What could be anything ‘Rosy’ about Leprosy? For many centuries, humanity suffered from this dreaded disease leading to stigma, discrimination, suffering, disability, poverty, and eventually alienated individuals from society to die a slow death. However, on the parallel front many developments took place especially during the last century that created a favorable and sustainable environment in lowering the burden of leprosy and afflicted consequences across the world. With the successful introduction of multidrug treatment (MDT) in 1980s, World Health Organization (WHO) in 1991 gave a global call for eliminating leprosy as a major public health problem by the year 2000. People were skeptical as the progress was slow but well awaited. This was backed up by sound epidemiological knowledge and practices, apparent lack of extra-human disease reservoir, availability of free MDT, no evidence of drug resistance, simplified information system (SIS) through integrated health service approach, interagency coordination, and a high affirmation.

On earth, number of newly detected leprosy cases at the beginning of 2013 stood at 232,857 (4.00/10,000) with a prevalence of 0.33/10,000 population. The leprosy burden continues to be highest in south-east Asia region accounting for 71.47% of newly detected cases and 66.2% prevalence. Pockets of high endemicity still remain in Angola, Brazil, Central African Republic, India, Madagascar, Nepal, United Republic of Tanzania, Democratic Republic of Congo, and Mozambique. Figure 1 depicts new case detection rate per lac population, world, 2013. In India, reported new cases decreased from 169,709 (2005) to 134,752 (2012) with a prevalence rate (PR) crumbling down from 2.4 (2004) to 0.73/10,000 (2012).

Leprosy elimination means reduction of case transmission to a predetermined low level, i.e. PR of less than 1 case/10,000 population. However, new cases would continue to occur in small numbers as a result of disease making appearance in individuals who acquired their infection several years earlier due to the long incubation period of the disease. But due to increased coverage of MDT to previously uncovered areas together with improved community awareness, the number of new cases is expected to fall steadily. Our country officially declared itself free from leprosy as major public health problem in December 2005 (0.8/10,000) but barring some (18.64%) of 642 districts in the country where PR is still above one case/10,000 population, it continues to be so at national level. In 2013, the PR continues to between 2-4 in Chhattisgarh and Dadra & Nagar Haveli while the states of Bihar, Maharashtra and West Bengal which had achieved elimination earlier have shown slight increase in PR of more than one case/10,000 population. There are approximately 800 leprosy-designated self settled colonies in the country inhabited by old-treated cases and their ‘normal’ families.

National program authorities were convinced and engaged during their final phase of country elimination leading to well-structured sample-based intense monitoring, situational analysis, corrective interventions, learning, and capacity building of various stakeholders. In India, this exercise was carried out in administrative, technical, and financial collaboration with government of India, WHO (headquarter, regional, country-office), International Federation of Anti Leprosy Associations (ILEP), and National Institute of Health and Family Welfare (NIHFW), New Delhi through participation of academic/leprosy institutions, medical colleges (departments of Community Medicine/Preventive and Social Medicine and Dermatology), leprosy nongovernmental organizations (NGOs), including state and district authorities, annually, during 2002 to 2004. With the evolution of time, newer generation of medical officers/chief medical officers were being inducted in government machinery who may not necessarily have been administratively exposed to leprosy control activities. To fill this unmet need, another project activity during this period included capacity building of medical officers and chief medical officers in endemic states to strengthen their supervisory and management skills in leprosy control. Authors were involved with LEM (India) exercise at central level and intend to share their view and experience with public health fraternity.

The specific objectives of LEM was to assess:
1. NLEP activities on specified elimination indicators in various states of the country,
2. Progress of integration of leprosy control activities with the general health care system,
3. Quality of MDT services provided at field level,
4. Implementation of SIS,
5. Community awareness about leprosy, and
6. The validity of diagnosis among newly detected leprosy cases.

