

# EVALUATION OF THE LEPROSY SURVEILLANCE SYSTEM IN PARAÍBA, 2019–2023

*AValiação do Sistema da Vigilância da Hanseníase na Paraíba, 2019-2023*

*EVALUACIÓN DEL SISTEMA DE VIGILANCIA DE LA LEpra EN PARAÍBA, 2019-2023*

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## ABSTRACT

Leprosy is a disease associated with sociodemographic factors. The surveillance of leprosy aims to diagnose cases among individuals who currently live or have lived with the patient, as well as their probable sources of infection. This study aimed to evaluate the quality of the Leprosy Surveillance System in Paraíba through the Notifiable Diseases Information System (SINAN) from 2019 to 2023. It is a descriptive, retrospective epidemiological study with a cross-sectional design. The results indicate that more than 70% of the Leprosy Surveillance System database in Paraíba is of low quality, although the system is consistent and representative compared to the national database. Therefore, improvements are necessary in the Leprosy Surveillance System in Paraíba, with an emphasis on the ongoing education of healthcare professionals to enhance the quality of notifications and the clinical management of the disease.

**Keywords:** *Leprosy; Health Surveillance System; Epidemiology.*

## RESUMO

A Hanseníase é uma doença relacionada a fatores sociodemográficos. A Vigilância da Hanseníase tem como objetivo diagnosticar casos entre indivíduos que convivem ou conviveram com o paciente e suas prováveis fontes de infecção. O presente estudo teve como objetivo avaliar a qualidade do Sistema de Vigilância da Hanseníase na Paraíba, através do Sistema de Informação de Agravos de Notificação (SINAN) no período de 2019 a 2023. Trata-se de um estudo epidemiológico descritivo, retrospectivo, com corte transversal. Os resultados indicam que mais de 70% do banco do Sistema de Vigilância da Hanseníase na Paraíba possui uma baixa qualidade, embora o sistema seja consistente e representativo em relação ao banco nacional. Conclui-se que são necessárias melhorias no Sistema de Vigilância da Hanseníase na Paraíba, com ênfase na educação permanente dos profissionais de saúde, visando à qualidade das notificações e ao manejo clínico da doença.

**Descritores:** *Hanseníase; Sistema de Vigilância em Saúde; Epidemiologia.*

## RESUMEN

La lepra es una enfermedad relacionada con factores sociodemográficos. La Vigilancia de la Lepra tiene como objetivo diagnosticar casos entre personas que viven o han vivido con el paciente, así como sus probables fuentes de infección. El presente estudio tuvo como objetivo evaluar la calidad del sistema de vigilancia de la Lepra en Paraíba, a través del Sistema de Información de Enfermedades de Declaración Obligatoria (SINAN) en el período de 2019 a 2023. Se realizó un estudio epidemiológico descriptivo, retrospectivo, con un corte transversal. Los resultados muestran que más del 70% de la base de datos del Sistema de Vigilancia de la Lepra en Paraíba presenta baja calidad, aunque el sistema es consistente y representativo en relación con la base de datos nacional. Por lo tanto, son necesarias mejoras en el sistema de vigilancia de la lepra en Paraíba, con énfasis en la educación continua de los profesionales de la salud, con el fin de mejorar la calidad de las notificaciones y el manejo clínico de la enfermedad.

**Descriptores:** *Lepra; Sistema de Vigilancia de la Salud; Epidemiología.*

## INTRODUCTION

Leprosy is a chronic infectious disease characterized by the reduction or loss of thermal, tactile, or pain sensitivity, with a slow and progressive course and an incubation period ranging from two to seven years<sup>(1)</sup>. It is transmitted by the bacillus

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*Mycobacterium leprae* through saliva droplets during prolonged contact with untreated multibacillary patients. This bacillus has a tropism for nerve and peripheral cells, being responsible for certain deformities when not properly treated<sup>(2)</sup>.

According to data from the World Health Organization (WHO), in 2023, 182,815 new cases of leprosy were reported worldwide, with more than 90% of these occurring in Brazil<sup>(3)</sup>.

Addressing leprosy requires the provision of structured services, especially within Primary Health Care, with the strengthening of integrated activities aimed at expanding access to diagnosis, treatment, prevention of disabilities, and rehabilitation of patients at all levels of health care, in order to ensure the actions of the Leprosy Control Program<sup>(4)</sup>.

