

Recording of Leprosy Cases in India: Need for a User-Friendly and Effective App

India, despite achieving the status of leprosy elimination at the national level in December 2005, accounted for 58% of new cases reported globally for 2019–2020, with 114,451 new cases being detected during this period.^[1] India has the highest leprosy burden in the world and is among the 22 “global priority countries” that contribute 95% of the total cases of leprosy worldwide.^[2] Children accounted for 6.86% of the total cases. The annual new case detection rate was 8.1 per 100,000 and the grade 2 deformity rate was 2.39%.^[3] Although 65,164 new cases were detected during 2020–2021, this number may not represent the true picture due to the limitations imposed by COVID lockdowns in the data capture.^[1]

Role of Online Applications in Health

The rapid integration of information and communication technology into medicine and health has been driven by the increasing availability and quality of medical software applications (apps). The Ministry of Health and Family Welfare (MoH and FW), Government of India, has undertaken various initiatives with the use of these technologies by developing apps for improving the efficiency and effectiveness of the public healthcare systems. They are considered useful not only for recording and reporting cases but also for effectively managing communicable as well as non-communicable diseases (NCD) in the community to support the Ayushman Bharat Comprehensive Primary Healthcare (CPHC) program.^[4]

Apps for notification of infectious diseases are meant for reporting their occurrence and help to detect outbreaks, whereas certain applications provide online tools for early suspicion and diagnosis of various diseases. The National Health Portal, Integrated Disease Surveillance Program portal, mDiabetes, Nikshay, TB detect, mSwasthya, India Fights Dengue, and CoWIN are some of the successful online services supported by apps, which have been helpful in measuring the disease burden, program planning, and evaluating the performance of health interventions.

Nikusth and the Rationale Behind its Launch

The sustained effort of the National Leprosy Eradication Program (NLEP), a centrally sponsored scheme under the umbrella of the National Health Mission (NHM), has been instrumental in bringing down the prevalence of leprosy in India below the global elimination target. However, new cases of leprosy continue to arise each year due to the continued transmission of the disease in the community. Several major issues regarding delay in

case detection, the hidden caseload in the community, low awareness regarding leprosy in the community, and lack of quality monitoring within the program have continued to persist and dent the long-term goals of the program. To strengthen the program with special emphasis on monitoring and feedback, Nikusth, an online reporting system, with a patient-tracking mechanism based on district health information software 2 (DHIS 2), developed by the Indian Council of Medical Research (ICMR) was launched by the Government of India as a new initiative in 2017–2018.^[3] DHIS 2 is an open-source health data analysis and management platform built with free and open-source Java frameworks, supported by the health information systems program (HISP).^[5] It can be used to monitor patient health, improve disease surveillance, map disease outbreaks, and speed up health data access for health facilities and government organizations and is used in more than 40 countries in Africa, Asia, and Latin America.

The main objective of introducing Nikusth was to enable comprehensive reporting of all detected leprosy cases. Additionally, the effective implementation of Nikusth would lead to better monitoring and patient tracking, creation of a national database of leprosy cases, early data analysis of various indicators of leprosy burden in the country, and prompt feedback. A total of 1,422 participants, including district-level representatives from 34 States/union territories (UTs) were trained for data entry into the Nikusth reporting system according to the release by the MoH and FW posted in December 2020.^[6]

Data flow in Nikusth application

The hard copies of patient information collected using the leprosy assessment forms at the PHC level by a medical officer are sent to the respective blocks where data consolidation of all PHCs is done. Data entry operators (DEOs) then enter this data into the Nikusth online system at the block level every fortnightly or monthly depending on their availability. Apart from the DEOs, currently, even the district leprosy officers (DLOs), district leprosy consultants (DLCs), and state leprosy officers (SLOs) have been entering the data in the application.^[7] Data aggregated at the block level are sent to the district level, which are then made available at the national level.

Nikusth provides an option to enter sizeable data of each leprosy patient and includes basic demographic details, signs, symptoms, disease classification (multi/paucibacillary), sensory assessment, disability status,

including the World Health Organization (WHO) disability grading and EHF (eye, hand and foot) score, lepra reaction and neuritis, treatment details and status including release from treatment (RFT), contact tracing, disability prevention and medical rehabilitation activities, and Information, education and communication (IEC) training.^[8] However, only one-time entry of data, that is, at the time of filling the leprosy assessment form, is being done in Nikusth at present and the patient is issued the NLEP patient card for further follow-up. Monthly and annual progress reports, along with other cumulative data, are made available on this platform. Thus, the Nikusth application serves as an online database for leprosy data in our country and serves as a major source to calculate various leprosy-related demographic indicators.

