming 41 (91%) out of 45 patients informed that the diagnosis and treatment (MDT) is available at the Govt. or Municipal hospitals (Chart 15). 38 (62%) out of 61 patients receive information about leprosy through the 'health worker' and 20 (32.7%) patients have obtained information through visual and print media (Chart 16). Overall, 36 (45.5%) out of 79 patients either did not respond or did not choose any of the choice to most

Chart 15: Availability of diagnosis and treatment

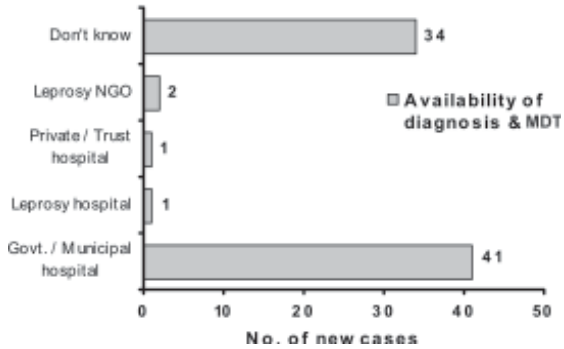
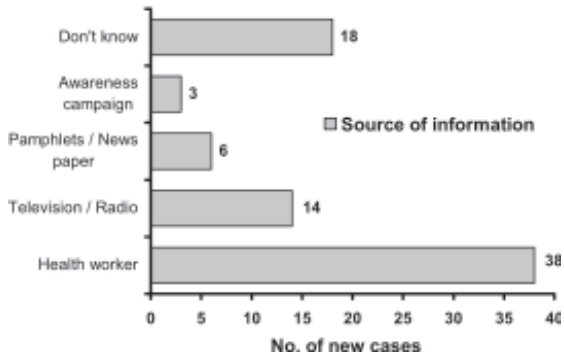


Chart 16: Source of information about leprosy



Discussion:

In the context of current epidemiological background, it is clear that the leprosy trends are changing rapidly that might contribute to increase in disease morbidity. The most generally observed risk factors were age, duration of the disease, sex, type of leprosy, occupation and treatment with MDT. Studies show that the risk for developing new disability is higher for males and for multibacillary (MB) leprosy patients and the risk increases with age and duration of the disease.

Association between age, sex and type of leprosy:

The age specific analysis shows that 65% of the PB patients were less than 30 years of age and 77% of the MB patients were more than 30 years of age. This indicates that leprosy affects more adults belong to the productive age group and likely to develop consequences, if not detected early. These findings were consistent with the study where majority (62%) of the PB patients had onset of the disease during 10 - 29 years of age, while most (50%) of the MB patients acquired the disease in the 20 - 39 years of age[4]. While no significant difference was observed among the male and female ratio, 22.8% patients were child cases (less than 14 years of age) and 66.6% of them were female.

High proportion of child patients (23%) coupled with lower mean age (< 30 years) among all patients (58%) interviewed reflect active transmission of infection in the slum community. In a study conducted during 2005, 54% and 8.5% new patients detected through rapid survey had disease duration of less than 12 months and more than 48 months respectively. However it is not known as to what proportion of leprosy cases are reporting late or not reporting[5]. There was no significant association observed between the education and economic status with the type of leprosy.

Delayed new case detection:

The most challenging task is to ensure 'early' detection of new cases and 'timely' treatment with MDT during the integration phase. In this study, the mean (±SD) delay in detection was 15 months (1 year & 3 months), which is very significant from the epidemiological point of view. Miema et al opined that 'keeping detection delays short will be more difficult when leprosy incidence decreases, because both the general population and the health workers will become less experienced in recognizing symptoms of leprosy[6].

Interestingly, 35.4% patients had noticed the signs and symptoms for more than 1 year, yet did not report to the health system for diagnosis. Moreover the new leprosy cases without obvious skin lesions are often missed to get diagnosed at an early stage by the health system.

WHO expressed concern that the 'leprosy patients lose many years before starting treatment, often because the health services are not in a position to recognize leprosy or are not encouraged to do so'[7]. Shetty et al points out that the focus has now moved from early detection to timely detection, which is neither too early nor too late[8].