LEM survey was undertaken in 13 high priority states (Andhra Pradesh, Bihar, Chhattisgarh, Delhi, Jharkhand, Karnataka, Madhya Pradesh, Maharashtra, Orissa, Tamil Nadu, Uttar Pradesh, Uttaranchal, and West Bengal). In each state, districts were divided into two strata according to the existing PR of leprosy (≥ and <3.5/10,000) using sampling proportional to population size, and a sample of 20% of the total districts in each stratum per state was considered to be representative of the state. In each district, at least 3-5 health facilities in rural areas and one in urban area were randomly selected.

The field investigators for administrative purpose were labeled as LEM monitors and validators. Three days standardization training was undertaken for all the investigators at NIHFW, New Delhi, which included overview of National Leprosy Eradication Program (NLEP), clinical diagnosis and management, activities under disability limitation and rehabilitation, survey design, protocols, guidelines, training module, study instruments, recording and reporting (SIS) forms, and itinerary formalities along with logistic arrangement, maps, and contact details of officers (national/state/district). Each team was familiarized with method of data collection, interview, interpretation, recording, and subsequently taken to local health facilities in New Delhi for uniform hands-on training followed by role-play, presentation, discussion, and doubts clearance. Leprosy/dummy patients were mobilized from leprosy institution to NIHFW, New Delhi during training sessions. Each validator independently evaluated series of patients to pen their diagnosis of leprosy (multi/pauci bacillary) or non-leprosy before leaving for field survey.

During 2004 LEM, a total of 77 districts were covered and 518 health facilities were visited, including 418 (80.6%) in rural areas. LEM monitors interviewed 4,481 leprosy patients and 10,800 community members. They reviewed 37,460 patient’s records (MB and PB) and examined still larger number of MDT blister packs at the state, district, and health facility stores. Finally, validation teams traced, travelled and examined 1081 newly detected leprosy cases in districts enrolled during reference period. Each team before leaving the selected district shared their preliminary findings with district authorities. Salient observations noticed in the survey were:

- Prevalence and detection rates found in the LEM survey were close to those reported by states with few exceptions. However, operational factors like over/under stocking of drugs, wrong diagnosis, re-registration of cases, and gaps in regular cleaning/updating the leprosy registers were noticed suggestive of poor monitoring across all states. All the states reported a prevalence/detection ratio of less than one except...
Delhi and West Bengal, highlighting recycling of cases in these two states. The overall proportion of disability Grade-2 among new cases covered by LEM was 1.4%. It was lower than 2% in all states except Delhi (3.7%) and West Bengal (3.5%). Overall, proportion of MB among new cases was 38.3%, ranging from 19.2% in Andhra Pradesh to 56.8% in Madhya Pradesh. Females among new cases were 35% (17.5% in Delhi to 45% in Andhra Pradesh). The diagnosis of leprosy was being made and treatment initiated at 80% of the visited health facilities. In 47.1% of health facilities SIS guidelines were available, 94.6% had SIS patient cards, 94.9% had SIS treatment registers, 84.2% SIS MDT drug registers and in 98% facilities SIS MDT monthly report formats were available. However, compilation of health facility/block reports at the district headquarters was incomplete at majority of states due to delay in sending block reports on time to districts. The status of MDT stock, in patient-months, in various health facilities was 2.8 for MBA, 4.6 for MBC, 3.4 for PBA and 4.0 for PBC. On further analysis, only 16.7% of health facilities had 3 months MDT stock of all categories of blister packs, in relation to the number of registered cases. High proportion of damaged/expired drugs was found in Chhattisgarh, Maharashtra, Tamil Nadu, Uttaranchal and West Bengal.

The median distance to collect MDT was 2.0 km and median travel cost was Rs. 10/-. Accompanied MDT was provided as an option for patients who needed more than one month of treatment in 59.9% of health facilities. The overall cure rate after assessment of cohort analysis of the leprosy cases was 83.9% for MB and 93.4% for PB cases. The default rate was 6.5% for MB and 3.7% for PB cases. The MB default rate was high in West Bengal (29.9%), Delhi (27.8%) and Uttaranchal (10.9%). For purpose of monitoring, only 33.8% of health facilities were found calculating at least three NLEP indicators. Out of the 1081 newly detected leprosy cases examined by validators, the proportion of cases which were wrongly diagnosed was 9.4% (11.1% for PB, and 8.0% for MB cases). The proportion of re-registered cases was 18.7% (8.8% for PB, and 25.5% for MB cases). The proportion of wrong grouping was 12.8% (6.6% for PB cases, and 17.8% for MB cases). Approximately 5.0% of leprosy cases were non-existent. Nearly 60.0% of interviewed community members were aware of at least one sign/symptom of leprosy; the disease is curable and the treatment is available free of cost, but only 12.0% could mention the correct cause of leprosy (germs/microbiological agent), whereas rest ascribed it to curse of god, low immorality, hereditary, or did not know.