Leprosy is a notifiable condition, but only confirmed cases are reported to the epidemiology sector within the corresponding epidemiological week, through the Leprosy Notification/Investigation Form of the Notifiable Diseases Information System (SINAN)<sup>(3)</sup>.

In 2023, 21,293 new cases of leprosy were reported in Brazil, representing an 8.6% reduction compared to 2022. Thus, it is extremely important to strengthen and organize surveillance of all contacts so that new cases can be detected and treated early, contributing to the reduction of disease transmission<sup>(5)</sup>.

In line with the findings of Jesus et al. (2023), there are still few scientific studies addressing the magnitude of leprosy; however, the few available point to a predominantly male prevalence, with low income, low educational attainment, and residing in urban areas within territories with high social vulnerability<sup>(6)</sup>.

Therefore, this study was based on the evaluation of the quality of the Leprosy Surveillance System in the State of Paraíba from 2019 to 2023. The study is relevant to public health and to the department of chronic and neglected diseases of the State, as the completeness, consistency, and representativeness of the data will allow for the accurate depiction of the epidemiological profile of the territory, as well as more grounded monitoring of cases after identifying existing gaps.

Thus, the objectives of this work were: to evaluate the quality of the Leprosy Surveillance System in the State of Paraíba contained in SINAN, from 2019 to 2023; to analyze the attributes related to data quality in terms of completeness, consistency, and representativeness in the leprosy epidemiological surveillance system; and to identify weaknesses and strengths of the system, proposing recommendations for improvement where necessary.

## METHODOLOGY

This is a descriptive, retrospective epidemiological study with a cross-sectional design, based on secondary, non-nominal data from the Leprosy Surveillance System of Paraíba, obtained from SINAN, covering the period from January 1, 2019, to December 31, 2023.

Data collection was conducted between July and August 2024. The sample included all cases of residents in the territory of Paraíba with a confirmed diagnosis of leprosy, regardless of type of entry, treatment, or cure criteria, and who were notified

during the aforementioned period. Duplicate cases in the database were excluded from the sample.

For calculation purposes, the following attributes were considered: data quality in terms of variable completeness, as well as their consistency and representativeness. This information was extracted from the mandatory, essential, and complementary fields of the Leprosy Notification Form. For data analysis, Microsoft Excel, Tabwin, and Epi Info™ 7 were used, with data presented in graphs and tables of relative and absolute frequency.

Regarding data quality (Box 1), 22 variables from the SINAN notification form were selected and evaluated (five mandatory variables, eight essential, and nine complementary), adapted from Mendes, Oliveira, and Schindler <sup>(7)</sup>, and distributed in the diagnostic and case follow-up fields.

Completeness was assessed for each variable by calculating the proportion of forms with missing data or filled as “unknown” in relation to the total number of valid notification forms, multiplying the result by 100 to obtain the percentage. The calculation of the incompleteness proportion followed the criteria proposed by Romero and Cunha <sup>(8)</sup>, with adaptations for the regular and poor categories (Table 1).

A variable was considered incomplete when the field was left blank or filled as “unknown.” For the specific variables “degree of physical disability at diagnosis”, “degree of disability at the time of cure”, and “bacilloscopy” fields filled with the options “not evaluated”, “not performed”, “unknown” or left blank were classified as incomplete.

**Box 1 – Variables selected for analysis of completeness and consistency of leprosy notification records, Paraíba, 2019–2023**

| Block     | Variable Name                                           | Criterion     |
|-----------|---------------------------------------------------------|---------------|
| Diagnosis | Education level                                         | Complementary |
|           | Occupation                                              | Complementary |
|           | Skin color/race                                         | Essential     |
|           | Clinical form                                           | Complementary |
|           | Number of skin lesions                                  | Complementary |
|           | Operational classification                              | Mandatory     |
|           | Mode of detection                                       | Essential     |
|           | Mode of entry                                           | Mandatory     |
|           | Initial therapeutic regiment                            | Essential     |
|           | Number of nerves affected                               | Complementary |
|           | Assessment of physical disability grade at diagnosis    | Essential     |
|           | Bacilloscopy                                            | Complementary |
|           | Number of registered contacts                           | Complementary |
| Follow-up | Number of supervised doses received                     | Essential     |
|           | Reactional episode during treatment                     | Complementary |
|           | Current therapeutic regimen                             | Essential     |
|           | Current classification                                  | Mandatory     |
|           | Number of contacts examined                             | Complementary |
|           | Number of supervised doses                              | Essential     |
|           | Date of discharge                                       | Mandatory     |
|           | Type of discharge                                       | Mandatory     |
|           | Assessment of physical disability grade at time of cure | Essential     |