These factors emphasize the need for sustaining the new case detection activities more vigorously during the integration phase. It was argued that there is no justification to stop search for new case detection as the whole program of leprosy elimination is based on early detection and curing of new cases[9].

Clinical profile of new leprosy patients

It is apparent that the low proportion of MB cases (16.4%) as reported in this study is a direct result of active case detection activities. Fischer et al pointed out that a shorter delay in

detection would lead to a decrease in the percentage with MB leprosy, as more PB leprosy would be found before possible self-healing or progression from PB to MB leprosy and the age at detection would be lower[10].

On the contrary, several longitudinal studies indicate a significant rise in MB proportion among new cases reported during 2000 to 2005, especially after the cessation of active case finding activities following integration. Majority of the patients interviewed (92.41%) belongs to tuberculoid (TT) & borderline tuberculoid (BT) type of leprosy and only 4 patients had visible disabilities. Incidentally, 57% of the patients clinically presented with single skin lesion (SSL) at the time of detection, which indicates the specificity of case detection activity through EVD.

Knowledge about leprosy and services:

The lack of awareness about leprosy in the community also results in delayed reporting of new leprosy cases with advanced disease as the signs and symptoms are asymptomatic in early stages of leprosy. The fact that only 18.6% and 30% of the patients were aware of the real cause and spread of leprosy respectively, anticipating that the people with suspect signs of leprosy to report voluntarily to the health facility is uncertain.

The GOI intensified IEC activities using local and mass media approaches and spends almost over 30% of its entire annual budget[11]. Inversely, only 32.7 % of the patients studied have received the information about leprosy through mass media.

Majority of the patients (91%) are aware about the availability of MDT at the Govt. and Municipal hospitals and this is possibly as 62% of the patients have received the information about leprosy and its services through the local health worker. A study on the utilization of MDT services by leprosy patients in an urban area revealed that a large number of patients avail services from private practitioners or at a specialized centre, which is not included in the NLEP[12].

Conclusion:

The strategy for leprosy control in urban areas have several bottlenecks as it did not take into confidence the available health infrastructure and resources already existing in urban areas. The current indicators used for monitoring the leprosy control work defy simple solution to measure the epidemiological factors under the integrated programme.

Such focussed investigation reflects the true epidemiological and clinical picture of the new leprosy cases that would remain undetected in the community. Social stigmatization in relation to leprosy continues to be one of the obstacles to promote self-reporting of new leprosy patients.

Therefore, community awareness and participation in leprosy elimination activities needs to be further encouraged. Most of the new leprosy patients are likely to suffer from the sequel of nerve damage during MDT and would require long-term care with sustained interventions.

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Acknowledgement:

We wish to thank the entire team of ALERT-INDIA and other LEAP partners for their painstaking effort in data collection during this study. We also thank Mr. Suhas Pore for the data analysis and Mr. Rupesh Zad for the secretarial assistance in preparing this manuscript. We are grateful to the people affected by leprosy who participated in the interview for this study.

Global Leprosy statistics (2008) :

Efforts have obviously been made by WHO to be as complete and as transparent as possible, since a clear distinction is made between countries reporting no new patients, and those which did not report. In spite of the efforts made, it would, however, be quite dangerous to try and draw many firm conclusions from these data.

Reliability of the data is another potential problem. It starts with the correctness of the diagnosis. Who is in charge of diagnosing leprosy cases at local level? How is it organised? What training did the staff receive? Are they regularly supervised?

Are all the newly detected cases effectively recorded and reported, including single lesion cases? Is a mechanism in place to check recording and reporting? Concerning classification, on what criteria is it based? On the number of skin lesions only! On the number of skin lesions and the number of nerves involved?

Is there a policy of systematic examination of skin smears for new cases? Even the reliability or the reproducibility of the data concerning grade 2 disabilities (in principle 'visible deformities') is not straightforward. For what proportion of patients was the disability status assessed? What criteria were used? Was it correctly reported?

It is difficult, and even dangerous, to try and analyse trends without an in depth knowledge of all the operational factors that might have affected the situation in a country.

