Best Practice: *Universal Surveys with Geotagged Data for Precision and Cost-Effective Planning and Service Delivery—India*

Sub-category:

- Health Information

Target Audience(s)

- Policy leaders
- Program managers
- Health staff
- Persons affected by leprosy
- Scientists
- Donors
- Other partners such as NTD NGOs

Contributors

S Anand, American Leprosy Missions
S Munuswamy, Public Health Foundation of India

Key Messages

The reality of leprosy is that even in high endemic areas, people affected by leprosy live scattered in communities, their numbers small in relation to the general population. Universal surveys with clear visual representations of geotagged data on maps can influence policy and inform with precision cost-effective interventions by government/NGOs for people with leprosy and related NTDs, increasing efficiency and improving joint action by government departments and partners.

Key Informant / Date Submitted

Shyamala Anand, American Leprosy Missions, May 2019

Country / Location

India / Andhra Pradesh & Odisha

Description of the Best Practice

Introduction

The reality of leprosy and related NTDs is that even in high endemic areas, people affected live scattered in communities, their numbers small in relation to the general population, often overlooked by health systems and development processes like water, sanitation, and hygiene (WASH) that have significant bearing on leprosy and other NTDs. Even where services are available, they are usually inconsistent, not easily accessible, and largely ineffective to deliver any significant changes on the ground.

In April 2018, American Leprosy Missions (ALM) and LEPRA Society in India launched a unique collaborative proof-of-concept integrated WASH and NTD project, *Ending NTDs through Women-led WASH—Accelerating Impact in India through Women's Self-Help Groups* (SHGs), in 128 villages in NTD-endemic, WASH-poor districts in Andhra Pradesh and Odisha. The Indian Institute of Public Health-Hyderabad (IIPH-H), Public Health Foundation of India, came on board as a research partner. Project locations had been chosen on the basis of available secondary WASH and NTD data. We hypothesised that if we could geotag precise locations of people suffering from leprosy and other NTDs, we could design service delivery pathways and possibly home-based care for people with leprosy and lymphatic filariasis (LF) morbidity and disability.

Sourcing the geotags for precise location of people suffering from Leprosy/NTDs had several objectives:

1. To reach rural/remote people with NTDs
2. To develop skills to screen for leprosy/NTDs
3. To have devices (smartphones) to source geotags at point of need
4. To develop skills to use smartphones
5. To access analytical skills for location optimization and efficient precision routing
6. To develop skills for home-based Morbidity Management and Disability Prevention (MMDP) care by local healthcare providers

Four objectives were comprehensively achieved in the pilot phase and the remaining two will be achieved during scale- up. Objective 1 was achieved by recruiting women from SHGs in the villages. They were trained in conducting surveys in the local language from a well-designed, validated paper-based screening questionnaire to achieve Objective 2 (as shown in Figures 1A and 1B).