**Source:** Adapted from Mendes, Oliveira, and Schindler, 2023.

**Table 2 – Analysis of completeness, according to the reference incompleteness percentage of the study**

| Degree of Completeness | Proportion (%) of Incompleteness |
|------------------------|----------------------------------|
| Excellent              | < 5                              |
| Good                   | 5–10                             |
| Regular                | 11–20                            |
| Poor                   | 21–50                            |
| Very poor              | > 50                             |

**Source:** Adapted from Romero and Cunha, 2006.

Consistency, defined as the logical coherence between two variables, was assessed by correlating the following data: “initial therapeutic regimen” and “operational classification”; “number of skin lesions” and “operational classification”; “registered contacts” and “examined contacts”; “positive bacilloscopy” and “operational classification.” For the evaluation, the classification proposed by Abath *et al.*<sup>(9)</sup> was adopted, which describes the following criteria: excellent, when consistency percentages are equal to or greater than 90.0%; regular, between 70.0% and 89.0%; and poor, if this percentage is less than 70.0%. All forms with blank fields or filled as “unknown” were excluded from the analysis.

Regarding data representativeness, this refers to the accuracy with which it describes the occurrence of an event, distributed by time, place, and person. To assess this, data from three variables selected from the Paraíba Leprosy database were compared with equivalent data extracted from the 2024 Leprosy Epidemiological Bulletin<sup>(5)</sup> of the Ministry of Health, using the last year of the study as a parameter. Thus, a variation parameter of up to 10% was established for the difference between the databases to be acceptable and the variables considered representative. However, for non-representativeness, a percentage difference greater than 10% between the databases was established.

Because only secondary data without individual identification were used, this study did not require approval by a Research Ethics Committee, as provided by Resolution No. 510/2016 of the National Health Council.

## RESULTS

From January 1, 2019, to December 31, 2023, 2,342 notifications of leprosy cases were registered in Paraíba. Regarding completeness, the variables “Operational classification”, “Current classification”, “Mode of entry”, “Initial therapeutic regimen”, “Skin color/race”, “Current therapeutic regimen”, “Number of registered contacts” and “Number of skin lesions” were rated as “excellent” or “good.” Only the variable “clinical form” received a regular evaluation (Table 2).

Variables rated as poor included “Education level”, “Mode of detection”, “Number of nerves affected”, “Assessment of physical disability grade at diagnosis”, “Number of supervised doses received”, “Number of contacts examined”, “Number of supervised doses”, “Type of discharge”, and “Date of discharge”. The variables “Occupation”, “Bacilloscopy”, and “Reactional episode during treatment” were categorized as very poor.

Thus, the quality of the evaluated variables was satisfactory in 36.4% of the elements assessed, as only eight out of the 22 variables studied were rated as good or excellent.

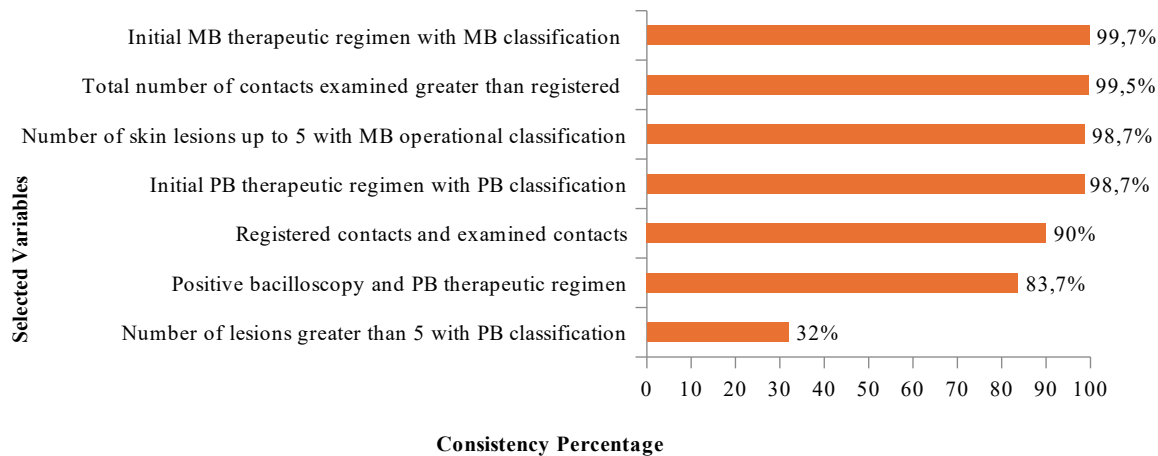
**Table 2 – Evaluation of incompleteness of variables in the Leprosy database of the State of Paraíba, 2019–2023**