Etienne Declercq, Editorial, Leprosy global statistics:beware of traps, Lepr Rev (2009) 80, 350-352

Annexure 1 **EVD Proposal Format**

EVD: Proposal

Name of District:

Name of Unit Coordinator:

Name of UHP / PHC selected:

Population (Approx.): Target population (Approx.):

No. of areas / pockets:

	2006-07	2007-08	2008-09
Total New Cases detected:			
MB cases among new cases:			
Child cases among new cases:			
Gr.2 cases among new cases:			

No. of Enumerators to be trained: Date of training:

Enumeration: Start date: End date:

No. of LTs engaged for EVD: Male: Female:

No. of NMS for EVD: No. of MOs for EVD:

Examination (1st round): Start date End date:

Examination (2nd round) Start date End date:

Examination (3rd round) Start date End date:

Date: _____ Signature

_____
Name & Designation

Annexure 2

EVD Form No. 1

EVD: Selection of Enumerators

UHP / PHC:		Block / District:	

Sr. No	Name of Enumerators	Area / Village	Age	Sex	Education	contact No
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
11						
12						
13						
14						
15						
16						
17						
18						
19						
20						
21						
22						
23						
24						
25						

Date:		Name of LT / NMS:	

Annexure 3

EVD Form No. 2

EVD: Honorarium to Enumerators for Training / Enumeration

UHP / PHC:		Block / District:	

Sr. No	Name of Enumerators	Area / Village	Amount	Signature
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				
21				
22				
23				
24				
25				

Date:		Name of LT / NMS:		Signature of MO:

Annexure 4

EVD Form No. 3

EVD: Action Plan for Enumeration of Population

UHP / PHC:		Block / District:	

Sr. No	Name of slum / village	Estimated Population	Period of Enumeration		Name of Enumerator
			From	To	
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					
14					
15					
16					
17					
18					
19					
20					
Total population targeted for Enumeration					

Date:		Name of LT / NMS:	

Annexure 5

EVD Form No. 4

EVD: Family Survey Form for enumeration & examination of households

House no.	
Date	

Name of Head of the family: _____

Full Address: _____

Information of family members (Item 1 to 4 to be filled by Enumerators; Item 5 – 9 to be filled by NLEP staff)

Sr. No.	Name	Age	Sex	Examination of households*			Suspect case	
				1st Visit Dt:	2nd Visit Dt:	3rd Visit Dt:	Signs and Symptoms	Diagnosis
1	2	3	4	5	6	7	8	9
1								
2								
3								
4								
5								
6								
7								
8								
9								
10								

* Mark '✓' after the examination is done and mark 'X' if the examination is not done during every visit

Information of known Leprosy patients in the family (to be filled by Enumerators / NLEP staff)

Sr. No.	Name	Age	Type of leprosy	Ref. No.	Active	Cured	Deformity	Remarks
1								
2								
3								

Results of enumeration and examination of family members (to be filled by NLEP staff)

Summary	Family members enumerated					Family members examined					Suspects	
	MA	FA	MC	FC	Total	MA	FA	MC	FC	Total	No.	Diagnosed
First Visit	X	X	X	X	X							
Second Visit	X	X	X	X	X							
Third visit	X	X	X	X	X							
Total												

Age: Child: 0 – 14 years; Adult: > 14 years

Name of the LT / PMW: _____ Name of the NMS: _____

Annexure 6

EVD Form No. 5

EVD: Enumeration of population

UHP / PHC:		Block / District:	

Sr. No	Name of Enumerators	Name of slum / village	No. of house holds	Population Enumerated				
				MA	FA	MC	FC	Total
1								
2								
3								
4								
5								
6								
7								
8								
9								
10								
11								
12								
13								
14								
15								
16								
17								
18								
19								
20								
Total population enumerated								

Date:		Name of LT / NMS:		Signature of MO:

Annexure 7

EVD Form No. 6

EVD: Action Plan for Examination of population

UHP / PHC:		Block / District:	

Sr. No	Name of slum / village	Enumerated Population	Period of Examination		Name of Examiner
			From	To	
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					
14					
15					
16					
17					
18					
19					
20					
Total population targeted for Examination					

Date:		Name of LT / NMS:	

Annexure 8

EVD Form No. 7

EVD: Examination of population by NLEP staff

UHP / PHC:		Block / District:	

Sr. No	Name of slum / village	No. of house holds	Population Examination					No. of suspects	No. of old cases
			MA	FA	MC	FC	Total		
1									
2									
3									
4									
5									
6									
7									
8									
9									
10									
11									
12									
13									
14									
15									
16									
17									
18									
19									
20									
Total population examined by LT									