Nikusth vs. Nikshay

Nikshay, launched in 2012, is an integrated information and communication technology system for tuberculosis (TB) in India and works as a comprehensive, single-window platform to digitize technical operating guidelines and TB treatment workflows through various independent modules.^[9] It is a highly successful and superior working model and its comparison with Nikusth is listed in Table 1.

Challenges of Nikusth

Although Nikusth was started with an intention to strengthen the present reporting system of leprosy in our country, a few challenges have been identified, which limit the optimal utilization of the application. The initial data entry is paper-based (leprosy assessment forms), and this

form is further sent to the block levels for entry into the application. This process could potentially lead to a lag in data entry and an inherent risk of data loss due to the lack of digitalization at the first point of data generation.

The follow-up information of the patient is routinely captured on the cards issued to the patients in the program. There is, however, no process for entering the follow-up data in the application, which is a major drawback. Because of this, there are no data regarding the regularity of treatment, development of lepra reactions while on treatment, adverse drug events, and the final treatment outcome of the patient. Thus, the overall purpose of effective monitoring of the detected leprosy patients is not fully served.

In addition, the mapping and tracking of a case from detection until RFT, linking of a suspect to the case, and follow-up of contacts are not possible through this application. Similarly, tracking patients declared as RFT for the development of grade 2 disability is also not possible.

Overall, Nikusth serves well for the initial registering of patient information and fails to be of any help beyond that point to plan any intervention or monitor and evaluate the patient. Moreover, there is no provision for Nikusth to receive and capture data from treating physicians and hospitals in the private sector. This is an important deficiency, as a good number of leprosy patients are diagnosed and treated by physicians, neurologists, and dermatologists working in the private sector across India, outside the framework of NLEP. Without registration, these patients go unreported, leading to a mismatch in the actual and reported number of cases in the country.^[10] Finally, there

Table 1: Comparison of Nikusth and Nikshay applications

Nikshay	Nikusth
Easy to use a downloadable mobile application.	Online software service, which cannot be downloaded.
Application is available for use by public health institutions, private health facilities, private labs and private chemists.	Data entry into the application is done only by DEOs and is not available for use by physicians both in public and private health sector.
Patients registered in Nikshay can access their digital health record on TB, including diagnostic details, treatment progress, adherence, direct benefit transfer details, through TB Aarogya saathi portal.	Patients do not have any access to the Nikusth app.
Entire patient data from enrollment to tests done, treatment adherence and outcome, and adverse events can be updated in real-time in the app.	Only data filled in the leprosy assessment form at the first visit are entered. There is no capture follow-up data.
Referral of patients, information about treating facilities nearest to them, and management of comorbidities are facilitated easily through the app.	Not being used to provide referral services, no information on patient services, facilities for reconstructive surgery, or management of disabilities.
Contact tracing of patients, their chemoprophylaxis, and follow-up of contacts for the development of disease are diligently done using the app.	No provision to capture follow-up data about contacts and disease development.
Patients who self screen for symptoms of TB using TB screening tool are also enrolled into Nikshay, wherein a 3 stage follow up is done of these presumptive cases till conclusion is reached.	This app does not provide for enrollment of screened cases, and no facility of follow up for diagnosis of any presumptive cases.
Direct benefit transfer of monetary assistance provided to the TB patient and the HCP by the government is directly linked to the app.	No such monetary benefits can be provided through the app.
Location of patients, statistics at each PHC, and treating facility level are readily available.	Data collated at district and national levels are available.

is no facility for deletion of patients, either after completion of treatment or death, and no option to reopen a case treated in the past, thus making the numbers only cumulative and not representative of the actual active disease burden, affecting the quality and comparability of data collected.