| N: 2,342                                             |       |      |                |
|------------------------------------------------------|-------|------|----------------|
| Variables                                            | n     | %    | Classification |
| Operational classification                           | 2,342 | 100  | Excellent      |
| Current classification                               | 2,342 | 100  | Excellent      |
| Mode of entry                                        | 2,334 | 99.7 | Excellent      |
| Initial therapeutic regimen                          | 2,329 | 99.5 | Excellent      |
| Skin color/race                                      | 2,286 | 98.6 | Excellent      |
| Current therapeutic regimen                          | 2,292 | 97.9 | Excellent      |
| Number of registered contacts                        | 2,168 | 92.6 | Good           |
| Number of skin lesions                               | 2,112 | 90.1 | Good           |
| Clinical form                                        | 1,909 | 81.5 | Regular        |
| Mode of detection                                    | 1,813 | 77.4 | Poor           |
| Number of supervised doses                           | 1,707 | 72.9 | Poor           |
| Number of supervised doses received                  | 1,707 | 72.8 | Poor           |
| Assessment of physical disability grade at diagnosis | 1,703 | 72.7 | Poor           |
| Number of nerves affected                            | 1,695 | 72.4 | Poor           |
| Type of discharge                                    | 1,661 | 71.0 | Poor           |
| Date of discharge                                    | 1,661 | 71.0 | Poor           |
| Education level                                      | 1,581 | 67.5 | Poor           |
| Number of contacts examined                          | 1,499 | 64.0 | Poor           |
| Reactional episode during treatment                  | 1,065 | 45.5 | Very poor      |
| Occupation                                           | 955   | 40.8 | Very poor      |
| Assessment of physical disability grade at cure      | 747   | 31.9 | Very poor      |
| Bacilloscopy                                         | 614   | 26.2 | Very poor      |

**Source:** DATASUS, 2024.

The results regarding the consistency of leprosy notifications in Paraíba, from 2019 to 2023, are presented in Figure 1. It is observed that only the variable describing the number of skin lesions greater than five with an operational classification of Paucibacillary (PB) had a low consistency classification (32%). Positive bacilloscopy with an initial PB therapeutic regimen had a regular result (83.7%), while the other evaluated variables were classified as excellent, as they achieved results equal to or greater than 90%.

**Figure 1 – Percentage consistency between related variables in leprosy case notifications in the Notifiable Diseases Information System, and total consistency classification, Paraíba, 2019–2023**



Source: DATASUS, 2024.

**Legend/Notes:** Consistency percentage: excellent –  $\geq 90.0\%$ ; regular – between  $70.0\%$  and  $89.0\%$ ; low –  $< 70.0\%$ .

The representativeness analysis was conducted by comparing the average of selected variables (2019–2023) extracted from SINAN Paraíba with the average of corresponding variables (2019–2022) obtained from the 2024 Leprosy Epidemiological Bulletin (Table 3). The results demonstrate similarity in the pattern between the evaluated databases, with a difference of less than 10% between them, which is in accordance with the established parameters. Thus, the Leprosy Surveillance System proves to be representative.

In the evaluated databases, the predominant skin color/race is brown (“parda”). About 8% of cases present with Grade 2 Disability detected at admission (Table 3).