Date:		Name of LT / NMS:		Signature of MO:

Annexure 9

EVD Form No. 8

EVD: Suspect cases referred for confirmation by NLEP staff

UHP / PHC:		Block / District:	

Sr. No	Name of slum / village	Name of the suspect	Age	Sex	Description of clinical signs	Remarks
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
11						
12						
13						
14						
15						
16						
17						
18						
19						
20						

Date: Name of LT / NMS: Signature of MO:

Annexure 10

EVD Form No. 9

EVD: New leprosy cases confirmed by 'Validator'

UHP / PHC:		Block / District:	

Sr. No	Name of slum / village	Name of the new leprosy case	Age	Sex	Type of disease	Deformity (Y / N)	Remarks
1							
2							
3							
4							
5							
6							
7							
8							
9							
10							
11							
12							
13							
14							
15							
16							
17							
18							
19							
20							

Date:		Name of LT / NMS:		Signature of MO:

Annexure 11

EVD Form No. 10

EVD: Receipt of Honorarium to NLEP staff

UHP / PHC:		Block / District:	

Sr. No	Name of NLEP staff	Designation	Amount (Rs.)	Signature
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				

Date:		Name of ADHS (L):		Signature:

Annexure 12 LEAP: Epidemiological Validation Drive – Patient Information Card

Name of UHP / PHC	Name of Ward / Block	Name of District

Patient ID No: MDT / TRC No: EVD code:

A. Demographic information

Name of patient:

Sex: M F Age: Year of birth:

Residential address:

B. Socio-economic information (Use 9 mark)

Education status: Illiterate Primary Secondary Graduate Technical

Marital status: Single Married Unmarried Divorce Seperated

Type of occupation: Student Service Business Unemployed Retired

Family income (Rs.): Nil < 2,000 2001- 5000 5001 - 10,000 >10,000

C. History of disease (Use 9 mark)

First symptom noticed: Skin patch Shiny skin Weakness in hand / feet Tingling sensation Nerve pain

Symptom noticed by: Self Family member Friend Teacher Doctor

Duration of symptoms: < 6 months 6 – 12 months 13 – 24 months > 25 months

Previous treatment: NO YES If Yes, where? Duration

Mode of detection: Survey: Sample School Contact SSD Referral Voluntary

If 'referral', by whom? Diagnosed by:

Date of detection: Date of starting treatment (MDT):

Family contact: No Yes Name of CC Relation

D. Clinical description at diagnosis (Use 9 mark)

Type of leprosy: PB ☐ MB (-ve) ☐ MB (+ve) ☐ BI report: ☐

No. of skin lesions: Nil ☐ 1 ☐ 2 - 5 ☐ 6 - 10 ☐ > 10 ☐

No. of nerve lesions: Nil ☐ 1 ☐ 2 ☐ 3 - 6 ☐ > 6 ☐

Lepra reaction: No ☐ Yes ☐ If YES, type of reaction: Type 1 / Neuritis ☐ Type 2 (ENL) ☐

Nerve status: (E - Enlarged / T - Tender)

Ulnar		Median		Radial		Lateral Popliteal		Posterior Tibial		Facial	
Rt	Lt	Rt	Lt	Rt	Lt	Rt	Lt	Rt	Lt	Rt	Lt

Loss of sensation:

Muscle paralysis:

Disability / deformity: No ☐ Yes ☐ Grades: EHF score: ☐

Eyes		Hands		Feet	
Rt	Lt	Rt	Lt	Rt	Lt

Type of deformity:

Claw hand		Ape thumb		Wrist drop		Foot drop		Claw toes		Lagophthalmos	
Rt	Lt	Rt	Lt	Rt	Lt	Rt	Lt	Rt	Lt	Rt	Lt

E. Knowledge about leprosy (Ask the following questions to the patient and 9 the option)

1. Do you know what causes leprosy? No ☐ Yes ☐ If, yes, select option

God's curse ☐ Past sins ☐ Hereditory ☐ Snake bite ☐ Injury / Burn ☐ Germs ☐

2. Do you know how leprosy spread? No ☐ Yes ☐ If, yes, select option

Mosquitoes ☐ Beggars ☐ Sex / Blood ☐ Physical contact with patient ☐ Through air ☐