Field reports were centrally collated, analyzed, and the findings shared with all stakeholders including medical colleges through national and state reports.

This complimentary massive public health monitoring exercise was well planned, executed, appreciated, and accepted by all. Further, this intense periodical short-term movement also led to infusion of catalytic motivation, sharing of experiences, and reinforced commitment of health workers from interior areas when they were visited by national and international experts, which further led to overall strengthening of supervisory environment in the states. In the history of public health achievements, LEM exercise would be considered as a remarkable developmental milestone in the journey towards leprosy elimination.

Because the disease is unevenly distributed, hence the importance of case finding and education surveys cannot be ignored in our country. There may not be any cost-effective analysis of such similar activities available, but block level leprosy awareness campaign (BLAC), special area project for elimination of leprosy (SAPEL), leprosy elimination campaign (LEC), and modified LEC (MLEC) have a special reference in context of leprosy elimination. With decline in prevalence of leprosy, there is a definite risk of low capacity to diagnose leprosy in field conditions coupled with poor societal governance, in-adequate system surveillance, complacency, under-reporting, decreased funding, and eventually leading to a fear of resurgence. This fear is not unfound as there are sporadic reports suggestive of under-diagnosis/misdiagnosis of new leprosy cases. (3,4) In addition, issues of sustenance and role diversification have been intense for dedicated leprosy institutes/NGOs/workforce.

With the approval of 12th five year (2012-17) plan, NLEP has infused spirits and renewed its commitment and emphasis on elimination of leprosy from high endemic areas in the country through improved domestic program funding; access to services through special area activity; involvement of women including leprosy affected persons in case detection; organization of skin camps for detecting leprosy patients while providing services for other skin conditions; capacity building including provision of contractual staff (public health consultant, surveillance medical officer, DPMR/Training consultant, district leprosy consultant, physiotherapist, para-medical worker etc); undertaking contact survey to identify the source in the neighborhood of each child or MB case in conjunction with sustained awareness generation activities. Priority area would be identified districts with Annual New Case Detection Rate of more than 10/100,000 population through active search of cases and validation of MB and child cases in a campaign mode. NLEP activities had integrated with general health care system in all the states by 2002-04 and currently services are being provided under unified National Rural Health Mission. However, a district nucleus team consisting of dedicated medical
officer, nonmedical supervisor, and a physiotherapist has been proposed, who are expected to visit respective PHCs and assess NLEP activities on regular basis. Training of newly inducted medical officers is planned in a phase manner. Modified SET scheme for NGO involvement is operational through decentralized state based approach since 2006-07 and a proposal to introduce new NGO Scheme is under consideration. An incentive of Rs. 8,000/ will be paid to all persons affected by leprosy undergoing major re-constructive surgery (RCS) irrespective of their financial status at the designated RCS centers, who are also given funds @ 5000/- per surgery for aids/appliance/drugs/dressings/ancillary etc. Funds are being released to national/regional leprosy institutions for their re-vitalization. National Sample Survey was carried in the year 2010 to assess leprosy burden, disability load and to ascertain IEC status. Drugs would be provided free of cost by WHO through Novartis upto 2020. To conclude, program has re-positioned itself to tackle ensuing challenges and making planned progression with a ‘hope’ of eliminating the disease from all the districts/blocks and probably, one day text-books of public health will be writing ‘obituary’ for leprosy as for small-pox.

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Central Leprosy Division, Directorate General of Health Services, Ministry of Health and Family Welfare, Nirman Bhawan, New Delhi.

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