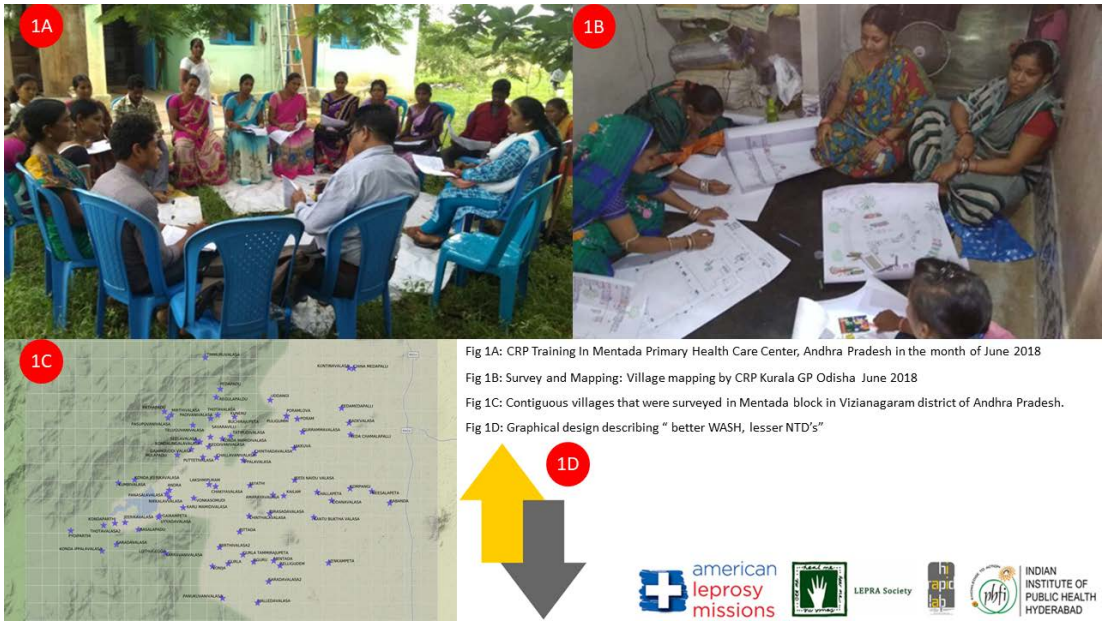

Fig 1A: CRP Training In Mentada Primary Health Care Center, Andhra Pradesh in the month of June 2018

Fig 1B: Survey and Mapping: Village mapping by CRP Kurala GP Odisha June 2018

Fig 1C: Contiguous villages that were surveyed in Mentada block in Vizianagaram district of Andhra Pradesh.

Fig 1D: Graphical design describing " better WASH, lesser NTD's"

To achieve Objectives 3 and 4, appropriate android smartphones that had been pre-loaded with photo-based geotagging software were provided to the women and they were trained adequately several times. Data collected were analysed by IIPH-H; location optimization and efficient routing models were arrived at, partly achieving Objective 5 (as shown in Figures 2A and 2B, see next page).

In the future, data collection will be digitized and analytics automated thereby enabling real-time analytics in the hands of the women. Further, home-based MMDP digital services are presently being designed and developed.

Objectives and Methodology

Goals

- To understand the actual prevalence of people with leprosy/NTDs along with precise and reliable location details
- To understand more precisely the ecosystem around people affected by leprosy/NTDs (e.g., socio demographics, WASH status, availability of NTD-specific healthcare, etc.)
- To explore, design, and develop (in the scale-up phase) a digital, local-population-led, globally linked platform with personalized home-based leprosy/NTD MMDP data linked to appropriate secondary resources

Methodology

A universal survey with geotagged photographs for high levels of reliability and precision was carried out to capture information on WASH and NTDs from all 21,319 households in 128 villages. Geotagged photographs of the front of all houses were taken, with due permission from survey participants, to improve process reliability and accuracy of input data. A massive exercise was undertaken by LEPRA Society and IIPH-H on training, piloting, and ensuring reliability of data collected.

The study design was based on **evidence** of existing healthcare and social services currently being delivered/piloted based on geocoordinates. The uniqueness of this study was to extend the concept to resource constrained, rural, remote settings. Another unique point is universal household evaluations, instead of sample-based evaluation, to document and understand the presence and ecosystem of every person in the areas suffering from leprosy/NTDs and their specific needs by photo-based geotagging.

Implementation of Practice

Step 1: The survey questionnaire was designed based on existing validated information/inputs from field personnel. Simultaneously, 90 local women from SHGs in 128 villages were recruited based on their aptitude and were trained on-site as Community Resource Persons (CRPs) on WASH and NTDs for their communities.

Step 2: CRPs were trained on conducting universal data collection with a paper-based questionnaire and on taking geotagged photographs with focus on WASH- and NTD-specific indices using smartphones.

Household surveys were conducted by CRPs in their own villages. Large villages had more than one CRP. A few (2-3) smaller villages were assigned to a single CRP.

Step 3: Survey data were transcribed and linked to geocoded household information. People requiring support for managing leprosy/NTDs were referred to appropriate government resources. Several health promotion activities were conducted focusing on reducing NTDs and improving WASH. A graphical image, as shown in Figure 1D, was also developed.

Step 4: Data were analysed for information on people with leprosy/NTDs and location optimization; efficient routing models were mapped (Figures 2A and 2B).