3. Do you know what are the signs & symptoms of leprosy? No ☐ Yes ☐ If, yes, select option

Deformities ☐ Wounds ☐ Nodules ☐ Loss of limb ☐ Joint pain ☐ Skin patches ☐

4. Did you received any information about leprosy? No ☐ Yes ☐ If, yes, select option

Health worker ☐ TV / Radio ☐ Newspaper ☐ Hoardings ☐ Pamphlets ☐ Exhibitions ☐

5. Do you know where diagnosis & treatment for leprosy is avilable? No ☐ Yes ☐ If, yes, select option

Leprosy hospital ☐ Govt. hospital ☐ Private hospital ☐ NGO centres ☐ Private Practitioner ☐

Need referral services No ☐ Yes ☐ If YES, referred to which LRC ☐

Name: _____ ***Designation:*** _____***: Date:*** _____

So they say . . . .

High degree of active transmission reported:

"Active case detection reveals that there are a large number of previously undetected leprosy cases in the study population. The high degree of active transmission of leprosy in the study population is indicated by the large number of children affected by leprosy. The high proportion of multibacillary cases and Grade 2 deformity cases are also pointers to the gravity of the situation. Thus a policy for active case detection, in selective areas demonstrating higher burden of child leprosy and Grade 2 deformity, would aid in the estimation of the real burden of leprosy".

VP Shetty, UH Thakar, E D'souza, SD Ghate, S Arora, RP Doshi, AV Wakade & DV Thakur. Detection of previously undetected leprosy cases in a defined rural and urban area of Maharashtra, Western India, Lepr Rev (2009), 80, 22–33

Continous monitoring of trends suggested:

"Since, vertical surveys and other means of case detections were discontinued, the new cases could now the detected only through voluntary reporting. The findings of the present study show to what extent the expectations were fulfilled. Studies done elsewhere have reported encouraging findings as well as poor response in case detection; however, there is a need to maintain referral chains / hospitals and periodical sample surveys to get actual status and prepare estimates through continuous monitoring of trends in different parts of the country".

S. Daniel, S. Arunthathi & PSSS Rao. Impact of integration on the profile of newly diagnosed leprosy patients attending a referral hospital in South India. Ind. J. Lepr (2009), 81, 69 - 74

New case detection is less than incidence:

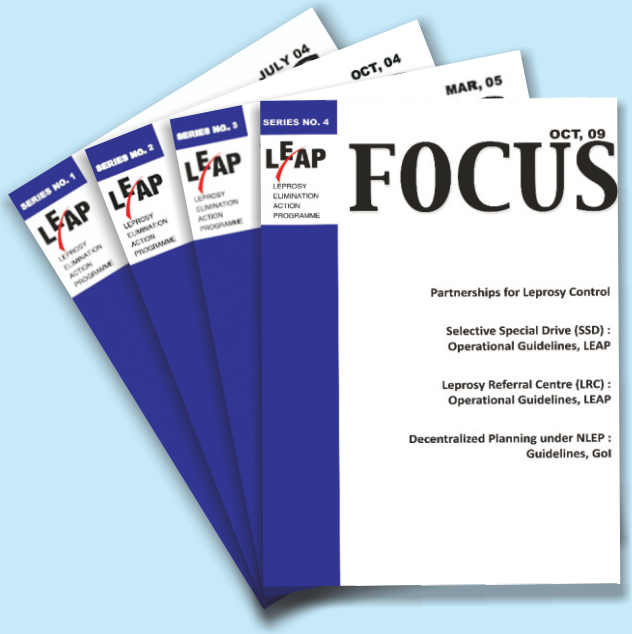
"It seems likely, however, that some new cases never come for diagnosis and treatment, so the number of cases detected is lower than the number of incident cases. The global incidence rate of leprosy seems to be declining slowly but the decline is faster in some areas than in others; in a few places the incidence rate seems to be rising."