**Table 3 – Evaluation of the representativeness of the Leprosy Surveillance System – Paraíba/Brazil, 2019–2023**

| Evaluated Criterion (2019–2023)               | Result (% found)      | Comparative Study (2019–2022)            | Result of Comparative Study (2019–2022) | Evaluation Classification |
|-----------------------------------------------|-----------------------|------------------------------------------|-----------------------------------------|---------------------------|
| Distribution of cases by sex                  | Male (56.6%)          | Epidemiological Bulletin – Leprosy, 2024 | Male (56.5%)                            | Representative            |
| Mode of entry                                 | New case (78.8%)      |                                          | New case (77.8%)                        |                           |
| Distribution by race/skin color               | Brown (parda) (68.5%) |                                          | Brown (parda) (59%)                     |                           |
| General detection rate                        | 9.65                  |                                          | 9.67                                    |                           |
| Proportion of Grade 2 Disability at admission | 8.3%                  |                                          | 10.6%                                   |                           |
|                                               |                       |                                          |                                         |                           |

Source: DATASUS, 2024 and Leprosy Epidemiological Bulletin, 2024.

Legend/Notes: G2D: Grade 2 Disability

## DISCUSSION

The present study reinforces the importance of evaluating the quality of leprosy records in the State of Paraíba, in terms of completeness, consistency, and representativeness, as such action is extremely necessary for public health programs<sup>(10)</sup>.

It was found that the system in question presents low quality, with more than 70% incompleteness among the analyzed elements, with the variable “bacilloscopy” showing the worst result due to lack of completion.

This finding was also observed in the State of Pernambuco, as a study conducted in 2009 found that only 24.7% of the forms had this field completed<sup>(12)</sup>. That same study also refers to the low quality of the “number of nerves affected” variable, which contrasts with the results obtained here.

The essential variables “initial therapeutic regimen” and “operational classification” were rated as excellent, similar to the findings in a study on the quality of leprosy records at a reference center in the state of Minas Gerais<sup>(12)</sup>. The work highlights the importance of treatment and the most appropriate therapeutic plan for each individual, and how the correct completion of these variables supports this decision.

With more than 70% of variables showing incompleteness, the Leprosy Surveillance System in Paraíba is consistent with the findings of Reis, Lages, and Lana<sup>(13)</sup>, who report that even with specialized reference centers for the diagnosis and treatment of leprosy, the State of Minas Gerais needs to intensify professional training to ensure the correct completion of information in notification forms.

The consistency of the information system evaluated in this study was considered high, as only one out of seven assessments was rated as low. Inconsistency was found in the relationship between “number of lesions greater than 5” and “paucibacillary operational classification”. Similar findings were reported by Aguiar<sup>(14)</sup> in Teresina, the capital of the state of Piauí, in 2012, who described that the conformity between these two variables is of utmost importance, since the operational classification guides treatment.

The data evaluated here are consistent with a study conducted in João Pessoa, Paraíba, which describes significant operational weaknesses regarding data entry in the information system. The authors also state that, given the neglect of leprosy, it is necessary to properly record the data contained in the forms, as this is essential for the effectiveness of leprosy epidemiological surveillance in the state<sup>(7)</sup>.

Regarding representativeness, the system proved to be excellent in relation to the variables listed, being in accordance with national data obtained through the 2024 Leprosy Epidemiological Bulletin. The evaluation of the Leprosy database in Paraíba reveals that, as in the country as a whole, the most affected individuals in the state are male and of brown (“*parda*”) skin color. With regard to the mode of entry, almost 80% of cases are new cases.

Therefore, it is recommended that the State Leprosy Coordination conduct training sessions and workshops, regionally, for health professionals, focusing on high-quality notification, clinical management of leprosy, and grade 2 disability, with the aim of improving the flow of care and early diagnosis.

For the Regional Health Management Offices, periodic evaluation and monitoring of leprosy cases are recommended, together with their respective municipalities, in order to assist them in active case finding and diagnosis within their own territories.

## CONCLUSION

Based on the results obtained, it was possible to identify that the Leprosy Surveillance System in Paraíba is consistent and representative. However, it presents operational weaknesses regarding the completeness of notifications, which were found to be of low quality in more than 70% of the variables analyzed.

The correct completion of these elements is of utmost importance for the diagnosis, treatment, follow-up, and closure of cases. The absence of this information can directly influence clinical management and the organization of policies to address leprosy in Paraíba, as it hinders the evaluation of control actions.

There is a large number of “blank” or “ignored” fields in the notification forms, which directly interferes with the monitoring and systematic evaluation of the Leprosy Epidemiological Surveillance System in Paraíba, representing a limitation for this study, as it does not allow for a more accurate analysis of some variables.

It is expected that the present analysis may guide the planning, implementation, and evaluation of leprosy case records in the Notifiable Diseases Information System in Paraíba, enabling a better understanding of the epidemiological scenario of the disease in the State.

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