Conducting the survey and capturing 75,000 geotagged photographs took 6 months to complete. This includes data collection and entry. Supervision was conducted by three project field staff in each state. Decisions on universal survey over sampling were based on the aim of finding every person with leprosy/NTDs. Resource requirements were rationalized by engaging CRPs from the villages and by also surveying WASH indicators at the household level. Due to budget constraints, data collection was manual and 36 smartphones brought in from another LEPRA project were circulated among CRPs for geotagged photographs. This survey cost approximately USD 10,000.

Results—Outputs and Outcomes

For the purpose of illustrating this best practice, maps with leprosy data from a survey of 11,233 households in 78 villages in one state are shared.

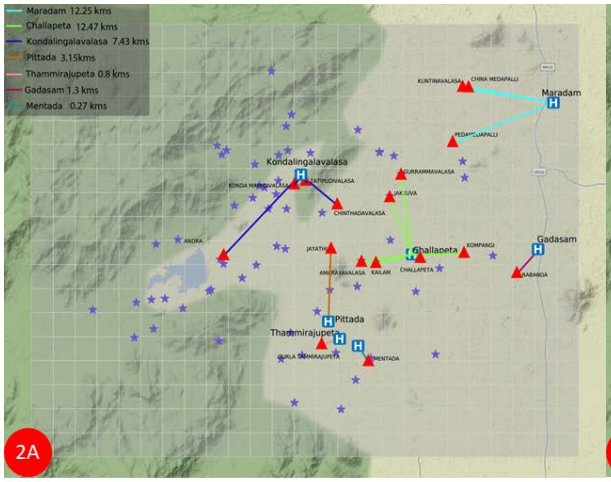

Fig 2A: The shortest distance connecting villages with people affected by leprosy to the nearest health facility is shown.

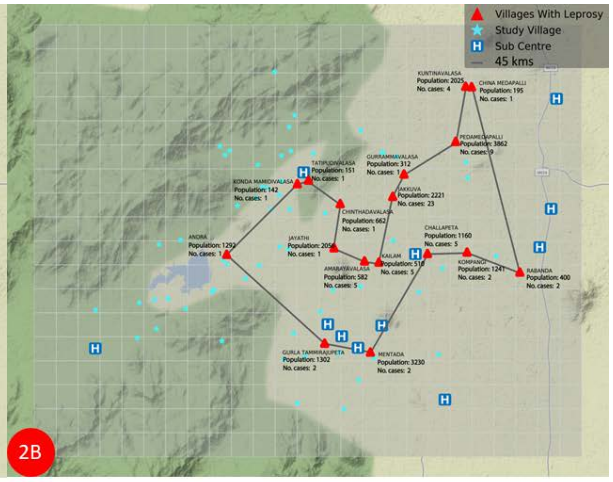

Fig 2B: The shortest euclidean distance connecting all villages with people affected by leprosy is shown.

- Maps show that 17 of the 78 villages in this high-endemic block have people affected by leprosy. Resources for services, campaigns, contact screening, and post-exposure prophylaxis (PEP) can now be targeted precisely.
- The shortest Euclidean distance connecting villages with people affected by leprosy to the nearest health care facility was arrived at, as shown in Figure 2A. The shortest Euclidean distance connecting all villages with people affected by leprosy was arrived at, as shown in Figure 2B.
- The maps show the location of sub-centres in relation to these villages (sub-centres are the most peripheral health units [PHC]; six sub-centres come under one PHC)

Leprosy and LF are chronic conditions requiring long term care and periodic assessment for complications. Treatment-seeking behaviour is usually poor among chronic cases and regular travel for care causes high out-of-pocket expenses. Home-based management by healthcare service providers addresses these biological, epidemiological, and socioeconomic challenges and is becoming increasingly possible with improved access and technologies.

Maps like the ones shown in Figures 2A and 2B provide government with excellent evidence and basis for optimum resource utilization at points of need.

Lessons Learned

What worked really well—what facilitated this?
Data collection by CRPs surveying their own villages.

What did not work—why did it not work?
Lack of digitization turned the survey into a massive exercise taking 6 months of project time.

Replicability and Scalability

Has the practice been implemented in more than one setting?
Yes. In Nepal, with ALM's partner in Lalgadh and IIPH-H.

What long term effects can be achieved if practice is sustained over time?