Need for Strategies to Improve Capture Leprosy Data Across India

Nikusth is presently being used more as an online application for developing a database of leprosy patients. Transforming the present application into an integrated dynamic platform for patient–doctor–laboratory–rehabilitation services coordination, which is accessible to all sectors would be ideal. It would not only benefit the program but also the patients. The value and effectiveness of such a comprehensive system have been demonstrated with the immense success of Nikshay, an indigenous Indian app developed for TB. With regard to TB, it is worth noting that in addition to Nikshay, numerous m-health (mobile health) apps addressing various functionalities such as individualized treatment dosing, adherence monitoring, self-diagnosis, e-learning, contact tracing, and assistance with data gathering are freely available on both android and *ios* platforms. A descriptive review on mobile health apps for improvement of TB treatment mentions that the number of m-Health apps in the field of TB has more than doubled since 2016, which demonstrates how fast technology is advancing in the management of this disease.^[11] This is in sharp contrast to leprosy where there are hardly any such apps available.

In this modern era of digitalization with easy access to smartphones, making Nikusth a web-based mobile application or linking up with a mobile-based app for leprosy, would improve data recording and yield better outcomes. A mobile-based application will provide a platform for quick and easy data entry and reduce the chances of data loss due to poor recall. In addition, provisioning for the entry of follow-up data of patients into the system will enhance the utility of the application manifold to facilitate efficient monitoring of patients until completion of the full course of treatment and beyond.

Need for a Newer Easy-to-Use Mobile Friendly App for Leprosy

The WHO in its document “Global Strategy for Leprosy 2016–2020” discusses the importance of “partnership with the private sector and promoting inter-sectoral collaboration” for achieving the set targets.^[12] In such a scenario, a unified interface for public and private sector Health care providers (HCP) of leprosy would widen the reach for data collection, making it complete and comprehensive. It would also benefit Indian leprosy immensely by providing continuous updates of data to help track and monitor case trajectories, clustering, and draw strategies. With the recent availability of internet technology even in remote villages of India and ease of access to smartphones, the development of

newer and simpler leprosy patient data recording apps on a handheld smartphone would facilitate the entry of data of patients at the first point of contact, thus providing real-time information regarding leprosy surveillance from anywhere in the country. The data thus collected would be more granular and actual patient tracking can be efficiently done through this approach.

A prototype of such a mobile application named LEPTRACK was launched in six districts of Chhattisgarh on a trial basis with plans to scale it up further,^[13] which is a welcome augury. The data entered in such mobile applications can also be saved as individual patient files in a PDF format and can be sent for entry into central national health portal. When more such smartphone apps are available pan India, data entry at the ground level (village/sub-center) could be made possible across the country, and it would help to identify pockets with high caseloads for a focused and strategic approach to limiting the disease. Ideally, they should also be enabled for making case referral possible to provide rehabilitation and reconstructive surgical services for the person affected by leprosy. In addition, there is a need to capture and register leprosy patients seen by private HCP across India, which usually go unreported and unaccounted. Keeping in mind the much wider access to such an app, appropriate security measures such as SMS authentication for patient registration, linking patient details with their Aadhar number, in addition to video-based training modules for data entry to reduce errors would be required to ensure the accuracy and uniformity of data captured.

However, to facilitate this type of registration of leprosy patient data across the country, there is a need to make leprosy a notifiable disease, a disease that is required by the legislation to be reported to government authorities. As leprosy is not yet a notifiable disease, there is a general lack of emphasis on disease reporting, data capture and its follow-up, especially in the private sector, as it is not mandatory. It is not out of place here to mention that reporting of TB through the Nikshay app has been highly successful, only after TB has been declared a notifiable disease by the Government of India in 2012.^[14] Thus, making a versatile and user-friendly leprosy app with the ability to serve these diverse requirements and groups of HCP is the need of the hour and all the required measures need to be taken to support the developing and facilitating of such a platform, for the accurate recording of disease burden and improve the range and quality of leprosy services across India.

Even on the global front, efforts are being made towards the development of a more inclusive mobile-based one-stop application for leprosy that helps not only in data management but also in diagnostics and follow-up along with benefit transfer. In Brazil, a cross-platform app based on an artificial intelligence model for classifying leprosy patients and choosing the appropriate treatment proved to be a promising option to reduce human errors and improve the coverage

and scalability of health services, especially in remote areas where there was a lack of skilled professionals.^[15] In addition, a mobile app that integrates brief text, complemented by photos and videos to provide information about the dermato-neurological examination in Portuguese for screening symptomatic cases, was also developed as a handy tool for clinical evaluation of leprosy suspects.^[16]

In conclusion, for India to reach the goals of the Global Leprosy Strategy of 2021–2030,^[17] there is a felt need to develop or upgrade to versatile user-friendly mobile apps to capture the data of leprosy patients managed by HCPs across India, both within and outside NLEP in diverse clinical settings.

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