WHO, Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities: Plan period 2006-2010

Rapid screening of population recommended:

"The objective of leprosy control is to reduce the burden due to leprosy. As to which indicator or group of indicators should be used for measuring the reduction depends on the influence of operational factors, ease of measurement and validity. Reliable and comparable information about the disease burden due to leprosy in populations, and how this is changing over time, is extremely critical to highlight leprosy among diverse priorities and interests and to decide on priorities within the leprosy control service. The leprosy control programme will have to rely on voluntary reporting or referral consequent to dissemination of information on leprosy disease and programme. Identification and examination on a voluntary basis of household contacts close to the time of diagnosis is done to ensure that there are not more probable cases as a result of the one already diagnosed. In special situations, a rapid screening of the population may be conducted to find any undetected new cases".

WHO, Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy, Plan Period: 2011-2015, SEA-GLP-2009.3



focus

'Focus' Series 1 (July, 04) focuses on leprosy elimination and leprosy integration with General Health Care (GHC) system.

Aims to share views, opinions, guidelines, data and experiences crucial for formulation and implementation of future strategies.

Fulfilling the above objective this document gives details of the "Raipur Declaration" from National Conference of Elimination of Leprosy, Raipur, 27th to 30th Jan '04 and the 'Line of Action' recommendations from New Delhi - National Workshop, 14th & 15th Oct '03.

The highlight of this series of 'Focus' is a list of Health Posts in Mumbai District with their population and leprosy status.

'Focus' Series 2 (Oct, 04) focuses on leprosy elimination strategies in the integration era.

It presents the basis and logical framework for the Leprosy Elimination Action Programme (LEAP) and sums up the perspectives in a historical context to guide actions in favour of the leprosy afflicted. It presents achievements of NLEP and outlines the major challenges for leprosy elimination; and suggests strategies needed for action. It includes a statistical overview of leprosy situation in India in the year 2004.

'Focus' Series 3 (Mar, 05) focuses on task based activities under the Leprosy Elimination Action Programme (LEAP).

LEAP is a strategy in direct response to leprosy patients' needs through community approach. Recommendations from WHO and NLEP are also outlined with inclusion of a special article titled "Leprosy: too complex a disease for a simple elimination paradigm" from WHO Bulletin for the readers.

'Focus' Series 4 (Oct, 09) focuses on SSD and LRC : Operational Guidelines.

It outlines the guidelines for strategic interventions of SSD and LRC under LEAP, to achieve the objectives of leprosy control during integration phase. It also includes a valuable NLEP guidelines on decentralised planning for monitoring the quality of interventions in leprosy control.

It is official now . . . .

Fresh Survey of Leprosy Affected Persons (LAPs)

The last survey of the LAPs in the country was conducted in the year 1981 in accordance of which 3919337 cases were reported having the prevalence rate of 57.6 per 10,000 population. As per information made available to the Committee, the incidence of leprosy has drastically declined to the level of elimination (one case per 10,000 population) but fresh cases are also reported in almost all States. As per figures submitted to the Committee, a total of 4,38,394 new cases have been reported during the last three years. The Ministry has clarified that new cases will continue for sometime which will gradually get reduced over the years because of long incubation period of the disease. It may take another twenty five to thirty years before Government could declare complete eradication of leprosy.

The Committee understands that the survey of leprosy has been stopped with the integration of MDT with general health services which is available free of cost in all Public Health Centres (PHCs). The age old social stigma associated with the disease poses major obstacle to self reporting and early treatment and thus persons in the initial stage of leprosy might not be coming to the PHC for treatment voluntarily. Since the number of fresh cases is increasing, the early detection of the disease is needed to check the physical deformities. Further, the Government should have official updated figures of the LAPs in the country to formulate any policy for their rehabilitation which calls for a fresh survey by the Government.

The Committee is of the view that the Panchayati Raj Institutions (PRIs) may be of great help in this venture. The Ministry in their latest written submissions have mentioned that they are considering to conduct one time multi-centric study to estimate the burden of leprosy cases i.e. active cases and leprosy cured persons with different grades of disabilities. This would help them in planning and strengthening of services to the LAPs. The Ministry agreed to involve the PRIs for such survey to gather authentic data information. The Committee appreciates the decision of the Ministry and urges upon it to start the survey without further loss of time.

Excerpts from Rajya Sabha Committee on petitions, 131st report on Petition praying for Integration and Empowerment of leprosy affected persons (C.S.II. – 131), Presented on 24th October, 2008, Rajya Sabha Secretariat, New Delhi, October, 2008