- Maps generated using granular data can significantly impact future research, funding, and implementation of development initiatives
- Overlay maps are a powerful visual platform to influence policy and practice
- Dynamic maps serve as monitoring and surveillance tools for national programmes and other key stakeholders in WASH and NTDs

What are the requirements to sustain the practice over time considering contextual factors, institutional support, human resources?

- Digitization
- Trained local people at the grassroots
- Government buy-in

Conclusions

How have the results benefited the population?

- House-to-house data collection enabled CRPs to reach every household and quickly understand WASH/NTD issues in their own villages
- The universal survey enabled CRPs to know which households to target their efforts
- Geo-tagged photographs have been useful to CRPs and project staff in generating evidence (albeit used with discretion) for lobbying with block level government functionaries for services

Why may that intervention be considered a "best practice"?

Geographic Information System (GIS) is becoming a vital tool in disease mapping, identifying prevalence patterns, enabling precise personalised intervention guidance and cost-effective delivery, and improving epidemic management, disaster response, program planning, etc. Several new GIS-based services are emerging in areas of local transportation, education, and home delivery using location-based precise services.

- Universal surveys with clear visual representations of geotagged data on maps can influence and inform policy with precision cost-effective interventions by government/NGOs, increasing efficiency and improving joint action by government departments and partners
- The availability of geo-tagged data of people requiring morbidity/disability care facilitates spatial optimization of routing for delivery of MMDP services
- Optimized routing improves the efficiency and effectiveness of any planned services
- Mapping can determine the best accessible locations for periodic facility-based specialized services like reconstructive surgery, podiatry, assistive devices, etc.

What recommendations can be made for those intending to adopt the documented "best practice" or how can it help people working on the same issue(s)?

- Universal surveys take time 1) to establish baselines and 2) to track change. This will involve having more trained local people on the ground.
- The survey has to be technology-based on a simple platform that will collect data and allow for screening, diagnosis, managing, information/education/communication (IEC) services, and self-care

Further Readings

1. Enwereji EE, Ahuizi ER, Iheanocho OC, Enwereji KO. Medical rehabilitation of leprosy patients discharged home in Abia and Ebonyi States of Nigeria. Oman Med J 2011;26(6):393-398.
2. Gómez L, Rivera A, Vidal Y, et al. Factors associated with the delay of diagnosis of leprosy in north-eastern Colombia: a quantitative analysis. Trop Med Int Health 2018;23(2):193-198.

3. Nicholls PG, Chhina N, Bro AK, Barkataki P, Kumar R, Withington SG, Smith WC. Factors contributing to delay in diagnosis and start of treatment of leprosy: analysis of help-seeking narratives in northern Bangladesh and in West Bengal, India. Lepr Rev 2005;76(1):35-47.
4. Ahlquist DA. Universal cancer screening: revolutionary, rational, and realizable. NPJ Precis Oncol 2018;2:23.
5. Delamater PL. Spatial accessibility in suboptimally configured health care systems: a modified two-step floating catchment area (M2SFCA) metric. Health Place 2013;24:30-43.
6. Gu W, Wang X, McGregor SE. Optimization of preventive health care facility locations. Int J Health Geogr 2010;9:17.
7. Henry M, GalAn N, Teasdale K, et al. Factors contributing to the delay in diagnosis and continued transmission of leprosy in Brazil—an explorative, quantitative, questionnaire based study. PLoS Negl Trop Dis 2016;10(3):e0004542.
8. Van Veen NH, Meima A, Richardus JH. The relationship between detection delay and impairment in leprosy control: a comparison of patient cohorts from Bangladesh and Ethiopia. Lepr Rev 2006;77(4):356-365.
9. Ashok A, Nandi A, Laxminarayan R. The benefits of a universal home-based neonatal care package in rural India: an extended cost-effectiveness analysis. In: Black RE, Laxminarayan R, Temmerman M, Walker N, eds., Reproductive, maternal, newborn, and child health: disease control priorities, 3rd edition, vol. 2. Washington (DC): The International Bank for Reconstruction and Development / The World Bank, 2016.
10. Howson CP, Cedergren B, Giugliani R, et al. Universal newborn screening: a roadmap for action. Mol Genet Metab 2018;124(3):177-183.